

あつんの呼吸の終焉

最期は穏やかに逝かせてあげたい、という願いは医師も同じ。しかし、一歩間違えば殺人罪に問われる現状では、積極的に協力できない。

西日本の病院で、当直の男性内科医(45)が看護師に呼び出されたのは今年2月、夜11時近くだった。「患者さんが人工呼吸器をはずしてくれと言ってきたんですけど」病室に駆けつけると、80代の男性患者が、マスク型の人工呼吸器をつけたまま、声を絞り出すように言った。

「楽になりたい。寝たいんです」男性は約2週間前から重篤の肺炎で入院していた。治療しても病状は回復せず、意識が明瞭なのが不思議なほど状態は悪かった。「呼吸器はしとったほうがいいよ」

意識がなく、家族の依頼だった。医師も動揺、初めての夜初めてはずしたのは、まだ医師になつてまもないころだ。もともと糖尿病で、脳梗塞を起こして倒れた80代の男性患者の主治医をしていた。男性はすでに10カ月ほど意識がなく、人工呼吸器につなが

いると圧迫感があり、ベッド脇のモニターも気になって熟睡できないのだという。自発呼吸が弱いの

で、人工呼吸器をはずせば亡くなる。そう思ったが、本人には告げられなかった。付き添いの子どもや妻が家族には率直に話した。「それでも、そうして下さい」家族は言った。人工呼吸器を取

るよう、看護師に指示した。翌朝8時前、男性は亡くなった。「『臨終です』と言いなながら、心の中で患者さんに『苦労様、よく頑張ったね』と言いました」この医師は約20年の医師生活の中で10回弱、患者の人工呼吸器をはずしたことがあるという。直近の1回を除いては、すべて本人は

人工呼吸器をつけるべきか、つけたとしていつはずすか、はずすなら同意書を取るか…

今回の事件について

いったん延命治療を始めてしまうと、それを中止することは大変な勇気が要ります。自分が手を下したことにより、確実に患者さんが亡くなることが分かるからです。延命治療を始めないことこそが大切でしょう

長野県、地域医療、39歳

心情的には理解できない部分もありますが、家族からの文書による承諾や、複数の医師や看護師の立ち会いなど、必要な手続きを踏んでいないので、問題は大きいと思います

埼玉県、麻酔科、40代

自分もそんな悲惨な患者さんを目の前にしたら、人工呼吸器を外せたらいいのとは考えますが、外したら叩かれるので、決してしません。保身のためです

北海道、脳神経外科、30代

行為そのものは、以前なら問題にもされなかったと思う。しかし、このような行為を医師一人で決めてはならないというコンセンサスがある現在は、処罰の対象になっても仕方がない。少なくとも、複数の医師と家族との話し合いの結果として行われたなら、何の問題もなかったのではないかと

青森県、小児科、49歳

の医師はそれを承諾した。人工呼吸器の呼吸回数を3日に2回ずつ減らしていくと、その都度、心臓の動きはゆっくりになっていった。回数を減らすたびにドキドキ止まった。その夜、先輩の医師が飲みに誘ってくれた。「これも仕方ないんだよ」先輩医師は言った。今はその思いがよくわかる。

「あれこれ医療行為をしないほうが安らかにお亡くなりになることでもあります。ご家族は口には出しませんが、ご自身も疲れているし、経済的負担も重荷になっていることがあるようです。その辺は長いおつきあいの中でわかります」救命効果のない延命治療をしたくないと考える医師は、患者以上

「本人が前から延命治療はして欲しくない并希望していたんです」家族は繰り返したが、本人の意

しかし現実には、この医師や射水市民病院の外科部長のように、いったんつけた人工呼吸器をはずす、という医師は少数派だ。「くわみず病院(熊本市)の大病史弘院長は数年前、食べ物や喉に詰まらせ、脳死に近い状態になった80歳代の男性の家族から、人工呼吸器をはずしてほしい、と懇願された。」

患者・家族との意思疎通について

家族の受け入れも大事だが、家族側から「医療費が高いので延命治療をやめて欲しい」などとは言いにくいと思う。医師がそれとなく延命治療の中断を申し出て、家族の責任の負担をとり除くことが賢明だと思う

奈良県、脳神経外科、40歳

意思を書面で確認することが必要。同時に、いつでもそれを変更できるという保障も大切

宮城県、内科、30代

家族の意思は、時として無駄な治療を長引かせるだけになることもあり、意思決定機関を設けるのも一つの方法ではないか

熊本県、小児科、50代

患者自身に延命治療を続けるか否かの決定能力がない場合、それまでに患者との間で交わした会話の内容をカルテに随時的に記録しておくことが、家族から理解を得る根拠として望ましいのではないか。それが現代流の「あうんの呼吸」だと思う

滋賀県、放射線科、46歳

医師が自分自身の法的立場を守るためにも、意思表示は文書に残してもらう必要がある。一方、患者の家族は、自分が「肉親の死を容認した」と他の親族や第三者に思われるのではないかと考え、心理的負担を感じる可能性は否定できない

兵庫県、産婦人科、49歳

終末期医療をめぐる主な事件

1991年4月 東海大学医学部付属病院

(神奈川県伊勢原市)

末期がんの男性患者(当時58)に対し、内科医が家族の要請を受け、塩化カリウムなどを注射して死亡させた。殺人罪で起訴され、95年3月、横浜地裁で懲役2年執行猶予2年の判決(確定)。判決は延命治療の中止や間接的安楽死、積極的安楽死が許される要件を示した。

1996年4月 京都府京北町立国保京北病院

(現・京都市立京北病院)

末期がんの男性患者(当時40代)に院長が筋弛緩剤などを投与。殺人容疑で書類送検されたが、97年12月、京部地検は嫌疑不十分として不起訴処分。

1998年11月 川崎協同病院(川崎市)

ぜんそくの重症発作で意識不明になった男性患者(当時58)の気道確保のための気管チューブを呼吸器内科医が抜き、筋弛緩剤を投与。患者は死亡。2002年12月、医師は殺人容疑で逮捕された。家族の要請などをめぐり、医師と検察側の主張が対立。05年3月に横浜地裁で懲役3年執行猶予5年の判決が出たが、医師は控訴。近く控訴審が始まる。

2004年2月 北海道立羽幌病院

(北海道羽幌町)

食事をのどに詰まらせた男性患者(当時90)の人工呼吸器を、担当医が家族の要請で取り外し。患者は死亡。05年5月、北海道警は殺人容疑で旭川地検に書類送検した。

思を記した文書はなかった。大石院長は断つた。「はずせば殺人になります」男性は人工呼吸器をつけ、意識も戻らないまま約1年後に亡くなった。くわみず病院では今も、回復しなくなったとき以外につけた呼吸器はずさない。安楽死や尊厳死には大まかに4つの分類がある。薬物注射などで



死亡させる「積極的安楽死」、苦痛を取り除くための薬物投与の副作用として死期が早まる「間接的安楽死」、人工呼吸器をはずすなど延命治療を中止する「消極的安楽死」、患者が事前に延命治療を拒否する意思を文書で記し、医師がそれを尊重する「尊厳死」だ。

いの途中ではずすのも同じこと。患者か患者の意思代行者として家族の依頼があったのなら、あの外科医の行為は患者の意思を尊重した倫理的で道義的な行為です」とはいえ現状では延命治療を途中で中止するのが難しい。そこで末期がんなど終末期になるまでに時間のある病気や高齢の患者には、事前に希望を確認しておく病院が多い。ただし、それをカルテには記入しても、文書化して署名してもらおう病院はあまりない。

