

Results: Based on systematic literature review, 51 possible QIs were extracted. The panel members concluded that "general" QIs for assessing cross-calling quality of ambulatory care should be added to the QIs besides disease specific management. Therefore, six general QIs were generated and evaluated. Finally, total 20 QIs, five to six QIs for each condition and four for general, were developed.

Conclusion: Developed with reliable and systematic method, this brief set of QIs can measure quality of the process of primary ambulatory care.

**Key words:** quality of care, process evaluation, primary ambulatory care, common disease, chronic management

## 緒言

## 方法

近年、我が国においても医療の質を評価する重要性が大きく論じられているが、科学的な手法を用いての医療の質を評価する試みが始まったのは比較的最近のことである<sup>1)</sup>。医療の質は、①構造、②プロセス、③アウトカムの3つのレベルで評価されるが<sup>2)</sup>、現在までのところ本邦での評価の中心は構造レベルであり<sup>3)</sup>、最近になってアウトカム評価による臨床評価はみられるようになったものの<sup>4) 5)</sup>、診療行為のそのものであるプロセスレベルの質評価は少ない。一般にプロセスレベルの評価は、実施の困難さはあるものの医療の質の評価としては最適とされ<sup>1)</sup>、評価には"quality indicator(QI)"が用いられることが多い。QIは、基本的レベルの診療行為であり、それが行われないうことはケアの質としては問題があると考えられる基準であり<sup>6)</sup>、例えば「〇〇の患者に対して、××が行われているか」というように表される。このようにQIを用いた評価は、一つ一つの診療行為をQIに照らし合わせて監査を行い質の定量化を行うことを基本としている。

また、今までのところ本邦では評価対象の中心は病院・入院診療であり<sup>3) 7) 8)</sup>、外来診療に対する評価はあまり行われてこなかった。しかしながら、外来診療はその対象とする患者数も入院診療の約5倍と多く<sup>9)</sup>、今後本邦においても、欧米のように外来診療を中心としたプライマリ・ケア・レベルにおける質評価・改善の重要性が増していくことは想像に難くない。

本研究では、プライマリ・ケアの外来診療場面において、高血圧、2型糖尿病、気管支喘息の3つのコモン・ディーズ管理に対する、プロセスレベルでの評価を行うための簡便なQIを開発した。これらのコモン・ディーズを対象とした理由としては、外来患者に占める割合も高く<sup>9)</sup>プライマリ・ケアの外来診療現場において専門医でなくても遭遇する機会が多いこと、すでにいくつかのガイドラインが出されていること、しかしながら現場での診療内容にはばらつきが大きいと予想されること、が挙げられる。

本研究では、おもに米国<sup>10)</sup>や英国<sup>11)</sup>においてQI作成方法としてすでに確立しているRAND appropriateness method (RAND method)<sup>12) 13)</sup>の変法を用いてQIの作成を行った。これは、系統的総説に基づいて作成された初期指標候補項目に対し、エキスパート・パネルのメンバーが評価、一堂に会しての意見交換会議、再評価を行うという手順を踏み、専門家の見解とエビデンスを系統的に組み合わせる方法である<sup>14)</sup>。本邦においてもこのような一定の手順に則って作成されたQIはごく少数だが存在し、その開発過程において本法が我が国においても妥当性を持つということが示されている<sup>9)</sup>。

作成の際には、具体的には以下の5つの手順をとった。すなわち、1. 系統的総説を基にした初期指標項目の抽出 2. エキスパート・パネルの設立 3. 指標プールの作成とエキスパート・パネルによる指標の評価 4. エキスパート・パネルによる会議 5. 指標の再構築と再評価、である。

### 1) 系統的総説を基にした初期指標項目の抽出

まず、各疾患の慢性外来マネジメントに関するエビデンスを系統的にまとめるため、文献の検索と集められた文献の系統的レビューを行った。文献検索は、英文文献に関してはPubMed/MEDLINEを、日本語文献に関しては医学中央雑誌を用いて行った。QIの作成はしばしば臨床ガイドラインに基づいて行われるため、"hypertension / 高血圧"、"diabetes mellitus / 糖尿病"、"bronchial asthma / 気管支喘息"の各疾患名を共通のキーワード (MeSH) とし、"practice guideline (PT)"の検索語を同時に用いた。得られた文献のタイトルバナーから、目的としている文献との内容の一致が見られないものを取捨選択して文献を選定した。英語文献においては、JNC-7<sup>15)</sup>、米国糖尿病学会からのガイドライン (ADA 2004)<sup>16)</sup>、Global Initiative for Asthmaのガイドライン (GINA 2003)<sup>17)</sup>、National Asthma Education

