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Perspectives on advance directives in Japanese society: A population-based questionnaire survey

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Abstract

Background

In Japan, discussion concerning advance directives (ADs) has been on the rise during the past decade. ADs are one method proposed to facilitate the process of communication among patients, families and health care providers regarding the plan of care of a patient who is no longer capable of communicating. In this paper, we report the results of the first in-depth survey on the general population concerning the preferences and use of ADs in Japan.

Method

A self-administered questionnaire was sent via mail to a stratified random sampling of 560 residents listed in the residential registry of one district of Tokyo, Japan (n = 165,567). Association between correlating factors and specific preferences toward ADs was assessed using contingency table bivariate analysis and multivariate regression model to estimate independent contribution.

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Results

Of the 560 questionnaires sent out, a total of 425 participants took part in the survey yielding a response rate of 75.9 %. The results of the present study indicate that: 1) the most important components to be addressed are the specifics of medical treatment at the end of life stage and disclosure of diagnosis and prognosis; 2) the majority of participants found it suitable to express their directives by word to family and/or physician and not by written documentation; 3) there is no strong need for legal measures in setting up an AD; 4) it is permissible for family and physician to loosely interpret one's directives; 5) the most suitable proxy is considered to be a family member, relative, or spouse. Multivariate analysis found the following five factors as significantly associated with preferences: 1) awareness regarding living wills, 2) experience with the use of ADs, 3) preferences for end-of-life treatment, 4) preferences for information disclosure, and 5) intentions of creating a will.

Conclusions

Written ADs might be useful in the Japanese setting when the individual either wishes: 1) to not provide a lot of leeway to surrogates and/or caregivers, and/or 2) to ensure his or her directives in the cases of terminal illness, brain death, and pain treatment, as well as regarding information disclosure.

Background

Advance directives (ADs) are one method proposed to facilitate the process of communication among patients, families and health care providers regarding the plan of care of a patient who is no longer capable of communicating. ADs are made while the patient is still competent; they specify the course of medical treatment to be provided by caregivers and/or designate someone to act as a proxy should the patient lose his or her capacity to make decisions.

In the United States, the moral arguments supporting ADs are based primarily on the concept of respect for autonomy or on the patient's right to self-determination. The Patient Self-Determination Act of 1990 aims to encourage patients to take the initiative to ensure that their values are respected at the end of their life [1]. Completion of formal documentation either in the form of ADs or durable powers of attorney are considered to be effective means in supporting patient autonomy and patient preferences regarding life-sustaining treatment. ADs and the use of a health care proxy have been recommended as a means to improve communication about the patient's preferences in making health care decisions [2-4].

Other research indicates that ADs should contain disease-specific information rather than general statements which do not offer much assistance in clinical situations, and should be seen as part of a more general plan for end-of-life decisions in which improved communication would be more important than a more formal preservation of rights, achieved by simply completing a document [3,5-7]. However, whether the disease-specific ADs really improve the patient-physician relationship has not yet been confirmed [8]. Moreover, several studies demonstrated that not many people execute ADs even when legally warranted as in the United States [9,10].

The factors of ethnicity and culture on the process of decision-making for end-of-life treatment have increasingly become a paramount issue to AD related research [2,11-14]. The significance of culturally shaped values has been described in studies between African American and white patients, Chinese and non-Chinese seniors as well as between other Asian subgroups. In particular, patients' respective religious and philosophical traditions are considered to be in direct correlation with attitudes towards end-of-life decision-making.

In Japan, discussion concerning patient autonomy and the significance of patient determination wishes has been incessantly on the rise during the past decade within academic circles as well as in the mass media [15]. Several studies have been conducted including questionnaires and interviews to physicians [16-18], questionnaires to the elderly [19], and brief nationwide pool surveys, although only having consisted of a few straightforward questions [20,21]. While these

studies have shown a gradual gain in attention and recognition of the meaning of ADs in Japan, there is to this date no in-depth survey of the general public's preferences, attitudes and behavior regarding ADs. According to our previous preliminary study conducted in 1996 on over 200 healthy males, we observed a general positive attitude towards ADs and a large amount of leeway regarding the carrying out of one's directives [22].