全国的なガイドライン、法律は必要か

今後、延命治療に関して、刑事、民事の訴訟対象になるのであれば、医師の自己防衛として必要であるが、それらを設けるのは、日本人の精神面での退化であり、欧米並みの訴訟社会への一歩である 奈良県、脳神経外科、40歳

大まかなガイドラインだけで十分。「こうしなければ」といった強制は不要。家族と「あうん」に至れば最高だから 神奈川県、内科、50代

限られた医療資源をどう配分するか、延命治療・終末期医療にどれほどの費用をつき込むのか、これは、国が責任を持って医療政策として宣言すべきこと。その意味で、ガイドラインは必要 三重県、精神科、30代

絶対に必要。主治医個人の意見や価値観に左右されてはいけない 山形県、神経内科、40代

アエラでは、医療従事者専用ポータルサイト「m3.com」や、医療関係のメーリングリストを通じて、医師の方々の声を募集したところ、3日間で約150件のご回答をお寄せいただきました。

「終末期における医師と患者・家族の間のあうんの呼吸は、患者や家族の責任をあいまいにしておくという意味でいい側面があった。このご時世ではいつまで続けられるのかわかりませんが……」終末期医療でとくに問題になるのは、脳梗塞などのように、突然意識がなくなる場合だ。人工呼吸器や栄養補給があれば何年間も生き続けられることもある一方で、本人の意思は確認できない。延命治療や終末期医療について、厚生省の研究班は07年までに指針を作る予定だ。指針の効果には異論もあるが、このまま司法の介入だけが増えれば、医師は防衛的にならざるを得ない。

「医師は『延命治療の中止はできません』と言っただけなので、ある意味では楽。本当に苦しいのは患者さんや家族です」医療倫理に詳しい尾藤誠司東京医療センター臨床疫学研究室長はこう指摘している。

ACCULTURATION AND END-OF-LIFE DECISION MAKING: COMPARISON OF JAPANESE AND JAPANESE-AMERICAN FOCUS GROUPS

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Keywords

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focus groups

ABSTRACT

Variation in decision-making about end-of-life care among ethnic groups creates clinical conflicts. In order to understand changes in preferences for end-of-life care among Japanese who immigrate to the United States, we conducted 18 focus groups with 122 participants: 65 English-speaking Japanese Americans, 29 Japanese-speaking Japanese Americans and 28 Japanese living in Japan.

Negative feelings toward living in adverse health states and receiving life-sustaining treatment in such states permeated all three groups. Fear of being *meiwaku*, a physical, psychological or financial caregiving burden on loved ones, was a prominent concern. They preferred to die *pokkuri* (popping off) before they become end stage or physically frail. All groups preferred group-oriented decision-making with family. Although advance directives were generally accepted, Japanese participants saw written directives as intrusive whereas Japanese Americans viewed them mainly as tools to reduce conflict created by dying person's wishes and a family's *kazoku no jo* – responsibility to sustain the dying patient. These findings suggest that in the United States Japanese cultural values concerning end-of-life care and decision-making process are largely preserved.

INTRODUCTION

Decision making at the end of life in a cross-cultural context can be particularly difficult because these emotion-laden decisions are embedded within a matrix of cultural beliefs and values. Variations in end-of-life care exist even in mainstream decision

making models in the United States, but the fundamental value is respect for a patient's autonomy.¹

¹ T.L. Beauchamp & J.F. Childress. 1994. Respect for autonomy, non-maleficence. In *Principles of Biomedical Ethics*. New York: Oxford University Press: 120-249; E.J. Emanuel & L.L. Emanuel. Proxy decision making for incompetent patient: An ethical and empirical analysis. *JAMA* 1992; 267: 2067-2071.

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Following this principle, and because many patients have lost decision making ability before end-of-life decisions are made, advance directives have risen to prominence in the US in order to preserve autonomy in end-of-life decisions.² However, some ethnic groups, such as Asian Americans and Mexican Americans, classically hold different models for the process of decision making at the end of life.³ For instance, disclosure of a terminal diagnosis and talking with patients about dying may be considered inappropriate behaviors.⁴ Competent end-of-life care requires attention to and proficiency with the beliefs and practices of diverse cultural groups.⁵ We address an added dimension to the current cross-cultural literature on end-of-life decision making by focusing on the effect of acculturation within a single ethnic population.

The population of Americans of Asian and Pacific Islander (API) heritage is one of the ethnic groups for which classic end-of-life decision making differs from that of other ethnic groups with Western background in the US.⁶ As the number of API elderly increases, US physicians are more likely to encounter difficulties in end-of-life decision making related to differences between usual behavior and API expectations concerning disclosure and hierarchical physician-patient rela-

tionships.⁷ Japanese Americans are the sixth largest API group in the US, with a complex immigration pattern resulting in a heterogeneous Japanese American society. At present, about two-thirds of Japanese Americans were born in the US. Many speak English as their primary language, receive education in the US and marry individuals of non-Japanese descent.⁸ Such heterogeneity complicates the understanding of cultural norms, and no qualitative studies have focused on decision-making preferences at the end of life in the Japanese-American population.

In Japan, however, decision making about end-of-life care has been extensively described.⁹ As in the US, the notion that a patient's preference for care should guide decision-making is generally accepted in Japan. The practical ramifications of this belief, however, differ between the US and Japan due to variation in cultural background, social structure, and the patient-physician relationship. For example, Japanese physicians often do not provide their patients with information sufficient to make decisions, and physicians and family members in Japan often overrule patient's preferences for medical care.¹⁰ For Japanese Americans, neither cultural norms nor the effects of acculturation has been described. While acculturation has been demonstrated in studies of behavioral risk factors for disease,¹¹ little is known about the effect of

² D.M. Cox & G.A. Sachs. Advance directives and Patient Self-Determination Act. *Clin Geriatr Med* 1994; 10: 431-443.

³ L.J. Blackhall et al. Ethnicity and attitude toward patient autonomy. *JAMA* 1995; 274: 820-825.; M. Ip et al. Ethical decision-making in critical care in Hong Kong. *Crit Care Med* 1998; 26: 447-452; P. McDonald-Scott, S. Machizawa & H. Satoh. Diagnostic disclosure: A tale in two cultures. *Psychol Med* 1992; 22: 147-157; R. Charlton & S. Dovey. Attitudes to death and dying in the UK, New Zealand, and Japan. *J Palliat Care* 1995; 11: 42-47.

⁴ J.A. Careese & L.A. Rhodes. Western bioethics on the Navajo reservation: Benefit or harm. *JAMA* 1995; 274: 826-829; G.L. Brotzman & J.D. Brotzman. Cross-cultural issues in the disclosure of a terminal diagnosis: A case report. *J Fam Pract* 1991; 32: 426-427.

⁵ L.O. Gostin. Informed consent: cultural sensitivity, and respect for persons. *JAMA* 1995; 274: 844-845; A. Oppenheim & C.L. Sprung. Cross-cultural ethical decision-making in critical care. *Crit Care Med* 1998; 26: 423-424; M. Kagawa-Singer & L.J. Blackhall. Negotiating cross-cultural issues at the end-of-life. *JAMA* 2001; 286: 2993-3001.

⁶ M.C. Brannigan. 1995. *The Pulse of Wisdom: The Philosophies of India, China and Japan*. Belmont: Wadsworth Press; M.D. Fetters. The family in medical decision making: Japanese perspectives. *J Clin Ethics* 1998; 9: 132-146.

⁷ G. Yeo. Ethical considerations in Asian and Pacific island elders. *Clin Geriatr Med* 1995; 11: 139-152; K. Braun. Death and dying in four Asian American cultures: A descriptive study. *Death Stud* 1997; 21: 327-359.

⁸ H. Kitano. 1988. *The Japanese American family: In Ethnic families in America*. C.H. Mindel et al. eds. New York: Elsevier.

