

表 1 日本老年医学会による“終末期”の定義

<p>“立場表明”を出す目的</p> <p>わが国に生活するすべての人は人生の最終局面である“死”を迎える際に、個々の価値観や思想・信仰を十分に尊重した最善の医療を受ける権利を有する。最善の医療とは単に医学的な知識・技術のみではなく、他の自然科学や人文・社会科学を含めたこの国のすべての知的・文化的成果を還元した医療であると思われる。日本老年医学会はすべての人がこの権利を有すると考え、この権利を擁護・推進する目的で“高齢者の終末期の医療およびケア”に関する日本老年医学会の“立場表明”を表明する。</p>
<p>“立場表明”における定義</p> <p>“立場表明”で述べる“終末期”とは、「病状が不可逆的かつ進行性で、その時代に可能な最善の治療により病状の好転や進行の阻止が期待できなくなり、近い将来の死が不可避となった状態」とする。</p> <p>〔論拠〕 高齢者は“終末期”にあると判断されても、わが国では余命を予測するための医学的成績の集積が現状では不十分であり、余命の予測が困難であるため、“終末期”の定義に具体的な期間の規定を設けなかった。</p> <p>“高齢者の終末期”の定義に関しては現在ではこのような曖昧なものであるが、“悪性腫瘍の終末期”、“脳卒中の終末期”、“痴呆疾患の終末期”、“呼吸不全の終末期”など、高齢者に多く不可逆的・進行性の過程をたどることの多い個別疾患ごとの検討が日本老年医学会の今後の課題となるであろう。</p> <p>また、高齢者が心身ともに個別性が高いことから年齢規定が不適切だと思われるので、“高齢者”に関して暦年齢による規定を行わなかった。</p>

肺疾患の場合は確実に“死”に向かいながらもこの間に急性代償不全のエピソードを繰り返していくが、どのエピソードも高齢者には潜在的に致死性であるので、正確な“死期”の判断は非常に難しい。

3. いわゆる老衰死

脳卒中などの疾患を契機に徐々に精神・身体機能が低下・衰弱して全身介助状態に至り、肺炎や心不全を引き起こしながら最終的に“死”に至る例がある。この経過は全体としてみれば特定の疾患や臓器不全によるものというより個体全体の“老化”の結果というべきものである。寝たきり・全面介助状態に至ると、患者の“人権”や“尊厳”が脅かされる可能性が高くなるので、この状態に至った“老衰”は“終末期”に準じて考えるべきだと主張が存在する³⁾。この場合も期間としては6カ月を超えることが少なくない。

このような“老衰”の過程で生じる“摂食不能”を放置すれば“死”に至るが、この“老衰死”は“脱水死”であり、通常苦しみは少なく、死亡までの期間も短く、治療による苦痛もない、ある意味で受け入れやすい死に方といえる。ヨーロッパ諸国ではこのような場合に人工栄養を施さないで安らかに“死なす”ことが社会的合意となっているようである⁴⁾。しかし、わが国ではこのような場合に補液な

どの医療処置を施さない例はきわめて少ない。それは、ひとつにはこの場合の“摂食不能”が“不可逆的”であると判断することが困難だからである。“老衰”の経過中に生じる“摂食不能”は肺炎などの急性疾患が原因のことが多く、これを治療すれば摂食可能となる場合が少なくないからである⁴⁾。

もうひとつ大事な点は、ヨーロッパ諸国と異なり日本ではこのような場合の医療措置に対する国民的合意が成立していないことである。一般国民を対象にしたアンケートによれば、たとえ植物状態に陥ったとしても人工栄養などの延命処置を希望するものが少数ながら存在し、しかも高齢者ほどその比率が増加する⁵⁾。医療における“自己決定権”の行使が、慣習としても制度としても成熟しているとはいえない日本社会においては、“老衰”の過程での“終末期”の判断は非常に難しい。

4. 痴呆の“終末期”

痴呆が高度になると身体活動は著しく低下し摂食量も減少する。他者とのコミュニケーションもなくなり、食事も受け付けなくなり、最終的には“老衰”の末期と同様の状態に至る。かりに全面介助状態になった時点からを“終末期”とすれば、この場合も6カ月を超えることは珍しくない。

以上述べたように、“ターミナルケア”、とくに

高齢者のそれを正確に定義するには非常な困難を伴い、具体的に確立されたあり方は皆無といってもよい。このような観点から、高齢者終末期医療のあり方を提言したアメリカ老年医学会は、“終末期”患者の代りに“死にゆく人びと (dying patient)”という用語を用いている⁶⁾。

ターミナルケアとは

遠からず“死”が避けられない状態となり患者の身体的苦痛・精神的苦痛の除去が医療の主眼となるとき、これを“ターミナルケア”とよぶ。“ターミナルケア”の目的は苦痛・苦悩の緩和により患者のQOLを維持・向上することにある。だからといって“終末期”に発生した治癒可能な急性疾患をすべて放置することではない。治療すればふたたび苦痛のない時間がある程度予測されるならば、当然に治療されねばならない。

“ターミナルケア”においてQOLの視点はとくに重要である。残された時間をどのような状態で過ごすことが有意義であるかは、患者個々の価値観によるところが大きい。患者の選択が保障されるためには適切なインフォームドコンセントが必要がある。そのうえで何の束縛もない自由意思で下されるのが“自己決定”である。

高齢者の“ターミナルケア”とは

高齢者の“ターミナルケア”の特徴を考えると、高齢者に特徴的な“終末期”に対する適切な医療のあり方を考えるということである⁶⁾。高齢者の“終末期”に対しては特徴的な医療がありうるということではない。この点を軽率に誤解すると、高齢者は予想される余命が短いので、非高齢者の“終末期”とは質的に異なる医療が許される、という誤りを冒す危険がある。これはエイジズム(年齢による差別)とよばれ、最近過少医療の問題として取り上げられることがある。適切な医療により救われる可能性がある高齢者が、“高齢”であるという理由で放置されてよいはずがない。

“ターミナルケア”における死の迎え方の自己決定

さきほどもすこし触れたが、患者が自己決定を

する場合には、決定するために必要な事柄についての知識を事前に求めて、よく理解していることが前提となる。わが国ではこの前提条件が満足させられていなかったり、自己決定をするべき本人自身以外の者が決定してしまうことが少なくない。たとえ患者の病気が悪性腫瘍の末期と診断された場合でも、患者本人が自分が受けたいと思う治療法を選択するためには、医師がその患者に、患者の病状ばかりでなく、いろいろの治療法の内容や、それぞれの治療法の効果や副作用などの危険性を比較できるようにわかりやすく説明をする必要がある。そうでないと患者はどの治療法を選択することができない。そのうえでその治療を医師が自分に実施することについての同意を医師に与えることもできない。この手続きがとられなければ、インフォームドコンセントは実施できない⁷⁾。ただこの前提を維持することが、実は高齢者の終末期においては困難なことが多い。前に述べたように慢性疾患の“終末期”、“老衰死”、そして痴呆の“終末期”などにおいては、患者本人の自由意志を確認することが事実上不可能なのである。そのため、患者の死の迎え方について事前の自己決定の問題が最近一般にも注目されつつある。

1. リビングウィル

アメリカでは1976年に“カリフォルニア州自然死法”が制定されて「成人が末期状態になったときに、生命維持装置を中止するか取り外すように医師に対して文書をもって指示する書面を作成する権利をカリフォルニア州民に認める」と定めた。リビングウィルとよばれるこの文書を書いておく権利を認める法律を世界ではじめて法制化したのである。その後、アメリカでは1991年PSDAによって連邦法でも同様の権利を認め、全米で同様の権利が認められた⁸⁾。ただしわが国では法制化されていない。

2. 心肺蘇生拒否の指示

脳死状態の際に心肺蘇生術を拒否する指示を前もって医師にしておく、医師は患者の診療記録簿の表面に“DNR order”(do not resuscitate order: 心肺蘇生術拒否指示)と表記し、その指示に従うことで、患者の心肺蘇生拒否の意思が保障される。わが国では法制化されていない。

表 2 尊厳死の宣言書(リビングウィル; Living Will)

年月日	年	月	日
<p>私は、私の傷病が不治であり、かつ死が迫っている場合に備えて、私の家族、縁者ならびに私の医療に携わっている方々につきの要望を宣言いたします。</p> <p>この宣言書は、私の精神が健全な状態にある時に書いたものであります。</p> <p>したがって、私の精神が健全な状態にある時に私自身が破棄するか、または撤回する旨の文書を作成しないかぎり有効であります。</p> <p>(1) 私の傷病が、現在の医学では不治の状態であり、既に死期が迫っていると診断された場合には徒に死期を引き延ばすための延命措置は一切おことわりいたします。</p> <p>(2) 但しこの場合、私の苦痛を和らげる処置は最大限に実施して下さい。そのため、たとえば麻薬などの副作用で死ぬ時期が早まったとしても、一向にかまいません。</p> <p>(3) 私が数カ月以上に涉って、いわゆる植物状態に陥った時は、一切の生命維持措置をとりやめて下さい。</p> <p>以上、私の宣言による要望を忠実に果たして下さいの方々に深く感謝申し上げますとともに、その方々が私の要望に従って下さった行為一切の責任は私自身にあることを附記いたします。</p> <p style="text-align: center;">年 月 日</p>			

3. 終末期医療の中止

終末期に患者の原因疾患の治療をしても病气そのものが治癒するわけでもなく、また病状が軽快するわけでもない。場合によってはその治療がかえって苦痛を与えたり体力を消耗させたりして患者にとってプラスにならない場合がある。そのような治療を患者が自らの希望で中止することで、いたずらに延命治療を受けずに自らの意思で自然死を迎えたいとする社会的な動きがある。これらを“尊厳死”とよんだりするが、わが国では法制化されていない。日本尊厳死協会が独自の“尊厳死宣言書”を発行し(表 2)、その法制化に向けて活動を行っている。その会員数は 10 万人を超えているが、その解釈に関しては主治医と大きな認識の違いがあることが明らかになっている⁹⁾。つまり患者である宣言書保有者が主治医にその宣言書をみせても、主治医側が患者の意図を認識しない場合が散見されるのである。その原因のひとつに、“終末期の定義が困難であること”があげられているのである⁹⁾。今後、われわれ実地医家も、“尊厳死宣言書”なる文書を患者に提出され、その扱いに思慮深さが要求されることもあろう。

