ORIGINAL ARTICLE

What do patients value in their hospital care? An empirical perspective on autonomy centred bioethics

S Joffe, M Manocchia, J C Weeks, P D Cleary

J Med Ethics 2003:29:103-108

Objective: Contemporary ethical accounts of the patient-provider relationship emphasise respect for patient autonomy and shared decision making. We sought to examine the relative influence of involvement in decisions, confidence and trust in providers, and treatment with respect and dignity on patients' evaluations of their hospital care.

Design: Cross-sectional survey.

Setting: Fifty one hospitals in Massachusetts.

Participants: Stratified random sample of adults (N=27 414) discharged from a medical, surgical, or maternity hospitalisation between January and March, 1998. Twelve thousand six hundred and eighty survey recipients responded.

Main outcome measure: Respondent would definitely be willing to recommend the hospital to family and friends.

Results: In a logistic regression analysis, treatment with respect and dignity (odds ratio (OR) 3.4, 99% confidence interval (CI) 2.8 to 4.2) and confidence and trust in providers (OR 2.5, CI 2.1 to 3.0) were more strongly associated with willingness to recommend than having enough involvement in decisions (OR 1.4, CI 1.1 to 1.6). Courtesy and availability of staff (OR 2.5, CI 2.1 to 3.1), continuity and transition (OR 1.9, CI 1.5 to 2.2), attention to physical comfort (OR 1.8, CI 1.5 to 2.2), and coordination of care (OR 1.5, CI 1.3 to 1.8) were also significantly associated with willingness to recommend. **Conclusions:** Confidence and trust in providers and treatment with respect and dignity are more closely associated with patients' overall evaluations of their hospitals than adequate involvement in decisions. These findings challenge a narrow emphasis on patient autonomy and shared decision mak-

ing, while arguing for increased attention to trust and respect in ethical models of health care.

See end of article for authors' affiliations

Correspondence to: S Joffe, Dana-Farber Cancer Institute, 44 Binney St, Boston, MA 02115, USA; steven_joffe@ dfci.harvard.edu.

Revised version received 30 March 2002 Accepted for publication 5 June 2002

Respect for persons is fundamental to the ethical provider-patient relationship. At least with regard to competent adults, however, "respect for persons" in bioethics has come to equal respect for patient autonomy.\(^1\) The Belmont Report (which has had an enormous influence on clinical medicine despite its origins in human experimentation)\(^2\) tells us that "respect for persons \(...\) divides into two separate moral requirements: The requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy".\(^3\) Though other principles make claims upon us,\(^4\) "there are relatively few bioethicists who argue that respect for autonomy is not the preeminent value governing the actions of health care providers".\(^5\) In bioethics, autonomy occupies a place "at the top of the moral mountain".\(^6\)

Without denying the importance of self determination, respect for persons seems intuitively to imply a broader set of obligations than just attention to patient autonomy. Childress has suggested that respect for autonomy might usefully be viewed as a subset (albeit a centrally important one) of respect for persons:

The principle of respect for autonomy is ambiguous because it focuses on only one aspect of personhood, namely self-determination, and defenders often neglect several other aspects, including our embodiment. A strong case can be made for recognizing a principle of "respect for persons", with respect for their autonomous choices being simply one of its aspects—though perhaps its main aspect. But even then we would have to stress that persons are embodied, social, historical, etc.⁷

Veatch's deontological principles governing the patientphysician relationship (autonomy, fidelity, veracity, avoiding killing, and justice) are also helpful,⁸ but still appear incomplete. A partial list of what we mean by the concept might add respect for the body, respect for family, respect for community, respect for culture, respect for the moral value (dignity) of the individual, and respect for the personal narrative. A richer understanding of respect for persons seems particularly important in light of evidence suggesting that disrespect is common in medicine.⁹⁻¹¹ Unfortunately, the concept of respect has not received sustained analysis in the bioethics literature.¹²

The principle of respect for autonomy, as Schneider noted, is subject to a variety of conceptual interpretations.13 One useful way to classify these interpretations, following Isaiah Berlin,14 might be to array them along a spectrum from negative to positive. A negative, or antipaternalist, understanding demands that health professionals refrain "from interfering with efforts of individuals to . . . pursue [their life] plans". This view particularly rules out the use of force, coercion, and deception,16 17 including when the provider's ultimate goal is the patient's best interests. The negative conception of autonomy rights need not be a weak one, as Mill demonstrated.¹⁸ Most important for our current purposes, however, this antipaternalist model makes no normative assumptions about patients' affirmative responsibilities to make medical decisions. In contrast, the positive or "mandatory autonomy" model holds that patients have an obligation to exercise self rule and therefore to take direct responsibility for most decisions.19 Several grounds are put forward for this position. Some argue that individuals, including when they are patients, have a duty to make the most of their capability for moral agency.²⁰ Others suggest that only patients can know the values and preferences that are critical to making decisions affecting their health.21-23 Finally, some claim that