⁹ S. Matsumura et al. Acculturation of attitudes toward end-of-life care: a cross-cultural survey of Japanese Americans and Japanese. *J Gen Intern Med* 2002; 17: 531-539. S. Bito et al. Japanese attitudes toward advance care planning for end-of-life decisions. *Gene* 2001; 2: 3-10; T.S. Elwyn et al. Cancer disclosure in Japan: Historical comparisons, current practice. *Soc Sci Med* 1998; 46: 1151-1163; E. Feldman. Medical ethics the Japanese way. *Hastings Cent Rep* 1985; 15: 21-24.

¹⁰ T.S. Elwyn et al. *op. cit.* note 9; A. Asai, S. Fukuhara & B. Lo. 1995. Attitudes of Japanese and Japanese-American physicians towards life-sustaining treatment. *Lancet* 1995; 346: 356-359; I. Kai et al. Communication between patients and terminal care: A survey in Japan. *Soc Sci Med* 1993; 36: 1151-1159.

¹¹ R. Benfante 1992. Studies of cardiovascular disease and cause specific mortality trends in Japanese-American men living in Hawaii and risk factor comparison with other Japanese populations in the pacific region: review. *Human biology* 64: 791-805.

acculturation on the end-of-life decision-making models of Japanese Americans. Variation in acculturation to US values may affect patient and family satisfaction with the process and outcome of such decisions.

This study aimed to understand and compare the end-of-life decision-making models of Japanese living in Japan and Japanese Americans. We explored attitudes toward disclosure, preferences for decision-making at the end-of-life, and advance directives. We were particularly interested in whether attitudes more prevalent in Japanese culture in Japan were retained or whether and how these views were altered by acculturation to US society.

METHODS

In order to perform a qualitative cross-cultural analysis regarding the relationship between acculturation and end-of-life decision making among Japanese Americans and Japanese in Japan, we conducted 18 focus groups with 122 participants in three groups of Japanese participants defined according to their country of residence and language: 1) Japanese living in Japan (five groups), Japanese-speaking Japanese Americans (four groups), and English-speaking Japanese Americans (nine groups). Language was used as the distinguishing characteristic of the two Japanese American groups because it is recognized as a key component of acculturation¹² and because classification based on other measures was beyond the capacity of this study. The focus groups were conducted in 1996 and 1997. We aimed to include people over the age of 65 because they are more likely to face end-of-life decisions in the near future. Four of the five focus groups in Japan were convened as gender-specific groups while all Japanese American focus groups were gender-mixed.

One moderator and at least one co-moderator conducted each focus group discussion. A Japanese moderator led the Japanese-speaking Japanese American focus groups and the same moderator

conducted the Japanese focus groups held in Japan. At least one Japanese co-moderator participated in the English-speaking Japanese American focus groups. Each focus group session included five to nine participants, all of whom provided written informed consent. Focus group discussions averaged two hours in length with the Japanese language focus groups lasting longer because of variation in social interaction and a longer time before Japanese participants opened up to full discussion. Given the cultural disparity between the Western and Japanese models of end-of-life decision-making, a grounded qualitative approach was employed¹³ within a framework derived from the Japanese thinking-and-behavior style that is based on group orientation.¹⁴ The study protocol was approved by the UCLA IRB.

The focus group protocol was developed by a health psychologist, a medical anthropologist and a physician, in concert with Japanese American and Japanese physicians. Except for language, the protocol was identical for all focus groups and was designed to generate an open-ended discussion of four topics: (1) experiences with end-of-life care and decisions for relatives and friends, (2) attitudes toward end-of-life care, (3) preferred decision-making models for end-of-life care, and (4) attitudes about advance directives.

Toward the conclusion of each focus group, the moderators presented to each group's participants a summary of their perceptions of the views expressed during the session. They also presented possible divergent views to participants at the end of each Japanese and Japanese-speaking Japanese American session to prompt additional discussion, to test social desirability of the prior discussion, and to challenge a potentially culturally framed mode of response.

All sessions were audiotaped and then transcribed verbatim in the language of the group. Initially, the full transcripts were read without coding so that the overall themes could be understood, and homogeneity and discrepancy within groups and among sets of focus groups could be noted. Two bilingual

¹² R.M. Suinn, C. Ahuna & G. Khoo. The Suinn-Lew Asian Self-Identity Acculturation Scale: Concurrent and factorial validation. *Educ Psychol Meas* 1992; 52: 1041-1046.

¹³ M.B. Miles & A.M. Huberman. 1994. *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks: Sage.

¹⁴ C. Pope, S. Ziebland & N. Mays. Qualitative research in health care. Analysing qualitative data. *BMJ* 2000; 320: 114-116.

Table 1. Description of the Three Focus Group Samples

	Japanese in Japan	Japanese-speaking Japanese Americans	English-speaking Japanese Americans
Number of focus groups	5	4	9
Number of participants	28	29	65
Source of participants	Community and clinic sites, Tokyo	Japanese housing complex and nursing home, Los Angeles	Japanese community centers and nursing home, Los Angeles
Dates of focus groups	October 1996 to January 1997	September to December 1996	January to March 1996
65 years or older (%)	71%	84%	52%
Male (%)	50%	79%	60%
Generation*			
<i>Issei</i>	Not applicable	1	7
<i>Shin-Issei</i>		17	0
<i>Kibei</i>		4	0
<i>Nisei</i>		7	38
<i>Sansei</i>		0	20

* We did not identify mixed generation participants. The participants were asked to select one of the five categories below.

Issei = first generation immigrants.

Shin-Issei = emigrated after World War II.

Kibei = born in the US, raised and educated in Japan, and then later returned to the US.

Nisei = second generation.

Sansei = third generation.

reviewers read all transcripts and then independently developed open codes that were applied to the entire text. We first developed preliminary codes during initial transcript review. Reviewers then re-read all transcripts and sentences and phrases were coded. The 'Participants' past experiences' section of each focus group required repetitive re-coding because this section yielded many diverse themes. When new codes were detected, prior text was re-reviewed. After the full text was labeled with open codes, the two coders' transcripts were compared. Discrepancies required a return to the textual elements to achieve agreement.¹⁵ As a second step, open codes were categorized and axial codes were added. Coded passages were sorted using the 'cutting and pasting' technique.¹⁶ Codes were collected within topics, and a framework developed to identify major themes in each topic category. Lastly, one reviewer evaluated the themes within focus group sets and then compared themes across the three sets of focus groups. A second reviewer checked the analyses for coherence. We present the themes developed from each area of inquiry and compare findings across the three sets of focus groups.

¹⁵ D.G. Willms et al. A systematic approach for using qualitative methods in primary prevention research. *Med Anthropol Q* 1990; 4: 391-409.

¹⁶ Y.S. Lincoln & E.G. Guba. 1985. *Naturalistic Inquiry*. Beverly Hills: Sage Publications.

RESULTS

Most participants were over age 65, with Japanese-speaking Japanese Americans more likely than other participants to be 65 years and over, with the remainder over age 40. Half of the sample from Japan was male with a male predominance in the Japanese American groups. (Table 1)

All three groups, Japanese living in Japan, Japanese-speaking Japanese Americans and English-speaking Japanese American, described extensive experience with end-of-life decisions. Focus group participants were not reticent to discuss death, their experiences, or what these events meant to them. Table 2 summarizes the findings in the areas of interest.