高齢者のターミナルケアの今後の課題

急速に超高齢社会に移行していくであろうわが国であるが、その 1 年間の死亡者数は今後増加の一途をたどることになる。1990 年代は死亡者数が 90 万人台で推移したのが 2000 年代に入り 100 万人を超えるようになってきている。いまから 35 年後の 2039 年には死亡者数がおよそ 170 万人になる。65 歳未満の死亡者数は 20 万人当りであり変動がないとの予測があり、死亡者の増加は高齢者の死亡者の増加と言い換えることができるのである。つまり 21 世紀は“高齢者のターミナルケア”の時代が到来する世紀なのである。

今後増加する高齢者の死亡者の増加は、わが国の病院での死亡者の割合の変化に決定的な変化を与える可能性がある。つまり病院で死亡することのできない高齢者が出現する可能性があり、その可能性に対して何らかの備えをする必要があるであろう。また、高齢者やその家族のなかには自宅や高齢者施設での看取りに関心を持ったり、“患者の自己決定”の浸透により自らの死に場所を自分で選択する高齢者も増加していくであろう。その際に彼らは自分の死に場所として病院を選択せ

ず、自宅や高齢者介護施設を選択することも十分ありうるのである。

そこでわれわれが考えなければならないのが“高齢者介護施設でのターミナルケア”および“在宅でのターミナルケア”である。わが国はそれらの場所での“終末期ケア”の経験にきわめて乏しいのである。

“高齢者介護施設でのターミナルケア”や“在宅でのターミナルケア”のあり方というのは、“高齢者のターミナルケア”を解説することよりさらに困難である。その経験の乏しさは知識の集積の欠如をもたらしている。過去に、それらの場所における“ターミナルケア”の実情を詳らかにした調査研究もほとんどないのである。今後、老年医学を専門にしている医師にとって、これらの問題は重要なものとなるであろう。

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ORIGINAL ARTICLE

Physicians' reports on the impact of living wills at the end of life in Japan

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Context: A growing number of Japanese people have completed advance directives, especially living wills, even though there is no legislation recognising such documents and little empirical research on their impact on clinical care at the end of life in Japan.

Objectives: To investigate physicians' attitudes about living wills and their experiences with patients who had completed a living will and later died.

Design: Self administered survey and qualitative study using open question and content analysis.

Setting: Japan.

Participants: Physicians known to have cared for a patient who had presented a living will prior to death.

Measurements: The physician's response to receiving a living will, communication about the living will, the impact of the living will on clinical care, demographics, and their opinion on advance directives, especially living wills.

Main results: Fifty five per cent of respondents approved of advance directives in general, and 34% had more opportunities to communicate with a patient and his/her family after receiving the living will. Sixty nine per cent of the physicians who received a living will did not, however, change their course of therapy as a consequence of receiving the living wills. Based on the analysis, we identified three areas of concern in the comments on living wills: (1) concerns relative to patients, physicians, and families; (2) social context, and (3) clinical and administrative concerns. The physicians raised various topics for discussion; they tended to describe the issues from a clinical perspective.

Conclusions: Our identified areas of concern should prove helpful in better understanding the clinical and ethical implications of living wills in Japan.

In recent decades, Japan has witnessed growing interest in the expression and enhancement of individual autonomy in medical decision making at the end of life.^{1,2} Written advance directives such as living wills and durable powers of attorney are designed to document patient preferences in event of the loss of patient decision making capacity, and have been advocated as a means to enhance patient autonomy in Japan. In 1992, the Japan Medical Association officially declared that a patient's advanced request for a death with dignity should be respected and that persons forgoing and terminating life support are immune from legal liability.³ Advance directives have no legal standing in Japan, however, and Japanese courts have not recognised the patient's right to exercise autonomy in the context of terminal illness. Not surprisingly, advance directives have not become widely adopted in Japan.

Opinion polls in Japan reveal the general public's growing interest in discussing end of life issues with doctors and support for allowing terminally ill patients to end life sustaining treatment.^{4,5} One organisation, the Japan Society for Dying with Dignity (JSDD), has helped many people to complete a written living will and many of these individuals have used them.⁶ Below is an example of one such living will drawn up by the JSDD (box 1).

The number of people who have registered with the organisation has increased exponentially, with membership reaching 93 799 by February 2001.⁷

In the United Kingdom, the British Medical Association cautiously approved the introduction of advance directives in a statement in May 1992.⁸ In addition, the High Court has recently ruled that advance directives by mentally competent patients about future treatment are legally binding on doctors. This followed a landmark judgment on a schizophrenic

Box 1 Dying with dignity declaration

(Living will)

To my family, my friends, and my medical attendants:
In preparation for a time when I might face an incurable illness and death is near, I declare that my wishes are as follows:

This declaration is made by me at a time when I am of sound mind. Therefore, this is effective and in full force unless I revoke or withdraw this declaration in writing while I am mentally sound.

1. I request that medical technology should not be used to artificially prolong my life if modern medicine concludes that my disease is irreversible or incurable and that my condition is terminal.
2. I request, however, that effective pain reduction should be fully achieved by any method, such as by the use of narcotics, etc, even though such treatment may shorten my life.
3. I request that all life sustaining procedures be withdrawn if I lie for several months in a condition known as "persistent vegetative state".

I express my heartfelt thanks to all those concerned who will faithfully comply with my requests. I further declare that I hereby absolve these people from any civil liability arising from any actions taken in response to and in fulfilment of the terms of this declaration.

Signature:

Date:

patient in Broadmoor Hospital who refused an amputation of his leg, which prevented doctors from amputating his leg at that time or in the future.⁹ There is still, however, no legislation

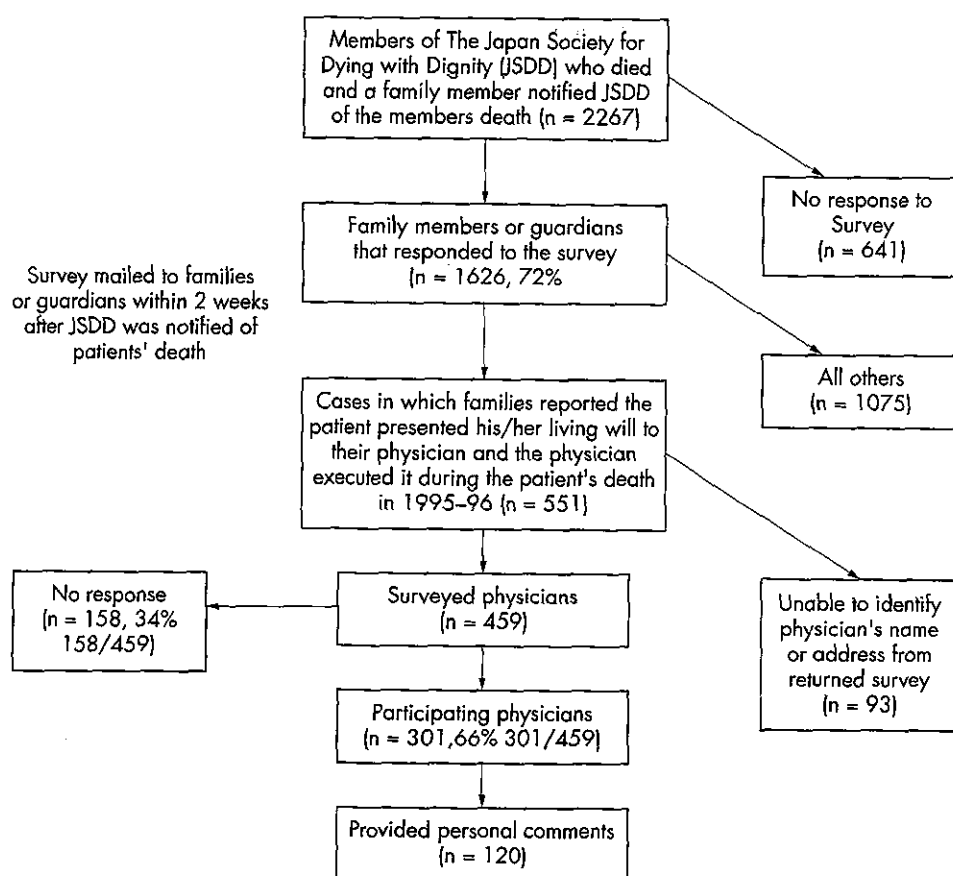


Figure 1 Sampling scheme of respondents.

in the UK which deals with patient autonomy in the case of terminal illness.

The 1991 Patient Self Determination Act in the United States requires all hospitals, nursing homes, and home health agencies to advise patients of their rights to accept or refuse medical care and to execute an advance directive.¹⁰⁻¹¹ This is usually a written directive for end of life care, a living will and/or a durable power of attorney created to help interpret what a patient's wishes might have been in light of his or her present condition and its possible treatment. Some studies have demonstrated, however, that only 10-15% of US adults have written advance directives, and often their physicians are unaware of them.¹²⁻¹⁴ One study suggests that doctors were ignoring their patients' instructions about their end of life treatment preferences.¹⁴ Encouraging results from a recent randomised, controlled trial revealed, however, that simple computer generated reminders can increase the rates of discussion and completion of advance directives among elderly patients with serious illness.¹⁵

Few Japanese studies have examined the situation of people with advance directives and physicians's attitudes and beliefs toward life sustaining treatment and advance directives.⁶⁻¹⁶⁻¹⁷ The purpose of this study was to investigate Japanese physicians's experiences with patients who had a living will at the time of death and their attitudes toward living wills, the most commonly used advance directive in Japan.