104 Joffe, Manocchia, Weeks, et al

patients have a duty not to burden others (including physicians) with their health care decisions.²⁴ Advocates of the mandatory autonomy view, of course, must defend a much more extensive set of normative claims.

Regardless of where on this spectrum one's preferred version of the principle of respect for autonomy falls, the question of how much patients actually wish to take responsibility for their medical decisions is of obvious importance. Accumulating data indicate that many patients prefer to delegate at least some decisions to their health care providers, particularly as the significance of the decision increases.²⁵⁻³⁰ Under the antipaternalist view of autonomy, this evidence suggests that the scope of the principle, or at least the proportion of health care interactions in which conflicts about autonomy are at issue, may be more limited than commonly assumed. Under the mandatory autonomy view, these data present a serious challenge to the normative assumptions underlying the model.

Trust is another potentially important aspect of health care relationships, one that may interact with autonomy in conceptually and practically interesting ways. Trust figures prominently in the work of a few bioethicists,31 though moral philosophy devotes relatively little attention to the concept.³² In recent sociological discourse, trust is "the expectation that arises within a community of regular, honest, and cooperative behavior, based on commonly shared norms, on the part of other members of that community".33 It is "the norm of generalized reciprocity". 34 This account, however, leaves out issues of vulnerability and power asymmetry that are central to many trust relationships,35 including most health care relationships.³⁶ Barber's two-dimensional conceptualisation of trust as "expectation of technically competent role performance" and "expectations of fiduciary obligation" better captures this complexity in the health care setting.³⁷ As Baier wrote: "trust is accepted vulnerability to another's power to harm one, a power inseparable from the power to look after some aspect of one's good".38 In this light, many argue that the health care relationship is a fiduciary one, in which "the physician is . . . necessarily a trustee for the patient's medical welfare".39 If so, then clinicians have obligations to patients that exceed contractual requirements and form the "foundation for professional ethics".40

Trust serves important practical functions. Whether in every-day economic and social life or in the special circumstance of illness, it reduces social friction and the need for constant vigilance that would otherwise be required.³³⁻⁴¹ Nevertheless, the concept of trust in professionals raises difficult philosophical questions. Veatch has even questioned the possibility of trust itself: "to the extent that it is impossible for professionals (1) to know what the interests of clients are, (2) to present value-free facts and behavior options, and (3) to determine a definitive set of virtues for a particular profession . . . [they] ought not to be trusted".⁴²

There is some evidence that trust in physicians has in fact decreased over the past quarter century,43 a period characterised also by increased attention to patient autonomy (and, parenthetically, to lawyers, contracts, and other formal means of social control in the broader society).44 Are these trends causally related? If so, was this relationship necessary or just a historical coincidence? It seems at least plausible that attitudes towards decision making responsibility and views about trust are related inherently to one another. One might argue that, without justified trust, caveat emptor reigns and patients would be well advised to take responsibility for most decisions regarding their medical care. Put somewhat differently, the absence of trust requires high levels of vigilance, or readiness to assert autonomy, on the part of the patient. In contrast, when morally valid trust obtains, some delegation of medical decisions would seem to be a reasonable option.

The relationship between trust and respect for persons (considered broadly) is less obvious than that between trust

and respect for autonomy. Respect as we are using it here refers to the actions and attitudes of providers, while trust refers to the actions and attitudes of patients. We view these as logically distinct concepts that are likely to interact in complex ways. We suspect that patients' willingness to trust can be explained, in part, by the extent to which they perceive that providers value them and the things that are important to them. One way in which providers can convey that they value their patients (and are therefore worthy of trust) is to treat patients with respect. In Baier's words: "To trust is to let another think about and take action to protect and advance something the truster cares about, to let the trusted *care for* what one cares about. Thoughtless care verges on 'careless care,' on plain failure to give care" (her italics). 45 Respectful care is unlikely to be perceived as thoughtless care.