Presenting bad news

Participants in all three groups indicated that talking about death and dying was not taboo in their daily conversations. Discussions were common among family members or with healthcare personnel when their lives were not threatened. Such discussions, however, did not occur with patients who were close to death. A common theme among the groups was the desire that 'bad news' should be given to the patient's family before the patient. One Japanese-speaking Japanese American woman described her experience as follows:

Table 2. Summary of Discussion Areas about End-of-Life Care Expressed by Japanese, Japanese-speaking Japanese Americans and English-speaking Japanese Americans

Theme	Japanese in Japan	Japanese-speaking Japanese Americans	English-speaking Japanese Americans
Presenting bad news	To family first, rarely to the patient	To family, then sometimes to the patient	Usually to family and then often to the patient
End-of-life care attitudes	Prefer sudden death and less family burden. Strong duty to care for family members	Prefer sudden death and less family burden. Some duty to care for family members	Prefer sudden death and less family and financial burden. Less strong duty to care for family members
Preferred decision making model	Decisions made by physician with family members Family members participate in decisions at physician's discretion	Family is main decision maker. Family is guided by the physician's professional advice	Family is main decision maker, but patient often participates Patient can play an important role in making decisions
Advance directives	Somewhat acceptable, but only in an informal fashion	Accepted, particularly to relieve family burden	Accepted. May be used to relieve family burden

When my husband . . . went to the doctor, he was told that he had cancer. Then he had an operation. He thought that only one region was involved. It was removed then, but in the meantime, it turned out to recur and spread, to be worse. His mother and sister also had cancer and had operations, but theirs did not spread. My husband still believed that only one region was involved. I already knew the truth, but I was not able to tell it to him.

In contrast, direct disclosure to the patient was more common and was a more acceptable behavior for English-speaking Japanese Americans. However, even they related their dissatisfaction with physicians who informed patients directly. They felt that the family should be informed first and then family members would share the appropriate information with the patient. One English-speaking Japanese American woman related the following:

I rather that the doctor talk to my husband, and my husband could talk with other members of the family. I think that my husband would evaluate whether it is the right thing to tell me or not.

Another English-speaking Japanese American stated:

In general, people are expected to be told. But in my feeling, and Japanese culture, a lot of families don't want to tell this person such bad news.

Compartmentalizing information was important not only to protect patients from bad news, but also because information was needed by the family in

order to make decisions. An important role of familial decision-making was to decide how much information a patient should receive. One participant in Japan related his experience:

[When my wife had cancer,] her physician disclosed the diagnosis to my son and me first. He asked us whether he should tell her that she had cancer. We discussed together and answered not to tell her the truth. Because we knew she was a sensitive person, she would be so surprised if she knew the truth. Our physician accepted our preference and did not tell anything to her.

Attitudes toward end-of-life care

Participants in all three groups idealized their end-of-life process as *pokkuri* which means in Japanese 'popping off' or 'dying suddenly without prolonged suffering'. Dying should occur without a troublesome end-of-life process. Thus, nearly all participants expressed negative feelings toward living in adverse health states. Nonetheless, they focused minimally on personal suffering. Instead, participants in all three groups were concerned about becoming a burden on their family, using the term *meiwaku*. Both Japanese and Japanese-American participants focused on the level of caregiving burden that would be borne by their families, and all groups expressed a strong unwillingness to burden others. One Japanese participant stated this attitude as follows:

If the patient remains unconscious like an only-breathing dead body, family members have to stay with him at the expense of their huge sacrifice during that time. It is a lot of burden, every morning, evening, midnight. I think the recent progress of medicine has created tragic cases in some ways.

Another Japanese participant stated:

[When I have a terminal illness] I strongly do not want to put a severe strain on my family. I do not want to give them hard pain. Therefore, I want to reject life-sustaining treatment. . . .

While the Japanese group expressed such burdens in terms of the family's physical and mental caregiving responsibility, Japanese American groups often expressed family burdens in financial terms. One English-speaking Japanese American participant said:

One of [the values] is not bothering [other] people. . . . When you are living there, if you know every day you're there it is very expensive. Somebody has got to pay for it. If your children are having to, it's coming out of their inheritance or they are having to pay for it. . . .

Preferred decision-making model

Concerning the preferred decision-making model for end-of-life care, all groups we studied preferred a group-oriented (particularly a family-oriented) model. This model resulted in decision-making by a consensus among the physician and the family, and at times, the patient. All groups rejected a decision-making model focusing purely on an autonomous individual. One Japanese-speaking Japanese American stated,

[The decision maker] should not be one person. If you have four or five family members, they should equally discuss and decide.

An English-speaking Japanese American remarked similarly,

[One group] really can't make the decision because they don't have the decision endorsed by everyone in the family.

In making a group decision, all sets of focus group participants desired some degree of familial control of information flow to the patient, particularly when the news was very bad, such as revealing a fatal prognosis. Although decision-making was centralized in family consensus across all groups, there were some differences concerning who should be the principal decision-maker and how much information should be disclosed.

Generally speaking, the Japanese focus group participants wanted end-of-life decisions to be made by the physician with the family's input. They permitted the physician to make the final decision, but they expected the decision to incorporate the family's perspective. However, there were repeated expressions of concern that physicians overrule family decisions. One Japanese focus group participant said,

I believe that my family will convey my wishes on my behalf even if I can't speak anymore. But eventually, when my family's wishes and the doctor's opinion conflict, we may have to obey the doctor's opinion. . . .

Dissatisfaction with aggressive life-sustaining treatment and excessive physician paternalism punctuated many of the Japanese focus group discussions. Another Japanese participant stated:

Once we are hospitalized, we hesitate to talk about our own preferences. . . . There is an atmosphere that we have to obey the physician's opinion. So when a doctor gives his or her suggestions, we have to say 'Yes, please'.

Another Japanese participant expressed his frustration with his physician:

My mother had bile duct cancer, and in the end she was inserted with tubes. And even if she insisted that she did not want to [have any more tests], she was forced to have laboratory tests. I have never forgotten the scene. I will never be able to forgive those doctors. It's more than ten years since then, but I hate to recall that, even now.

On the other hand, the two sets of Japanese American groups described more of a partnership role for the physician in end-of-life decisions and never raised the issue of paternalistic behavior. One

Japanese-speaking Japanese American woman described her experience in this way:

[My husband] existed like a vegetable. He was on many life – prolonging machines. The doctor called us, and we – I and my son and relatives – discussed together. Finally the doctor and our family reached the same opinion. We were sure that our Dad did not want to live with such machines.

English-speaking Japanese Americans retained a family-oriented decision-making model, but focused more on the patient's role, particularly if the patient was young or long-term care was required. They more often accepted the patient's participation in the discussion, and at times even welcomed the patient as a main decision-maker.

In increasing the patient's role in decision-making, both sets of Japanese American groups advocated more information disclosure to the patient compared to the Japanese focus groups. In this way, the patient could be more involved in the decision-making process. However, even the English-speaking Japanese American groups often felt that the family should decide whether the patient should play a role in decision making. An English-speaking Japanese American said:

I think [the decision is made] usually in the family. In the discussion with them, maybe they will decide on whether the patient enters into the discussion. . . .