and Prevention Program のガイドライン (NAEPP 2002)<sup>18)</sup>, British guideline on the management of asthma 2003<sup>19)</sup> の推奨基準はそのまま採用した。日本語文献に関しては, 研究開始時, 高血圧, 糖尿病に関しては我が国での系統的レビューを基にしたガイドラインは作成されておらず, 気管支喘息に関して日本アレルギー学会の喘息予防・管理ガイドライン<sup>20)</sup> の基準はそのまま採用した。今回は当該疾患を診断された患者に対する外来診療の質を評価することを想定したため, 主に慢性期の外来マネジメントに関する項目を抽出した。さらにこれらの項目を QI として適切な表現に修正し, 各候補項目に対し文献上各項目が影響を与えるとされる臨床アウトカム, エビデンスレベルについても表記したもの (I : randomized controlled trials, RCT. II : non RCT clinical trials. III : cohort or case control studies. IV : time series. V : opinions or descriptive studies) を箇条書きの形で列記し, 一覧表を作成した。

## 2) エキスパート・パネルの設立

プライマリ・ケア医 7 名, 臓器別専門医 6 名 (循環器医 2 名, 糖尿病専門医 2 名, 呼吸器科医 2 名) をエキスパート・パネルのメンバーとして選出した。エキスパート・パネルメンバーは研究者を通じて選出依頼され, 臓器別専門

医はその専門のエキスパートとして認知されているものを選出した。また, メンバーの診療セッティングに偏りがないように, 大学病院勤務, 総合病院勤務, 開業医が含まれるように選出した。依頼された医師がパネルへの参加を辞退された場合は, 代替りの候補を推薦するよう依頼した。最初に依頼された者のうち 1 名を除いてすべてのメンバーが参加を承諾した。プライマリ・ケア医は, 高血圧, 糖尿病, 気管支喘息のすべてのパネルに参加し, それぞれ臓器別専門医 2 名を加えた 9 名ずつのエキスパート・パネルを設立した。

パネルメンバーの属性を表 1 に示す。

## 3) 指標プールの作成とエキスパート・パネルによる指標の評価

初期抽出項目の一覧表を電子メールで各メンバーに送り, それぞれの項目について, 質評価の指標としてどのくらい適切であるかについて評価を依頼した。評価は, 「データ取得性」, 「スタンダードとしての適切性」の 2 つの項目に関して, 9 段階で評価を記入してもらうようにした。9 段階は「データ取得性」については, 「1」を「診療録から信頼しうるデータを取得することは全く不可能」, 「9」を「診療録から信頼しうるデータを問題なく取得できる」とした。

表 1 : エキスパート・パネルメンバーの属性

	所属 (都道府県)	コンセンサス会議
コア (プライマリ・ケア医)		
A	大学病院総合診療部 (三重)	出席
B	内科開業医 (広島)	出席
C	総合病院消化器科 (神奈川)	出席
D	大学病院総合診療部 (金沢)	欠席
E	内科開業医 (大阪)	出席
F	総合病院内科 (愛知)	出席
G	大学医学教育センター (東京)	欠席
高血圧 (循環器専門医)		
H	総合病院循環器科 (東京)	出席
I	厚生労働省 (医系技官)	出席
糖尿病 (糖尿病専門医)		
J	総合病院内科 (千葉)	出席
K	糖尿病開業医 (東京)	出席
気管支喘息 (呼吸器専門医)		
L	大学病院呼吸器科 (新潟)	出席
M	大学病院呼吸器科 (東京)	出席

この際、それは診療録へ記載すべき事項であるか（記載がないこと自体がすでに質が悪いことを意味するか）を鑑みながらの評価を依頼した。「スタンダードとしての適切性」については「1」を「全く不適切」、「9」を「きわめて適切」として、評価を記入してもらうこととした。この際に、パネルメンバーには、「理想的なスタンダード」ではなく、2004年時点での平均的なプライマリ・ケア医の診療として「最低限クリアすべきスタンダード」を念頭において評価するよう依頼した。併せて、引用すべき文献に漏れがないか、項目内容へのコメントがあれば記載してもらうよう依頼した。回収された9段階評価は、それぞれの項目に対して中央値・最小値・最大値が計算された。