We know little about how patients actually value trust, respect, and autonomy, or how they weigh these principles against one another. In the current study, we used patients' reports to gain insight into the ethics of medical encounters.⁴⁶⁻⁴⁹ Specifically, we studied the relationships between patients' experiences and their overall evaluations of the hospitals in which they recently received treatment. The fundamental assumption underlying the analysis was that, if patients value a dimension of care highly, then problems in that dimension will increase the likelihood that they will report negative overall evaluations of the hospital. In contrast, problems in a less highly valued dimension of care will have a more limited impact on evaluations. We tested three hypotheses: 1) treatment with respect and dignity is strongly associated with positive evaluations; 2) trust in nurses and physicians is highly correlated with evaluations, and 3) adequacy of involvement in decisions has a limited effect on evaluations. These hypotheses, if confirmed, suggest a model of the patient-provider relationship that elevates trust and respect to a central place alongside attention to patient autonomy.

METHODS

Design of primary survey

We reanalysed data from the Massachusetts Health Quality Partners (MHQP) Statewide Patient Survey Project. Massachusetts Health Quality Partners conducted the survey to provide hospitals with feedback to help them focus quality improvement efforts. ⁵⁰ Participants were adult obstetric, surgical, and medical patients discharged from one of 51 hospitals in Massachusetts between January and March, 1998. At 37 hospitals, patients from all three services were surveyed; at 11 hospitals without obstetric services, only medical and surgical patients were surveyed, and at three hospitals, only obstetric patients were surveyed. These institutions account for over 80% of adult medical/surgical discharges and over 90% of maternity patients in Massachusetts.

Patients were excluded if: 1) they were under 18; 2) they were not discharged to home; 3) they had died; 4) they were maternity patients who had an abortion or stillbirth, their infant died, or they gave the infant up for adoption; 5) they were hospitalised for a psychiatric disorder or substance abuse; 6) they were listed as "observation" patients; or 7) they did not spend at least one night in the hospital.

A sample of 600 patients was randomly selected from each hospital's list of eligible patients. For each hospital, this sample was divided evenly between participating medical, surgical, and maternity services—that is, 200 patients/service if all three services were participating. In all, 27 414 questionnaires were mailed. A reminder postcard was sent two weeks after the initial mailing, and replacement questionnaires were mailed to non-respondents two weeks later. Questionnaires were available in English, Spanish, Russian, Khmer (Cambodian) and Portuguese. A total of 12 680 respondents (46.3%) constitute the sample for this analysis.

	Number	Per cent
Sex		
Female	8848	69.8
Male	3832	30.2
Race		
White	11 375	92.5
Black	274	2.2
Asian	178	1.5
Hispanic	316	2.6
Other	161	1.3
Education		
No university education	7857	65.5
University education	4144	34.5
Self reported health status		
Poor/fair	2671	21.1
Good/very good/excellent	10 009	78.9
Discharge service		
Obstetrics	3526	27.8
Medicine	4542	35.8
Surgery	4612	36.4

Measures

Specific hospital experiences were assessed with 33 Picker Institute questions encompassing seven dimensions of care (see Appendix).⁴⁸ These dimensions included: 1) regard for patients; 2) coordination of care; 3) information and education; 4) physical comfort; 5) emotional support; 6) involvement of family and friends, and 7) continuity and transition. We modified two dimensions (regard for patients and emotional support) to permit separate consideration of adequacy of involvement in decisions, treatment with respect and dignity, and confidence and trust in staff (see Appendix for details).

Problem responses were defined a priori for each question; the Picker Institute codes any response other than the best possible response as a problem. Problem scores were then calculated for each of the seven dimensions of care as follows:

Problem score = (problem responses \div total questions answered) \times 100

Four additional items probed the patient's perception of the courtesy and availability of physicians and nurses on a five-point scale. We summed these questions to create an eighth dimension, which we similarly scaled from 0 (no problem) to 100 (most possible problems). We dichotomised the problem scores for each dimension into the quintile of patients reporting the most problems versus the remaining 80%.

We measured trust by combining two questions: "Did you have trust and confidence in the doctors treating you?" and "Did you have trust and confidence in the nurses treating you?" Response choices included "yes, always," "yes, sometimes," and "no". Patients who responded "yes, always" to the questions about both physicians and nurses were coded as expressing trust in providers.