Attitudes about advance directives

Participants in all three groups accepted the concept of advance care planning for terminal illness. However, there was universal concern that advance directives might conflict with the expected role of family members in end-of-life decision-making. This contradiction was expressed poignantly in the dissonance between what participants would want for themselves and what they would want for loved ones. Nearly all participants rejected aggressive treatment for themselves in the setting of future terminal illness. Nevertheless, they desired that a loved one should be kept alive, even if they knew that this individual's explicit wish was to forgo aggressive care. While most participants accepted that the

family would override the patient's preference under these circumstances, there was profound ambivalence. Focus group participants were concerned about the conflicts caused by these feelings. Many Japanese participants described this feeling in terms of *kazoku no jo*, which denotes the family's requirement to act in a benevolent fashion toward the patient:

*Even if the patient's will is clear, it is hard for the family to withdraw treatment – this is *kazoku no jo* [benevolence of family].* (Japanese participant)

*As family members' *jo*, we'd like to do our best to give any treatment that we can for our loved one.* (Japanese-speaking Japanese American)

You don't want your mom to die. Even if she is just a vegetable, she is still something [to family members], no matter what you say. (English-speaking Japanese American)

Notably, these similar attitudes translated into vastly different behaviors concerning advance directives between the Japanese groups and the Japanese American groups. The Japanese groups were reluctant to give power to advance directives and they disliked the concept of written documents. In addition, they voiced reluctance to involve lawyers and hospitals in end-of-life decisions. A Japanese participant related the following reasoning:

I do not want too much [life-sustaining treatment] . . . I want to be allowed to die as naturally as possible. But, things like this, can we request the doctor [to let us die naturally] after we lose consciousness? No, we can't. . . . So what shall I do? You may say if I write a living will, it will be only my idea. We do not follow individualism. I have my family and my doctor. I don't want them to regret only because I write my will. That is what worries me most.

In contrast, the Japanese American groups readily accepted advance directives. However, these documents were viewed not as a way to promulgate their autonomy in end-of-life care, but as a way to relieve familial burdens. Some participants said that they already had signed an advance directive.

For example, one Japanese-speaking Japanese American remarked that his reason for completing an advance directive was to reduce his family's emotional conflict over not beginning life-sustaining treatment:

Personally, I need to write it [advance directive] because all my family is living in Japan and I am alone in the US. So, in order to avoid [being] a burden on others, I would like to deal with everything related to myself. Yes, I want to leave one [advance directive].

For some English-speaking Japanese Americans, advance directives were seen as a tool to solve the conundrum of accepting the notion that a patient's preferences should be followed while also permitting the family to act with benevolence. These participants expressed concern that family members who let a patient die without life-sustaining treatment would regret their decision even if it followed a patient's wishes.

DISCUSSION

The findings from these 18 focus groups reveal openness toward end-of-life topics among both Japanese and Japanese-Americans. Personal experiences differed among the three sets of groups principally because of differences in disclosure of information and decision making styles. Participants in all three groups expressed traditional Japanese cultural themes concerning attitudes toward end-of-life care, but the manifestation of these attitudes in terms of decision making and advance care planning differed. Taken together, these findings suggest that Japanese values concerning end-of-life care are preserved among first and second generation Japanese Americans, but acculturation affects how these values are manifest within US society.

Preserved values

Japanese cultural values appear to be preserved in the Japanese-speaking and English-speaking Japanese American groups. Such values, deeply held

by the focus group participants in Japan, are largely distinct from Western views.¹⁷

Family control of information disclosure to the patient was emphasized among all three sets of focus group participants. Most participants insisted on the provision of information to family members before informing the patient if the news was very bad. It should be noted that, even in Japan, not all bad news was withheld from patients; much information about adverse (but not terminal) diagnoses would be revealed directly by a physician to a patient.¹⁸ For worse news, physicians and family members together decide on the appropriate level and timing of disclosure. In Japan, this remains the dominant mode of information disclosure toward the end of life.¹⁹ The demise in 1989 of the prior emperor Hirohito, who had terminal pancreatic cancer, was a typical example. The diagnosis was not disclosed to him or to the public until his death. Newspapers that prematurely reported his diagnosis were severely criticized.²⁰

From the perspective of a Western, individual autonomy based model, such secrecy might be considered unacceptable, but Japanese and Japanese-descent Americans found this mode of privacy of information to be acceptable concerning disclosure to others. Surveys conducted in Japan show that nearly three-quarters of Japanese people would not want to disclose the diagnosis to a family member who has terminal cancer. Yet a majority of them want to be told when they have a terminal illness.²¹ Older Koreans in the U.S reported similar attitudes toward end-of-life decisions in a prior study. Those

¹⁷ L.J. Blackhall et al. *op. cit.* note 4; M. Kagawa-Singer & L.J. Blackhall, *op. cit.* note 5.

¹⁸ T.S. Elwyn et al., *op. cit.* note 9.

¹⁹ A. Akabayashi, M.D. Fetters & T.S. Elwyn. Family consent, communication, and advance directives for cancer disclosure: A Japanese case and discussion. *J Med Ethics* 1999; 25: 296–301; S.O. Long. Family surrogacy and cancer disclosure: physician-family negotiation of an ethical dilemma in Japan. *J Palliat Care* 1999; 15: 31–42.

²⁰ Y. Takahashi. The demise of the last emperor: Its influence on Japanese society from a thanatological viewpoint. *Crisis* 1989; 10: 168–178.

²¹ Y. Morioka. Informed consent and truth telling to cancer patients. *Gastroenterol Jpn* 1991; 26: 789–792; N. Tanida. Japanese attitude towards truth disclosure in cancer. *Scand J Soc Med* 1994; 22: 50–57.

individuals wanted to know critical clinical information about themselves, but did not want family members to be told.²²

Participants repeatedly underscored the discordance between what they would want done for themselves at the end of life and what they feel compelled to do for family members. They eschew prolonged survival in adverse health states yet they focused on the physical, psychological and financial burdens on family caregivers rather than on personal suffering. Many participants explained this feeling as 'I do not want to be a *meiwaku* (annoyance) for my loved ones'. Japanese Americans and Japanese alike expressed a powerful unwillingness to be a burden on their family.

The conflict between the family's preferences and the patient's will permeated all three sets of focus groups. Patients desired to reduce caregivers' burdens, whereas caregivers' responsibility according to *kazoku no jo* does not permit them to give up on a loved one, even if she or he were in poor clinical condition.²³ The participants were cognizant of this emotional conflict.

This shared value of *meiwaku* and the discordance with *kazoku no jo* leads to the most notable difference between Japanese and Japanese Americans: their acceptance of advance directives. Some Japanese Americans had completed or desired advance directives to relieve family members of responsibilities, however, the intent of the Japanese Americans differs from the autonomy model.²⁴ The advance directive would function as a 'proxy for the proxy', supporting and redirecting the actions of family members whose *jo* would prevent the withdrawal of life-sustaining treatment. This reveals that apparent acceptance of advance directives must be understood in a cultural context. For Japanese Americans, advance directives are not meant to be expressions of autonomy as much as a means to

alleviate the emotional burden of family members for accepting withdrawal of the life-sustaining treatments of their loved one. Japanese participants perceived the same need, but rejected formal signed advance directives.

The notion that end-of-life decisions should be settled by group consensus of family members is another value that appears to be preserved across the three groups. Many prior studies have demonstrated that some ethnic groups in the US, such as Native Americans, African-Americans, Mexican Americans and Korean Americans, prefer the family unit to participate in end-of-life decisions.²⁵

Most participants in this study also desired that their family members be involved in significant medical decisions. In Japanese culture, important decisions must account for how one's behavior influences others.²⁶

This notion derives from the Japanese respect for harmony and interdependence, rather than individual autonomy,²⁷ as in the Japanese proverb '[we should] make everything right with harmony'²⁸ This model subjugates autonomy to the more compelling value of collective well-being.

In Ruth Benedict's classical analysis, she concluded that Japanese culture is a 'culture of shame'.²⁹ 'Shame' in this context meant that Japanese people tended to avoid confrontation with others. Japanese would choose preferences reflecting 'our' wishes (including loved ones) rather than 'my' wishes. This feeling is rooted in *enryo* (reservation) behavior, a core feature of Japanese culture.³⁰

²² L.J. Blackhall et al. *op. cit.* note 3; S.T. Murphy et al. Ethnicity and advance care directives. *J Law Med Ethics*. 1996; 24: 108-117; B.A. Koenig, J. Gates-Williams. Understanding cultural difference in caring for dying patients. *West J Med* 1995; 163: 244-249.