METHODS

Based on a survey of 1626 families, which looked at patients who had obtained and showed their living wills to their physicians,⁶ we constructed a database of 551 physicians who, according to either a family member or a guardian had seen a living will and followed it when the patient died. The patients who were the topic of this previous investigation had obtained a living will from the JSD. Between 1995 and 1996 a family member or guardian had notified the JSDD of the patient's death. Within two weeks of receiving the notification of the

patient's death, the JSDD mailed a questionnaire designed to collect data about the patient's death, including the name and address of the deceased patient's physician. For 92 (16.7%) physicians, the address or physician's name was incorrect, and they were hence excluded. The remaining 459 physicians, all reported by family members as having seen and followed the patient's living will, were the target subjects of this research. (figure 1).

For the purposes of this study, we defined "obtaining a living will" as registering with the JSDD and receiving a standardised written living will, and "presenting a living will" as showing a completed written living will to the patient's physician. Physicians who limited life sustaining treatment in accordance with the written living will were defined as having "followed the living will".

The major variables of the structured, anonymously administered instrument included the physician's response to being shown a living will, the impact of the living will on communication with the patient and family, the impact of the living will on clinical care, and physician demographics. To analyse these structured items, we tabulated and calculated the frequency distributions according to those who gave written opinions, those who did not, and the totals.

The final item on the instrument asked for physician comments about living wills. We analysed this qualitative data using the process of immersion/crystallisation.¹⁸⁻¹⁹ Three investigators formed the primary analysis team (Masuda, Fetters, and Mogi) and independently identified domains and subthemes from multiple readings of the descriptions of the respondents. Subsequently, we developed a master list of areas of concern and subthemes that incorporated each investigator's contributions. Differences in interpretation were minimal.

Though the survey was distributed anonymously, a small number of respondents volunteered contact information. This provided a unique opportunity to conduct a re-evaluation of the study's results by some family members or guardians: we contacted 12 who were available by phone to verify our results.²⁰ They all supported the breadth and depth of the

Table 1 Physicians' receipt of and response to living wills

	Physicians' comments(+) n=(%, /120)	Physicians' comments(-) n=(%, /181)
Did you receive the patient's living will, and if so, how did you respond?		
1. I received the living will, agreed to it, and executed it.	91 (76)	53 (29)
2. I received the living will, and agreed to it, but I did not execute it.	12 (10)	11 (6)
3. I received the living will, but neither agreed nor disagreed with it.	4 (3)	1 (1)
4. I received the living will, but disagreed with it, and refused to execute it.	0 (0)	0 (0)
5. I never received the living will.	0 (0)	105 (58)
6. Other	13 (11)	11 (6)
Did you have more opportunities to communicate with your patient and his/her families after receiving the living will?		
1. Yes	65 (54)	38 (21)
2. No	24 (20)	23 (13)
3. No, because the patient died suddenly.	11 (9)	5 (3)
4. I never received the living will.	0 (0)	105 (58)
5. Others	20 (17)	10 (6)
Did you change your course of therapy as a result of receiving the living will?		
1. Yes	27 (23)	11 (6)
2. No	78 (65)	57 (31)
3. I never received the living will.	0 (0)	105 (58)
4. Others	15 (13)	8 (4)

{+} These physicians supplied personal comments; {-} these physicians did not supply personal comments.

analysis. This study was approved by the ethics committee of the Department of Geriatrics, Nagoya University School.

RESULTS

From a single mailing of 459 questionnaires, we received 301 responses, and of these 149 provided written commentaries that were analysed using qualitative techniques. Interestingly, the comments of 29 of these 149 participants illustrated they had a poor understanding of living wills (figure 1). One hundred and twenty two physicians were midcareer physicians. One hundred and sixty physicians majored in internal medicine and 141 majored in surgery and other specialties: these other specialties included five orthopaedists, four otorhinolaryngologists, and three radiologists.

While all the physicians surveyed were reported by a family member or guardian as having seen and agreed to the living will, 105 denied ever having seen the patient's living will. Of the remaining 196 physicians, 144 agreed to it and followed it. Of the physicians who reported they had received the patient's living will, 103 physicians said they had discussed the living will with the patients and/or their families after receiving the living will. Remarkably, 38 physicians who acknowledged being shown the living will reported that the living will influenced clinical outcomes (table 1).

PHYSICIANS'S COMMENTS ON LIVING WILLS

Based on our analysis of these comments from the physicians, we identified three areas of concern; (A) concerns about living wills relative to patients, physicians, and families; (B) social context of living wills, and (C) clinical and administrative concerns about living wills.

A. Concerns about living wills relative to patients, physicians, and families

1. Living wills and patients

The respondents mentioned both positive and negative influences of living wills on patient care. The most common concern was these physicians's feelings that they needed to take into account patient's state of mind at the end of life. Some physicians pointed out that patients might change their mind in the face of impending death and raised concerns about the stability of such advance decisions. Issues related to patient knowledge and preparation for making this type of decision were also frequent. For example, a chest physician stated: "I think it is quite meaningful for terminally ill patients to exercise autonomy about life sustaining treatments

Box 2 Dominant concerns and subthemes about living wills in Japan

A. Concerns about living wills relative to patients, physicians, and families

1. Patients
2. Families
3. Physicians
4. Patient/family/physician interaction

B. Social context of a living will

1. Trends favouring completion of a living will
2. Relationship of a living will to "dying with dignity" and "euthanasia"
3. Societal understanding of a living will
4. Need to discuss medical ethics
5. Perception about development of a living will in Western culture and implications for Japan

C. Clinical and administrative concerns about a living will

1. Confusion around the procedures for completing and executing a living will
2. Patient individuality and complexities of implementing a living will
3. Difficulty of explaining when a condition is terminal
4. Complications of second opinions
5. Barriers to effective treatment in curable patients

by presenting a living will. However, autonomy requires a considerable amount of knowledge. Without enough knowledge, a living will could be dangerous."

2. Living wills and families

Some physicians addressed the impact of living wills on their relationships with families. The primary positive perceptions related to increased opportunities to communicate with the family and the underlying essential role the family plays in interpreting the patient's wishes when a patient is no longer able to communicate. For example, a cardiologist described his positive experience, stating: "The living will gave me the chance to have more time to communicate with the patient's family". Potential negative influences were also identified. The most common concern was the feeling that a living will directed too much family energy toward making sure the patient could have a "natural death" without giving enough consideration to understanding the patient's preferences for end of life care. A second concern related to insufficient communication of the

patient's preference to limit end of life care to the family, and the family's subsequent insistence on care incompatible with the patient's directive. For example, some respondents commented on the confusion created when family members request treatments such as cardiopulmonary resuscitation even though the patient has requested a natural death. There were also concerns about the instability of the preference the patient had expressed in the living will and about family members with ulterior motives seeking to change the treatment.

3. Living wills and physicians

Many of the physicians who were shown a patient's living will did not routinely provide life sustaining treatment in their clinical practices, but still felt that living wills had played a valuable role. Again, some physicians emphasised the positive effect of a living will, in that it provided an overarching focus on the patient's preference for palliative care and allowed physicians to plan how to accomplish those goals. Other physicians were more cautious and believed that living wills could result in adverse outcome if handled by a physician lacking technical skills in providing compassionate, palliative care. This negative opinion is summarised by a surgeon who wrote: "There is a chance that physicians with marginal skills and little compassion could take advantage of living wills and carry out terminal care negatively. To make the best use of a living will, at this point, we need not the system first, but physicians with skill and character who can handle terminal care."

B. Social context of a living will

1. Inhumane medical care as a factor driving interest in living wills

Several physicians expressed their belief that the inhumane nature of the medical culture was a driving force behind patients obtaining living wills and reflected the need for physicians to do a better job of focusing on care of the patient. Some attributed the problem to the poor quality of education in palliative care that physicians receive in their medical training. A gastroenterologist wrote: "Physicians tend to have shallow ideas on living and dying. I think that it exposes holes in current medical education. With remorse and sincerity, we have to face the mortifying feelings of a patient who dies in an untrustworthy medical system."

2. Physician perspectives on death with dignity

This survey on living wills stimulated several physicians to mention their own beliefs about "death with dignity". They articulated concerns about the enduring need to respect human dignity regardless of whether the patient has a living will and disappointment that patients cannot seem to die with dignity unless they have completed a living will. For example, one cardiologist stated: "It is more of a problem that people cannot die with dignity without a living will. I consciously try to respect the dignity of every death."

3. Cultural issues associated with living wills and perceptions of death

The term "living will" has been imported directly into the Japanese language and it is pronounced *libingu uiru*. It is written in katakana, the written language that delineates words of foreign aetiology. This writing convention inevitably identifies living wills as distinctly foreign to Japanese culture. For some Japanese, this causes uneasiness, suggesting that it doesn't mix well with Japanese culture, while for others the ubiquitous use of a foreign sounding term for an issue of great importance to all Japanese people is a source of consternation. Those critical of its use, however, have not been able to suggest an alternative phrase, using Japanese terms. Some participants in the survey chided their physician colleagues for their shallow perceptions about the meaning of death. Moreover, they were critical of the superficiality of public discussions about life and death in

Japan. Some alluded to the role indigenous religious/philosophical traditions could play in informing a Japanese sense of a natural death, though these opinions were held by only a minority.

BACKGROUND

At present, a majority of Japanese feel that modern biomedical and mediatechnological innovations affecting human life and death have effected a changed in our common understanding of the process of death and dying. Historically, death was a natural event, and the criteria for death/cessation of heart beat and respiration was unquestioned. An individual's death should be a personal and private matter as well as a familial, communal, and society matter. It has been so regarded for many thousands of years in Japanese society and culture. It is well understood that our traditional sociocultural understanding of human life admits the natural process of death as a positive event marking of the end of life.²¹

Clinical and administrative concerns about a living will

1. Confusion about the procedures for obtaining and following a living will

All respondents are clinicians, and many of them commented on pragmatic issues for obtaining and completing living wills. No official format or regulations exist that support the implementation of a living will in Japan. Some of the respondents requested information from the JSDD about how to apply for a living will and to obtain application forms from bodies other than the the JSDD.