The survey also asked: "Did you feel like you were treated with respect and dignity while you were in the hospital?" Response choices included: "yes, always," "yes, sometimes," and "no". Patients who responded "yes, always" were coded as experiencing respectful, dignified treatment.

We evaluated the adequacy of involvement in decisions with the question: "Did you have enough say about your treatment?" Response choices included: "yes, definitely," "yes, somewhat," and "no". Patients who responded "yes, definitely" were coded as having adequate involvement.

We measured overall evaluations of the hospital experience by the answer to the question: "Would you recommend this hospital to your friends and family?"⁵¹ Response choices included "yes, definitely," "yes, probably," and "no". Patients who responded "yes, definitely" were coded as indicating an unqualified willingness to recommend.

Table 2 Selected experiences and evaluations of hospital care

Experiences of care	Number	Per cent
Treatment with respect and dignity?*		
Yes, always	10 530	84.7
Yes, sometimes	1636	13.2
No	264	2.1
Confidence and trust in the nurses treating y	/ou?†‡	
Yes, always	9656	77.2
Yes, sometimes	2543	20.3
No	316	2.5
Confidence and trust in the doctors treating	you?†‡	
Yes, always	10 945	87.3
Yes, sometimes	1404	11.2
No	192	1.5
Enough say about your treatment?*		
Yes, definitely	8254	67.8
Yes, somewhat	311 <i>7</i>	25.6
No	807	6.6
Would you recommend this hospital to your	friends and far	nily?
Yes, definitely	9552	77.2
Yes, probably	2328	18.8
No	498	4.0

^{*}This question was initially included in the "Regard for patients" dimension. For purposes of this analysis, however, it was removed and considered separately.
†This question was initially included in the "Emotional support"

Finally, the survey asked about age, sex, education, ethnicity, and health status. Hospital and service (medicine, surgery, obstetrics) were also recorded.

Analysis

The outcome of our analysis was unqualified willingness to recommend the hospital. Because scores for the dimensions of care were highly correlated, we estimated a logistic regression model to evaluate the independent associations between predictor variables and willingness to recommend. To reduce potential confounding, the model controlled for age, sex, race, education, self reported health status, hospital, and hospital service (medicine, surgery, obstetrics). To assess for heterogeneity of relationships, we also tested interaction terms among demographic variables (age, sex, education, ethnicity, and health status) and the major predictor variables (respect, trust, involvement in decisions). Results are reported as adjusted odds ratios (OR) and 99% confidence intervals (CI). Statistical analyses used Stata 5.0 for Windows (Stata Corp, College Station, TX).

The Office for the Protection of Research Subjects at the Dana-Farber Cancer Institute determined that this secondary data analysis was exempt from United States federal requirements for institutional review.

RESULTS

The mean age of respondents was 53.8 years (standard deviation=20.4, range 18 to 102 years). The predominance of women (see table 1) resulted from the inclusion of obstetrics. Most subjects were white, about one-third had a university education, and most reported being in good to excellent health. Respondents were slightly older (53.8 ν 50.0 years, p<0.001) and more likely to be women (68.0% ν 64.9%, p<0.001) than non-respondents.

Approximately 85% of patients reported always receiving respectful, dignified treatment; 77% indicated always having confidence and trust in nurses, while 87% said they always had confidence and trust in their doctors; 68% "definitely" had

[†]This question was initially included in the "Emotional support" dimension. For purposes of this analysis, however, it was removed and considered separately.

^{‡71.2%} of respondents responded "yes, always" to the questions about confidence and trust in both doctors and nurses.

106 Joffe, Manocchia, Weeks, et al

Table 3 Multivariate predictors of unqualified willingness to recommend the hospital*

Dimension of care†	Odds ratio‡	99% confidence interval
Treatment with respect and dignity	3.4	(2.8 to 4.2)
Confidence and trust in providers	2.5	(2.1 to 3.0)
Courtesy and availability of staff	2.5	(2.1 to 3.1)
Continuity and transition	1.9	(1.5 to 2.2)
Attention to physical comfort	1.8	(1.5 to 2.2)
Coordination of care	1.5	(1.3 to 1.8)
Having enough say about treatment	1.4	(1.1 to 1.6)
Information and education	1.2	(1.0 to 1.5)
Emotional support	1.2	(1.0 to 1.5)
Inclusion of family and friends	1.2	(1.0 to 1.5)
Regard for patients	0.8	(0.6 to 1.0)

^{*}Model includes 10 820 respondents with complete data for all

enough say about their treatment; and 77% expressed unqualified willingness to recommend the hospital (see table 2)