#### 4) エキスパート・パネルによる会議

2004年4月に、選出されたエキスパート・パネルのメンバーを招集し、コンセンサス決定のための小会議を行った。会議は疾患ごとに、臓器別専門医を入れ替えながら順次行い、プライマリ・ケア医は全ての会議に参加した。いずれの会議においても、まず研究者が研究趣旨について説明を行い、メンバーより文書による参加同意を得た後に協議に入った。協議の司会はコンセンサス会議の経験のある研究者の1人が務め、回収された各評価項目の結果と各自の評価結果を記載した一覧表を配布した後に、必要と判断された項目について協議を行った。協議が必要と判断された項目は、「適切性」に関して中央値が6～7点、最大-最小値の開きが5点以上、メール上でコメントのあった項目、とした。それぞれの検討項目に関してパネルの中で大まかなコンセンサスを見だした時点で次の検討項目に移り、最終的に全ての検討項目に対して大まかなコンセンサスを得るような協議を促した。協議は1会議90分を目安として行い、全ての協議は録音され、後にテープ起こしを行い、確認のための分析を行った。

#### 5) QI 項目の再構築と再評価

エキスパート・パネル協議後に、パネルにより不適切とされた項目（当初の「適切性」の評価が5以下の項目、またはパネル協議により不適切と判断された項目）を削除し、協議によって示唆された項目内容の変更を行った評価項目一覧表を各メンバーに送付した。それらの変更をふまえ、再度、各メンバーに各項目の適切性、データ取得性について9段階評価を行ってもらい結果を集計した。集計した結果を再度メールで各メンバーに送付して意見を出し合ってもらい、最終的に各疾患5項目程度に絞るよう意見を集約し、質評価指標セットとした。

## 結果

初回候補項目として抽出された項目は、高血圧12項目、糖尿病20項目、気管支喘息19項目の計51項目であった。パネルメンバーによる項目評価の結果を図1に示す。適切性、データ取得性のいずれにおいても中央値が3点以下の項目はなかった。「適切性」の中央値は、高血圧においては3分の2の項目が8～9の範囲であったが、糖尿病、気管支喘息では4～7、8～9の範囲をとった項目数が約半数ずつであった。初回の評価で最大-最小値の開きが5点以上であった項目は、高血圧5、糖尿病6、気管支喘息1項目であった。

エキスパート・パネルの会議には、13名のパネルメンバーのうちプライマリ・ケア医2名を除く全員が参加した。当初、疾患ごとの評価指標項目のみを抽出していたが、パネル協議において外来診療全般の質をみるための評価指標の必要性が指摘され、「全般」の候補項目としてその場で6項目が提案された。

候補項目の「適切性」について評価が分かれた項目に関しては、パネルメンバー間においてエビデンスについて意見の不一致はないものの、これをQIとしたときに、どこまで何を含めるかに関して、専門医・プライマリ・ケア医間あるいは診療セッティングの違いによって見解の相違がみられた。また、情報源としての診療録の信頼性について懸念が表明された。

エキスパート・パネルによる会議の結果、2回目の評価候補項目として高血圧7項目、糖尿病8項目、気管支喘息6項目、全般6項目が残った。2回目の評価では、全ての項目で「適切性」の値は8～9の範囲にあった。「データ取得性」に関しては、概ね8～9の範囲であった（図1）。さらにメール上でのパネルメンバー間の意見の集約、文言の修正を行い、最終的に高血圧5項目、糖尿病6項目、気管支喘息5項目、全般4項目、計20項目のデータセットとなった（付録1）。

最終的に当初の候補項目の約7割が採用されなかったが、その主要な理由は、世界的にみて標準的な内容のケアではあるが日本では実施率が低くこの時点で「最低限クリアすべきスタンダード」とするのは不適當、あるいは日本では保険適応が無い、診療録から信頼できるデータを収集することは困難、QIに該当する患者が少ない、項目数の限定、であった。

## 考按

今回我々は、プライマリ・ケアの外来診療場面において

しばしば遭遇する高血圧、2型糖尿病、気管支喘息の3つのコモン・ディジーズに対する診療プロセスを評価するためのQIを、modified RAND appropriateness methodを用いて開発した。本研究は、外来での慢性期管理に対する体系的な作成手順に則って作成されたQIとしては、わが国で初めてのものである。

本研究では診療の質を評価するために、ガイドラインではなくQIを作成した。診療の質を論じる際には、ガイドラインで十分ではないかという考えもあるが、本研究で作成されたQIは以下の点でガイドラインとは異なっている。QIは、レトロスペクティブに質を測定するための指標であるが、一方ガイドラインはそのまま用いて医療の質の測定を行うことは困難である。またQIは、最も基本的な「最低限クリアすべきスタンダード」な基準を示しているが、ガイドラインはプロスペクティブに、「理想的な」ケアを行っていくためのガイドである<sup>23) 24)</sup>。