2. Patient uniqueness and complexities of implementing a living will

These physicians work in a variety of clinical settings and commented on living wills based on their clinical experiences. For example, a senior neurologist discussed troubling neurological cases such as occur with dementia, and the difficulty in respecting patient autonomy as the patient's decision making capacity withered away, and family influence increased. Another issue raised was the difficulty of interpreting the individual patient's intended meaning for a death with dignity in the context of clinical uncertainty. Even if the patient's preference was clear, the outcome for any patient could change, based on the response to treatment. One surgeon explained: "With intensive care of stroke patients, some could recover, but with severe functional difficulties. In these cases, if we give up the treatment in the first place, many would die. So should we just leave such patients in a coma since they have a living will? Or can the physician force a long and painful recovery on the patient and his/her family for the physician's own self satisfaction? This really bothers me."

3. Difficulty of explaining when a condition is terminal

Many physicians described the difficulty of determining the point when a patient should be considered incurable and the patient's living will implemented. Some patients may have an incurable condition, but still be able to survive for years in a debilitated state requiring only basic medical support. A senior haematologist summarised this concern: "The prerequisite condition for implementing a living will is that the disease is incurable. But it is not always easy to judge whether a patient is really at an incurable stage. Also decision making is hard when a patient's life is expected to be prolonged for another year or so."

4. Barriers to effective treatment in curable patients

Some physicians raised concerns about living wills being used to block the provision of routine, curative treatments. One surgeon was strongly influenced by his experience with a patient who had a living will and refused treatment. His experience was so troubling, he gave up general surgery to become a plastic surgeon. He wrote: "Regarding his living will,

I accepted his family's request not to use dialysis and a respirator for the renal and respiratory failure in his terminal condition. However, in his case, I still believe that we could have cured his colon cancer if only he had cooperated with our treatment. He strongly wanted to deteriorate without any treatment and we failed to change his mind. All of the medical staff were caught feeling like they assisted his suicide. We did try our best to get this very pessimistic patient to open his heart, and it still is a very painful memory."

DISCUSSION

To our knowledge, this represents the first large scale study in Japan to investigate physicians' experiences with, and attitudes towards, patients who died having completed a living will. Because advance directives have no legal standing and living will use is not widespread in Japan, this research provides a unique opportunity to examine the use of a written advance directive to extend patient autonomy to treatment decisions at the end of life. While a family member or guardian reported that these physicians had seen the patient's living will and acted in accordance with the patient's preference as written in the living will, over a third of the physicians denied having seen the living will. This group likely includes physicians who really did not recall seeing the living will, though there may have been physicians reluctant to confirm receipt of the living will.

These physicians highlighted many potential limitations of living wills, including: inadequate communication about how to interpret it; potential liability; the vagueness of living wills; potential for differing patient and family expectations, and other ethical dilemmas. As in previous research, these physicians report that patients have difficulty making advance judgments on complex medical procedures and choices about quality of life since these can change with time and circumstances.²² Others showed that advance directives might be better suited to patients's end of life care goals than those that focused on specific medical interventions.²³ For some physicians, withholding or withdrawal of life sustaining treatment is perceived as harmful to the patient because this action predictably results in the patient's death. It is widely held that Japanese physicians are trained to save lives, not to end them.

Possible study limitations should be addressed. First, the data represented physician reports, and due to the anonymous nature of the investigation, could not be corroborated with other clinical data to assess their accuracy. Second, while patients who have obtained a living will are a minority and might not be representative of the general population, the physicians who were providing care for these patients are probably reasonably representative of Japanese physicians providing care for adult patients. Most respondents were active clinicians providing medical and surgical care to patients in a variety of clinical settings. Third, only half of the physicians who recalled seeing the living will, provided written comments. While their views might differ from others who did not provide comments or who did not respond to the survey, their experiences are still real and compelling.

Currently, when a patient registers with the JSDD, the patient receives two copies of the living will, one for the patient and one for return to the JSDD. Since many physicians denied seeing the patient's living will, physicians should always be given a copy of the living will to keep with the patient's chart. Of the physicians who recalled seeing the living will, almost a fifth reported that it influenced clinical outcomes. Since living wills have no legal standing, this level of compliance could be interpreted as being surprisingly high and, despite the limitations, as real, since many comments illustrated physicians's poignant concerns that patients were allowed to forgo physician recommended treatments. This suggests that many Japanese physicians are willing to respect autonomous patient preferences to forgo treatments as expressed through a written living will. At the

same time, many physicians expressed consternation with interpreting patient preferences while accommodating family inputs in highly variable settings, all in the face of clinical uncertainty, a point that most assuredly reflects the experiences of physicians who have grappled with following written advance directives in the US and elsewhere. Further research tied to clinical settings in which living wills are implemented could provide a more robust understanding of living will use and adherence as advanced expression of autonomy in the cultural context of Japan.

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ORIGINAL ARTICLE

Current admission policies of long-term care facilities in Japan

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Background: The rapidly aging society in Japan is putting demands on long-term care facilities for the elderly who require care. In Europe and the USA, there is ongoing reform of elderly care services, but the establishment of system based on social insurance is still being explored in Japan.

Methods: Two studies were conducted, the first in 2000 and the second in 2001, involving 91 long-term care facilities located in or around the city of Nagoya. Questionnaires were sent to facility directors, chief administrators or head nurses to inquire about their admission policies for six major patient categories. Two educational lectures on methicillin-resistant *Staphylococcus aureus* (MRSA) and urinary incontinence were given between the distribution of the questionnaires.

Results: For all six categories featured on the questionnaire, the acceptance rate in both studies was the highest in geriatric hospitals, and an improvement in acceptance rates was seen in the second study in all three types of care facilities. When the effect the lectures had on changes in admission policies at these facilities was examined, no correlation was found.

Conclusions: Lectures should be given to facility management and personnel to raise their awareness of key issues and improve their efficiency.

Keywords: acceptance rates, admission policies, lectures, long-term care facility, MRSA.

Introduction

Japan has the fastest growing aging society in the world.¹ As with other developed countries, advanced medical technology has contributed to a considerable increase in life span and as a result, the number of elderly who require care has been increasing steadily, and the demand for institutional care is likely to intensify in the future. In Europe and North America, where a more gradual shift to an aging society has occurred, innovative elderly care services are being explored² and reforms

are ongoing. In April 2000, a public long-term care insurance system was introduced in Japan, and ways to establish an elderly care system based on social insurance were explored. Based on the 'Gold Plan' and 'New Gold Plan'³ formulated by the Health and Welfare Ministry, a reorganization of care facilities including nursing homes (NH), geriatric intermediate care facilities (GICF, which provide a certain amount of medical care), and geriatric hospitals (GH)^{4,5} was initiated. In order to improve facility standards and personnel placement, the two plans recommend the sharing of expertise by emphasizing more nursing care in nursing homes and more medical care in GICF and GH.^{2,5} However, reports have shown that the elderly do not systematically have access to institutional services³ because of an insufficient number of long-term care facilities³ and restrictive acceptance policies that limit the admission of carriers of methicillin-resistant *Staphylococcus aureus* (MRSA) and persons with other conditions.^{6–8}

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It appears that admission to long-term care facilities is more frequently denied to the following types of patients: bacteria carriers, including MRSA carriers and *Pseudomonas aeruginosa* carriers, and persons requiring medical care, including nasogastric tube-feeding, persons requiring indwelling urinary catheter, persons requiring intermittent catheterization, patients with tracheostoma and patients who require intravenous hyperalimentation. Various studies have so far examined admission policies for MRSA carriers,^{6,9} but very few have focused on other conditions. Therefore, we conducted two studies to examine the possible factors that prevent the admission of certain elderly patients into long-term care facilities. The first study was carried out in June 2000, immediately after the new public insurance plan was introduced, and the second in May 2001. In addition to MRSA status, we examined five other possible factors for admission refusals in long-term care facilities.

A general lack of knowledge among medical and welfare staff has been shown to be the primary factor for admission refusals of patients with MRSA infections⁷ and the same holds true for elderly persons requiring a urinary catheter. Therefore, between the first and the second study, we gave two lectures to participating facilities, one on MRSA and one on urinary incontinence, in order to examine the effect of education on admission policies.

Methods

The study group comprised 91 long-term care facilities (35 NH, 40 GICH, 16 GH), all located within 20 km of the city of Nagoya. A telephone survey was conducted with either the director, chief administrator or head nurse of each facility and prior to the telephone survey, a questionnaire was sent to all facilities to inform them of the study. Some of the participants answered the questionnaire by mail, and we therefore did not need to telephone them.

The survey was carried out twice, once in June 2000, and later in May 2001. Using the same questionnaire on both occasions, we inquired about the facilities' admission policy for the following types of elderly patients: (1) MRSA carriers, (2) *P. aeruginosa* carriers, (3) nasogastric tube-fed persons, (4) gastrostomy tube-fed persons, (5) persons requiring an indwelling urinary catheter, and (6) persons requiring intermittent catheterization (Table 1). Additional questions about the admission policy for patients with a tracheostoma and patients requiring intravenous hyperalimentation were added to the questionnaire that was distributed to GH.

We categorized responses as 'possible' if the answer to whether or not the facility would admit someone with conditions attached. We categorized answers such as 'under consideration' or 'we would consider admission on a case by case basis' as 'others', and did not include

Table 1 Questionnaire: The study on the current admission policy in the long term care facility. Please answer the following questions. Your answers will be gathered and analyzed statistically. Your privacy is strictly protected.

-
- 1 Acceptance of MRSA carriers
1. Possible 2. Impossible 3. Others ()
 - 2 Acceptance of *Pseudomonas aeruginosa* carriers
1. Possible 2. Impossible 3. Others ()
 - 3 Acceptance of nasogastric tube-fed persons
1. Possible 2. Impossible 3. Others ()
 - 4 Acceptance of gastrostomy tube-fed persons
1. Possible 2. Impossible 3. Others ()
 - 5 Acceptance of persons requiring an indwelling urinary catheter
1. Possible 2. Impossible 3. Others ()
 - 6 Acceptance of persons receiving intermittent catheterization
1. Possible 2. Impossible 3. Others ()
- For the hospitals only
- 7 Hospitalizing patients with a tracheostoma
1. Possible 2. Impossible 3. Others ()
 - 8 Hospitalizing IVH
1. Possible 2. Impossible 3. Others ()
-

Thank you very much for your cooperation. We will gather information by the phone at a later date.

these in our statistical analysis. In both studies, the acceptance rate was compared and examined among the NH, GICF, and GH for each question on the survey. In addition, we looked at the change in acceptance rates from 2000 to 2001 for each type of facility examined.

Between the distribution of the first and second questionnaire, lectures on MRSA and urinary incontinence were given to facility personnel, who attended these lectures voluntarily. We then categorized the facilities into two groups, a participating group, consisting of facilities whose personnel had attended the lectures, and a non-participating group (facilities where lectures had not been given). The lecture on MRSA focused mainly on general characteristics, pathogenicity, and infectivity. The lecture on urinary incontinence covered classification, causes, and means by which people adapt to having intermittent catheterization. The effect of the lectures was examined by comparing the pre- and postlecture acceptance rates.

Statview-J5.0 was used for analysis. Chi-squared test was used to compare the acceptance rates between three groups and between 2000 and 2001. Paired *t*-test was used to compare the acceptance rates between pre- and post lecture. The statistically significant difference was set at $P < 0.05$.

Results

In the study conducted in May 2000, 26 NH (74.3%), 34 GICF (85%), and 14 GH (87.5%) responded to our questionnaire, and in the second study on June 2001, 29 NH (82.9%), 35 GICF (87.5%), and 13 GH (81.3%) responded.

On whether they would admit MRSA carriers, in the first study, 8 NH (33%), 12 GICF (40%), and 7 GH (54%) replied 'possible', and in the second study, 9 NH (43%), 21 GICF (64%), and 7 GH (58%) gave that answer. In both studies, no statistically significant difference was found in the admission rates among the NH, GICF, and GH, despite the fact that acceptance rates in each facility did improve, as the second study results indicate (Fig. 1).

On whether they would accept *P. aeruginosa* carriers, in the first study, 8 NH (33%), 13 GICF (45%), and 8 GH (62%) responded 'possible', and in the second study, 13 NH (52%), 23 GICF (72%), and 8 GH (73%) replied 'possible'. In both studies, the GH showed the highest acceptance rate, followed by the GICF and NH, but no statistically significant difference was found among the facilities. Each type of facility improved their admission rate, as the second study results show, and a statistically significant difference was found in the GICF ($P < 0.05$) (Fig. 2).

On whether they would admit nasogastric tube-fed patients, in the first study, 12 NH (46%), 26 GICF (81%), and 13 GH (93%) answered 'possible', and in the second study, 16 NH (66%), 28 GICF (88%), and 12 GH (100%) responded 'possible'. In both studies, the GH had the highest acceptance rate, followed by the GICF and NH. In the first study, a statistically significant difference was found between the NH and GICF ($P < 0.01$), and in the second study, between the NH and GH ($P < 0.05$). Each type of facility improved their acceptance rate in the second

study, but no statistically significant difference was found (Fig. 3).

On whether they would accept gastrostomy tube-fed patients, in the first study, 12 NH (46%), 24 GICF (73%), and 13 GH (93%) replied 'possible', and in the second study, 16 NH (67%), 28 GICF (90%), and 13 GH (100%) answered 'possible'. Both studies revealed similar responses to the question of whether the facilities would admit nasogastric tube-fed patients. In the first study, a statistically significant difference was found between the NH and GICF ($P < 0.05$), and between the NH and GH ($P < 0.01$), and in the second study, between the NH and GICF ($P < 0.05$), and between the NH and GH ($P < 0.05$). Each type of facility showed an improvement in their acceptance rates in the second study, but no statistically significant difference was found (Fig. 4).

On whether they would accept patients requiring an indwelling urinary catheter, in the first study, 19 NH (73%), 29 GICF (88%), and 13 GH (93%) answered 'possible', and in the second study, 23 NH (92%), 32

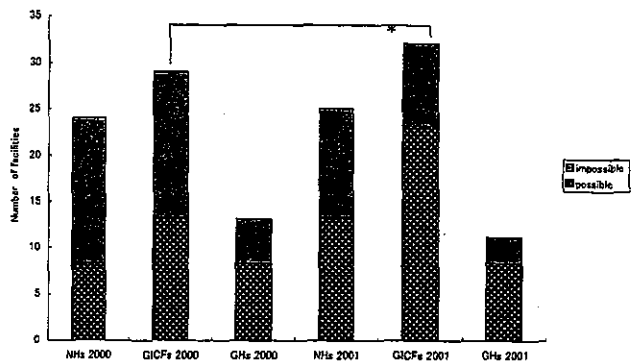


Figure 2 Admission policy for *Pseudomonas aeruginosa* carriers. Chi-squared test was performed to compare acceptance rates between 3 groups and between 2000 and 2001: * $P < 0.05$.

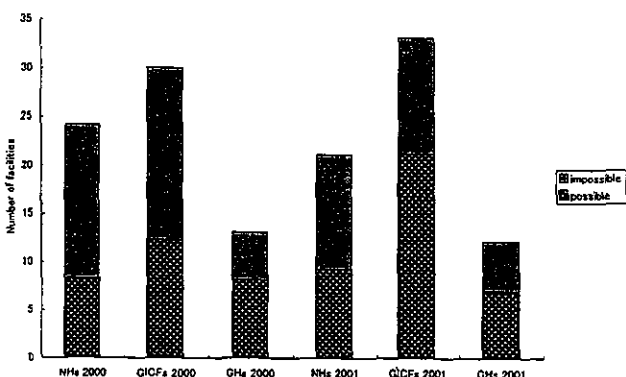


Figure 1 Admission policy for MRSA carriers. Chi-squared test was performed to compare acceptance rates between 3 groups and between 2000 and 2001. P value did not reach statistical significance.

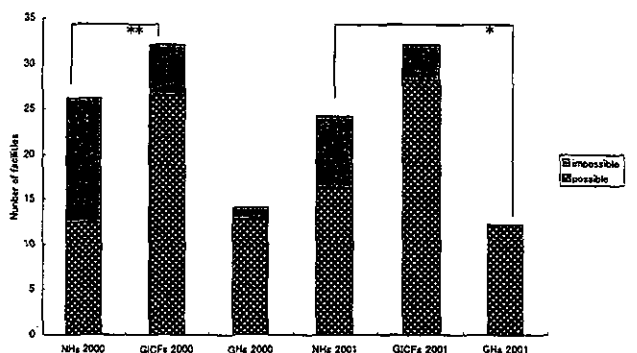


Figure 3 Admission policy for nasogastric tube-fed persons. Chi-squared test was performed to compare acceptance rates between 3 groups and between 2000 and 2001: * $P < 0.05$, ** $P < 0.01$.

GICF (94%), and 13 GH (100%) responded 'possible'. As seen with the other responses, the acceptance rate was the highest in the GH, followed by the GICF and NH, but no statistically significant difference was found. Each type of facility showed an improvement in their acceptance rates in the second study, but no statistically significant difference was found (Fig. 5).

On whether they would admit patients requiring intermittent catheterization, in the first study, 15 NH (58%), 19 GICF (66%), and 12 GH (86%) replied 'possible', and in the second study, 12 NH (57%), 26 GICF (87%), and 10 GH (83%) answered 'possible'. The acceptance rates in each type of facility showed the same tendency as that observed for the question on the acceptance of patients requiring an indwelling urinary catheter, except for the difference between the GICF and GH that appeared in the second study. A statistically significant difference was found between the NH and GICF in the second study ($P < 0.05$). Each type of facility improved their acceptance rates in the second study,

but no statistically significant difference was found (Fig. 6).

The admission rate of NH for all six categories, in the first study, was found to be 33% for MRSA carriers as well as *P. aeruginosa* carriers, the lowest of all, and in the second study, 43%, again the lowest of all (Fig. 1). In both studies, a statistically significant difference was found between the admission rates for MRSA carriers and that for patients requiring an indwelling urinary catheter ($P < 0.01$). The lectures on MRSA were attended by 26 facilities (28.6%) and 28 (30.8%) attended those on urinary incontinence. In order to examine the effect of these lectures, we investigated only those facilities that had answered both questionnaires in 2000 and 2001, dividing them into participating and non-participating groups.

For the lecture on MRSA, we studied 61 facilities (20 in the participating group, 41 in the non-participating), and for the lecture on urinary incontinence, 61 facilities (18 in the participating group, and 43 in the non-participating). An improvement in the acceptance rates for MRSA carriers was observed in the second study, in both groups. A statistically significant difference was not found in the change of the acceptance rate in either group (Fig. 7).

For the lecture on urinary incontinence, the number of facilities in the non-participating group that answered that it would be impossible for them to accept patients requiring intermittent catheterization decreased from 15 to 7, and the number of facilities that provided answers that we categorized as 'others' increased from 4 to 9. However, no statistically significant difference was found in either group (Fig. 8).

Finally, the responses to the questions added to the surveys distributed to the GH showed that 10 of 14 facilities deemed it 'possible' to accept patients with a tracheostoma, and 8 of 14 facilities considered it 'possible' to accept patients with intravenous alimentation

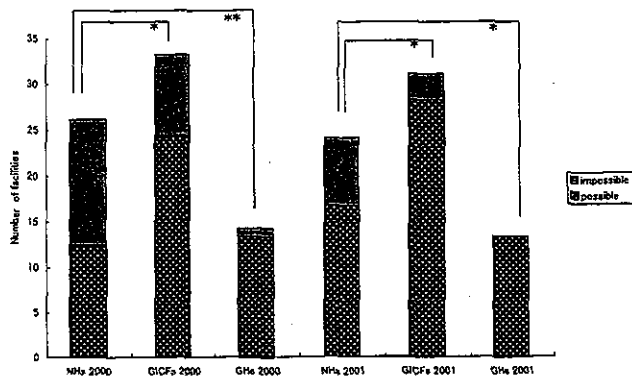


Figure 4 Admission policy for gastrostomy tube-fed persons. Chi-squared test was performed to compare acceptance rates between 3 groups and between 2000 and 2001: * $P < 0.05$.