²³ J.H. Muller & B. Desmond. Ethical dilemmas in a cross-cultural context: A Chinese example. *West J Med* 1992; 157: 323-327.

²⁴ A. Akabayashi, B.T. Slingsby & I. Kai, Perspectives on advance directives in Japanese society: A population - based questionnaire survey. *BMC Med Ethics* 2003; 4: E5

²⁵ L.J. Blackhall et al., *op. cit.*, note 3; J.A. Careese & L.A. Rhodes, *op. cit.* note 4; K. Braun, *op. cit.* note 7; L. Crawley et al. Palliative and end-of-life care in the African American community. *JAMA* 2000; 284: 2518-2521.

²⁶ M.C. Brannigan. Relationality and consensus in Japan: Implications for bioethics policy. *Health Care Anal* 1999; 7: 289-296; T. Morita et al. Family experience with palliative sedation therapy for terminally ill cancer patients. *J Pain Symptom manage* 2004; 28: 557-565.

²⁷ T. Doi. 1997. *The anatomy of dependence*. Tokyo. Kodansha International.

²⁸ Sanseido ed. 2001. *Shinmeikai Japanese Proverb Dictionary*. Tokyo: Sanseido: 1505.

²⁹ R. Benedict. 1946. *The Chrysanthemum and the Sword*. Boston. Houghton Mifflin Co.

³⁰ T. Kuwayama. 1989. *The Japanese conception of self: The dynamics of autonomy and heteronomy*. Los Angeles: University of California Los Angeles: 910-916; H.L. Kitano. *Japanese-Americans: The evolution of a subculture*. Englewood Cliffs: Prentice Hall.; T.S. Lebra. 1976. *Japanese patterns of behavior*. Honolulu: University of Hawaii Press; T. S. Lebra.

In Japanese culture, stating one's personal preferences or opinions is often regarded as ill-mannered or selfish. Priority is given to 'collective welfare' rather than 'individual welfare.' The focus group findings suggest that these values continue to be compelling for Japanese Americans. For Japanese and many Japanese Americans, 'autonomy' rests at the family level. In comparison to the individual autonomy model, decision making in Japanese culture is based on 'familial autonomy.'³¹

Influences of acculturation

Despite the preservation of cultural values and shared overall decision-making model, some attitudes toward end-of-life decision-making behavior appear to change with acculturation to mainstream US culture and attitudes toward health care and autonomy (see Table 2).

First, disclosure of a terminal diagnosis became more acceptable with acculturation. Such information, however, is still disclosed to the family, who then deliberate and may choose to give the information to the patient in due time and in the proper format. Healthcare providers need to be aware that in disclosing bad news to an acculturated Japanese American, one would not be able to predict the acceptability of disclosure without inquiring. This inquiry can usually be asked of the patient in a tactful fashion.³² Based on these focus group findings, in most cases disclosure would be directed first toward the family.

A second area of difference by acculturation is found in the decision-making model. The dominance of the physician in decision making is diminished in the US where there is a less hierarchical physician-patient relationship.³³ Associated with this less subordinate relationship is greater trust in

one's physician reported by Japanese Americans compared to Japanese living in Japan.³⁴ While the structure of decision making retained a group-orientation, the role of the patient was more prominent among English-speaking Japanese Americans, for whom the patient played a prominent role in decision-making within the family.

Third, while all three groups accepted the concept of advance care planning, Japanese participants rejected formal advance directives. People in Japan do not wish to introduce legal mechanisms into intimate healthcare decisions that they see as the purview of the family and physician. This is consistent with the less frequent personal use of lawyers in Japan compared to the US.³⁵ Furthermore, legal documents tend to be confrontational, a posture to be avoided in Japan, and may interfere with decision making at the level of the family unit.³⁶

Last, the perception of the family's caregiving obligation seems to shift to some degree with greater English-speaking comfort. Japanese-speaking Japanese Americans reported less familial caretaking expectation than the Japanese in Japan, and English-speaking Japanese Americans reported that the healthcare system would attend to long-term care. Noteworthy, however, the children of the English speaking Japanese were not included in the focus groups and therefore we do not know how much obligation the adult children of these participants may feel. Similarly, adult children in Japan were not included; changing economic conditions and urbanization in Japan may affect the propensity and ability of children to be intimately involved in the daily care of their parents at the end of life due to geographic distance and obligation to their own children. In Japan, participants still strongly held the expectation that family members would look after disabled or dying loved ones,³⁷ although it is not always actuated.³⁸ Usually, the eldest son and

1984. Nonconfrontational strategies for management of interpersonal conflict. In *Conflict in Japan*. E.S. Krauss, T.P. Rohlen, & P.G. Steinhoff, ed. Honolulu. University of Hawaii Press: 41-84.

³¹ D.J.R. Macer 2004. End of Life Care in Japan. In *End of Life Care Across the World*. R.H. Blank, ed. Boston, MA. MIT Press: 109-129.

³² Kagawa-Singer & L.J. Blackhall, *op. cit.* note 5; M.D. Fetters. *op. cit.* note 6.

³³ A. Akabayashi et al. *op. cit.* note 19; A. Asai et al. Medical decisions concerning the end-of-life: A discussion with Japanese physicians. *J Med Ethics* 1997; 23: 323-327; G.J. Annas & F.H. Miller. The empire of death: How culture and economics affect informed consent in the US, the UK, and Japan. *Am J Law Med* 1994; 20: 347-394.

³⁴ D.M. Tarn et al. Trust in One's Physician: The Role of Ethnic Match, Autonomy, Acculturation, and Religiosity Among Japanese and Japanese-Americans. *Ann Fam Med* 2005; 3: 339-347.

³⁵ R.B. Leflar. The cautious acceptance of informed consent in Japan. *Med Law* 1997; 16: 705-720.

³⁶ Y. Masuda et al. Outcomes of written living will in Japan: A survey of the deceased's families. *Bioethics Forum* 2001; 17: 41-52.

³⁷ N. Yamamoto & M.I. Wallhagen. The continuation of family caregiving in Japan. *J Health Soc Behav* 1997; 38: 164-176.

³⁸ N. Ikegami. Growing old in Japan. *Age Ageing* 1998; 27: 277-278.

his wife are obligated to live with their parents and care for them. On the other hand, many Japanese American elderly remarked that they did not resist living in a nursing home or living apart from their children.³⁹ Often, however, this is due to reluctance on the part of the elderly to impose upon the Americanized lifestyles of their children, not because they themselves would not like to have this familial care.

LIMITATIONS

Our qualitative study has several methodological limitations. First, the study samples were derived from limited geographic areas in Japan and the United States. Because the participants were sampled in Tokyo and Los Angeles, they represent only urban residents. In Japan the population in rural areas tends to have more conservative views than the urban population.⁴⁰ Similarly, Japanese Americans in Los Angeles are likely to be different from those elsewhere in the US. Japanese-Americans in Los Angeles have easy access to Japanese newspapers, Japanese associations and Japanese temples. In addition, the Los Angeles samples were recruited from Japanese agencies and organizations, thus selecting individuals with strong ties to the Japanese American community. These constraints limit the generalizability of our findings.

Second, a formal analysis of acculturation was not performed in this study and we identify acculturation to US society only by primary language. Although language preference is a key component of acculturation, other factors also affect acculturation.⁴¹ Since language was the only indicator used for acculturation, the more multi-dimensional aspects of this construct were not discernable.

Third, the majority of our subjects were old. The US focus groups included few third generation (Sansei) participants. In fact, many participants pointed out that their children or grandchildren

have different attitudes toward end-of-life decision making, indicating that changes will continue to occur over time.