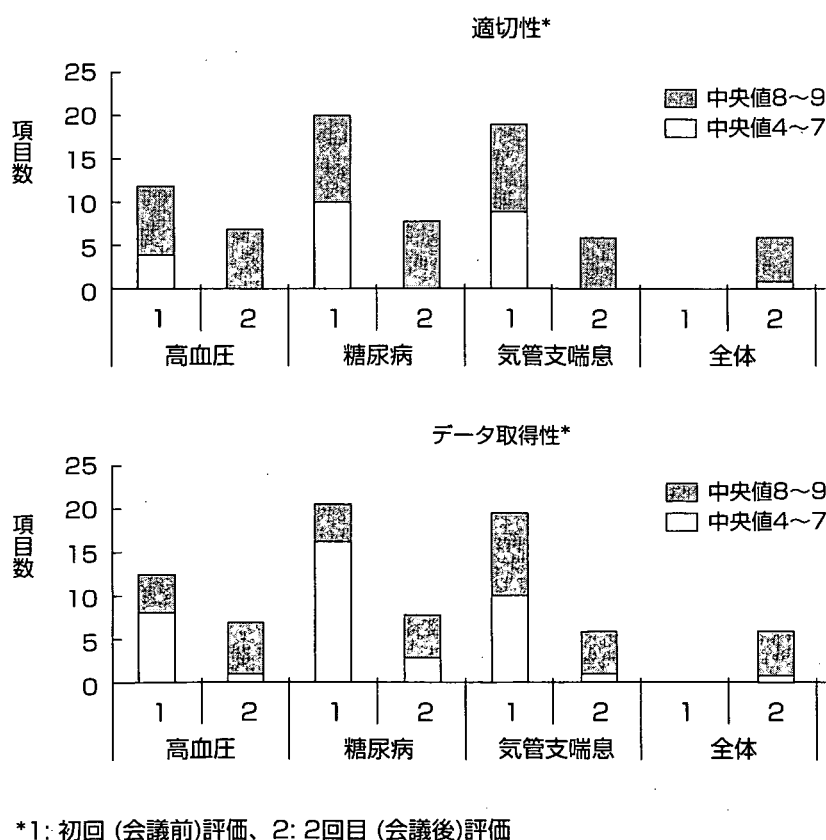
今回のQI作成プロセス全体を通じて、パネルメンバーから情報源としての診療録に関し繰り返し懸念が表明された。先行研究においても、パネルメンバーあるいはユーザーから、しばしば情報源としての診療録に対して懸念が表明されている<sup>23) 24)</sup>。診療録への記載は、実際に行われた診療行

為と関連し<sup>25)</sup>、アウトカムとも関連することが明らかになっているが<sup>26)</sup>、一方で、特に予防医療や患者指導などに関しては診療録のみを情報源とした場合には、実際より低く評価してしまう傾向があることも明らかになっている<sup>27) 28)</sup>。QIのような診療録を主たる情報源とする外的基準では、ある診療行為が実際に行われるということ、それが診療録に記載されるという2つの要素を総合して評価していることを理解し、この2つの要素のいずれもが改善されるよう努力していくべきであろう。また、評価に際しては診療録の他、レセプトや患者調査との組み合わせといった工夫も検討する必要があるであろう。

本研究のその他の限界に関して、RAND methodはエキスパート・パネルの構成によっては導き出されるQIが変化する可能性があるということが指摘されており<sup>29)</sup>注意が必要である。また、作成されたQIはエビデンスに基づくものであるが、作成時から時間が経つと見直しが必要になる可能性がある。我々の作成したQIも2004年時点でのエビデンスに基づいており、今後見直しが必要になるかもしれない。

今回開発された各QI項目は、簡便性を優先してターゲットとなる状況も項目数も絞り込んだが、QIセットとしての

図1 パネルメンバーによる項目評価値の分布



質の検討は今後の課題である。本項目同士、また疾患間での関連性の検討は現時点では行われておらず、アウトカムとの関連の検討は今後の予定である。そのために、我々は現在まで全国の十数施設において400以上の診療録を対象に今回作成したQIを用いてデータ取得を行い、疾患ごとあるいは全体のQIセットとしての質の検討を加えているところである。今後、日常の外来診療の中で質改善のツールとして使用可能になるように修正を加えていく予定である。