In the multivariate model (see table 3), perceptions of respectful, dignified treatment correlated most strongly with unqualified willingness to recommend. Trust and confidence in providers and courtesy and availability of staff were also closely associated with willingness to recommend. Continuity and transition, attention to physical comfort, coordination of care, and having enough say about treatment were also significant, though weaker, predictors of willingness to recommend. Information and education, emotional support, inclusion of family and friends, and regard for patients did not achieve significance in the model. Finally, one interaction term (between age and trust) was of borderline significance. This interaction, which was not incorporated into the final model, indicated that willingness to recommend tended to be more strongly associated with trust among older patients.

DISCUSSION

We reanalysed a Massachusetts-wide survey to evaluate correlates of patients' evaluations of hospitals in which they had recently received treatment. As expected, we found that confidence and trust in providers and treatment with dignity and respect strongly influenced evaluations. In contrast, adequacy of involvement in decisions had a weaker, though still significant, impact. These data suggest that, among the experiences measured in this survey, hospitalised patients on average value involvement in decision making less than other aspects of treatment. If the survey measures fairly represent the range of experiences patients have, then these results have important implications for an autonomy-centred account of biomedical ethics. Our findings extend a growing literature, based primarily on patient self report, documenting that many individuals prefer to delegate responsibility for at least some health care decisions. 25-29 Our study adds the observation that, despite the implications of the shared decision making model, $^{\rm 21~52~53}$ having less involvement in decisions than desired does not necessarily lead to marked dissatisfaction with the hospital experience.

The strong relationship noted in our study between experiences of respect and overall evaluations of the hospital provides patient-centred support for respect for persons as a first principle of bioethics, and indicates the need for a better understanding of respect in the patient-clinician relationship.

Few studies have investigated the nature, determinants, or consequences of respectful treatment. In a study of family planning clinics by Morris, respect as rated by independent observers strongly predicted patients' evaluations of their experiences.54 Beckman et al noted that relationship problems, particularly such examples of disrespect as demeaning patient or family views, failing to understand their perspectives, and desertion, were common features of malpractice suits.11 Burack et al documented that disrespectful behaviours were both prevalent among housestaff on a ward team and rarely challenged by senior staff. 10 Lazare wrote of the important and underappreciated roles of shame and humiliation in medicine.9 And Kass lamented such everyday occurrences as failure to introduce oneself, inappropriate use of first names, inattention to patients' nakedness, arguments among staff in the presence of patients, and devaluation of disabled patients.12 What these examples of disrespect have in common is not the affront to autonomy, but rather the suggestion that patients lack full worth. The ability to distinguish the two in the context of specific examples supports the contention that respect for persons might signify more than just respect for their autonomy.

Trust has also received little empirical attention,⁵⁵ though studies are beginning to appear.⁵⁶⁻⁶⁰ Research on the demographic and structural determinants of trust in physicians documents the importance of patient ethnicity,⁵⁶ continuity of care,⁵⁶⁻⁵⁷ and payment method.⁵⁷⁻⁵⁸⁻⁶⁰ Dimensions of trust include interpersonal competence, technical skill, and advocacy.⁵⁹⁻⁶¹ One critical aspect of interpersonal competence, we suspect, is the provider's ability to convey an attitude of respect. Respectful providers are likely to be perceived as trustworthy. Our survey confirms that, despite theoretical concerns,⁴² patients place great value on trust in their health care providers. Its importance to patients suggests that efforts to understand and enhance trust are warranted.

Our analysis had several limitations. First, the survey was restricted to Massachusetts, and other areas may differ. Second, we were unable to consider directly how patients value other dimensions of care, such as technical quality. However, the questions about trust and confidence do capture, at least in part, patients' views about the competence of their caregivers. 59 61 Third, although the response rate is consistent with other surveys of this type, respondents might differ from non-respondents. Observed demographic differences were slight, however, and it is improbable that selection bias could account for our main conclusions. Fourth, our findings apply only to adults hospitalised for medical, surgical, or obstetric indications. They should not be generalised to populations that were not represented in our sample, including somepsychiatric patients—who are most at risk for violations of their autonomy. It is also likely that patients' attitudes towards the dimensions of medical care evaluated here vary by cultural and other factors. Exploration of such variation was beyond the scope of this project. Finally, our results reflect patients' evaluations across a broad spectrum of encounters. Patients in value-laden situations or with severe illness might differ.