Based on these findings, our present study serves as the first stratified sampling in-depth survey of laypersons' preferences and behaviors regarding ADs. This study has the following objectives: 1) to identify preferences towards ADs as well as attitudes, awareness, experience, 2) to determine the factors associated with those preferences, and 3) to provide data to serve as a foundation for later investigating suitable ways of implementing ADs in Japan.

Participants and methods

A self-administered questionnaire was sent via mail to a stratified random sampling of 560 residents listed in the residential registry of one district of Tokyo, Japan ($n = 165,567$) in May of 1998. This list, which is divided by town, constitutes addresses of all residences in alphabetical order. We gained access to it after receiving approval from the head of the district. 14 towns were first randomly chosen from 69 towns within the defined area (sampling rate: 1/5). Participants were then randomly selected from each of the 14 areas based on the population size of each town (sampling rate: 1/60). The total sampling rate was 1/300. In the cover letter, it was made clear that the questionnaire was research-related, completely participatory and that all respondents would be treated anonymously. All questionnaires were collected either by return mail or by dispatched students.

The questionnaire is composed of 13 questions designed to delineate participants' awareness, preferences, attitudes and behavior towards ADs and advance care planning as well as to deconstruct the specific factors underlying participants' specific decision-making processes regarding ADs (Appendix 1) [see 1]. Preferences toward ADs (Question 3 in the appendix) were set as a dependent variable. Association between correlating factors and specific preferences toward ADs was assessed using contingency table analysis. Factors identified in bivariate analyses as being significantly associated with one's preference towards ADs were entered into a multivariate regression model to estimate independent contribution. A p value less than 0.05 was considered significant. Data analysis was performed using SPSS 10.0 J.

Additional File 1. Appendix: Survey concerning Advance Directive

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Results

Response rate and socio-demographic characteristics of the respondents

Of the 560 questionnaires sent out, 4 were returned due to an incorrect address. 341 questionnaires were returned via-mail within 3 weeks, and later dispatched students collected 84. 19 respondents informed us that they decided not to participate in the survey. In total, 425 participants took part in the survey, yielding a response rate of 75.9 %. Socio-demographic characteristics, experience with hospitalization and death as well as self-rated health status are shown in Table 1. The mean age of respondents was 44.7 years of age with a SD 14.2. The majority had junior college level education and more than 70% of participants claimed to be non-religious. While less than 20% of respondents had hospitalization experience in the past, over 40% have had a family member with such experience. Over 50% of respondents have had a family member, relative or friend pass away in the last five years. Approximately 90% of respondents rated their health status as good or fairly good.

[Table 1.](#) Socio-demographic characteristics ($n = 425$)

Awareness regarding living wills

156 respondents (36.7%) claimed to know of living wills and 170 respondents (40.0%) replied that they have heard of the terms but were unfamiliar with their meaning. 97 (22.8%) respondents answered that they were unaware of the terms and two people (0.5%) did not answer. Of the 156 who responded to know of living wills and ADs, only 12 (7.7%) respondents had actually written one out. 139 (89.1%) answered that they had not written one and five (3.2%) did not answer.

Preferences toward ADs: a dependent variable

In the case of suddenly becoming ill or getting into an accident where one loses all capability to communicate, 115 (27.1%) respondents "strongly agreed" and 227 (53.4%) respondents "moderately agreed" that it is better to have expressed one's wishes regarding medical treatment in advance. Conversely, 78 (18.4%) respondents "moderately disagreed" and 5 (1.2%) respondents "strongly disagreed."

