なことになってしまうと，逆に本末転倒ではないかということを非常に危惧します．

弱者への圧力，安易な啓蒙

■**田中**　ですから，リビング・ウイルやアドバンス・ディレクティブが成立する前提として，平等な社会があるということが必要で，これは声を大にして言わなければいけない．つまり，弱者が遠慮するような社会であったり，弱者が暗黙のうちにプレッシャーを感じるような社会である限り，これらは機能しないわけで，医師としては非常に気をつけなければいけないですし，いま，患者の最善の利益といったときには家族との関係が必ず出てきますけれども，家族のなかの誰が患者の意思を代弁しているのかということの情報収集を医師の責任で行う場合にも，細心の注意を払わなければなりません．つまり，あくまでも弱者を守らないと，自分の最期を自分で決めるという，非常に民主的で潔くて，カッコよく見える行為もさまざまな危険性をはらむということです．

■**尾藤**　現状においては，先生がおっしゃったように，まず平等な社会があって，医療を受ける側と提供する側とに良好な関係があって……．

■**田中**　コミュニケーションがちゃんと成立していて……．

■**尾藤**　変な啓蒙がなくて……．

■**田中**　そうです(笑)．圧力がないということですよね．

■**尾藤**　患者さんには啓蒙はしちゃダメなんです．患者さんが自然にもっているものを大事にして，「実はこういうものを書いておいたんだけど」というものについては尊重すべきだと思いますが，安易な啓蒙は怖いです．

事前指示への反感

■**田中**　アメリカの病院では，入院のときに「リビング・ウイルはあるか．アドバンス・ディレクティブはもっているか」というふうに聞くんですが，それを押し付けがましいと感じない患者がいるでしょうか．私は，ほとんどいないと思います．結局それは，病院が“DNR”にすればするほど儲かるという素地があるから，病院は必死にそうしたいのだということが，透けて見えているわけです．患者は，ぜんぜんそういうことは信用していないから，「そういうときには『わからない』と答えろ」と……．

ただ漠然と「やめる」というのは許されないから、「始めない」という選択をとることは現実にたくさんある

尾藤誠司氏

■**尾藤**　見え見えですから(笑)．

■**田中**　ですから，いまの日本で，本当に患者さんが自分の人生観に基づいて，自発的に，「自分はこのような治療を受けたい」ということを文書で残していただけるなら――まだまだ例外的なことだと思うのですが――，そういう現象が広がれば，それはもちろんすばらしいことです．

非常にありがたいことではあるんですね．でも，それは誰も強制できることではないし，ましてや，そうでないから困っているというふうに迷惑顔をするということは，医療側は決してしてはいけない．アメリカでは，迷惑顔をする医療機関が増えているのですね．これは，非常に危険なことです．

■**尾藤**　まったくですね．

■**田中**　もろもろの条件を考えたうえで，患者さんが進んでそういうことをしてくださるなら，どんなにすばらしくて，ありがたいだろうとは思いますけどね．

「医療の差し控え」と「医療の中止」

治療を「やめる」というチョイスは現場にない

尾藤　最後に，臨床現場における「医療の差し控え」と「医療の中止」のことをお話しさせていただこうと思います．

いまのリビング・ウイルの話にもつながるんですけれども，現場で私が問題だと思っているのは，寝たきりになる可能性がかなり高いけれども，社会復帰できる可能性もなくはないという状態の人たちがいるわけですが，現状では，治療を「やめる」というチョイスは現場にはないと思っているのです．ないというよりも，許されないのではないかという感じでしょうか．

これが，倫理的に許されないのか，法的に許されないのかということすら曖昧なのですが，おそらく医師は，ただ漠然と「やめる」というのは許されないから，「始めない」という選択をとることは現実にたくさんあります．救急の現場では，非常に重症の方への治療に際して，人工呼吸器がつきっぱなしになる可能性が高い場合がある．だから始めない．

倫理的な差異，心情的な差異

尾藤　こういうことはたくさんあるわけですが，これはおそらく「やめられない」という前提があるからこそ，そういうふうになってしまうわけです．倫理的にちゃんとやめることができれば……．

田中　とりあえず始めておいて，あとで考えるという選択肢があり得るわけですね．

尾藤　その通りです．倫理的なことだけ突き詰めていくと，「始めない」ということと「やめる」ということには，たいした差はないんです．

田中　倫理的にはイコールですよね．

尾藤　ただ，医療者，特に医師の感覚として，始めないことで人を殺すことはないんだけれども，やめるというのは人を殺す可能性が大きい．その心情的な差異はすごく大きいと思うんです．

田中　それは，ご家族にとってもおそらく同じだと思います．

尾藤　その通りです．この部分については，今後，かなりのディスカッションが必要だと思います．倫理的に差はないのだといっても，やはりありますからね(笑)．

田中　気持ちのうえではたいへん大きな差があります．

尾藤　そうです．そしてひょっとしたら法的にも，あるかもしれない．

田中　日本医師会は，開始しないことと中止することをひとくくりにして，区別していませんね．東海大事件の判決(編集室注 1)では中止のほうに重きを置いて，「中止してもかまわない」ということを，はっきり言っているわけですので，ほんとうは問題にはならないはずなのですが，医療者側にとっても，家族にとっても，気持ちのうえでの段差が大きいというのはおっしゃる通りで，ここのところは，確かにもう少し公的な場所での話し合いが必要だと思います．ほんとうは差はないはずのことですからね．

求められるオープンな議論

「始めない」より「やめる」がベターな場合も

尾藤　「始めない」というチョイスはすべきではないだろうというケースも，少なからずあると思います．そして，始めて数カ月経ってから「やめる」というチョイスをしたほうがよいのではないかというケースも，現場には少なからずあるわけですが，「やめるなんて，そんなことは無理でしょう」という前提が現場にできてしまっているんですね．そして，そこには実は何の根拠もないわけです．

田中　東海大事件の判決でも，治療の中止というのは安楽死ではなく，認められるということをはっきり言っているんです．安楽死か，安楽死ではないかの定義というのは，耐え難い苦痛があるかどうかだけの違いなので，もし苦痛がない場合には「治療の中止」という言い方をしているわけです．ですから，治療の中止というものは，条件

はあるものの判決でも容認しているわけです．

ところが，現場ではそのあたりのことに非常に強い抵抗があって，特に羽幌病院のケース(編集室注2)のように抜管した医師が警察から事情聴取を受けたという報道が強いインパクトを与えています．人工呼吸器を始めなかったから逮捕されたのではなくて，いったん入れてから中止したから逮捕されたという理解が広まったことから，「やめられない」という理解になっているわけです．これは，判決からは導き出せない結論のはずです．

尾藤　これに関しては，本当にオープンな議論が必要ですね．

田中　その通りです．

医療者が変わらなければならないこと

羽幌病院のケースはどこが問題だったか？

田中　羽幌病院の例をとれば，人工呼吸器を取り外したこと，その行為自体は，判例からも，職業倫理指針からも問題はないのですが，あえて問題があるとすれば，まず，いわゆる回復不能な状況かどうかの検討をする時間が十分にあったのかという疑問があります．それからもう一つは，単独の医師が決定しているということです．この2点が，判例や職業倫理指針からみて問題だということで，警察が介入したのだと思います．

田中　ですから，とりあえず挿管して，それから2週間，1カ月，2カ月と十分な時間的余裕をもって診て，尾藤先生が最初にいわれたケースのように，十分に頑張ってみて，そのうえで，ご本人あるいはご本人の意思が確認できない場合はご家族が，ベストの推定である結論に達した場合に，それに従うのが医師としてむしろ倫理的なことである，というのが判例から汲み取れることです．羽幌病院の場合は，あまりにも拙速のきらいがあったということです．回復可能であるかどうかの判断に，時間をかけなさすぎたことと，単独の医師が判断したという，その2点が明らかに疑問点となって警察の介入を招いたのだと思います．

しかし，この2点をクリアしたら，大手を振って，胸を張って医療の中断ができるかというと，先生もおっしゃったように，われわれはもうマヒ状態に陥っております．

独りで決めない文化をつくる

尾藤　おそらく，われわれ医療者，特に医師がもう少し変わらないといけないということは確かだと思います．一つひとつのケースについて“魔女狩り”をするのではなくて，私たちの問題として捉えて，私たちの文化を変えていかなければいけないし，おそらくそこから，患者さんにとってよりよいサービスのとっかかりが出てくると思います．

そのために，まずいえることは，やはり独りで決めない文化をつくっていくことだと思います．診断や治療に関してはカンファレンスがあるのに，より難しい，教科書にも何も書いていないことについてカンファレンスがないというのは，非常に不自然です．さらに，こういうカンファレンスは，医者だけで集まってやっても，偏った意見しか出てこないと思いますので，いろいろな病院スタッフ，市民に入ってもらって対話していく必要があると思います．また，いまほとんど研究審査をしている倫理委員会というのを，もう少し臨床に巻き込んでいくようなことが必要です．

そうすることで，個人の荷も少しおりると思います．何年後には……という話ではなくて，いますぐにできることというのは，たぶんそのあたりではないかと思います．

倫理委員会にもっと案件をあげる

田中　倫理委員会に，現場からもっともっと案件をあげるべきです．そうすれば，次第に倫理委員会が倫理委員会として機能するようになってくると思います．

尾藤　それに，倫理委員会には，そういう話が実はすごく好きという方が多いと思うので，われわれのほうからオープンに，「私，このことで困っています」と言えばいいんです．そして，それは明日からでもできることだと思いますし，たい

そうなことではないはずです．

田中　そのとおりだと思います．幸いなことに，聖路加国際病院には，ターミナルケアカンファレンスもあり，CPCもあります．私は，まだまだ理屈が先走って，そこでは反発もあるとは思うのですが，研修医の皆さんには，とにかく懸案を倫理委員会にあげていいのだということは言っています．いざあげるとなると，準備は大変ですが，その準備をするうちに，何が問題なのかがわかってきたという研修医もいますので，私は，「大事なのはそこなのよ！」と申し上げたいのですね．

いったい自分は，何がわからなくて悩んでいるのだろうかということ，これは人に聞いていいことだし，上の先生でも独りで決めてはいけないのだから，合議していいのだということ，そういうことに気がつくだけでも意味があります．そして合議するためには，自分は患者さんや家族から，どういうことを情報として集めておいたら役に立つのだろうかと，そういうスタンスで考えることによって，研修医の方々も終末期が嫌でなくなるのではないかと思います．「嫌だなあ」という気持ちになるのは，何かもやもやと，自分ではわからないことに責任を取らされるような，ちょっと引きたくなるような雰囲気があるからです．研修医の皆さんが，終末期を嫌いにならないような雰囲気を，われわれが病院のなかのカルチャーとしてつくっていく，その責任があるんじゃないかと思います．

「わからない」問題を共有することが大切

研修現場でどのような教育が必要か？

尾藤　まさに，難しい問題を皆で共有したり，こういうものは難しいのだということを教育していかなければならないわけで，あいまいなことからは目をそらして，華やかな医学的事実ばかりを見ていこうというような文化にしない教育が必要ですね．特に，卒業直後にリアルな現場に出て，「ウワァーッ！」と思っている研修医の人たちが，医学的事実だけの世界にいかずに，現場に踏みとどまってもらうための教育というのが，すごく必要だと思います．

田中　ターミナルの患者さんがいる病室から，足が遠のかないような雰囲気を，われわれがつくっていかなければいけないですね．

尾藤　倫理委員会やカンファレンスをもつ，そういうカリキュラムも大事だとは思いますが，われわれが現場での姿を見せていくことが大事ですよね．

田中　われわれも，わからないことだらけのなかで悩んでいるわけです．指導医だから何もかもわかっているということはないわけですから，その「わからないこと」をシェアすることだと思います．実は，患者や家族といちばん接している医者は研修医なのです．研修医や看護師さんの集めた情報というのは，これらの判決が奨励しているような，「コミュニケーションの促進」ということにおいて，かなり重要だと思います．また，その意味で，指導医や倫理委員会が，研修医や看護師の意見を尊重するというカルチャーも非常に大事だと思います．

（了）

〔編集室注1〕　東海大医学部付属病院(神奈川県)で91年，同院医師が末期がん患者に塩化カリウム製剤などを注射して心停止させた事件．横浜地裁は95年3月，殺人罪に問われた医師に有罪判決を言い渡し，安楽死の4要件と治療行為中止(尊厳死)の3要件を示した．

安楽死の4要件：①耐え難い肉体的苦痛があること，②死が避けられずその死期が迫っていること，③肉体的苦痛を除去・緩和するために方法を尽くし他に代替手段がないこと，④生命の短縮を承諾する明示の意思表示があること．

治療行為中止の3要件：①治療不可能で，死が不可避な末期状態，②中止を求める患者の意思表示があること(家族による推定も含む)，③死期の切迫の程度などを考慮し，自然の死を迎えさせる目的に沿って中止を決めること．

前者は「積極的安楽死」，後者は「消極的安楽死」と呼ばれたこともあったが，そのような用語が不適切であるとの議論もあり，最近ではあまり使われない．

〔編集室注2〕　北海道の道立羽幌病院で2004年2月，循環器内科の医師が，食事をのどにつまらせ心肺停止状態で搬送された90歳の男性患者の人工呼吸器のスイッチを切り，患者を死亡させていたケース．患者の家族の了承は

得ていたが，警察は回復の見込みがないとした判断が不十分として，殺人の疑いで医師から事情を聴いた．患者は，同医師による心肺蘇生措置により，心臓は動きだしたが自発呼吸は戻らなかった．2005年5月18日北海道警は，同医師を殺人容疑で書類送検した．今後旭川地検が起訴の可否について捜査を行う．

びとう せいじ：国立病院機構東京医療センター・総合診療科／国立病院機構本部研究課・臨床研究推進室長 〶152-8901 東京都目黒区東が丘2-5-1
たなか まゆみ：聖路加国際病院・内科 〶104-8560 東京都中央区明石町9-1

医療サービスの評価

その構成要素と評価の枠組みについて

尾藤誠司

Question & Answer

Q：医療の質を構成する要素は？

A：構造(ストラクチャ)，プロセス，アウトカムがあり，これらそれぞれに評価する方法がある．

Keyword：医療評価，医療の質，プロセス，アウトカム

「医療サービス」という言葉に違和感を持っている医療者は少なくないと思う．「サービス」という言葉には，なんだか営利企業が顧客におもねっているようなイメージが付きまとうのだ．実は，私も少し違和感を持っていて，もう少しうまい訳があればよいかな，と時々思う．しかしながら，「サービス」の本質的な意味は，プロフェッショナルが，最大限の誠意とともにその技量を対象者に対して提供する，ということである．その意味においては，心停止患者にACLSを行うことも「医療サービス」の範疇の中にある．接遇的な部分は医療サービスのほんの一部分にすぎない．すなわち，よい医療サービスとは，いかにその受け手――すなわち患者や市民――にとって益の大きな医療提供がなされるか，ということを示すものであり，医療サービスの評価とは，たとえば保険のシステムのようなきわめてマクロなものから，ベッドサイドにおける医療スタッフの細やかな対応まで，提供されるすべての医療に対して，それがどれほど“よいもの”か，査定することを示す．

この数年，医療サービスに関連するような言葉が巷をにぎわしている．「アウトカム評価」「DPC」「インディケーター」「テクノロジー・アセスメント」など，それまでは聞かれなかったような言葉を一般紙でも目にするようになってきた．これは，わが国において，いままで専門家の聖域に安住していた医療が，いよいよ評価される時代になってきたことを明確に示すものであろう．一方では，医療サービスがいったいどのような基準で評価されるのか，ということについて，一定の見解がもたれているとは言いがたい．

本稿では，医療サービスを評価する際の基本的な概念を紹介し，とくに，医療の質の評価について，その構成要素と，評価の方法などに関する一般的なレビューを行う．

医療サービスはどのような概念で構成されているか？

提供された医療サービスは，最大限に効果的なものでなければならない．これは感覚的に誰もが納得するものである．しかしながら，いかに効果的なものであったとしても，そのサービスを一部の人にしか提供できなかったり，そのために多大な費用を費やしてしまっては，一概にそれをよいものであるということはできない．いくつかの視点において統合されたうえで，よい医療である必要がある．その視点は，「3つのE(effectiveness, efficiency, equity)」と呼ばれるものである．

Effectiveness(効果)とは，現実世界の中で医療サービスがどれほどその受給者に寄与しているかを表すものである．患者の余命を明らかに伸ばす

治療法や，非常に精度の高い検査は“効果の高い”医療サービスであるといえる．Efficiency（効率）は，効果の絶対量ではなく，提供側の支出を勘案したうえでの効果の査定のことを示す．同じくらいの効果をもたらすプログラムであれば，支出は少ないほうがより“効率が高い”，すなわち，よいサービスであるといってよい．たとえば高血圧治療において，利尿薬とACE阻害薬に同じ効果があるのであれば，安価な利尿薬を第一選択とすることが，より効率的な医療の提供である[1]．最後のequity（公正性）とは，医療サービスを必要としている人たちに，必要に応じたサービスが差別なくなされているかどうかを表す．社会保険制度が不完全であり，医療保険の多くを民間保険によってまかなっている米国では，公正性の問題は医療サービス上の大きな問題点となっている(*J1*)．

よい医療サービスを規定する3つの要素

上記の概念を加味したうえで，医療サービスにおいて何が評価されるべきかを簡単にまとめたい．医療サービス評価の対象は，大きく分けて，①アクセス，②コスト，③クオリティ（質），の3つである[2]．簡単にまとめれば，医療に対するアクセスの評価は，主に公正性の評価，コストの評価は効率の評価（実際には，コストを評価しただけでは効率の評価にはならない），そして，質の評価は効果（効率も含む）の評価を主に行うことを目的としている．

上記の3つの要素の中で，わが国において改善が急務であるものは何であろうか？ アクセスに関していえば，国民皆保険制度の恩恵のために，無保険であることによって医療サービスの提供が受けられないという状況はほとんどない．さらに，すべての医療機関に対して国民が自由に診療を受けられる環境があり，先進国の中でもアクセスに関する問題は非常に小さいといえる．また，コストに関しても，将来的には医療費の増加が懸念される一方，少なくとも現時点においてはGDPの7％強と，英国を除けばほかの先進諸国に比較してかなり低い支出であり，急務の問題とは考えにくい．米国の現状は，この2点において惨憺たるものであり，解決すべき問題は山積みである（表1）．

表1　日本，英国，米国の医療サービスの比較

	日本	英国	米国
アクセス（公正）	○	△	△
コスト（効率）	○	○	×
質（効果）	△	△	○

（近藤克則：「医療費抑制の時代」を超えて．p30より引用）

しかしながら，そのような環境にあり，さらには“エクセレントな医療の提供”がなされているイメージの強い米国でも，現在，医療の質の改善が大きなプライオリティとなっている．とくに，専門医療より，よりプライマリ・ケア・レベルでの医療の質の評価と改善に焦点が当てられている．

わが国の提供する医療の質は，はたしてどうなのだろうか？ その答えはよくわからない．エビデンスがないからである．しかしながら，とくにプライマリ・ケアにおいて，その質に大きなばらつきがあることが推察される．わが国において，医療サービスの向上を考えるうえでまず取り組むべきは，質の部分であろう．それが正当に評価され，根拠として提示されたうえで，初めて改善への方策を立てることが可能になるのである．

JIMノート

J1　日米英の医療保険制度

日本のように，国民のほぼすべてが社会保険に加入しており，なおかつどの医療施設にも直接かかることができるシステムは少ない．米国では，高齢者を対象とした社会保険であるMedicare，公共福祉プログラムであるMedicaidがあるが，保険の中心は民間保険であり，また，多くの人々は経済的な理由から民間保険にも入ることができていない．また，英国は，医療サービスへの支出は基本的に税金でまかなっている．

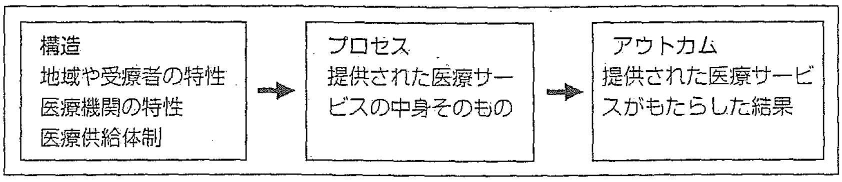

図1 医療の質の概念図

医療の質はどのような枠組みで評価されるのか？

それでは，医療の質というものが，どのように評価されるのかについて説明したい．医療の質は3つのレベル，すなわち，①構造，②プロセス，そして，③アウトカム，のレベルで評価が行われる(図1)[3]．

構造とは，医療サービスを提供するうえであらかじめ備わっている環境を指す．今までわが国において行われてきた病院管理的な視点による医療の質評価の多くは，この構造レベルでの評価である．たとえば，入院患者ケアを評価する際に，その施設に栄養サポートチームや感染対策委員会があるかどうか，日中，1人の入院患者に対して何人の看護師を配置することができるか，などがこれにあたる．構造レベルでの評価は，マクロな視点で把握がしやすいため，評価の中では最も簡便な方法である．一方，構造レベルの評価は，実際の医療サービスが提供される前段階のものであり，間接的な評価の意味合いしか持たないこと，さらに，非常に低いレベルの質の医療に関しては評価が可能であるが，一定レベル以上の質評価には向かないなどの欠点がある．

プロセス評価とは，提供される医療そのものの妥当性について評価することを指す．医療行為の具体的な内容に入っていくために，評価の方法はよりミクロな視点のものとなる．たとえば，心筋梗塞で入院した患者に対してアスピリンの処方がなされているか，というような個別の医療内容をチェックしていく方法である．次稿(東論，p200)でもあるように，一般的に臨床評価指標やインディケーターといわれるものは，主にこの医療プロセスを評価することを中心に構成されていることが多い．医療プロセスの評価は，医療行為そのものを評価する行為であるため，非常に直接的であり，また，改善点に具体性があるため，現在では医療の質を評価する方法としては中心的な役割を担っている．しかしながら，たとえば診療録を一つひとつチェックする煩雑さや，個人情報保護の問題など，方法の困難さに欠点があり，さらには，評価しているプロセスが本当に妥当なものであるかを評価する必要もあるなど，問題点も多い．

アウトカム評価は，提供された医療によって，その受給者，すなわち患者や市民がどのように恩恵や害を受けたか，という査定を行う方法である．特定の手術に対する施設間の死亡率のばらつきや，クリティカル・パス導入前後での平均在院日数の差などは，アウトカム評価の典型的な例である．この方法は，多くの臨床研究で行われている方法と類似しているため，医療者にとっては最もなじみやすい方法であろう．アウトカム評価は，プロセス評価に比較すればずいぶん煩雑さが少ないといえるが，アウトカムの差がはたして本当に医療の質の差であるかどうかについては一概に言えないことが多く，結果の妥当性を吟味する必要が常にある．最近では，死亡率や在院日数など従来から行われていたアウトカムの評価だけではなく，たとえばQOLや患者満足度など，より患者側に立脚した視点でのアウトカム評価も行われるようになってきた[4]．これらの“患者立脚型アウトカム”は，医療者のフィルターをかけることな

く評価することが可能なため，米国などでは，民間保険会社が自社の提供するプログラムの質を示す指標として取り入れている．

3つのレベルでの医療の質の評価には，それぞれ利点と欠点がある．実際には，構造，プロセス，アウトカムのうちどれか1つを評価するよりは，たとえばプロセス，アウトカムの両方について評価し，総合的に医療の質を査定するほうが望ましい．

質の評価の問題点とバリア

医療の質は，継続的に評価され，改善に向けた努力がなされるべきであることは，おそらく疑う余地がない．しかしながら，実際にそれを行うにはいくつかの問題点や，越えなければならない壁が存在する．

第一には，妥当な目的を持って妥当な評価基準が設定されているかの吟味が，質評価には必要である.[4] たとえば，1つの施設における医療の質を評価する際にも，目的によって評価の方法は変わってくるであろう．その医療施設に対し，全国的にどのくらいのレベルにあるかを伝えるための評価，もしくは，優良施設かどうかを判別するための評価と，現在の診療レベルの問題点を指摘し，改善を促すための評価とでは，評価の基準や評価方法も異なっているべきである．どのような評価基準を設定するかについては，注意深い考察が必要であろう．第二には，設定された評価基準が，はたして評価尺度としての精度を保っているかどうかを検討する必要がある．ここ数年，わが国で開発されはじめている「エビデンスに基づいた診療ガイドライン」が，一部の専門家から反発を受けている現状もあるが，評価の基準はコンセンサスが得られるようなものである必要がある．さらには，医療者自身に，評価されることに対する警戒心が少なからずあるという点を考慮する必要がある．管理者や評価機関がトップダウンで行う医療の評価は，実行可能性が高い一方，評価される側にストレスを与える．また，評価そのものが目的化してしまい，実際のケアの向上よりも評価でよい点を取ることのみに医療提供者のインセンティブが働くという懸念もある．

おわりに

医療サービスを科学的な方法で評価する試みは，最近本格的に始まったばかりである．質を評価するにあたっては，自分たちの提供する医療の質には現時点で問題があるという認識が必要であり，それを受け入れることは少なからず痛みを伴うものであろう．市場原理を用いた差別化のための評価ではなく，国民の健康を司るプロフェッショナルとして，より自分たちのサービスを研鑽し続けるための自己評価，他者評価を続けていきたいものである．

文献

1）コクラン AL／森亨(訳)：効果と効率―保健と医療の疫学．サイエンティスト社，1999．＜コクランの書いた歴史的な名著．効果・効率に関する概念的なまとめと具体的な解説が詳細に記されている．すべての医療人が読むべき文献の1つ＞
2）尾藤誠司：ヘルスサービス研究とその可能性―米国の医療改革を参考として．医療 52：650-656，1998．＜医療サービスの構成概念，アクセス・質・コストの意味や医療評価におけるキーポイントを簡潔にまとめたレビュー＞
3）Donabedian A：The definition of quality and approaches to its assessment. Health Administration Press, Michigan, 1980．＜医療の質を学ぶ人間すべてが出発点とするべき根幹の文献．医療における質というものが，初めて明確に概念化され解説されている＞
4）尾藤誠司：QOLの評価．精神科診断学 9：13-21，1998．＜患者立脚型健康アウトカムとしての“健康関連QOL”について，体系的に解説してレビュー＞

びとう せいじ
東京医療センター総合診療科／臨床疫学室
〠152-8902　東京都目黒区東が丘2-5-1
Tel：03-3411-0111　Fax：03-3412-9811

Negotiating End-of-Life Decision Making: A Comparison of Japanese and U.S. Residents' Approaches

Baback B. Gabbay, MD, Shinji Matsumura, MD, MSHS, Shiri Etzioni, MD,
Steven M. Asch, MD, MPH, Kenneth E. Rosenfeld, MD, Toshiaki Shiojiri, MD,
Peter P. Balingit, MD, and Karl A. Lorenz, MD, MSHS

Abstract

Purpose

To compare Japanese and U.S. resident physicians' attitudes, clinical experiences, and emotional responses regarding making disclosures to patients facing incurable illnesses.

Method

From September 2003 to June 2004, the authors used a ten-item self-administered anonymous questionnaire in a cross-sectional survey of 103 internal medicine residents at two U.S. sites in Los Angeles, California, and 244 general medical practice residents at five Japanese sites in Central Honshu, Kyushu, Okinawa, Japan.

Results

The Japanese residents were more likely to favor including the family in disclosing diagnosis (95% versus 45%, $p < .001$) and prognosis (95% versus 51%, $p < .001$) of metastatic gastric cancer. Of residents who favored diagnostic or prognostic disclosure to both the patient and family, Japanese residents were more likely to prefer discussion with the family first. Trainees in Japan expressed greater uncertainty about ethical practices related to disclosure of diagnosis or prognosis. Many Japanese and U.S. residents indicated that they had deceived a patient at the request of a family (76% versus 18 %, $p < .001$), or provided nonbeneficial care (56% versus 72%, $p < .05$), and many expressed guilt about these behaviors.

Conclusions

The residents' approaches to end-of-life decision making reflect known cultural preferences related to the role of patients and their families. Although Japanese trainees were more likely to endorse the role of the family, they expressed greater uncertainty about their approach. Difficulty and uncertainty in end-of-life decision making were common among both the Japanese and U.S. residents. Both groups would benefit from ethical training to negotiate diverse, changing norms regarding end-of-life decision making.

Acad Med. 2005; 80:617–621.

The ethical principle of autonomy can be defined as the ability of individuals to act intentionally in an informed manner, free from control or interference from others.[1] As such, this principle guides physicians' practice of informing individuals about their condition—even if the disclosure may dishearten them—and investing them with responsibility for their own treatment decisions.[2]

However, the way that the principle of autonomy is applied is deeply enmeshed in the cultural values of physicians, patients and families, especially with regard to end-of-life decision making. For example, physicians in the United States strongly uphold the principle of universal disclosure with regard to cancer, and almost all American cancer patients are informed of their diagnosis in some manner when the disease is discovered.[3] In contrast, Japanese physicians often view the family rather than the individual as the autonomous unit to be respected. Subsequently, they often do not inform patients of a cancer diagnosis, and physicians often defer to the family's rather than the patient's preferences for disclosure.[4–7]

Attitudes and practice regarding disclosure may be changing today in Japan as they changed in the United States during the 1960s and 1970s. In 1961, 88% of U.S. physicians did not inform cancer patients of their diagnosis, although approximately 20 years later a large majority upheld disclosure.[3,8] A recent study described younger versus older Japanese physicians as more supportive of full disclosure and individual autonomy.[9] Another study in Japan noted that the diagnosis of cancer shared was shared with 27% of adult patients in 1993 versus 71% of patients in 1998.[10] These observations coincide with Japanese efforts to improve palliative care for its aging population. Although in 1990 there were only three specialized wards for palliative care in Japan, by 2002, there were 89 such wards.[11]

Physician trainees reflect the cutting edge of changing attitudes and thus may be the best source of information about future patterns of medical care delivery. With that in mind, we surveyed Japanese and U.S. medical residents regarding their attitudes, experiences, and emotional responses to diagnostic and prognostic disclosure to patients facing incurable illnesses. We hypothesized that changing Japanese cultural norms would be associated with higher levels of trainee uncertainty. We studied Japanese and U.S. medical residents' self-reports of diagnostic and prognostic disclosures to identify how conflicting paradigms of decision making influence trainees' attitudes, experiences, uncertainty, and guilt related to such disclosures.

Method

Setting

We surveyed residents at five sites in central Honshu, Japan, and two sites in

---

For information about the authors, see the end of this report.

Correspondence should be addressed to Dr. Gabbay, Veteran's Integrated Palliative Program, 11301 Wilshire Boulevard, Mail Code 111G, Los Angeles, CA 90073; telephone: (310) 441-0234; fax: (310) 268-4272; e-mail: (bgabbay@mednet.ucla.edu).

Los Angeles, California, between September 2003 and June 2004. The Japanese sites were Asahi General Hospital (AGH) in Asahi City; Aso Iizuka Hospital (AIH) in Iizuka; Ryukyu University Hospital (RUH) in Okinawa; St. Luke's International Hospital (SLIH) in Tokyo; and University of Tsukuba Hospital (UTH) in Tsukuba. All five hospitals care for a relatively homogenous elderly Japanese population. Of these five hospitals, only AGH and SLIH possess an inpatient palliative care unit with 20 and 25 palliative beds, respectively.

The U.S. sites were Olive View–UCLA Medical Center (OV) in Sylmar, California, and the VA Greater Los Angeles Health care System (VA GLA) in Los Angeles, CA. OV is a 337-bed county-owned public hospital with an approximately 60% Hispanic patient population. VA GLA is a 945-bed tertiary care hospital with a predominantly indigent veteran patient population that is 32% African American and 11% Hispanic. VA GLA has an inpatient palliative care consult service and fellowship training program. All sites have strong university affiliations.

Questionnaire development and study design

Items were adapted by two of the investigators (KAL, SM) from a previous patient questionnaire.[12] Ten items assessed the residents' attitudes and experiences regarding end of life care, prognostic disclosure, and autonomy including case scenarios that addressed cancer diagnosis, prognosis, and treatment decisions. Scenario 1 described disclosing a metastatic gastric cancer diagnosis to a 50-year-old patient. Scenario 2 described disclosing a terminal prognosis to the same patient. Scenario 3 described a patient with postobstructive pneumonia and the participation of the patient, family, and physician in deciding whether or not to intubate.

The questionnaire assessed residents' attitudes about disclosure and decision making and their perceived certainty about their preferences. It also assessed residents' reports of providing treatment perceived as nonbeneficial, deceiving patients, and experiencing guilt about these actions. The questionnaire was translated into Japanese and back-translated into English to confirm accuracy. The study was reviewed and approved by the institutional review boards of the participating American and Japanese institutions. The questionnaire, which was administered anonymously, required fewer than five minutes to complete.

Participants, data collection, and analysis

We attempted to survey all the internal medicine residents who were training on site at the U.S. institutions and all the general medicine practice residents training on site at the Japanese institutions. Residents in Japan train for two years in general practice (internal medicine, obstetrics, pediatrics, primary care, surgery, and electives) before entering more specialized programs. First- and second-year residents at Japanese hospitals correspond to interns and second-year residents in the United States. Because some of the Japanese residents were surveyed at the beginning of their training year, and because they had received little clinical training in medical school, some of them had not yet exercised significant clinical responsibilities. The U.S. residents were all enrolled in three-year internal medicine residency programs. Since all of the first year residents were surveyed in the middle of their training year, the majority had begun to exercise significant clinical responsibilities, unlike some of the Japanese first-year residents.

A research assistant (BBG), fellow (SE), and attending physicians at each local institution approached residents as a group and up to three times individually during noon conferences, grand rounds, morning report, and before work rounds and asked them to complete the questionnaire. All questionnaire responses were entered in SPSS Version 10.0 Statistical Software. We used descriptive statistics to analyze and compare the Japanese and U.S. residents' responses using appropriate statistical tests. Tests of categorical responses used chi-square tests and proportional differences used t tests.

Results

Description of respondents

A total of 347 questionnaires were collected from 244 Japanese and 103 U.S. residents. The response rate varied from 64% to 100% across the seven sites and was 74% for the Japanese sites versus 71% for the U.S. sites overall. The study was not adequately powered to evaluate site differences within the United States and Japan, although our findings did not suggest meaningful differences in site responses within each country. A total of 152 Japanese residents (62.3%) and 45 U.S. residents (43.7%) were in their first year of postgraduate training (PGY1). Ninety (37.7%) Japanese residents and 58 (56.3%) U.S. residents were in at least their second year of postgraduate medical training (group difference, $p < .01$).

Preferences for disclosure of diagnosis and prognosis

When asked whom should be told a cancer diagnosis, 229 (94%) of the Japanese residents indicated "both—the patient and the family" compared to the U.S. residents, 54 (53%) of whom indicated the "patient" only (group difference, $p < .001$; see Table 1). However, the Japanese residents were less certain than the U.S. residents of their approach. Only 20 (8%) of the Japanese residents were "completely certain," compared with 64 (62%) of the U.S. residents (group difference, $p < .001$). Of those respondents who supported disclosing the diagnosis to both patients and family members, 99 (44%) of the Japanese residents reported they would inform the family first, while only a small minority (2%) of the U.S. residents said they would follow the same procedure (group difference, $p < .001$).

Regarding the disclosure of a poor prognosis, 175 (72%) of the Japanese residents again preferred to disclose the prognosis to "both—the patient and the family" compared to 46 (45%) of the U.S. residents, who indicated a preference to disclose to the "patient" only (group difference, $p < .001$). Furthermore, 56 (23%) of the Japanese residents chose to disclose the prognosis solely to the family, compared to only one (1%) U.S. resident (group difference, $p < .001$). The Japanese residents expressed more uncertainty than did the U.S. residents about their approach. Only 12 (5%) of the Japanese residents were "completely certain," compared to 50 (49%) of the U.S. residents (group difference, $p < .001$). Of those who answered they would disclose to both patient and family, 67 (40%) of the Japanese residents favored

Table 1

Comparison of 244 Japanese and 103 U.S. Residents' Preferences for Patient and Family Participation in End-of-Life Decision Making, September 2003 to June 2004*

Scenario	Japanese residents no. (%)	U.S. residents no. (%)
Scenario 1 *A physician diagnoses a 50-year-old person with advanced gastric cancer widely metastatic to the lungs and liver. The physician believes that the cancer cannot be cured.*		
What person should be told about the diagnosis?[†]		
Patient only	12 (5)	54 (53)
Family only	3 (1)	0 (0)
Both the patient and the family	229 (94)	47 (46)
Neither	0 (0)	1 (1)
How certain do you feel about that decision?[†]		
Completely certain	20 (8)	64 (62)
Mostly certain	110 (45)	36 (35)
Somewhat certain	63 (26)	2 (2)
Not at all certain	45 (18)	0 (0)
Entirely uncertain	6 (3)	0 (0)
If you answered "both—the patient and the family," whom should you tell first?[†]		
Patient first	90 (40)	42 (91)
Family first	99 (44)	2 (2)
Tell them both at the same time	36 (16)	3 (7)
Scenario 2 *The physician believes that the patient will die of the cancer.*		
What person should be told that the patient will die?[†]		
Patient only	10 (4)	46 (45)
Family only	56 (23)	1 (1)
Both—the patient and the family	175 (72)	52 (51)
Neither	3 (1)	4 (4)
How certain do you feel about that decision?[†]		
Completely certain	12 (5)	50 (49)
Mostly certain	83 (34)	44 (43)
Somewhat certain	66 (27)	7 (7)
Not at all certain	75 (31)	1 (1)
Entirely uncertain	8 (3)	0 (0)
If you answered "both—the patient and the family," whom should you tell first?[†]		
Patient	66 (39)	34 (85)
Family	67 (40)	1 (3)
Tell them both at the same time	36 (21)	5 (13)

* Tests of categorical responses use chi-square tests and proportional differences use t-tests.

[†] $p < .001$.

disclosure to the family first, while 34 (85%) of the U.S. residents favored disclosure to the patient first (group difference, $p < .001$). The differences in attitudes and certainty we noted between Japanese and U.S. residents were maintained when we restricted these comparisons to housestaff with equivalent clinical experience.

Preferences for patient, family, and *physician involvement in decision* making

All the residents were asked to rate how involved the patient, family members, and the physician should each be in a decision about whether or not to intubate a patient with cancer and postobstructive pneumonia. The Japanese and U.S. residents assigned a similar relative hierarchy of importance in the involvement of the patient, family, and physician in the decision. On a five-point scale (1 = not at all involved, 5 = very involved) both groups of residents rated the importance of the patient's involvement highly, although the U.S. residents rated it as of slightly higher importance (4.67 for the Japanese residents versus 4.95 for U.S. residents, $p < .001$) Both Japanese and U.S. residents accorded family members a similar and only slightly lower importance (4.12 versus 4.14, $p = .86$). The Japanese residents rated the importance of physician involvement somewhat lower than did their U.S. counterparts (3.51 versus 4.39, $p < .001$).

Experiences deceiving patients, providing nonbeneficial care, and associated guilt

One hundred six (43%) Japanese and 101 (98%) U.S. residents had cared for at least one dying patient during their medical training (group difference, $p < .001$; see Table 2). Of these respondents, 78 (78%) Japanese, and 18 (18%) U.S. residents had hidden a cancer diagnosis at the family's request (group difference, $p < .001$). Of those who had concealed the diagnosis, 35 (45%) Japanese residents and 11 (61%) U.S. residents reported feeling guilty "all of the time" or "most of the time" as a result. Fifty-seven (56%) Japanese residents and 73 (72%) U.S. residents stated that they had provided nonbeneficial medical treatment to a cancer patient (group difference, $p < .05$). Twenty-eight (49%) of the Japanese residents who had provided such treatment felt guilty "all of the time" or "most of the time," but only 21 (29%) of the corresponding U.S. residents reported feeling guilt "all of the time" or "most of the time" as a result.

Discussion

Our study identified patterns of information disclosure and-end of-life care provision, including important cross-cultural differences, in the Japanese and U.S. residents we studied. We found that the Japanese residents were more likely than the U.S. residents to involve the family in disclosing both a cancer diagnosis and prognosis, and more likely to inform the family first. At the same time, the Japanese residents indicated

Table 2

Comparison of 106 Japanese and 101 U.S. Residents' Experiences with Disclosure and Treatment in End-of-Life Care, September 2003 to June 2004*

Question	Japanese residents no. (%)	U.S. residents no. (%)
Have you ever hidden a cancer diagnosis at the family's request?†	78 (76)	18 (18)
Have you ever felt guilty if you did hide the diagnosis?		
All of the time	12 (15)	6 (33)
Most of the time	23 (30)	5 (28)
Some of the time	29 (37)	4 (22)
A little of the time	10 (13)	2 (11)
Never	4 (5)	1 (6)
Have you ever provided treatment to a cancer patient believed to not have benefit?‡	57 (56)	73 (72)
Have you ever felt guilty if you did provide such treatment?		
All of the time	13 (23)	8 (11)
Most of the time	15 (26)	13 (18)
Some of the time	19 (33)	28 (38)
A little of the time	8 (14)	14 (19)
Never	2 (4)	10 (14)

* Among residents who reported previously caring for at least one terminally ill cancer patient. Tests of categorical responses use chi-square tests.
† $p < .001$.
‡ $p < .05$.

more uncertainty than did their U.S. counterparts about their approach towards information disclosure.

The findings of our study regarding attitudes about disclosure and the relative importance of the family in decision making by Japanese and U.S. residents are consistent with those in previously published descriptions. Residents' cultural values have been associated with the approach to disclosure and with group versus individual decision making in prior surveys.[12,13] Traditionally, in Japan, the individual is perceived as the socially embedded self and as part of several groups ranging from the family to the nation. As a result, groups, not individuals, tend to make decisions.[14] The physician frequently accepts the family's final decision regarding whether or not to disclose.[15] Families place importance on protecting members from the psychological stress of being diagnosed with cancer.[13]

In our study a substantial proportion of both Japanese and U.S. residents reported having concealed a cancer diagnosis from a patient, and over three-fourths of each group expressed at least some guilt about it. Among Japanese residents 76 percent reported concealing a cancer diagnosis, a figure consistent with Japan's traditional communication paradigm. The fact that nearly half expressed guilt most of the time and 82% expressed guilt at least some of the time regarding this behavior suggests that a shifting Japanese paradigm toward a more individual autonomy-driven model may be producing increased uncertainty and guilt among Japanese trainees.

A recent survey of Japanese physicians and patients demonstrated major differences in attitudes regarding disclosure, the relative roles of decisionmakers, and use of life-sustaining treatments.[16] Other surveys indicate a greater desire for disclosure among Japanese cancer patients themselves, although families are still reluctant to disclose a cancer diagnosis to one another.[17–19] Japanese trainees who are seeking to gain skill in how best to communicate diagnosis and prognosis are likely to be caught in the middle of this attitudinal shift, as our study shows.

We note the somewhat counterintuitive finding that the Japanese residents rated the importance of physician involvement in end-of-life decision making lower than did their U.S. counterparts. One might expect that in a culture where physicians are accorded more leeway about what to divulge to patients, the importance of the physician would be rated more highly than in the United States. On the other hand, although we cannot be certain, the responses of the Japanese residents in our study could also indicate that they regard their activities in managing information or making decisions as ones of service to the patient and family rather than as constituting a separate role.

Although hiding a diagnosis was less common among the U.S. residents, 18% of those residents in our sample reported having done so. Blackhall et al.'s[20] previous study of African-American, European-American, Korean-American, and Mexican-American elders in Los Angeles demonstrated that many nonwhite respondents were uncomfortable with explicit disclosure and preferred a group decision making process. It may be that residents' reports of withholding information reflects the challenges residents face within Los Angeles' culturally diverse community.

Our findings suggest that both U.S. and Japanese residents could benefit from improved skills in negotiating potentially conflicting values. Given increasing cultural and racial diversity among the aging and seriously ill,[21] U.S. medical training programs may be well-served to add curricular elements that address cross-cultural issues surrounding information disclosure. Medical trainees in Japan may benefit from acquiring skills to negotiate changing cultural norms. We have found that experiential approaches including role play, simulated family conferences,[22] and film[23,24] may offer effective methods to teach skills that require a high level of resident engagement and emotion.

Our study has several limitations. First, our survey respondents represent a convenience sample, although they were drawn from training programs in major Japanese and U.S. institutions. Second, some of the differences we noted (e.g., in certainty) could reflect cultural differences. Third, the survey evaluated the residents' perceptions only, and was unable to evaluate residents' actual behavior. This means we cannot examine the ethical issues involved in actual care being delivered in the two countries. Nevertheless, our findings do suggest a need to understand better why residents perceive conflict in information disclosure, and also to develop methods for helping trainees master skills in communication as part of their training.

In summary, we found that residents' approaches to end-of-life decision making in the United States and Japan reflect known cultural preferences related to the role of patient and family in disclosure of diagnosis and prognosis. We found that many trainees in both Japan and the United States experience uncertainty and report guilt about their approach towards communication as well as towards end-of-life care delivery. Our findings underscore the need for culturally sensitive ethics training in medical education, and a better understanding of how physicians' own cultural perspectives influence their practices.

At the time this was written, **Dr. Gabbay** was a *fourth-year medical student at the David Geffen* School of Medicine at UCLA. He began his psychiatry residency at Harbor/UCLA Medical Center, Torrance, California, in June 2005.

Dr. Matsumura is a visiting research fellow, the International Research Center for Medical Education at the University of Tokyo in Tokyo, Japan.

Dr. Etzioni is assistant program director, the Interdisciplinary Palliative Fellowship at VA Greater Los Angeles, Los Angeles, California.

Dr. Asch is the deputy associate chief of staff for Health Services Research and Development, VA Greater Los Angeles, and associate professor of medicine, David Geffen School of Medicine at UCLA, Los Angeles, California.

Dr. Rosenfeld is director, Veterans Integrated Palliative Program, VA Greater Los Angeles, and associate clinical professor, David Geffen School of Medicine at UCLA, Los Angeles, California.

Dr. Shiojiri is residency program director, Asahi General Hospital, Asahi, Japan.

Dr. Balingit is assistant clinical professor of medicine, David Geffen School of Medicine at UCLA, Olive View-UCLA Medical Center, Sylmar, California.

Dr. Lorenz is research associate, the VA Greater Los Angeles, and assistant professor of medicine, *David Geffen School of Medicine at UCLA*, Los Angeles, California. He is a VA Health Services Research and Development Career Development Awardee.

The authors wish to thank the following local collaborators in Japan for their assistance with survey distribution: Dr. Hiroshi Imura (Aso Iizuka Hospital), Dr. Tetsuhiro Maeno (University of Tsukuba Hospital), Dr. Yuko Y. Takeda (Ryukyu University Hospital), and Dr. Mayuko Saito (St Luke's International Hospital). An earlier version of this article was presented at the annual meeting of the American Academy of Hospice and Palliative Medicine in January 2005.

References

1 Lo B. Resolving Ethical Dilemmas: A Guide for Clinicians. Philadelphia: Lippincott Williams & Wilkins, 2000, 11.

2 Lo B, Quill T, Tulsky J. Discussing palliative care with patients. ACP-ASIM End-of- Life Care Consensus Panel. American College of Physicians/American Society of Internal Medicine. Ann Intern Med. 1999; 130:744–49.

3 Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. JAMA. 1979; 241: 897–900.

4 Elwyn TS, Fetters MD, Sasaki H, Tsuda T. Responsibility and cancer disclosure in Japan. Soc Sci Med. 2002; 54: 281–93.

5 Mizushima Y, Kashii T, Hoshino K, et al. A survey regarding the disclosure of the diagnosis of cancer in Toyama Prefecture, Japan. Jpn J Med. 1990; 29: 146–55.

6 Seo M, Tamura K, Shijo H, Morioka E, Ikegame C, Hirasako K. Telling the diagnosis to cancer patients in Japan: attitude and perception of patients, physicians and nurses. Palliat Med. 2000;14:105–10.

7 Akabayashi A, Slingsby BT, Kai I. Perspectives on advance directives in Japanese society: a population-based questionnaire survey. BMC Med Ethics. 2003; 4:E5.

8 Oken D. What to tell cancer patients. A study of medical attitudes. JAMA. 1961;175:1120–28.

9 Elwyn TS, Fetters MD, Gorenflo W, Tsuda T. Cancer disclosure in Japan: historical comparisons, current practices. Soc Sci Med. 1998;46:1151–63.

10 Horikawa N, Yamazaki T, Sagawa M, Nagata T. Changes in disclosure of information to cancer patients in a general hospital in Japan. Gen Hosp Psychiatry. 2000;22:37–42.

11 Takeda F. Status of Cancer Pain and Palliative Care. J Pain Symptom Manage. 2002;24:197–99.

12 Matsumura S, Bito S, Liu H, Kahn K, Fukuhara S, Kagawa-Singer M, Wenger N. Acculturation of attitudes toward end of life care: a cross-cultural survey of Japanese Americans and Japanese. J Gen Intern Med. 2002; 17: 531–39.

13 Mizuno M, Onishi C, Ouishi F. Truth disclosure of cancer diagnoses and its influence on bereaved Japanese families. Cancer Nurs. 2002;25:396–403.

14 Davis AJ, Konishi E. End of life ethical issues in Japan. Geriatr Nurs. 2000;21:89–91.

15 Fukui S. Information needs and the related characteristics of Japanese family caregivers of newly diagnosed patients with cancer. Cancer Nursing. 2002;25:181–86.

16 Ruhnke GW, Wilson SR, Akamatsu T, et al. Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. Chest. 2000;118:1172–82.

17 Long SO. Family surrogacy and cancer disclosure: physician-family negotiation of an ethical dilemma in Japan. J Palliat Care. 1999; 15:31–42.

18 Matsumura S, Fukuhara S, Kurokawa K, Bito S, Ohki M. Nihonjin no gankokuchi ni kansuru kibou to soreni eikyou wo ataeru shoyouin no kento. [The preferences of disclosure about cancer diagnosis among Japanese and the factors associated with these preferences.] Jpn Med J. 1997;3830:37–43.

19 Kakai H. A double standard in bioethical reasoning for disclosure of advanced cancer diagnosis in Japan. Health Commun. 2002; 14:361–76.

20 Blackhall LJ, Murphy ST, Grank G, Michel V, Azen S. Ethnicity and attitudes toward patient autonomy. JAMA. 1995;274:820–25.

21 Addressing diversity. U.S. Department of Health and Human Services, Administration on Aging (http://www.aoa.gov/prof/adddiv/adddiv.asp). Accessed 11 April 2004.

22 Jubelirer SJ, Welch C, Babar Z, Emmett M. Competencies and concerns in end of life care for medical students and residents. W V Med J. 2001; 97:118–21.

23 Lorenz KA, Steckart MJ, Rosenfeld KE. End of life education using the dramatic arts: the Wit Educational Initiative. Acad Med. 2004; 79: 481–86.

24 Wit Film Project: Innovative medical education for end-of-life care. Inter-Institutional Collaborating Network On End-Of-Life Care (IICN) (http://www.growthhouse.org/witfilmproject/). Accessed 11 April 2005.

Families' and Physicians' Predictions of Dialysis Patients' Preferences Regarding Life-Sustaining Treatments in Japan

Yasuhiko Miura, MD, PhD, Atsushi Asai, MD, Masato Matsushima, MD, PhD,
Shizuko Nagata, MD, Motoki Onishi, MD, Takuro Shimbo, MD,
Tatsuo Hosoya, MD, PhD, and Shunichi Fukuhara, MD

● *Background:* Substituted judgment traditionally has been used often for patient care in Japan regardless of the patient's competency. It has been believed that patient preferences are understood intuitively by family and caregivers. However, there are no data to support this assumption. *Methods:* A questionnaire survey was administered to 450 dialysis patients in 15 hospitals to determine their preferences for cardiopulmonary resuscitation (CPR) and dialysis therapy under various circumstances. Simultaneously, we asked family members and physicians of these patients about patient preferences to evaluate their ability to predict what their patients would want. The accuracy of families' and physicians' judgments was assessed by means of κ coefficient. *Results:* Three hundred ninety-eight pairs, consisting of a patient, 1 of his or her family members, and the physician in charge, participated from 15 hospitals in Japan, with a response rate of 88%. Sixty-eight percent of family members correctly predicted patients' current preferences for CPR, 67% predicted patients' preferences for dialysis when they were severely demented, and 69% predicted patients' preferences for dialysis when they had terminal cancer. Corresponding figures for physicians were 60%, 68%, and 66%. When using κ coefficient analysis, those results indicated that neither family members nor physicians more accurately predicted their patients' wishes about life-sustaining treatments than expected by chance alone. (All κ coefficients <0.4.) *Conclusion:* Our study suggests that patients who want to spend their end-of-life period as they want should leave better advance directives. *Am J Kidney Dis* 47:122-130.
© 2005 by the National Kidney Foundation, Inc.

INDEX WORDS: Medical ethics; advance directives; patient preferences; substituted judgment; dialysis withdrawal; cardiopulmonary resuscitation (CPR).

SUBSTITUTED JUDGMENT is considered to be an ethically justifiable alternative when a patient is unable to make autonomous medical decisions and his or her advance directives are unavailable.[1,2] Ethically speaking, substituted judgment is regarded as a satisfactory method only when a surrogate decision maker can correctly predict the patient's wishes about health care and act in strict accordance with these wishes or when such decisions are made regarding the best interests of patients if their wishes are not known. However, studies to date suggested that physicians and/or patients' family members generally have little understanding of the patient's preferences regarding life-sustaining treatment.[1,3-5] A survey conducted in Japanese hospitals in the early 1990s showed that Japanese physicians could not predict their patients' preferences about full disclosure of medical information and palliative care.[6]

In clinical settings in Japan, medical decisions often are made by physicians and family members for competent and incompetent patients. Paternalism remains strong in the physician-patient-family relationship, and autonomous decisions by the patient are not necessarily valued by physicians, the patients' families, or even the patients themselves.[7-9] Our previous study showed that Japanese patients tend to value their families' involvement in end-of-life decision making.[9]

From the Department of Internal Medicine, Division of Nephrology and Hypertension, and Department of Internal Medicine, Division of General Medicine, Jikei University School of Medicine; Department of Bioethics, Faculty of Medical and Pharmaceutical Science, Kumamoto University, Tokyo; Department of General Medicine and Clinical Epidemiology, Kyoto University School of Medicine; and Department of Epidemiology, Kyoto University Graduate School of Medicine, Kyoto, Japan.

Received April 7, 2005; accepted in revised form September 27, 2005.

Originally published online as doi:10.1053/j.ajkd.2005.09.030 on December 6, 2005.

Support: This study was supported by the Grant for Scientific Research expenses for Health and Welfare Program; Funds for Comprehensive Research on Long Term Chronic Disease (Renal Failure). Potential conflicts of interest: None.

Address reprint requests to Yasuhiko Miura, MD, PhD, Nomura Hospital, 8-3-6, Shimo-renjaku, Mitaka, Tokyo, 181-8503, Japan. E-mail: yamiura-circ@umin.ac.jp

0272-6386/05/4701-0015$30.00/0
doi:10.1053/j.ajkd.2005.09.030

Direct communication between a patient and physician and between a patient and his or her family members does not always occur in a health care setting.[7] Japanese physicians and family members traditionally have tried to make medical and social decisions in the best interests of patients without telling them the truth and without asking for their preferences. Patients have tended to assume that their physicians and family members would make the best overall decisions for them, while taking their wishes into consideration. They therefore assume that there is no need to communicate their wishes to their caregivers and close relatives.[10] It also is argued that the sick and their family members share common values that are rooted in Japanese culture, so that patients' wishes for health care can be perceived through implicit communication. This type of nonverbal communication has been called "ishin-denshin" in Japan: when someone does not explicitly ask a favor from someone else, the other person should infer what is desired and provide the inferred favor accordingly.[10,11]

We suspect that the traditional belief in the existence of common preferences regarding health care and ishin-denshin could be false or, at best, illusory. Regardless of willingness to meet others' wishes and regardless of mutual expectations, if wishes or values become highly diverse or complicated, indirect communication no longer works. If such beliefs are fictitious or outdated, substituted judgment for competent patients should be discouraged. A recent report that reviewed published data regarding Japanese patients' preferences for the use of advance directives suggested that advance directives were desired by approximately 80% of the general public and physicians.[12] Another study reported that few people actually formalized their preferences for health care treatment in written form, and physicians tended to make their decisions according to the family's wishes; this occurs in Germany and the United States, as well as in Japan.[13]

The purpose of this study is to assess how accurately family members and physicians can predict patients' wishes about medical care and treatment, including dialysis and cardiopulmonary resuscitation (CPR), under various medical scenarios. To the best of our knowledge, no other study to date conducted in Japan has aimed to assess the ability of family members and physicians to understand and/or predict the wishes of patients. We targeted patients who had been undergoing long-term dialysis treatment, their families, and their physicians.

METHODS

This study was ethically and methodologically approved by the committee of the Department of Clinical Research, Sakura National Hospital, in 1997.

One of the authors previously participated in an informal clinical study group consisting of 20 nephrologists at 16 hospitals throughout Japan. We decided to ask the physicians at those hospitals to join our survey. Two of the nephrologists at 1 hospital did not respond: 18 physicians in 15 hospitals took part in the study, and they were asked to include up to 30 of their ambulatory dialysis patients in the

Table 1. Patient Characteristics

Mean age (y)	57 ± 12 (23-87)
Sex	
Female	144 (36)
Male	254 (64)
Duration of dialysis (y)	8.3 ± 5.5 (1.7-30.4)
Dialysis modality	
Hemodialysis	283 (71)
Continuous ambulatory peritoneal dialysis	115 (29)
Level of education	
Graduated from middle high school	96 (24)
Graduated from high school	192 (48)
Graduated from 2-year college	16 (4)
Graduated from 4-year university or higher	73 (18)
Level of annual income (yen)	
<3,000,000*	145 (36)
3,000,000~5,000,000†	74 (19)
5,000,000~7,000,000‡	41 (10)
7,000,000~10,000,000§	26 (7)
10,000,000~12,000,000‖	11 (3)
>12,000,000¶	17 (4)
Cause of end-stage renal disease	
Chronic glomerulonephritis	255 (64)
Diabetic nephropathy	50 (13)
Polycystic kidney	17 (4)
Nephrosclerosis	15 (4)
Unknown	19 (5)
Other disease	19 (10)

NOTE. N = 398. Values expressed as mean ± SD (range) or number (percent).

*US $27,000

†US $27,000 ~ 45,000

‡US $45,000 ~ 64,000

§US $64,000 ~ 91,000

‖US $91,000 ~ 110,000

¶US ~ $110,000

study. Questionnaires were sent to the physicians on September 1, and the sampling was terminated on November 30, 1997. The questionnaire was delivered to patients who agreed to participate in this study. Participants were chosen consecutively and on the basis of convenience by their physicians, and sampling was terminated when 30 patients had been enrolled. Family members were handed the questionnaire from the patients at their homes so there was an opportunity to discuss their answers, but it was clearly stated on the first page of the questionnaire: "Please do not discuss the answers with each other."

The 3-page questionnaire consisted of questions about patient preferences regarding CPR and dialysis treatment (see appendix online with article at www.ajkd.org). We used a 5-point Likert scale consisting of "Yes," "Probably yes," "Uncertain," "Probably not," and "No." Patients' wishes regarding CPR were determined by using 3 health scenarios. The first scenario asked whether they would want CPR if they experienced cardiopulmonary arrest in their current condition: current health status is defined as "the state of the patient's health when the patient answers the questionnaire." It should be noted again that all our subjects were ambulatory patients who could visit their clinics without assistance. The second scenario asked whether they would want CPR if the same thing happened when they had serious dementia. In this scenario, the patient has lost self-perception, is unable to recognize his or her family, and has become completely dependent. The third scenario inquired about their wishes for CPR if they had terminal cancer with an expected survival of 6 months. In this scenario, the patient is mentally competent and pain can be controlled by medication. The survival rate with discharge after CPR was stated to be less than 10%. The survey also inquired about patients' wishes regarding continuation of dialysis treatment in the second and third scenarios (serious dementia and terminal cancer). Finally, patients were asked about their experiences of discussing their preferences for CPR and dialysis therapy discontinuation with their families and physicians and how accurately they thought their physicians and family members would understand and represent their general preferences. Patient demographics also were explored. Medical charts of patients were viewed by their nephrologists to obtain information about type and duration of dialysis therapy and patients' underlying diseases. At the same time, we asked family members and physicians about patients' preferences for CPR and dialysis to assess their ability to predict their patients' wishes in various scenarios. Preferences for CPR and dialysis were scored on the same 5-point Likert scale described earlier.

The accuracy of estimates by physicians and family members was assessed by means of weighted κ coefficient. A κ value exceeding 0.75 was considered to be "excellent agreement"; a value between 0.4 and 0.75, "fair to good agreement"; and a value less than 0.4, "poor agreement."[14] We used STATA, release 8 (StataCorp, College Station,TX) for statistical analysis.

RESULTS

Patient characteristics are listed in Table 1. Of 450 patients asked to participate, 412 agreed to answer the questionnaire. Three hundred ninety-eight complete sets of questionnaires were re-

Table 2. Family Members' Understanding of Patients' Preferences About CPR

		Patients' Preferences					
Family's Estimation		Yes	Probably Yes	Uncertain	Probably No	No	Total
Current situation	Yes	67	25	17	21	19	149
	Probably yes	20	13	17	17	15	82
	Uncertain	14	10	15	21	23	83
	Probably no	10	0	6	13	20	49
	No	2	1	2	3	18	26
	Total	113	49	57	75	95	389
	Agreement, 68.32%; expected agreement, 57.34%; κ coefficient, 0.2573						
If demented	Yes	11	6	7	17	19	60
	Probably yes	1	7	12	23	19	61
	Uncertain	1	7	18	24	48	98
	Probably no	6	4	6	36	55	107
	No	3	1	0	10	54	68
	Total	22	25	43	110	194	394
	Agreement, 68.21%; expected agreement, 60.76%; κ coefficient, 0.1899						
If with terminal cancer	Yes	8	7	10	14	22	61
	Probably yes	2	5	6	18	19	50
	Uncertain	2	8	13	26	50	99
	Probably no	2	6	12	32	67	119
	No	5	1	0	9	49	64
	Total	19	27	41	99	207	393
	Agreement, 66.60%; expected agreement, 61.02%; κ coefficient, 0.1432						

Table 3. Family Members' Understanding of Patients' Preferences for Continuation of Dialysis Treatment

		Patients' Preferences					
Family's Estimation		Yes	Probably Yes	Uncertain	Probably No	No	Total
If demented	Yes	22	19	23	21	17	102
	Probably yes	1	12	19	23	18	73
	Uncertain	4	9	35	33	40	121
	Probably no	2	2	7	25	31	67
	No	1	0	2	10	17	30
	Total	30	42	86	112	123	393
	Agreement, 67.43%; expected agreement, 58.68%; κ coefficient, 0.2117						
If with terminal cancer	Yes	46	38	20	24	10	138
	Probably yes	15	33	26	21	18	113
	Uncertain	13	21	17	11	22	84
	Probably no	4	7	7	12	13	43
	No	0	1	2	3	7	13
	Total	78	100	72	71	70	391
	Agreement, 68.99%; expected agreement, 61.87%; κ coefficient, 0.1867						

turned, which included responses of the patient, family members, and physician, giving a final response rate of 88%. (There were no responses from family members in 14 sets of questionnaires.) Some respondents did not answer all the questions, so the number of responses to each question varied from 389 to 398.

Sixty-four percent of patients were men, and 71% were undergoing hemodialysis for long periods (average, 8.3 years). Sixty-four percent of patients had chronic glomerulonephritis, and 13%, diabetic nephropathy. Of 398 family members, 79% were spouses, 16% were the patient's children, and 4% were close relatives. Eighteen nephrologists participated as substitute decision makers for their patients. All were caring for dialysis patients at the 15 hospitals surveyed.

Understanding by family members of patient preferences regarding CPR and dialysis therapy, agreement rate, expected agreement rate, and κ coefficient are listed in Tables 2 and 3. Results for physicians are listed in Tables 4 and 5. Correct agreement rates of family members ranged from 66.6% to 68.99%, and those of physicians, from 60.45% to 75.25%. As listed in the tables, κ coefficients for each question ranged from 0.1432 to 0.2573 for patients and their family members and 0.0693 to 0.1433 for patients and their physicians.

Figure 1 and Table 6 show patients' perceptions of the accuracy of their family members' and physicians' understanding of their preferences. One hundred eighty-five patients (47%) thought their families could accurately or almost accurately judge their overall wishes regarding life-sustaining treatment, including CPR or dialysis therapy, and 120 patients (31%) thought their physician could do so. Conversely, 218 family members (56%) thought they could accurately or almost accurately judge the patient's overall wishes, and 196 physicians (50%) thought they could do so. Table 6 shows the mutual understanding regarding patients' preferences about CPR and dialysis discontinuation. Among patients and family members, κ coefficients were 0.2214, and among patients and physicians, 0.0974.

Whether discussion took place with family members and physicians regarding patient preferences for CPR is shown in Fig 2. Thirty percent of patients answered that they had discussed their preferences for CPR with their family members, and only 5%, with their physicians.

We reanalyzed only results in which the patient believed that a family member would accurately or almost accurately judge their preferences (n = 185): the κ coefficient increased, but did not exceed 0.4 (Table 7, question A). Reanalyzing only results in which patients thought they had already discussed their preferences with family members (n = 114), the κ coefficient also increased, but did not exceed 0.4 for any scenario (Table 7, question B). When reanalyzing results in which patients believed their physicians would accurately or almost accurately judge their pref-

Table 4. Physicians' Understanding of Patients' Preferences About CPR

		Patients' Preferences					
Physicians' Estimation		Yes	Probably Yes	Uncertain	Probably No	No	Total
Current situation	Yes	50	19	24	24	34	151
	Probably yes	46	25	21	28	38	158
	Uncertain	13	3	8	13	12	49
	Probably no	3	3	4	7	10	27
	No	4	0	0	5	3	12
	Total	116	50	57	77	97	397
	Agreement, 60.45%; expected agreement, 57.35%; κ coefficient, 0.0728						
If demented	Yes	1	0	1	0	6	8
	Probably yes	2	5	5	11	15	38
	Uncertain	3	1	4	13	16	37
	Probably no	10	15	28	56	77	186
	No	6	4	5	31	83	129
	Total	22	25	43	111	197	398
	Agreement, 75.25%; expected agreement, 72.05%; κ coefficient, 0.1146						
If with terminal cancer	Yes	1	0	2	2	4	9
	Probably yes	2	5	6	15	27	55
	Uncertain	1	1	5	13	8	28
	Probably no	10	12	13	47	87	169
	No	5	9	15	23	84	136
	Total	19	27	41	100	210	397
	Agreement, 72.86%; expected agreement, 70.84%; κ coefficient, 0.0693						

erences (n = 120), the κ coefficient showed the same tendency (Table 7, question C). Only 19 patients answered that they had already discussed their preferences with their physicians, so we did not analyze this result.

DISCUSSION

Patient preferences regarding CPR and withdrawal of dialysis therapy from the same participants were analyzed in detail and have been published.[15] Thus, the purpose of this study is to assess how accurately family members and physicians can predict those patients' preferences in the same medical scenarios.

Our results suggest that the decision-making process in the Japanese clinical setting presents several ethical problems. First, neither family members of long-term dialysis patients nor care-

Table 5. Physicians' Understanding of Patients' Preferences for Continuation of Dialysis Treatment

		Patients' Preferences					
Physicians' Estimation		Yes	Probably Yes	Uncertain	Probably No	No	Total
If demented	Yes	5	2	6	8	7	28
	Probably yes	12	23	27	29	34	125
	Uncertain	5	7	26	27	18	83
	Probably no	7	7	25	37	49	125
	No	1	3	4	12	17	37
	Total	30	42	88	113	125	398
	Agreement, 68.41%; expected agreement, 64.29%; κ coefficient, 0.1433						
If with terminal cancer	Yes	29	30	18	10	17	104
	Probably yes	34	42	37	35	25	173
	Uncertain	12	15	6	14	13	60
	Probably no	4	13	11	9	13	50
	No	0	0	1	4	4	9
	Total	79	100	73	72	72	396
	Agreement, 66.73%; expected agreement, 63.07%; κ coefficient, 0.0990						

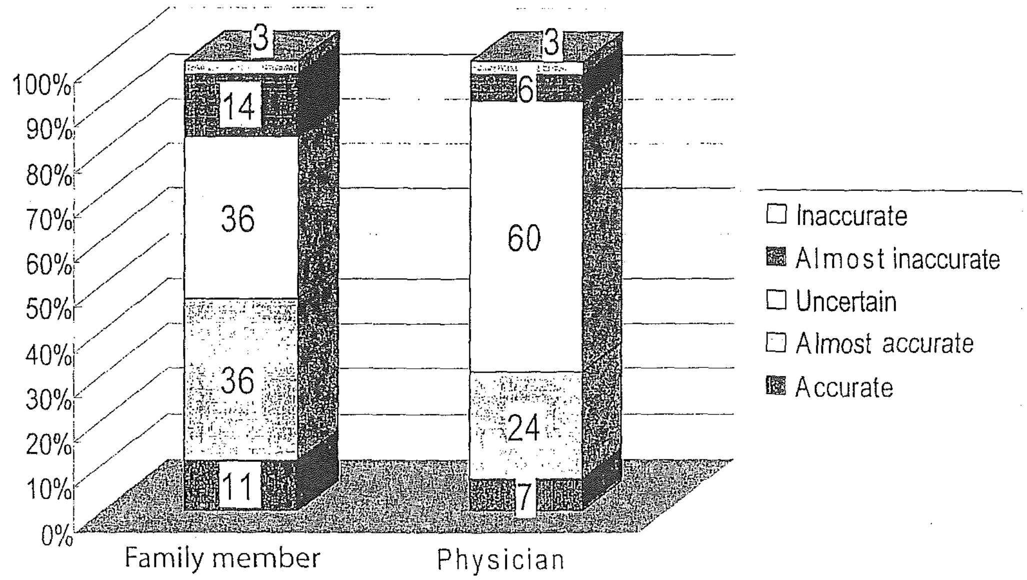

Fig 1. Patients' perceptions of the accuracy of their family members' and physicians' understanding of their preferences. Family members, *n* = 390; physicians, *n* = 395; all numbers in figure shown as percentages.

giving physicians could correctly assess or predict their patients' current or future preferences in terms of health care better than could be expected by chance alone. Concordance rates were consistently low regardless of the medical scenario or patient quality of life in certain hypothetical situations. Our findings strongly suggest that the tacit communication currently assumed to exist in Japanese clinical settings cannot satisfy patients' health-related preferences and fails to respect their autonomy. We believe that our data constitute reliable evidence against the Japanese belief that one's wishes are intuitively known to others and thus can be realized without explicit communication (ishin-denshin).

The Japanese Society of Dialysis Therapy reported that more than 230,000 patients were undergoing long-term dialysis treatment in Japan as of December 31, 2003. Average age for the introduction of dialysis therapy was 65.4 years,

Table 6. Mutual Understanding Regarding Patients' Preferences About CPR and Dialysis

		Patients' Perception					
		Accurate	Almost Accurate	Uncertain	Almost Inaccurate	Inaccurate	Total
Patients and family							
Family's understanding	Accurate	6	5	7	3	0	21
	Almost accurate	32	87	52	23	3	197
	Uncertain	4	34	74	21	2	135
	Almost inaccurate	0	16	7	6	2	31
	Inaccurate	1	0	0	2	3	6
	Total	43	142	140	55	10	390
	Agreement, 91.99%; expected agreement, 76.86%; κ coefficient, 0.2214						
Patients and physician							
Physician's understanding	Accurate	2	12	13	0	0	27
	Almost accurate	10	50	95	8	6	169
	Uncertain	10	29	116	13	7	179
	Almost inaccurate	4	3	14	2	1	24
	Inaccurate	0	0	0	0	0	0
	Total	26	94	238	23	14	395
	Agreement, 81.90%; expected agreement, 79.95%; κ coefficient, 0.0974						