Some might reasonably argue that the question about patients' experiences of decision making involvement ("Did you have enough say about your treatment?") does not map perfectly onto the concept of autonomy as understood by ethicists and theorists of shared decision making. Some patients who reported not having enough say in their treatment may have been referring to relatively minor infractions, which would not be expected to lead to much dissatisfaction. Other patients may have been excluded from important choices affecting them without even being aware of the existence of those choices. Such marked violations of autonomy, which are clearly of concern, may not even have been captured by our survey. Nevertheless, one-third of respondents reported a desire for more involvement than they actually experienced. That such patients were only slightly

[†]See Appendix for a description of the items included in each dimension.

[‡]Adjusted odds ratios based on a logistic regression model with unqualified willingness to recommend the hospital as the dependent variable. The model controls for hospital, hospital service (obstetrics, medicine, surgery), self reported health status, age, sex, race, and education.

more likely than others to evaluate their hospital experience poorly is striking. Similarly, the popular conceptions of respect, dignity, and trust likely differ from those in philosophical discourse. Ethical concepts, however, must be operationalised to be useful. As Callahan wrote: "while it is not altogether fair to hold a good concept, sensibly deployed in careful writing, to the test of whether it is proof against popular misuse, concepts must always be used in some culture unless they are to remain solely in dictionaries and textbooks".

By noting that perceptions of inadequate involvement in decisions have a limited effect on patients' evaluations of their hospital experiences, we neither condone paternalism in the provider-patient relationship nor suggest that efforts to enhance shared decision making are misguided. Our primary purpose is to highlight the central roles of respect and trust in patients' experiences of illness, rather than to criticise the value of patient autonomy. Indeed, it is eminently possible that a concerted programme to enhance involvement in decisions might lead to significant improvements in patients' evaluations when compared with standard practice. Further research to clarify this question would be of great interest, though even in the absence of measurable effects such programmes might plausibly be judged worthwhile on independent grounds.

Finally, we wish to emphasise that our analysis is descriptive rather than normative. We do not recommend that patients' perspectives should unilaterally determine ethical frameworks. We do, however, believe that data such as those presented here can contribute to the search for reflective equilibrium in bioethics. 63 64 In this spirit, our findings challenge a narrow emphasis on autonomy and shared decision making, while arguing for increased attention to trust and respect in ethical models of health care.

ACKNOWLEDGMENTS

We would like to thank the Massachusetts Health Quality Partners (MHQP) and the hospitals participating in the MHQP Statewide Patient Survey Project for their cooperation. Massachusetts Health Quality Partners can be contacted through its website at http:// www.mhqp.org. We also wish to express our gratitude to Lisa Lehmann, MD, MSc. for her thoughtful comments on an earlier draft of this manuscript.

Dr Joffe was the recipient of a fellowship from the Agency for Healthcare Research and Quality (T32 HS00063), and was a Faculty Fellow at the Center for Ethics and the Professions at Harvard Univer-

Authors' affiliations

\$ Joffe, Department of Pediatric Oncology, Dana-Farber Cancer Institute, Boston and Department of Medicine, Children's Hospital, Boston, USA M Mannochia, Blue Cross Shield of Rhode Island Providence, and University of Rhode Island, Department of Sociology, Kingston, USA J C Weeks, Department of Adult Oncology, and the Department of Medicine, Brigham and Women's Hospital, Boston, USA P D Cleary, Department of Health Care Policy, Harvard Medical School, Boston, USA

REFERENCES

- 1 Jonsen AR. The birth of bioethics. New York: Oxford University Press,
- 2 Cassell EJ. The principles of the Belmont report revisited. How have respect for persons, beneficence, and justice been applied to clinical medicine? *Hastings Cent Rep* 2000;**30**:12–21.
- 3 National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The Belmont report: ethical principles and guidelines for the protection of human subjects of research. In: Sugarman J, Mastroianni AC, Kahn JP, eds. Ethics of research with human subjects. Frederick, MD: University Publishing Group, Inc, 1998:19–30.

 4 Beauchamp TL, Childress JF. Principles of biomedical ethics [4th ed]. New York: Oxford University Press, 1994.
- 5 Caplan AL. Can autonomy be saved? In: If I were a rich man could I buy a pancreas? and other essays on the ethics of health care. Bloomington: Indiana University Press, 1992: 256-81.