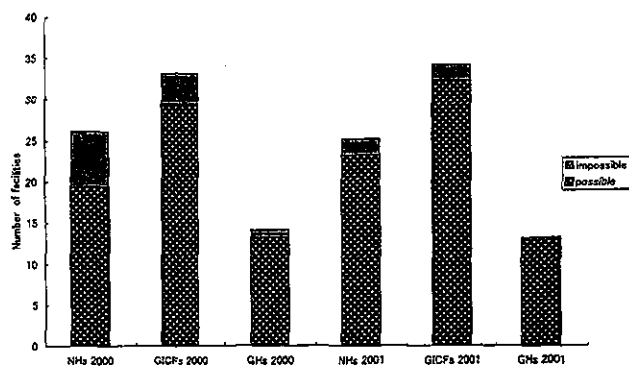


Figure 5 Admission policy for persons requiring an indwelling urinary catheter. Chi-squared test was performed to compare acceptance rates between 3 groups and between 2000 and 2001. P value did not reach the statistical significance.

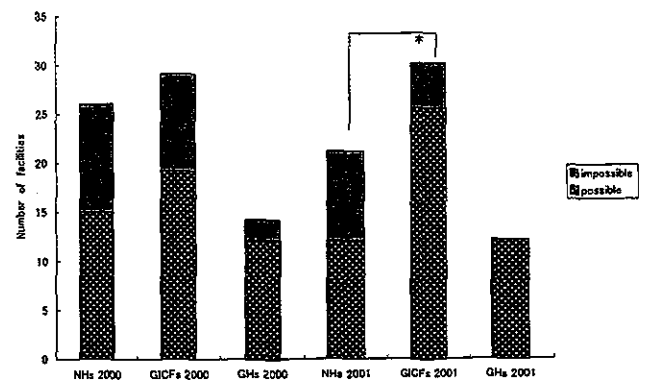


Figure 6 Admission policy for persons requiring intermittent catheterization. Chi-squared test was performed to compare acceptance rates between 3 groups and between 2000 and 2001: * $P < 0.05$.

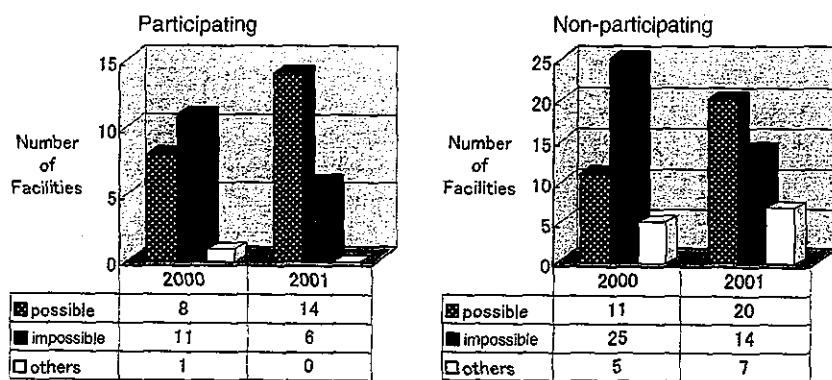


Figure 7 Effect of the lecture on MRSA on admission rates. The numbers are the sum of 3 groups. Paired *t*-test was performed to compare acceptance rates between 2000 and 2001. *P* value did not reach statistical significance.

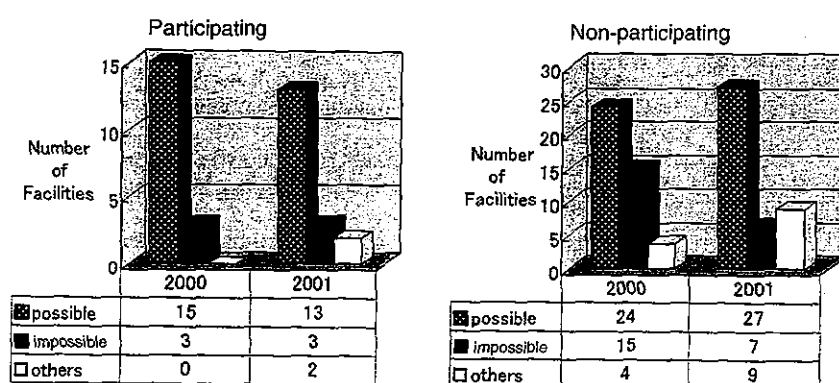


Figure 8 Effect of the lecture on urinary incontinence on admission rate. The numbers are the sum of 3 groups. Paired *t*-test was performed to compare acceptance rates between 2000 and 2001. *P* value did not reach statistical significance.

in the first study. In the second study, 9 of 13 facilities responded that it would be 'possible' for them to accept patients with a tracheostoma, and 8 of 13 facilities said that it would be 'possible' for them to accept patients with intravenous alimentation.

Discussion

The aim of this study was to clarify the admission policies that are currently in place in long-term care facilities by studying 91 such facilities (NH, GICF, and GH) in and around the city of Nagoya.

As possible factors affecting admission policies, we defined six categories: (1) MRSA carriers, (2) *Pseudomonas aeruginosa* carriers, (3) nasogastric tube-fed patients, (4) gastrostomy tube-fed patients, (5) patients requiring an indwelling urinary catheter, and (6) patients requiring intermittent catheterization.

With regards to MRSA carriers, a number of studies show a positive correlation between MRSA colonization and a higher death rate 6 months later.¹⁰ Other research, however, indicates that there is no clear causal relationship between MRSA colonization and infection in long-term care facilities.⁹ It has also been pointed out that infection and the prevalence of MRSA would not occur in long-term care facilities that practised strict isolation^{6,11,12} because unlike hospitals, long-term care

facilities are rarely overcrowded with patients taking antibiotics,⁷ those with a central venous catheter¹³ and critically ill patients⁶ all of whom are considered to be the biggest carriers of this infection. Therefore, some studies have suggested that refusing admission to MRSA carriers into long-term care facilities is discriminatory.^{6,14} In our study, the acceptance rate for MRSA carriers in NH was 33% in 2000, and 43% in 2001. The results obtained in a previous study by Washio and Fujishima,⁷ who reported that the acceptance rate for MRSA carriers was 33.3% in nursing homes, are consistent with our results. Although the acceptance rate for MRSA carriers in NH improved in the second study, it was still low in comparison with the other five categories, which suggests that refusing to admit MRSA carriers is an ingrained response by these facilities. The acceptance rate for *P. aeruginosa* carriers is also low in NH and the results indicate that patients who are carriers of other bacteria might be also dealt with unfairly. There is a pressing need for facility personnel to receive education on the nature and management of these conditions, and for further studies to be conducted.

The acceptance rate for nasogastric tube-fed patients, gastrostomy tube-fed patients, and patients requiring an indwelling urinary catheter were the highest in GH, followed by GICF and NH in both studies. GICF had a higher acceptance rate for patients requiring intermit-

tent catheterization than GH in 2001, but overall the rate was the highest in GH, followed by GICF and NH. Because all these conditions are categorized as requiring medical care, it seems appropriate that the highest acceptance rate was found in GH, where medical facilities, medical care and medically trained staff are more readily available than in GICF and NH. However, some reports have indicated that GH residents do not all require medical care, and that there are high medical demands in NH.^{5,15} Therefore, our results do not necessarily reflect the fairness and appropriateness of the admission policies we investigated. In addition, we did not ask the facilities whether or not they had sufficient staff to take care of additional residents, although a shortage of care staff may be one of the reasons why facilities claimed they were unable to accept new residents from the four categories chosen for the study. Because the shortage in human resources for geriatric care has long been recognized and studied,¹⁶ the government needs to examine its standards of human resource placement as a factor in limiting the admission of elderly who require care into long-term care facilities.

A comparison of the results from the two studies shows that, except for a decline in the acceptance rates for persons receiving intermittent catheterization seen in NH and GH, all of the facilities improved their acceptance rates for all patient categories. In particular, the acceptance rate for *P. aeruginosa* carriers in GICF in the second study showed a statistically significant difference. These improvements probably reflect the ongoing efforts made by these facilities to improve care. Other possible reasons are that, because of the introduction of the public long-term care insurance plan, senior citizens now have more choices of where to obtain care. Also, the expansion of care facilities has stimulated competition among them^{3,5} and we assume that therefore long-term care facilities are concerned that their admission refusals could create a negative reputation among the elderly, of which there are many, still awaiting admittance into these facilities.^{17,18} We did not investigate this issue in the present study, but expect to in the future.

The effect of the lectures on a change in admission policies was examined, but no correlation was found. We first assumed that lecture participants would mainly be care staff and decided that basic, practical information was appropriate for them. Thus, we focused on the general characteristics, pathogenicity, and infectivity of MRSA, and the classification, causes, and means by which people adapt to receiving intermittent catheterization for urinary incontinence. However, the lectures were mainly attended by chief administrators and directors, and not by the staff members who actually care for the elderly in these facilities. The content of the lectures might have been inappropriate; instead they should have been specifically aimed at encouraging admission. Yet another possible reason for the results obtained is

that both the participating and the non-participating groups already had some prior knowledge of these conditions. If that is the case, then public information or guidelines on admission policies may be needed, rather than knowledge. Further examination into the type of information that should be provided and the level of knowledge of participants is needed.

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[原著論文]

痴呆の行動・心理症状 (BPSD) および 介護環境の介護負担に与える影響

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抄録

痴呆の行動・心理症状 (behavioral and psychological symptoms of dementia ; BPSD) および介護環境が介護負担に与える影響について明らかにするため、要介護高齢者の介護者 116 人を対象に、Zarit 介護負担尺度 (ZBI) 等を用いて記名式質問紙調査を行った。介護者の要因のうち介護負担と有意な相関を認められたのは、介護者の続柄、介護期間、相談者および交替者の有無、体の痛みの有無であった。また、介護負担感と強く相関した BPSD は、便・尿失禁、夜間の不穏等介護者の生活を侵害する行動、幻覚や不幸な様子等対応が困難な行動などであった。また、「要介護者がいなくなればよい」「死んでしまいたい」という介護者の危険な感情は介護負担と強い相関があった。要介護者の属性と病状、介護環境および BPSD を説明変数とした ZBI の回帰分析では痴呆性老人日常生活自立度、相談者の有無、「しゃべり続ける」「不幸な様子」「尿失禁」という BPSD が有意な予測値として抽出され、調整済み説明率 $R^2 = 0.401$ であった。以上より、介護負担の評価のうえでは BPSD および介護環境が重要であることが示された。

Key words : 要介護高齢者, 介護負担, BPSD

老年精神医学雑誌 14 : 465-473, 2003

序 言

公的介護保険制度施行後、要介護高齢者には認定された要介護度に応じてサービスが供給されているが、痴呆性高齢者では介護ニーズの評価がむずかしく、必要なサービス量を決定する適切な方法がまだ確立されていない。たとえば痴呆性高齢者では、初期から火の不始末や徘徊などの痴呆の行動・心理症状 (behavioral and psychological symptoms of dementia ; BPSD) がみられ、見守りなどのケアを要することが多いが、痴呆の進行に伴って活動が低下し逆に要するケアが少なくなることもあり、必ずしも痴呆の重症度と必要なサービス量は相関するわけではない。

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このため筆者らは、BPSD・介護環境が介護負担に与える影響について明らかにする目的で、要介護高齢者の介護者に質問紙調査を行った。

I. 対象および方法

1. 対象

調査は、①名古屋大学医学部附属病院老年科外来に通院する患者の介護者 62 例と②A市社会福祉協議会居宅介護支援事業所でケアプランが作成されている高齢者の介護者 54 人の合計 116 人を対象として行った。大学病院では 2 人の医師の外来にておもに痴呆のために通院している患者を対象に選択した。今回の調査では介護者をもたない症例や、介護者自身が高齢であるなどの理由により自己記入式質問紙に回答が困難と思われる症例は対象から除外した。

2. 調査項目および調査方法

主のアウトカムを介護負担として、対象の基本属性のほか、病状や介護者要因、介護環境を調査した。生活満足感、さらに介護負担の結果として生じうる希死念慮などの危険な感情を重要性が高いものとして調査に加えた。

調査は自己記入式質問紙を対象となるおもな介護者に配布して行ったが、これはあらかじめ12人の高齢者ボランティアによる予備調査で回答のしやすさを検討したうえで作成し、介護者が記入したのち、郵送にて回収した。

1) 患者属性および病状

年齢・療養期間のほか、要介護認定で用いられる主治医意見書の分類に従い、障害老人日常生活自立度（以下、寝たきり度）および痴呆性老人日常生活自立度（以下、痴呆自立度）について、①老年科外来通院患者については主治医に、②A市居宅介護支援事業所でケアプランが作成されている高齢者については介護者に評価を求めた。BPSDの評価には、要介護認定調査との整合性を重視して一次調査表に含まれている19のBPSDをもととし、Sanford⁹⁾やGreeneら⁸⁾、Baumgartenら⁹⁾、朝田⁹⁾のリストを参考に補足し、計35項目の網羅的なBPSDリストを作成した。BPSDは回答を簡易にするため、頻度を問わずその有無のみの回答を求めた。

2) 介護者

おもな介護者の続柄と年齢・おもな介護者が介護を続けている期間のほか、介護者の体の痛みの有無および介護のために住む場所をかえたり仕事を辞めたりした有無について調べた。そして、介護を要するようになるまえの要介護者-介護者の人間関係を「不良」から「良好」までの5件法にて、「(要介護者が) かわいそう」「親しい人を失ったという喪失感」「(要介護者の病状なら) 死んだほうがまし」「(要介護者を) 施設に入れるにはつらい」という気持ちを「感じない」「多少感じる」「感じる」の3件法にて調査した。

3) 介護環境

同居人数・世帯の年収・現在利用しているサービス、介護の交代要員や相談できる者の有無につ

いて調査した。

4) 介護負担

負担感にはZarit介護負担尺度(Zarit Burden Interview; ZBI)¹⁰⁾日本語版を用いて調査したが、このなかの22項目の全体的な負担感を問う質問は「まったく負担を感じない」を0点、「極度の負担」を100点としたときの点数の質問（以下、負担感得点）に置きかえて、ZBI 21項目の尺度得点などとの相関をみた。さらにBPSDのうちあると答えた項目について、それぞれどのくらいの負担であるかを「まったく負担を感じない」を0点、「極度の負担」を10点としてつけた点数を質問した。

5) 負担の結果としての感情

介護者自身の現在の生活満足度を100点満点として点数で表すよう求めた。さらに、「(要介護者は) いなくなればよい」「(介護者自身が) 死んでしまいたい」という危険な感情について3件法にて調査した。

3. 分析方法

パラメトリックな項目については平均値と標準偏差を算出し、ノンパラメトリックな項目については度数分布表を作成した。相関性についてはパラメトリックな項目についてはPearsonの相関係数を、ノンパラメトリックな項目についてはSpearmanの順位相関係数を算出した。またパラメトリックな群間の比較にはANOVAを使用し、ノンパラメトリックな群間の比較には、2群間の検定にStudentのt検定を用いた。また、回帰分析はステップワイズ法を用いて行った。いずれも有意確率は5%未満を有意とした。データの分析はSPSS11.0J (SPSS社)を用いた。

II. 結 果

老年科外来群およびA市居宅介護支援所群の間では、寝たきり度・痴呆自立度にて有意差が認められたものの、本研究にて主のアウトカムとするZBI・負担感では有意な差は認められなかった(表1)。本研究では介護負担と関連する因子について明らかにすることを主眼としているため、以

表1 対象者の基本情報

	名大病院老年科	A市居宅介護支援所	全体
n数	62人	54人	116人
年齢	78.9 ± 8.0歳	80.9 ± 10.2歳	79.8 ± 9.1歳
要介護期間	40.4 ± 41.8か月	53.6 ± 41.8か月	46.6 ± 42.1か月
要介護度	3.8 ± 1.4	2.5 ± 1.8	3.1 ± 1.7
障害老人日常生活自立度	2.4 ± 1.5	3.8 ± 2.1 *	3.2 ± 2.0
痴呆性老人日常生活自立度	2.5 ± 0.8	1.7 ± 1.5 *	2.0 ± 1.3
介護者の年齢	58.6 ± 11.0歳	63.3 ± 11.7歳	60.8 ± 11.5歳
ZBI	36.1 ± 17.0	34.3 ± 13.8	35.3 ± 15.6
負担感得点	53.2 ± 24.9	60.5 ± 26.4	56.6 ± 25.8

mean ± SD

* p < 0.05

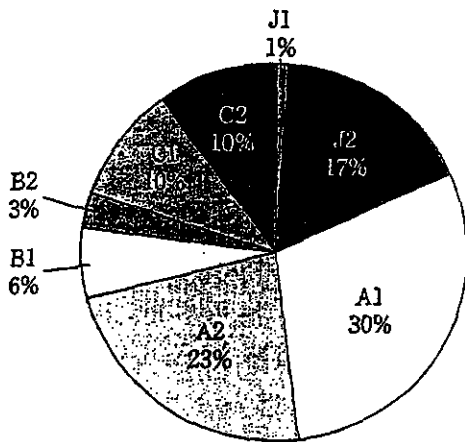


図1 障害老人日常生活自立度

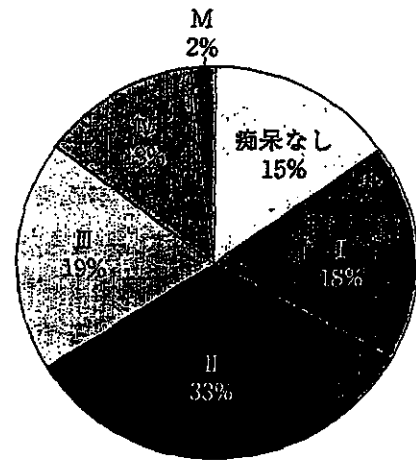


図2 痴呆性老人日常生活自立度

後兩者を合わせて解析・検討した。

1. 要介護者の属性と重症度、介護環境

全体の要介護高齢者の年齢は平均 79.8 ± 9.1 歳、介護を要するようになってからの期間は平均 46.6 ± 42.1 か月であった。調査の回答はおもな介護者によったが、嫁が 27.8%、娘が 30.4%、配偶者が 30.4% とおよそ 1/3 ずつを占めた。

おもな介護者の 84.4% は女性で、年齢は平均 60.8 ± 11.5 歳と介護者自身が高齢の場合が多く、介護者が介護に携わっている期間は平均 45.3 ± 42.2 か月であり、これは患者が介護を要する期間とおおむね合致し、おもな介護者はあまり変動していないことが推察された。また、79.3% と多くの介護者は自分自身が体の痛みをもち、家族のだから介護のために仕事を辞めた例は 19.5%、住

居をかえた例は 13.2% あった。介護を始めるまえの介護者-要介護者の人間関係で「やや不良」または「不良」と答えたものは 27.2% あった。

寝たきり度および痴呆自立度は図 1, 2 に示した。要介護度は自立または未申請の者が 6.1%、要支援が 8.7%、要介護 1 が 23.5%、要介護 2 が 24.3%、要介護 3 が 14.8%、要介護 4 が 12.2%、要介護 5 が 10.4% であった。

また全体の 94.4% が何らかの介護サービスを利用しており、デイサービス 73.8%、ショートステイ 25.2%、ヘルパー 25.2%、介護用具 21.5%、訪問看護 10.3%、訪問診療 8.4%、入浴 3.7%、訪問歯科診療 2.6%、訪問リハビリテーション 0.9% の順に多かった。

また介護者は、「(要介護者が) かわいそう」と

表2 BPSDの頻度と負担感との相関および項目別負担感得点

BPSD	あると 答えた数	相関係数(Spearman's ρ)		負担感得点 (/10点)
		ZBI	負担感得点	
金銭の管理ができない	77	0.308**	0.386**	6.8 ± 3.3
知っているはずの人がわからない	68	0.043	0.071	5.2 ± 2.8
現在と昔のことを混同したような言動がある	64	0.256	0.219	5.2 ± 2.5
尿失禁する	63	-0.009	0.188	6.0 ± 3.4
物事に関心を示さない	61	0.218	0.349**	5.6 ± 3.0
説明しても否定したりゆがんだ解釈をする	60	0.321*	0.291*	5.1 ± 2.6
目的もなく動き回る	56	0.301*	0.267*	5.8 ± 2.5
大声をだす	54	0.380**	0.215	4.8 ± 2.7
夜間不眠あるいは昼夜の逆転がある	53	0.135	-0.027	5.2 ± 2.6
火の不始末や火元の管理ができない	52	0.117	0.186	6.0 ± 3.5
外出すると病院、施設、家などに一人で戻れなくなる	51	0.150	0.219	6.9 ± 2.9
便失禁する	48	0.030	0.358*	6.1 ± 3.3
憂うつ・不幸そうである	46	0.230	0.224	4.5 ± 2.1
まとわりついたり同じ質問を繰り返す	43	0.322*	0.232	5.3 ± 2.4
家族のことがわからない	41	-0.051	0.011	5.0 ± 2.8
実際にはないものが見えたり、聞こえたりする	40	0.230	0.297	5.2 ± 2.6
泣いたり、笑ったりして感情が不安定になる	39	0.366*	0.259	4.7 ± 2.4
やたらと物を隠す	37	0.456**	0.371*	5.5 ± 2.7
食欲が異常に増えたり減ったりする	36	0.258	0.124	5.4 ± 2.7
助言や介護に抵抗する	35	0.310	0.076	5.1 ± 2.3
一人で外に出たがり目が離せない	33	0.084	0.238	5.7 ± 2.7
暴言や暴行	32	0.071	0.028	4.8 ± 3.1
物を盗られたなどと被害的になる	30	0.502**	0.485**	5.3 ± 3.0
「家に帰る」等と言いつつ落ち着きがない	29	0.238	-0.006	5.3 ± 2.7
不潔な行為	29	0.107	-0.019	5.6 ± 3.1
作話をしたり周囲に言いふらす	28	0.479**	0.209	4.7 ± 2.8
しつこく同じ話をしたり、不快な音を立てる	28	-0.069	-0.235	4.3 ± 3.2
無意味な作業に熱中する	24	0.022	0.171	4.4 ± 2.7
一人でしゃべり続けたり、家族の団楽や会話を妨害する	24	0.253	0.213	4.1 ± 2.1
夜半に騒いんだり家族を起こしたりする	24	0.143	0.011	4.9 ± 2.4
他人との間で非常識な言動やトラブルがある	23	0.231	0.028	4.6 ± 3.0
いろいろなものを集めたり、無断で持ってくることもある	18	-0.022	0.288	4.6 ± 2.6
食べられない物を口にする	15	-0.163	-0.076	4.3 ± 2.9
物や衣類を壊したり、破いたりする	12	0.134	0.231	4.6 ± 2.8
周囲が迷惑する性行動	1	-	-	5.0 ± 0.0

負担感得点は mean ± SD

* $p < 0.05$, ** $p < 0.001$

「思う」46.0%、「多少思う」38.9%、「思わない」15.0%、「親しい人を失ったという喪失感」は「感じる」25.2%、「多少感じる」31.5%、「感じない」43.2%、「(要介護者の病状は) 死んだほうがまし」は「思う」46.0%、「多少思う」38.9%、「思わない」15.0%、「(要介護者を) 施設に入れるにはつらい」は「思う」41.6%、「多少思う」43.4%、「思わない」15.0%、という感情をもって

2. BPSD (表2)

全体としてBPSDのなかで、よくみられたものは順に、①金銭の管理、②知っているはずの人物がわからない、③現在と昔のことを混同、④尿失禁、⑤関心の低下であった。BPSDとしてみられた場合の項目ごとに算出した負担平均点数は、①一人で自宅に戻れない、②金銭の管理、③便失禁、④火の不始末、⑤尿失禁の順に高かった。

BPSDの有無と、①家族のだれかが介護のため

に住む場所をかえたか、②家族のだれかが仕事を辞めたか、③介護にやり甲斐があるか、④休める日があるかとの関連について検討したところ、①については不眠 (Spearman's $\rho = -0.269$) に、②については尿失禁 ($\rho = -0.300$) ・物を壊す ($\rho = -0.266$) ・便失禁 ($\rho = -0.239$) ・家族のことがわからない ($\rho = -0.207$) ・知人のことがわからない ($\rho = -0.188$) に、③については物を壊す ($\rho = -0.298$) ・まとわりつく ($\rho = -0.256$) ・大声 ($\rho = -0.245$) ・無意味な作業 ($\rho = -0.219$) ・憂うつ不幸そう ($\rho = -0.203$) ・不潔行為 ($\rho = -0.202$) ・火の不始末 ($\rho = -0.193$) ・暴言暴行 ($\rho = -0.190$) に、④については便失禁 ($\rho = -0.293$) ・尿失禁 ($\rho = 0.254$) ・異食 ($\rho = 0.224$) に有意な相関が認められた。これらより、とくに尿・便失禁があると家族は仕事を辞めなくてはなくなることが多く、介護のため休める日も少なく、負担感としても大きくなっている構造が推測される。

対象者全体において、35項目のBPSDの合計数は平均 11.7 ± 7.9 (SD) 項目で、項目別負担感の合計は平均 63.5 ± 52.1 点であった。BPSDの項目数の合計はZBIと $r = 0.396$ ($p < 0.001$)、負担感得点と $r = 0.202$ ($p < 0.030$) と有意な相関を示し、またBPSDの項目別負担感の合計も同様にZBI ($r = 0.442$, $p < 0.001$)、負担感得点 ($r = 0.282$, $p < 0.002$) と有意に相関した。

3. 介護者の負担感

ZBIの平均点は 35.3 ± 15.6 (SD) /84点で、Cronbachの α 係数0.915と高い信頼性を示した。負担感得点は 56.6 ± 25.8 点であり、ZBIと $r = 0.623$ の中等度の相関を示した ($p < 0.001$)。また痴呆症例のみに限った場合、ZBIの α 係数は0.918とやはり高い信頼性を示し、負担感得点とは $r = 0.528$ ($p < 0.001$) の中等度の相関を示した。これらより痴呆・非痴呆が混在した場合でも痴呆症例に限った場合でも、ZBIは介護者の負担感をよく示していることが示唆された。

患者属性・病状では、痴呆自立度でZBIと $r = 0.334$ ($p = 0.003$) の有意な相関をみたものの負担

感得点とは有意ではなく ($r = 0.154$, $p = 0.163$)、要介護度や寝たきり度についてはいずれもZBIおよび負担感得点と有意な相関は認めなかった。

また、介護者要因のなかでZBIおよび負担感得点と有意な関係を認めたのは、①介護期間 (ZBI $r = 0.223$, $p = 0.021$, 負担感得点 $r = 0.219$, $p = 0.018$, 以下同)、②相談者の有無 ($p < 0.001$, $p = 0.024$)、③介護者の体の痛みの有無 ($p = 0.019$, $p = 0.001$) であった。相談者の有無はこのほか、将来の不安 ($\rho = 0.280$)、施設に入れるのがつらい ($\rho = 0.193$)、自分なら死んだほうがましと病状を悲観する気持ち ($\rho = 0.194$) に有意な相関があり、相談できる者の重要性が示唆された。そして、介護を交替する者の有無は負担感得点と有意な相関があったものの ($p = 0.049$)、ZBIとは相関がみられなかった。同様に、介護者の続柄は負担感得点とのみ関連をもち ($p = 0.018$)、①嫁、②配偶者、③娘、④息子の順に負担感が高かった。介護者の性別、年齢、世帯の年収、介護を要するまでの人間関係には有意な相関は認められなかった。

BPSDのうちZBIと相関の高かったのは、①昼夜逆転 ($r = 0.375$)、②便失禁 ($r = 0.344$)、③物を隠す ($r = 0.335$)、④幻覚 ($r = 0.307$)、⑤会話を妨害する ($r = 0.306$) であり、負担感得点と相関の高かったのは、①便失禁 ($r = 0.352$)、②夜半に騒ぐ ($r = 0.210$)、③尿失禁 ($r = 0.206$)、④憂うつ・不幸そうである ($r = 0.192$)、⑤落ち着きがない ($r = 0.190$) であった。BPSDのすべての項目を変数としてZBIの回帰分析を行ったところ、便失禁 (標準化係数 $\beta = 0.324$)、物を隠す ($\beta = 0.240$)、不眠 ($\beta = 0.214$)、関心の低下 ($\beta = -0.204$)、暴言 ($\beta = 0.173$) が変数に投入され、調整済み説明率は $R^2 = 0.300$ であった。

さらに要介護者の属性と病状、介護環境およびBPSDのうちZBIと有意な相関を示した項目を説明変数としてZBIの回帰分析を行ったところ、痴呆自立度 ($\beta = 0.114$)、相談者の有無 ($\beta = 0.289$)、しゃべり続ける ($\beta = 0.294$)、不幸な様子 ($\beta = 0.304$)、尿失禁 ($\beta = 0.205$) が有意な予測値とし