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## 文献

- 1) Brook RH, McGlynn EA, Shekelle PG: Defining and measuring quality of care: a perspective from US researchers. *Int J Qual Health Care* 12:281-295, 2000
- 2) Donabedian A: The definition of quality and approached to its assessment. Health Administration Press, Ann Arbor, MI, 1980.
- 3) 財団法人 日本医療機能評価機構 [http://jcqhc.or.jp/html/jikohyouka\\_v5.htm](http://jcqhc.or.jp/html/jikohyouka_v5.htm):
- 4) 栗田啓, 高嶋成光: 独立行政法人下で求められる医療の質 臨床評価指標の導入に向けて 臨床評価指標の設定と評価 がん診療について. *医療* 59:17-19, 2005
- 5) 藤兼俊明: 独立行政法人下で求められる医療の質 臨床評価指標の導入に向けて 呼吸器ネットワークにおける臨床評価指標とネットとしての取り組み. *医療* 59:20-22, 2005
- 6) Wenger NS, Shekelle PG: Assessing care of vulnerable elders: ACOVE project overview. *Ann Intern Med* 135:642-646, 2001
- 7) 益子邦洋, 有賀徹, 上嶋権兵衛, 山本修三, 坂本哲也, 井上徹英, et al: 三次救急医療機関の機能を評価する指標の開発と今後の課題. *日本救急医学会雑誌* 13:769-778, 2002
- 8) 尾藤誠司, 松井邦彦, 茅野眞男: デルファイ変法を用いた急性心筋梗塞に対する医療の質評価指標作成の試み. *医*

療と社会 13:115-124, 2004

- 9) 平成 17 年 患者調査 :[http://www.dhtk.mhlw.go.jp/toukei/cgi/sse\\_kensaku](http://www.dhtk.mhlw.go.jp/toukei/cgi/sse_kensaku): 2007.5.22
- 10) Shekelle PG, MacLean CH, Morton SC, Wenger NS: Assessing care of vulnerable elders: methods for developing quality indicators. *Ann Intern Med* 135:647-652, 2001
- 11) Hemingway H, Crook AM, Feder G, Banerjee S, Dawson JR, Magee P, et al: Underuse of coronary revascularization procedures in patients considered appropriate candidates for revascularization. *N Engl J Med* 344:645-654, 2001
- 12) Brook RH, Chassin MR, Fink A, Solomon DH, Koscoff J, Park RE: A method for the detailed assessment of the appropriateness of medical technologies. *Int J Technol Assess Health Care* 2:53-63, 1986
- 13) Shekelle PG, Kahan JP, Bernstein SJ, Leape LL, Kamberg CJ, Park RE: The reproducibility of a method to identify the overuse and underuse of medical procedures. *N Engl J Med* 338:1888-1895, 1998
- 14) Naylor CD: What is appropriate care? *N Engl J Med* 338:1918-1920, 1998
- 15) Chobanian AV, Bakris GL, Black HR, Cushman WC, Green LA, Izzo Jr JL, et al: The Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure: the JNC 7 report. *JAMA* 289:2560-2572, 2003
- 16) Standards of medical care in diabetes. *Diabetes Care* 27 Suppl 1:S15-S35, 2004
- 17) 2003 Update: Workshop Report, Global Strategy for Asthma Management and Prevention, in, 2003
- 18) National Asthma Education and Prevention Program. Expert Panel Report: Guidelines for the Diagnosis and Management of Asthma Update on Selected Topics--2002. *J Allergy Clin Immunol* 110:S141-S219, 2002
- 19) British guideline on the management of asthma. *Thorax* 58 Suppl 1:i1-94, 2003
- 20) 宮本 昭: EBM に基づいた患者と医療スタッフのパートナーシップのための喘息診療ガイドライン 2004 (成人編). 協和企画, 東京, 2004.
- 21) Campbell SM, Braspenning J, Hutchinson A, Marshall MN: Research methods used in developing and applying quality indicators in primary care. *BMJ* 326:816-819, 2003
- 22) McGory ML, Shekelle PG, Ko CY: Development of quality indicators for patients undergoing colorectal cancer surgery. *J Natl Cancer Inst* 98:1623-1633, 2006
- 23) Campbell SM, Hann M, Hacker J, Durie A, Thapar A, Roland MO: Quality assessment for three common con-