Reasons for ADs

Table 2 shows reasons for wanting to express one's wishes. The most popular reason for wanting to express one's wishes with more than 60% responses were "I want to undergo the treatment of my choice", "I hope to not burden my family with end-of-life decisions", and "I want to decide for myself."

[Table 2.](#) Reasons for ADs (n = 342)

Contents to be noted in one's AD

Table 3 exemplifies the requested contents to be noted in one's AD. Four items in particular were indicated by more than 70% of respondents: treatment related decisions in the case of becoming terminally ill; brain death or long-term comatose; treatment related decisions regarding "pain" during terminal stages; and preferences for information disclosure.

[Table 3.](#) Contents to be noted (n = 342)

Degree of detail in one's AD

Regarding the degree of detail of one's preferences in the AD, only 22 (6.4%) of respondents specified "as detailed as possible," 263 (76.9%) respondents indicated "general preferences," 15 (4.6%) respondents marked "other," 29 (8.5%) claimed to "do not know" and 13 (3.8%) did not answer.

Degree of leeway regarding one's AD

Upon the supposition that one has created an AD, the majority of respondents (234, 68.4%) claimed that they would like to be treated according to one's AD "as much as possible; however the AD does not need to be strictly observed when seen reasonable." Only 45 (13.2%) responded with "in absolute accordance," 37 (10.8%) respondents indicated "just as a reference," 4 (1.2%) respondents marked "others," 12 (3.5%) respondents specified "do not know" and 10 (2.9%) did not answer.

Recording of one's AD and one's attitude toward legalization

Regarding the means of how one would like to record his or her AD, 166 (48.5%) of respondents specified "written document," 145 (42.4%) respondents indicated "orally to a family member or acquaintance," 2 (0.6%) respondents marked "other," 22 (6.4%) claimed to "do not know" and 7

(2.0%) did not answer. Of the 166 who indicated "written document," 90 (54.2%) specified that the legalization of ADs is "necessary," while 40 (24.1%) of respondents claimed it to be "unnecessary," 33 (19.9%) marked "do not know" and 3 (1.8%) of respondents did not answer.

Reasons against the use of ADs

Table 4 describes the reasons for not wanting to express one's wishes. Four reasons were indicated by more than 40% of respondents: "My family will make such decisions when the time is needed"; "My physician will make such decisions when the time is needed"; "I am currently healthy and there is no need to consider such decisions"; and "It is impossible to think of such decisions for it is impossible to imagine oneself in such a situation."

[Table 4.](#) Reasons against the use of ADs (n = 83)

Experience with the use of ADs

In reply to the question of whether or not one has ever thought that it was good that an acquaintance, friend or family member made an AD, the vast majority of respondents (358, 84.2%) indicated "no" while 53 (12.5%) specified "yes," 14 (3.3%) did not answer.

Preferences for end-of-life treatment

Upon the supposition that one is in extreme pain and death is approaching with no hope of recovery, the majority of respondents (196, 46.1%) agreed and 174 (40.9%) of respondents fairly agreed "to refuse all life-sustaining treatment and elect only to have the pain subdued" while only 9 (2.1%) disagreed and 30 (7.1%) moderately disagreed "to have life-sustaining treatment regardless of the pain." 16 (3.8%) respondents did not answer.

Preferences for information disclosure

Once again, upon the supposition that one is in extreme pain and your death is approaching with no hope of recovery, the majority of respondents (193, 45.4%) agreed and 150 (35.3%) of respondents fairly agreed "to have all information concerning your diagnosis, etc. disclosed to you" while only 18 (4.2%) disagreed and 51 (12.0%) moderately disagreed "to have nothing disclosed to you". 13 (3.1%) respondents did not answer.

Intentions of creating a will

Lastly, 124 (29.2%) respondents claimed to have the intention to create a will while only 39 (9.2%) have no intention to do so. However, the majority of respondents (254, 59.8%) specified as "undecided" in terms of intending to create a will. 8 (1.9%) respondents did not answer.

Bivariate analysis

Six factors were identified as significantly associated with attitudes towards ADs: 1) experience with hospitalization and death ($\chi^2 = 6.5$, $p < 0.05$), 2) awareness regarding living wills ($\chi^2 = 36.7$, $p < 0.001$), 3) experience with the use of ADs ($\chi^2 = 20.2$, $p < 0.001$), 4) preferences for end-of-life treatment ($\chi^2 = 28.9$, $p < 0.001$), 5) preferences for information disclosure ($\chi^2 = 21.6$, $p < 0.001$), and 6) intentions of creating a will ($\chi^2 = 22.9$, $p < 0.001$). Socio-demographic factors such as sex, age, education, religion as well as self-rated health status were not significantly associated.

Multivariate analysis (Table 5)

[Table 5.](#) Correlates for positive preference towards ADs

Factors significantly associated with attitudes towards ADs in bivariate analyses were entered into the multivariate regression model controlling sex, age, education, religion and health status. Ages

were entered as dummy variables. Significant factors were the following five: 1) awareness regarding living wills, 2) experience with the use of ADs, 3) preferences for end-of-life treatment, 4) preferences for information disclosure, and 5) intentions of creating a will. Experience with death was narrowly eliminated, possibly due to its association with experience with the use of ADs.

Discussion

The aim of the present study was to delineate layperson's preferences, attitudes and behavior towards ADs and to determine the factors associated with those attitudes in Japan. Consequently, such data will serve as a foundation for later investigation on suitable ways of implementing ADs.

Results agree with previous studies in that the majority of individuals responded in favor of expressing their directives beforehand [20-22]. Among those who lay in favor of ADs, the results of the present study indicate that:

- 1) The most important components to be addressed are the specifics of medical treatment at the end of life stage and disclosure of diagnosis and prognosis;
- 2) The majority of participants found it suitable to express their directives by word to family and/or physician and not by written documentation;
- 3) There is no strong need for legal measures in setting up an AD;
- 4) It is permissible for family and physician to loosely interpret one's directives;
- 5) The most suitable proxy is considered to be a family member, relative, or spouse.

These results provide a representative description of the general public's preferences and attitudes towards ADs in Japan. Results indicate a tendency towards leaving leeway for interpretation by those who one trusts and an avoidance away from the establishing of "set-guidelines" and documents, especially legal forms.

The lack of need for legal documents

In Japan, there has been a historical lack of rights assertion and of the employment of legal documents [23,24]. Although the issue of ADs and their possible legalization have been discussed in the past [24], as to this date in Japan, no advance directives including living wills from organizations such as the Japan Society for Death and Dying are legally binding.

This lies partly due to the fact that rights talk in Japan connotes a situation of *conflict*. As Feldman comments [23],

Rights talk in Japan appears most likely to be used in conflicts where there is more than one individual who believes s/he is aggrieved. Because the cultural myths about rights powerfully suggest that asserting rights is a sign of selfishness and conceit, people are understandingly reluctant to individually and in isolation assert their rights (pp. 163)

With this in mind, the legalization of ADs may appear not as an authentication of the documents but rather as an instigation of "rights talk." However, we are not proposing that Feldman's explanation of rights talk as being conflictive is justification of using oral ADs over written ones; rather, we are suggesting that the sociological connotations involved with legal documents is a factor behind the evasion from the legalization of ADs.

Expression of one's will: (Oral or written)

Results indicate that oral ADs may be considered a suitable approach to implementing ADs in Japan. However, in cases when one wishes to make certain that directives are carried out aptly, a written document may become necessary. Oral ADs are often forgot, misinterpreted, or may not be directly conveyed to one's medical providers. Accordingly, we propose the usage of a written document (an unofficial, non-legal form will do) in the following cases: 1) when one wants to make

certain that all expressed determinants are recognized and followed strictly; and/or 2) when one's medical providers feel that a written document will be needed for evidence-related reasons.

The issue of leeway: situational decision-making

While the above explanation elucidates the possible factors behind the oppositions towards legal documents, it leaves us with the question of why the circumvention from non-legal written ADs and why the extensive range of leeway.

The issue of leeway and the apparent circumvention from written ADs can be deconstructed by understanding the held conception that one's views and attitudes concerning an event are greatly influenced by how one perceives the event while experiencing it. Konishi and Davis suggest that this type of situational decision-making is considered the norm in Japanese health care [25]. Situational decision-making is indicative of one's relative position in the context of the situation influences how one subjectively perceives appropriate action.

ADs oppose this way of thinking for one is forced to make end-of-life decisions without being able to experience his or her relative position in the context of the situation. Those who are against ADs responded that "people had no ability to imagine the exact circumstances that lay ahead" and that "there is great concern as to whether or not one can predict beforehand one's intentions in regards to an event that lies ahead without having experienced such." Needless to say, this exemplifies recognition of the logical limitations of ADs and furthermore describes the inclination to situational decision-making.

These limitations are overcome by entrusting one's decisions to a trusted family member or friend who is capable of making decisions upon *actually experiencing the situation*. Entrusting one's decisions in the context of medical treatment to one's family, close ones or medical professionals has been regarded as a dominant cultural characteristic of Japanese health care [14,26-28], though this is not strict to Japan [29].

Considering the minority

Results of this study show that only a minority of people hold or intend to create an AD. These results parallel a previous report, where only 10% to 25% of patients ever complete an AD of any sort [30]. However, the fact that only a minority of patients is requesting the advocacy and use of ADs does not make their use any less imperative.

In the present study, although the majority of participants expressed the need for leeway, and no strong need for legalization, a certain number of individuals have expressed the need for ADs "to be as specific as possible," "to be followed in the strictest of terms," and "to undergo legalization." We need to recognize that not all patients of a single culture fit the characteristics of the majority. That is, although most patients in Japanese society can be described by the characteristic of situational decision-making, we need to accommodate those who wish to use a written AD; only by doing so are we capable of actually respecting each individual's way of thinking.

Defining the minority in a homogenous culture: sub-cultures

Cultural differences between physicians and patients have been considered to intensify the process of making end-of-life decisions [12]. In Japan, current sociological changes in family dynamics indicate a possible need for a proxy who can represent the individual's values and beliefs. We propose that the use of an AD is necessary in such cases where the values of patient and family differ. In this sense, even within the same homogenous culture and ethnicity, individual patients may diverge sub-culturally; that is, cross-cultural dilemmas inevitably exist even within the same culture [11,13].

The first step to appropriately deal with this cross-cultural divergence that exists within a single culture and ethnicity is to understand the actual perspectives of patient and family [12,31]. The next is to define a treatment plan that is acceptable both to the patient and family, and to the health care team. In short, the key is effective communication between patient and health care staff, family and health care staff. Bowman et al. proposes that "when health care workers are

unsure of how a patient or family perceive a situation, it is best to simply ask. The mere acknowledgement of such differences frequently leads to improved communication" [12]. Further models for cross-cultural clinical encounter have been developed [32]. We suggest that models for cross-cultural clinical encounter be applied to patients even within the same culture and *ethnicity* in order to fully understand each patient as an individual with his or her own respective sub-culture.

ADs for information disclosure

Results showed that the ADs should contain the component of assuring full disclosure of diagnosis and prognosis. This issue of information disclosure may be unique to Japan's clinical medicine. Historically speaking, full disclosure of one's diagnosis and prognosis has not been the norm; many patients in Japan have voiced that they would rather be told a white lie of having gastric ulcers, even if the truth is subliminally understood, over being disclosed the terrifying truth of having stomach cancer [26,27]. Japan's ADs are unique in that they often serve as directives concerning one's preferences for being disclosed medical information (i.e. diagnosis and prognosis). As proposed in a previous report, ADs can be used as directives for disclosure "as a verbal or written declaration from the patient that indicates his or her preference for disclosure of information in the event cancer is diagnosed" [26]. In this sense, ADs can act as documented testimonies ensuing either (1) full disclosure of information directly to the patient and not via the family, or (2) nondisclosure of one's diagnosis often as in the case of cancer. This component of Japanese ADs can serve as a mediating tool to the growing divergence between patients who prefer to be disclosed all medical information and those patients who prefer nondisclosure. Although several previous reports have referred to this type of approach when discussing the issue of information disclosure [26,33,34], this study is the first to reconfirm researchers' propositions with the general public's preferences.

Multivariate analysis: associative factors

Multivariate analysis revealed approximately five factors associated with one's disposition towards ADs. Results concerning one's level of awareness and personal experience with ADs were both directly associated with one's preference towards them. Avoidance from ADs may be related to one's lack of awareness and experience with them. Although one previous report claims that "no evidence [was found] that lack of knowledge about Living Wills or proxy directives was a reason from patients not completing such documents" [11], our findings are consistent with several other studies where awareness, education, and experience with ADs were found to be significant associative factors in completion rates of ADs [1,35-37]. Moreover, the factor of considering end-of-life treatment decisions and information disclosure tells us that those who have a firm stance regarding future medical treatment are more comfortable with the idea and use of ADs. The factor of intending to create a will may exist as an associated factor due to their similarity as "planning ahead" strategies.

Previous reports describe that the factor of age is associated with the process of execution or nonexecution of ADs [36-38]. This report diverges from previous results in that age was not seen as a significant factor; we believe this is due to the difference in sampling. Gordon and colleagues' study used a sample ranging in age from 60 years and above; Cook and colleagues incorporated a sample restricted to intensive-care-unit patients averaging with a mean age of over 60 years; and lastly, Havens' conducted a systematic random sampling of those names listed in a telephone book in which the mean was over the age of 50 years. In contrast to these non-stratified samples, this survey has utilized a stratified random sampling from the residential registry. In light of this fundamental difference in sampling, we are unsure as to whether the incongruity regarding the factor of age was due to differences in statistical measures or due to differences in the nature of sampling pools, i.e. city population, national characteristics, ethnicity.

Limitations

This study's sampling is limited to residents who reside in a condensed metropolitan area of Japan. Further research is needed comparing our results with similar data collected in rural area. However, this research provides the first in-depth questionnaire survey with a systematic stratified

sampling focusing on the utilization of ADs in detail. We recognize the need for further research concerning disease-specific ADs and further the implementation of advance care planning in the clinical setting.

Conclusions

This study identified the preferences and attitudes towards ADs; major findings included an expressed degree of leeway for interpretation of one's AD by one's physician and family, a need for ADs to ensure the observance of one's directives in the cases of terminal illness, brain death, and pain treatment, as well as regarding information disclosure, and lastly, a lack of strong need for legal measures in setting up an AD. Results were also able to delineate five factors significantly associated with preferences: 1) awareness regarding living wills, 2) experience with the use of ADs, 3) preferences for end-of-life treatment, 4) preferences for information disclosure, and 5) intentions of creating a will.

In light of these findings, we surmise that written ADs might be useful in the Japanese setting when the individual either wishes: 1) to not provide a lot of leeway to surrogates and/or caregivers, and/or 2) to ensure his or her directives in the cases of terminal illness, brain death, and pain treatment, as well as regarding information disclosure.

List of abbreviations

Advance Directive (AD)

Competing interests

None declared.

Authors' contributions

AA conceived and designed the study, collected data, supervised data analysis and contributed to the writing of the paper. BTS contributed to the data analysis, interpretation of data, and the writing of the paper. IK was involved in the conception and design of the study and its ongoing management

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