- 6 Callahan D. The social sciences and the task of bioethics. *Daedalus* 1999;128:275–93.
- Childress JF. The place of autonomy in bioethics. Hastings Cent Rep 1990;20:12-17.
- 8 Veatch RM. The patient-physician relation. Bloomington: Indiana
- University Press, 1991.

 9 Lazare A. Shame and humiliation in the medical encounter. Arch Intern Med 1987;**147**:1653-8.
- 10 Burack JH, Irby DM, Carline JD, et al. Teaching compassion and respect. Attending physicians' responses to problematic behaviors. J Gen Intern Med 1999;14:49–55.
- 11 Beckman HB, Markakis KM, Suchman AL, et al. The doctor-patient relationship and malpractice. Lessons from plaintiff depositions. Arch Intern Med 1994;154:1365-70.
- 12 Kass LR. Practicing ethics: where's the action? Hastings Cent Rep 1990;**20**:5–12
- 13 Schneider CE. The practice of autonomy. New York: Oxford University Press. 1998.
- 14 Berlin I. Two concepts of liberty. In: Four essays on liberty. Oxford: Oxford University Press, 1996:118–172.
- 15 See reference 8: 69.
- 16 **Dworkin G**. The theory and practice of autonomy. Cambridge: Cambridge University Press, 1988.
- 17 **Korsgaard CM**. The reasons we can share: an attack on the distinction between agent-relative and agent-neutral values. In: Creating the kingdom of ends. Cambridge: Cambridge University Press, 1996:
- 18 Mill JS. On liberty. Indianapolis: Hackett Publishing Company, Inc, 1978
- 19 See reference 13: 10.
- 20 Morreim EH. Balancing act: the new medical ethics of medicine's new economics. Washington, DC: Georgetown University Press, 1995.
- 21 Eddy DM. Anatomy of a decision. JAMA 1990;263:441-3.
- 22 Coulter A. After Bristol: putting patients at the centre. BMJ 2002;324:648–51.
- 23 See reference 8: 47-53
- 24 See reference 20: 140.
- 25 Ende J, Kazis L, Ash A, et al. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989;4:23–30.
- 26 Deber RB, Kraetschmer N, Irvine J. What role do patients wish to play in treatment decision making? Arch Intern Med 1996;156:1414–20.
 27 Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? JAMA 1984;252:2990–4.
 28 Arora NK, McHorney CA. Patient preferences for medical decision
- making: who really wants to participate? Med Care 2000;38:335-41.
- 29 McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. BMJ 2000;321:867-71.
- 30 Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. JAMA 1997;**277**:1485–92.
- 31 Pellegrino E, Thomasma D. The virtues in medical practice. New York: Oxford University Press, 1993.
- 32 Baier A. Trust and antitrust. Ethics 1986;96:231-6.
- 33 Fukuyama F. Trust: the social virtues and the creation of prosperity. New York: Free Press Paperbacks, 1995.
- 34 Putnam RD. Bowling alone: the collapse and revival of American community. New York: Simon & Schuster, 2000.
- 35 See reference 32: 240-4.
- 36 Parsons T. The sick role and the role of the physician reconsidered. Milbank Mem Fund Q 1975;53:257–78.
- Barber B. The logic and limits of trust. New Brunswick, NJ: Rutgers University Press, 1983.
- 38 Baier A. Trust and its vulnerabilities. In: Moral prejudices. Cambridge, MA: Harvard University Press, 1994: 130-51
- 39 See reference 4: 430.
- 40 See reference 31: 67
- 41 See reference 34: 135.
- 42 Veatch RM. Is trust of professionals a coherent concept? In: Pellegrino ED, Veatch RM, Langan JP, eds. Ethics, trust and the professions: philosophical and cultural aspects. Washington, DC: Georgetown University Press, 1991: 159–73.
 43 Pescosolido BA, Tuch SA, Martin JK. The profession of medicine and the
- public: examining Americans' changing confidence in physician authority from the beginning of the 'health care crisis' to the era of health care reform. J Health Soc Behav 2001;42:1-16.
- 44 See reference 34: 145-7
- 45 See reference 38: 138.
- 46 Cleary PD. The increasing importance of patient surveys. BMJ 1999;319:720–1.
- 47 Cleary PD, Edgman-Levitan S. Health care quality. Incorporating consumer perspectives. JAMA 1997;278:1608–12.
- 48 Cleary PD, Edgman-Levitan S, Walker JD, et al. Using patient reports to improve medical care: a preliminary report from 10 hospitals. *Qual Manag Health Care* 1993;**2**:31–8.
- 49 Cleary PD, Edgman-Levitan S, McMullen W, et al. The relationship between reported problems and patient summary evaluations of hospital care. QRB Qual Rev Bull 1992;18:53-9.
- 50 Massachusetts Health Quality Partnership. Massachusetts acute care hospital statewide patient survey project. Boston, MA: Massachusetts Health Quality Partnership, 1998.

108 Joffe, Manocchia, Weeks, et al

- 51 Burroughs TE, Davies AR, Cira JC, et al. Understanding patient willingness to recommend and return: a strategy for prioritizing improvement opportunities. *Jt Comm J Qual Improv* 1999;**25**:271–87. 52 **Charles C**, Whelan T, Gafni A. What do we mean by partnership in
- making decisions about treatment? BMJ 1999;319:780-2.
- 53 Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med 1999;49:651-61.
- 54 Morris NM. Respect: its meaning and measurement as an element of patient care. J Public Health Policy 1997;18:133–54.
 55 Pearson SD, Raeke LH. Patients' trust in physicians: many theories, few
- measures, and little data. J Gen Intern Med 2000;15:509–13
- 56 Doescher MP, Saver BG, Franks P, et al. Racial and ethnic disparities in perceptions of physician style and trust. Arch Fam Med 2000:**9**:1156–63
- 57 Kao AC, Green DC, Davis NA, et al. Patients' trust in their physicians: effects of choice, continuity, and payment method. J Gen Intern Med 1998;13:681-6
- 58 Kao AC, Green DC, Zaslavsky AM, et al. The relationship between method of physician payment and patient trust. JAMA 1998;**280**:1708–14.
- 59 **Mechanic D**, Meyer S. Concepts of trust among patients with serious illness. Soc Sci Med 2000;51:657-68.
- 60 Pereira AG, Pearson SD. Patient attitudes toward physician financial
- incentives. Arch Intern Med 2001;161:1313–17.

 61 Thom DH. Physician behaviors that predict patient trust. J Fam Pract 2001:**50**:323-8.
- 62 Callahan D. Autonomy: a moral good, not a moral obsession. Hastings Cent Rep 1984;14:40–2.
- 63 Rawls J. A theory of justice. Cambridge, MA: Harvard University Press,
- 64 **Zussman R**. The contributions of sociology to medical ethics. *Hastings Cent Rep* 2000;**30**:7–11.

APPENDIX: DIMENSIONS OF CARE ON PICKER **INSTITUTE SURVEY**

- 1. Regard for patients*
 - a. Doctors spoke in front of patient as if s/he weren't there
 - b. Nurses spoke in front of patient as if s/he weren't there
- 2. Coordination of care
 - a. Organisation of care in the emergency room
 - b. Organisation of the admissions process
 - c. Wait before going to hospital room
 - d. One doctor in charge
 - e. Conflicting statements from various staff
 - f. Tests and procedures performed on time
- 3. Information and education
 - a. Enough information in the emergency room
 - b. Delays explained
 - c. Doctors gave understandable answers

- d. Nurses gave understandable answers
- e. Test results explained
- 4. Attention to physical comfort
 - a. Help getting to bathroom
 - b. Rapid response to call button
 - c. Rapid treatment of pain
 - d. Maximal efforts to control pain
 - e. Appropriateness of pain medications
- 5. Emotional support+
 - a. Doctor discussed anxieties and fears
 - b. Nurse discussed anxieties and fears
 - c. Easy to find someone to talk to
 - d. Help understanding bill
- 6. Involvement of family and friends
 - a. Family/significant others were able to talk to doctors
 - b. Appropriateness of information given to family/ significant others
 - c. Information given to family/significant others to help care for patient
- 7. Continuity and transition
 - a. Purpose of discharge medications explained
 - b. Side effects of discharge medications discussed
 - c. Danger signals after discharge described
 - d. Resumption of usual activities discussed
- 8. Courtesy and availability
 - a. Courtesy of doctors
 - b. Courtesy of nurses
 - c. Availability of doctors
 - d. Availability of nurses

*The questions on treatment with dignity and respect and on having enough say about treatment were initially included in the "Regard for patients" dimension. For purposes of this analysis, however, they were removed and considered sepa-

†The questions about confidence and trust in doctors and in nurses were initially included in the "Emotional support" dimension. For purposes of this analysis, however, they were removed and considered separately.