- ditions in primary care: validity and reliability of review criteria developed by expert panels for angina, asthma and type 2 diabetes. Qual Saf Health Care 11:125-130, 2002
- 24) Saliba D, Solomon D, Rubenstein L, Young R, Schnelle J, Roth C, et al: Feasibility of quality indicators for the management of geriatric syndromes in nursing home residents. J Am Med Dir Assoc 6:S50-S59, 2005
- 25) Kosecoff J, Fink A, Brook RH, Chassin MR: The appropriateness of using a medical procedure. Is information in the medical record valid? Med Care 25:196-201, 1987
- 26) Kahn KL, Rogers WH, Rubenstein LV, Sherwood MJ, Reinisch EJ, Keeler EB, et al: Measuring quality of care with explicit process criteria before and after implementation of the DRG-based prospective payment system. JAMA 264:1969-1973, 1990
- 27) Campbell SM, Roland MO, Shekelle PG, Cantrill JA, Buetow SA, Cragg DK: Development of review criteria for assessing the quality of management of stable angina, adult asthma, and non-insulin dependent diabetes mellitus in general practice. Qual Health Care 8:6-15, 1999
- 28) Stange KC, Zyzanski SJ, Smith TF, Kelly R, Langa DM, Flocke SA, et al: How valid are medical records and patient questionnaires for physician profiling and health services research? A comparison with direct observation of patients visits. Med Care 36:851-867, 1998
- 29) Campbell SM, Hann M, Roland MO, Quayle JA, Shekelle PG: The effect of panel membership and feedback on ratings in a two-round Delphi survey: results of a randomized controlled trial. Med Care 37:964-968, 1999

付録1 作成されたQIセット

	QI項目の内容
高血圧	<ol style="list-style-type: none"> <li>1. 初診から3カ月以内に、以下の全てについての記載がある：糖尿病および高脂血症の合併の有無、心音所見</li> <li>2. 降圧剤投与開始前に以下の評価全てを行っている：心電図、尿検査、カリウム</li> <li>3. 最近の1年間で、生活習慣改善指導（減量、運動療法、食事療法、減塩、節酒のいずれか）が行われた記載がある。</li> <li>4. 最近の1年間で、カリウム、クレアチニン、脂質プロファイル（T cho, HDL, LDL, TGのいずれか3つ）が全てチェックされている。</li> <li>5. 自己血圧測定を勧められているか、測定された自己血圧測定値の記載がある。</li> </ol>
糖尿病	<ol style="list-style-type: none"> <li>1. 最近の1年間で、以下の全てについての記載がある：蛋白尿、血圧、体重</li> <li>2. 最近の1年間で、眼病変についての記載がある。</li> <li>3. 過去1年間に1回でもHbA1cが8.0以上であった患者に対して、HbA1cは3カ月ごと（またはそれ以上の頻度で）にチェックされている。</li> <li>4. 新たに診断された患者に対しては、食事療法指導を行った記載がある（栄養指導の指示箋、あるいはカロリー数または単位数の記載がある）。</li> <li>5. 経口血糖降下薬で6カ月以上常にHbA1c8.0以上の患者に対して、インスリンが導入されている。されていない場合、その理由が明記されている。</li> <li>6. 高血圧と蛋白尿を合併している患者に対して、現在ACE阻害薬またはARBが投与されている。されていない場合、その理由が明記されている。</li> </ol>
喘息	<ol style="list-style-type: none"> <li>1. 最近の1年間で、発作の回数またはPEF値の記載がある。必要な場合には治療のステップアップ/ステップダウンが行われている。</li> <li>2. 呼吸機能の評価は、2年に1回以上行われている。</li> <li>3. 喘息患者に対して、発作時の症状緩和のための短時間型β2吸入薬が処方されている。</li> <li>4. 過去6カ月間に急性増悪があった患者、または夜間発作のある患者またはβ2吸入を1日1回以上使う患者に対して、発作予防のコントローラーとして吸入ステロイドが使用されている。</li> <li>5. 吸入療法に関して、1日の吸入回数と量が記載されている。</li> </ol>
全般	<ol style="list-style-type: none"> <li>1. 喫煙習慣についての記載がある。喫煙患者については、喫煙/禁煙状況についての記載が、1年に1回以上ある。</li> <li>2. 6カ月に1回以上、患者の症状や訴えが記載されている。</li> <li>3. 標的疾患に対する薬剤が変更になった次の診察時に、変更薬剤に関する副作用や効果についての記載がなされている。</li> <li>4. アセスメントとプランに関する記載が6カ月に1回以上ある。</li> </ol>

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

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### Keywords

cross-cultural  
comparison,  
ethics,  
end-of-life care,  
Japanese,  
family relations,  
focus groups

### ABSTRACT

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

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

### INTRODUCTION

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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



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

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

## METHODS

In order to perform a qualitative cross-cultural analysis regarding the relationship between acculturation and end-of-life decision making among Japanese Americans and Japanese in Japan, we conducted 18 focus groups with 122 participants in three groups of Japanese participants defined according to their country of residence and language: 1) Japanese living in Japan (five groups), Japanese-speaking Japanese Americans (four groups), and English-speaking Japanese Americans (nine groups). Language was used as the distinguishing characteristic of the two Japanese American groups because it is recognized as a key component of acculturation<sup>12</sup> and because classification based on other measures was beyond the capacity of this study. The focus groups were conducted in 1996 and 1997. We aimed to include people over the age of 65 because they are more likely to face end-of-life decisions in the near future. Four of the five focus groups in Japan were convened as gender-specific groups while all Japanese American focus groups were gender-mixed.

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

conducted the Japanese focus groups held in Japan. At least one Japanese co-moderator participated in the English-speaking Japanese American focus groups. Each focus group session included five to nine participants, all of whom provided written informed consent. Focus group discussions averaged two hours in length with the Japanese language focus groups lasting longer because of variation in social interaction and a longer time before Japanese participants opened up to full discussion. Given the cultural disparity between the Western and Japanese models of end-of-life decision-making, a grounded qualitative approach was employed<sup>13</sup> within a framework derived from the Japanese thinking-and-behavior style that is based on group orientation.<sup>14</sup> The study protocol was approved by the UCLA IRB.

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

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

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

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

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

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

Table 1. Description of the Three Focus Group Samples

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

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

*Issei* = first generation immigrants.

*Shin-Issei* = emigrated after World War II.

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

*Nisei* = second generation.

*Sansei* = third generation.

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

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

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

## RESULTS

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

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

### Presenting bad news

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

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

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

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

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

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

Another English-speaking Japanese American stated:

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

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

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

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

#### Attitudes toward end-of-life care

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

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

Another Japanese participant stated:

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

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

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

### Preferred decision-making model

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

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

An English-speaking Japanese American remarked similarly,

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

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

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

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

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

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

Another Japanese participant expressed his frustration with his physician:

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

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

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

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

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

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

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

### Attitudes about advance directives

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

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

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

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

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

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

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

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

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

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

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

## DISCUSSION

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

### Preserved values

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

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

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

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

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

<sup>18</sup> T.S. Elwyn et al., *op. cit.* note 9.

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

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

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

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

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

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

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

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

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

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

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

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

<sup>22</sup> L.J. Blackhall et al., *op. cit.*, note 3; J.A. Careese & L.A. Rhodes, *op. cit.*, note 4; K. Braun, *op. cit.*, note 7; L. Crawley et al. Palliative and end-of-life care in the African American community. *JAMA* 2000; 284: 2518–2521.

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

<sup>27</sup> T. Doi. 1997. *The anatomy of dependence*. Tokyo. Kodansha International.

<sup>28</sup> Sanseido ed. 2001. *Shinmeikai Japanese Proverb Dictionary*. Tokyo: Sanseido: 1505.

<sup>29</sup> R. Benedict. 1946. *The Chrysanthemum and the Sword*. Boston. Houghton Mifflin Co.

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

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

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

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

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

### Influences of acculturation

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

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

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

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

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

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

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

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

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

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

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

<sup>35</sup> R.B. Leflar. The cautious acceptance of informed consent in Japan. *Med Law* 1997; 16: 705–720.

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

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

<sup>38</sup> N. Ikegami. Growing old in Japan. *Age Ageing* 1998; 27: 277–278.



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

## LIMITATIONS

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

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

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

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

## CONCLUSIONS AND RECOMMENDATIONS

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

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

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

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

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

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

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

<sup>42</sup> R.M. Suinn et al., *op. cit.* note 12.

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

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

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

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Research article

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## Attitudes and behaviors of Japanese physicians concerning withholding and withdrawal of life-sustaining treatment for end-of-life patients: results from an Internet survey

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### Abstract

**Background:** Evidence concerning how Japanese physicians think and behave in specific clinical situations that involve withholding or withdrawal of medical interventions for end-of-life or frail elderly patients is yet insufficient.

**Methods:** To analyze decisions and actions concerning the withholding/withdrawal of life-support care by Japanese physicians, we conducted cross-sectional web-based internet survey presenting three scenarios involving an elderly comatose patient following a severe stroke. Volunteer physicians were recruited for the survey through mailing lists and medical journals. The respondents answered questions concerning attitudes and behaviors regarding decision-making for the withholding/withdrawal of life-support care, namely, the initiation/withdrawal of tube feeding and respirator attachment.

**Results:** Of the 304 responses analyzed, a majority felt that tube feeding should be initiated in these scenarios. Only 18% felt that a respirator should be attached when the patient had severe pneumonia and respiratory failure. Over half the respondents felt that tube feeding should not be withdrawn when the coma extended beyond 6 months. Only 11% responded that they actually withdrew tube feeding. Half the respondents perceived tube feeding in such a patient as a "life-sustaining treatment," whereas the other half disagreed. Physicians seeking clinical ethics consultation supported the withdrawal of tube feeding (OR, 6.4; 95% CI, 2.5–16.3;  $P < 0.001$ ).

**Conclusion:** Physicians tend to harbor greater negative attitudes toward the withdrawal of life-support care than its withholding. On the other hand, they favor withholding invasive life-sustaining treatments such as the attachment of a respirator over less invasive and long-term treatments such as tube feeding. Discrepancies were demonstrated between attitudes and actual behaviors. Physicians may need systematic support for appropriate decision-making for end-of-life care.

## Background

As medical technology becomes more advanced, judgments about whether to undertake invasive medical procedures have increasingly become a serious and difficult issue to resolve; this is true not only for patients in whom medical testing clearly demonstrates an end-of-life status but also for patients in a comatose state with very little prospect of recovery and for frail, elderly individuals [1-3]. To resolve these issues, various points must be clarified. For example, the fact that terms such as "end-of-life," "death with dignity," and "life-sustaining treatment" that are generally used as if their definitions were unequivocal are, in reality, extremely relative in nature and entail significant differences in nuance depending on the circumstances and the manner in which individuals understand these terms [4,5]. In reality, it is very difficult to assign a definition to a term that portrays an image of "life-sustaining treatment." There is further debate as to whether joint or individual consideration is appropriate for issues such as candidate suitability for various medical interventions and withholding or withdrawal of medical interventions [6].

Some studies have indicated the effect of cultural factors and attitudes toward decision-making in end-of-life care [7-9]. We might expect discrepancies in public awareness with respect to these topics; however, there are also questions regarding the degree of the differences in the awareness of the aforementioned topics within a particular group of physicians. Although some surveys have investigated physicians' attitudes toward end-of-life care and life-sustaining treatment [8-11], evidence concerning how Japanese physicians think and behave in specific clinical situations that involve withholding or withdrawal of medical interventions is yet insufficient.

Our research first entailed an anonymous web-based internet survey of physicians regarding general discrepancies in clinical and ethical judgment in the withholding or withdrawal of potentially life-extending medical interventions. We then made a comparative study of the relationship between the distribution of awareness, differences in the distribution of physician characteristics, and discrepancies in clinical judgment.

We also investigated the extent to which physicians utilize conferencing, clinical ethicists, and ethics committees in cases of difficult ethical judgments.

## Methods

We carried out a cross-sectional internet survey targeting physicians who self-accessed the survey homepage that was advertised through mailing lists, public medical journals. The survey did not involve a sampling process using means such as membership lists of specific medical organ-

izations. For the survey, cooperation was sought from a non-specific pool of physicians. Further, it was anonymous in nature, and accessing the survey homepage was regarded as consent for survey participation. Encouragement toward accessing the homepage was limited to advertising through physician mailing lists, academic journals, and commercial medical journals. Four mailing lists were used for the advertisement: "Total Family Care" mailing list comprising approximately 2,500 primarily independent practitioners and primary care physicians, "Internist" mailing list comprising approximately 1,000 of the board members of the Japanese Society of Internal Medicine, "pEBM" mailing list comprising primarily evidence-based medicine (EBM) physicians, and "EML" mailing list comprising primarily emergency care providers. Journal advertisements were printed in bimonthly and biweekly Japanese medical journals in general medical fields with an emphasis on those for internal medicine.

The survey questions investigated the awareness regarding the withholding or withdrawal of potentially "life-extending treatment" in three case scenarios pertaining to medical intervention, namely, Case 1, Case 2, and Case 3. These three scenarios concerned judgment for the initiation/withholding of tube feeding for an elderly individual in a stroke-induced comatose state with a high potential for long-term prolongation, judgment for the attachment/withholding of a respirator in a patient with an identical status to the above patient with the additional occurrence of severe pneumonia, and judgment for the discontinuation/withdrawal of artificial feeding when a patient is in a prolonged comatose state for more than 6 months and the withdrawal of tube feeding has been requested by the patient's family (Appendix). Based on these three scenarios, the survey sought responses as to whether the available treatment options should or should not be withheld or withdrawn. The survey also used an analogous method to seek responses concerning actual actions in routine practice. Further, the survey also assessed whether physicians viewed two particular medical interventions as either "life-sustaining treatment" or not these two interventions were the continuation of artificial feeding through a gastrostomy for a patient in the third aforementioned scenario and the attachment of an artificial respirator when this patient developed severe pneumonia and would likely require more than 7 days until separation from the respirator could be undertaken.

In addition to the case scenario questions, we inquired the extent to which physicians make use of resources such as conferencing, consultation with clinical ethicists, and application to ethics committees when faced with difficult cases pertaining to ethical judgment.