CONCLUSIONS AND RECOMMENDATIONS

Recognizing these limitations, we believe that we have conducted one of the first studies of the acculturation of attitudes and decision-making model concerning end-of-life care. We draw several conclusions from these data that have implications for the end-of-life treatment of Japanese and Japanese-Americans.

Universal application of an autonomy-based end-of-life decision-making model to all Japanese Americans would not conform with the cultural norms of many of these individuals. A monolithic autonomy model would likely produce conflict among more traditional patients, families and providers, resulting in ill feelings among family and friends and perhaps suboptimal clinical outcomes. The repercussion of such experiences may subsequently deter future discussions about care at the end of life, with the family as well as other community members.

Culturally sensitive and skilled end-of-life care requires recognition that attitudes toward end-of-life care and models of end-of-life decision making are modified by acculturation. The clinician who recognizes that a patient might adhere to a non-Western model of end-of-life care can carefully explore the patient's and family's expectations and negotiate more appropriate channels for information disclosure and facilitate decision making, and when appropriate, advance care planning.⁴²

Japanese health care providers should note the dissatisfaction expressed by the Japanese focus group participants toward physicians' paternalistic attitude in end-of-life decisions. Further research should explore the effect of the strongly hierarchical Japanese physician-patient relationship on the dying process for both patients and families. Other cross-cultural studies indicate similar variations

³⁹ W. McCormick et al. Attitude toward use of nursing homes and home care in older Japanese Americans. *J Am Geriatr Soc* 1996; 44: 769-777.

⁴⁰ S. Okuno et al. Elderly Japanese people living in small towns reflect on end-of-life issues. *Nurs Ethics* 1999; 6: 308-315.

⁴¹ R.M. Suinn et al., *op. cit.* note 12; L.S. Meredith et al. Development of a brief scale to measure acculturation among Japanese Americans. *J Community Psychol* 2000; 28: 103-113.

⁴² R.M. Suinn et al., *op. cit.* note 12.

among countries exist, but little study has been conducted in this area internationally.⁴³

Finally, this exploratory study demonstrates the need for additional qualitative and quantitative evaluation of end-of-life attitudes and models within and between cultural groups. Understanding cultural differences and the effect of acculturation may reduce cultural conflicts and misunderstandings and lead to improved care for patients and families at the end of life.

⁴³ J.L. Vincent. Cultural Differences in End-of-life Care. *Crit Care Med* 2001; 29: N52–N55.

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Development of a national clinical guideline for artificial hydration therapy for terminally ill cancer patients

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ABSTRACT

Background. Although a large difference in physician practice in artificial hydration therapy for terminally ill cancer patients can cause unnecessary suffering from over- or under-hydration of patients, no clinical guideline is available in Japan. This paper illustrates a summary of a nationwide project to construct a clinical guideline for artificial hydration therapy.

Methods. The Japanese Society of Palliative Medicine constructed a national multidisciplinary committee (6 palliative care physicians, 6 surgeons, 4 anesthesiologists, 3 oncologists, 2 home-care physicians, 5 nurses, a social worker, 2 bioethicists, a lawyer, and 2 epidemiologists) to develop a clinical guideline for artificial hydration therapy for terminally ill cancer patients, using evidence-based and formal consensus-building methods with the Delphi technique.

Results. After systematic literature review, three sequential sessions of discussion by the Delphi method, and external review, a clinical guideline was constructed. This guideline includes general recommendation, specific recommendations (31 recommendations for medical aspects, 9 recommendations for nursing, and 7 recommendations for ethics), background descriptions, case examples, communication examples, complete reference list, and structured abstracts of all relevant original articles.

Conclusion. The Japanese Society of Palliative Medicine constructed a clinical guideline for artificial hydration therapy for terminally ill cancer patients, using the evidence-based and formal consensus-building methods. The clinical efficacy of this guideline should be tested in future.

Introduction

Recent literature revealed a large difference in physician practice in artificial hydration therapy for terminally ill cancer patients¹. This means the possibility that patients may undergo unnecessary suffering from over- or under-hydration. The establishment of a clinical guideline can contribute to patient well-being by clarifying the best practice recommended from empirical evidence and expert experience available. To date, we have had several clinical practice guidelines²⁻⁷, however, they are general recommendations rather than for specific clinical questions, and, in Japan, relevant guideline is unavailable.

In this paper, we aimed to report the methodology in developing a clinical guideline about artificial hydration therapy, general recommendations, and the specific recommendations regarding the quality-of-life-related medical aspects of the guideline. The original paper (available from the authors, in Japanese) further includes specific recommendations from nursing, psycho-social, and ethical aspects, background descriptions, case studies, and structured abstracts of all relevant original articles.

Methods

We had first decided to focus our discussion on artificial hydration therapy, not all artificial nutrition therapies, because enteral nutrition is rarely performed in our current practice. The primary aim of the guideline is thus to help clinicians make a clinical decision about artificial hydration therapy to ensure better quality care for terminally ill cancer patients.

The target population is adult cancer patients with incurable cancer, except for the head and neck, esophagus, and liver primary origin, without adequate oral intake refractory to appropriate palliative treatments who are likely to die within one to two months. We defined “terminally ill cancer patients” as cancer patients with estimated survivals of 1-2 months or less, and recommended the clinical estimation of patient prognoses to be assessed by a multidisciplinary team on the basis of validated methods (e.g., the Palliative Prognostic Score, Palliative Prognostic Index^{8,9}). The targeted users are healthcare professionals who treat the target population as described above.

The health objectives for this guideline are quality of life, dying, and death. We assume that the determinants of the quality of life, dying, and death vary among individuals, and individuality is essential to define what is important for each patient. In general, palliation

of physical distress, peace of mind, having a good family relationship, not being a burden to others, completion of life, fighting against cancer, maintaining hope, and not being aware of death are important to achieve a good death for Japanese ¹⁰.

Conceptual framework (Figure 1)

We second determined the conceptual framework used in this guideline. We strongly recommended clinicians to respect patient and family value, to individualize the treatment suitable for each patient, to assess the situation comprehensively from a medical, practical, psycho-social, ethical, and legal point of view, and to reevaluate the treatment efficacy periodically. On the basis of this conceptual framework, clinicians should first clarify the general treatment goal consistent with patient and family values. Second, clinicians should comprehensively assess the situation, especially the potential effects of artificial hydration therapy on patient physical symptoms, survival, daily activities, and psycho-existential well-being, in addition to ethical and legal issues. Third, clinicians should decide one treatment plan after discussion with patients and families. Finally, most importantly, clinicians should periodically reevaluate the treatment efficacy at planned intervals, and adjust the treatment suitable for each patient.

Development process

The Hydration Guideline Task Force developed this guideline, following the Japanese national recommendation to develop a clinical guideline ¹¹. The Task Force consisted of 32 experts: 6 palliative care physicians, 6 surgeons, 4 anesthesiologists, 3 medical oncologists, 2 home-care physicians, 5 nurses, a social worker, 2 bioethicists, a lawyer, and 2 epidemiologists (Appendix). The Japanese Society of Palliative Medicine approved each member had enough clinical and professional competency to complete this task.

First, the Task Force gathered clinical questions using a questionnaire survey on the members of the Japanese Society of Palliative Medicine. We then structured each question into the PICO-style question, but we had noticed there was no adequate empirical evidence for most of such structured question. We thus reconstructed more than 100 original clinical questions into unstructured questions.

Next, the Task Force performed a systematic literature review, and obtained 116 original articles and 6 relevant clinical guidelines. The principle search term was (palliative OR hospice OR end-of-life OR terminal OR advanced OR cachexia OR cachexic) AND (neoplasms OR neoplastic OR cancer OR carcinoma OR malignant OR malignancy) AND (“nutritional support” [MeSH] OR nutrition OR “fluid therapy” [MeSH] OR rehydration OR dehydration OR hydration). All articles were formulated into structured abstracts and distributed to all members with the full texts. Evidence-level tables were: I: Systematic review, meta-analyses; II: one or more randomised controlled trials; III: non-randomised intervention trials; IV: observational studies; V: descriptive studies; VI: expert opinion, physiological findings ¹¹. The Task Force decided to use an original recommendation table for this project to articulate the levels of each recommendation (Table 1).

After drafting recommendations, the Delphi technique was performed to examine the validity of each statement ^{12,13}. The members were requested to rate the validity of all recommendation statements on a 9-point Likert-type scale from 1 (not appropriate) to 9 (appropriate). On the first evaluation, the median value was ≥ 8 in 131 items (the difference between the minimum and maximum was ≤ 5 in 94 items and ≥ 6 in 37 items), and in the remaining 6 items the median values were 7 or 7.5. The median, minimum, and maximum values were disclosed to each member, and differences in opinions were discussed and resolved in a face-to-face conference. In the second evaluation, in all statements, the median value was ≥ 8 and the difference between the minimum and maximum was 5 or less.

Finally, six external reviewers (3 palliative care physicians, a medical oncologist, 2 nurses) and five bereaved family members of cancer patients provided free comments. After circulated those comments, the final Delphi evaluation achieved the median value was ≥ 8 and the difference between the minimum and maximum was 5 or less in all statements. We determined that the major difference had been resolved, and adopted this as the final version.

Results

In this paper, we report a general recommendation part and recommendation examples regarding quality-of-life-related medical aspects of artificial hydration therapy, due to the limitation of text number.

General recommendations

[Respect for patient's and family's value, wishes, and individuality]

1. The aims of artificial hydration therapy should be consistent with overall treatment goal on the basis of each patient's and family's value. Improvement of laboratory findings and nutritional status alone is not primary end-point for artificial hydration therapy.
2. Patient's and family's wishes should be respected in the treatment decision.
3. Artificial hydration therapy should be individualized to each patient's and family's situation. Routine use or un-use of artificial hydration therapy is not supported.

[Evaluation]

4. The indication of artificial hydration therapy should be based on comprehensive assessment about patient overall quality-of-life, satisfaction, physical symptoms, survival, psycho-existential well-being, daily activities, and ethical and legal issues.
5. Dehydration and/or water depletion in the terminal stage does not always cause discomfort for patients. Improvement in objective findings, such as laboratory findings, urine volume, and central venous pressure, are not primary end-points in artificial hydration therapy.
6. Periodical reevaluation and timely adjustment of treatment regimens is essential to maximize the treatment benefit of artificial hydration therapy.

[Maximization the balance between benefits and burdens]

7. Artificial hydration therapy should maximize the balance between benefits and burdens of artificial hydration therapy.

[Importance of nursing and psycho-social care]

8. For terminally ill cancer patients suffering form decreased oral intake, not only artificial hydration therapy, pharmacological treatment to improve appetite, nursing care, psycho-social interventions, and support in the decision-making and daily activity is of great importance.

[Summary of medical recommendations]

9. For terminally ill cancer patient with poor performance status and/or decreased oral intake from progressive malignancy-related etiology other than bowel obstruction, artificial hydration therapy alone is unlikely to improve patient overall quality of life.
10. For terminally ill cancer patient with better performance status and decreased oral intake due to bowel obstruction, artificial hydration therapy can improve patient overall quality of life.
11. Artificial hydration therapy can deteriorate distress related to ascites, pleural effusion, and peripheral edema in terminally ill cancer patients.
12. Artificial hydration therapy is unlikely to alleviate the sensation of thirst of terminally ill cancer patients. Intensive nursing care is of most importance to alleviate the sensation of thirst.
13. In some terminally ill cancer patients, artificial hydration therapy can contribute to improvement in quality of life through alleviating opioid-induced delirium and acute dehydration/water depletion.
14. Subcutaneous hydration can be appropriate for terminally ill cancer patients for whom intravenous line is difficult to be instituted and/or distressing.

Specific recommendations

1. General QOL

Rationale

In patients with poor performance status and median survival of 4 days, a randomized controlled trial demonstrated no significant benefits of 1000mL/day hydration compared with 100mL/day hydration⁴⁴, and this finding is consistent with other observation studies^{21, 40}.

On the other hand, some audit trials demonstrated that artificial hydration therapy could contribute to maintaining quality of life in patients with better performance status^{14, 15, 16, 19, 28, 34}. The backgrounds of the patients who received considerable benefits from this

intervention included better performance status, bowel obstruction, and estimated survival of several months or longer.

Available empirical evidence thus suggests that 1) artificial hydration therapy is ineffective in improving general quality of life in cancer patients close to death, 2) artificial hydration therapy can be effective in improving general quality of life in cancer patients with better performance status, bowel obstruction, and estimated survival of several months.

Recommendations

R010: To improve general QOL in terminally ill cancer patients who are expected to live for 1–2 months, are incapable of oral fluid intake due to intestinal obstruction, but show a performance status of 2 or better:

- Simple hydration at 1000–1500 mL/day (400–600 kcal/day, N 0 g/day). [C]
- Hyperalimentation at 1500 mL/day (1000 kcal/day, N 5 g/day). [C]
- Simple hydration at 2000 mL/day (800 kcal/day, N 0 g/day). [D]
- Hyperalimentation at 2000 mL/day (1600 kcal/day, N 10 g/day). [D]

R011: To improve general QOL in terminally ill cancer patients who are expected to live for 1–2 weeks, are incapable of oral fluid intake due to intestinal, and show a performance status of 3 or worse

- Simple hydration at 1000–1500 mL/day (400–600 kcal/day, N 0 g/day). [D]
- Hyperalimentation at 1000–2000 mL/day (800–1600 kcal/day, N 5–10 g/day). [E]

R012: To improve general QOL in terminally ill cancer patients who are expected to live for 1–2 weeks, are incapable of oral fluid intake due to progressive cachexia, and show a performance status of 3 or worse:

- Simple hydration at 1000–1500 mL/day (400–600 kcal/day, N 0 g/day). [E]
- Hyperalimentation at 1000–2000 mL/day (800–1600 kcal/day, N 5–10 g/day). [E]

2. Ascites

Rationale

We have had no intervention trials with primary end-points of ascites. One large multicenter prospective observation study suggested that patients receiving 1000mL/day or more hydration during the last 3 weeks experienced significantly severe ascites than those receiving no or less than 1000mL/day hydration⁴¹. This is consistent with another multicenter retrospective observation study, nation-wide opinion survey, and other small observation studies^{33, 43, 45}.

Available empirical evidence thus suggests that 1) less than 1000mL/day hydration is unlikely to deteriorate ascites, and 2) 1500–2000mL/day hydration can deteriorate ascites, and 3) volume reduction can alleviate ascites.

Recommendations

R020: To minimize ascites-related distress in terminally ill cancer patients who are expected to live for 1–2 months, are capable of oral fluid intake of 500 mL/day or more, and have symptomatic ascites:

- No artificial hydration therapy. [B]
- Artificial hydration therapy is limited to 500–1000 mL/day or less, if performed. [C]

R021: To minimize ascites-related distress in terminally ill cancer patients who are expected to live for 1–2 months, are incapable of oral fluid intake, and have symptomatic ascites:

- Artificial hydration therapy is limited to the volume of vomiting + 500–1000 mL/day or less, if performed. [C]

R022: To minimize ascites-related distress in terminally ill cancer patients who are expected to live for 1–2 months, are incapable of oral fluid intake and receiving artificial hydration therapy at 2000 mL/day, and show exacerbation of ascites: