Patients consider information and support needs to be important, and they were less satisfied with how well these needs were met than they were with the care delivery needs typically assessed by patient satisfaction surveys.

PATIENT'S PERSPECTIVE

Increasing Understanding of Patient Needs During and After Hospitalization

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In highly competitive industries, price reductions regularly occur simultaneously with performance improvements. As health care becomes more competitive, providers will be expected to both improve performance and reduce costs, not as a one-time event but as a way of life.[1,2]*

Performance measurement is a prerequisite for performance improvement, and understanding the extent to which patient needs are being satisfied is a critical aspect of performance measurement. Patient satisfaction measurement is a common and heavily researched method of evaluating how well health care providers meet patient needs.[3–9] Still, there are only a few published theoretical models of patient satisfaction,[10–12] and most patient satisfactions surveys in use have not been sufficiently validated.[13,14]

Many satisfaction surveys measure overall/global satisfaction by assessing the patient's inclination to recommend or return to the provider. Some collect

* Paul B. Batalden, MD, Professor and Director, Health Care Improvement Leadership Development, Dartmouth Medical School, telephone communication with author, Feb 23, 1998.

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Article-at-a-Glance

Background: The value of patient satisfaction surveys in health care improvement remains controversial. This study examined the value of alternative ways of identifying patient needs and estimating importance of those needs in improving the impact of satisfaction surveys.

Methods: Ninety-one acute myocardial infarction (AMI) patients from three southeast U.S. community hospitals were surveyed in 1992. Critical incident and person-focused interviews were used to identify patient needs. Besides overall/global satisfaction with care, patients rated satisfaction with and importance of 12 care delivery and 18 information and support needs. Unmet need scores (importance minus satisfaction) were estimated. Derived importance scores were assessed by correlating global satisfaction with individual need satisfaction scores. A two-step process for identifying priority areas for improvement was proposed.

Results: Patients identified and assigned greater scores to unmet needs for information and support needs (not included in typical satisfaction surveys) compared to typically assessed care delivery needs ($p < 0.0001$). Direct importance ratings differed substantially from those derived through correlation analyses ($r = 0.28$, $p > 0.3$ for care delivery needs and $r = -0.17$, $p > 0.4$ for information and support needs). Needs that received high importance and low satisfaction scores were all information and support needs.

Discussion: Needs that patients consider very important are usually ignored in typical patient surveys. Derived approaches typically used to assess importance of need from satisfaction data may provide misleading results. If satisfaction surveys are to result in real performance improvement, a fresh examination of the content and importance assessment strategies, as proposed, is needed.

patient ratings of satisfaction with specific aspects of the care delivery process, such as restfulness of atmosphere and ease of admission.[15] Others collect patient reports about care received, using questions such as, "Did the doctors talk in front of you as if you weren't there?"[16] Finding specific aspects of care that correlate most strongly with global satisfaction scores supposedly identifies priority areas for performance improvement.[17] However, there is dissatisfaction with existing surveys because many feel that they lead to little improvement in care.[18,19] We believe this results, at least in part, from the fact that these surveys do not include major areas of need considered to be important to patients.

This article presents two improvement strategies to increase the impact of patient satisfaction assessment: (1) more complete identification of patient and family needs; and (2) more accurate estimation of importance of those needs. Also, using a study of patients with acute myocardial infarction (AMI), we present empirical evidence of the weaknesses of current approaches and the merits of our proposed alternative strategies.

A two-step approach to identifying priority areas for improvement is discussed. Implications of our findings for expanding the scope of patient surveys (and health care itself) to better address the total burden of illness[20] are highlighted.

Identification of Needs

In early studies, understanding of patient needs started with the assumption that providers know the needs of the patients, based on professional standards and their own experiences.[13,21] In recent years, however, a number of patient-focused studies have clearly identified a much wider range of patient needs.[22–24]

We believe that even the best patient satisfaction surveys (as well as performance improvement efforts) are incomplete, because they do not adequately address information and support needs of patients (or their families), in addition to the more commonly addressed care delivery needs. Information and support needs (for example, how to keep the family together financially after a heart attack, how to know when it is time to take a child with asthma to the emergency room) are seldom addressed in satisfaction surveys conducted by health care providers, and certainly not at the level of detail to which care delivery needs (for example, efficiency of admission procedures, quality of hospital food) are addressed. In many cases information and support needs are not even recognized by providers. However, they can be identified by two different approaches: the critical incident and person-focused techniques.

The critical incident technique[25] involves asking patients to think back to specific stages in their disease experience and describe events that stand out in their

mind. For instance, a patient who had had an AMI or a heart attack is asked to think back to specific events in the attack and remember specific diagnostic experiences, treatments, recovery, and behavior change attempts. The patient is asked to describe things, good or bad, that stand out about each stage. Remembering times when faced with treatment decisions, these patients frequently report feeling alone and ill equipped to make an informed choice. This suggests the need for more help visualizing their options and how they perform on key decision criteria.

Person-focused techniques ask the patient "What is it like to be a person (not a patient) with the disease?" Interviewees talk about issues in their lives that bother them deeply and do not limit themselves to issues they believe to be the health care provider's responsibility. Later, subjects are asked "What is it like to be a patient?" or "What is it like to get health care from your provider?" But asking only patient-oriented questions limits issues to ones the interviewee considers relevant to the health care provider rather than letting the providers see the whole picture so they can better choose which needs to meet.

The needs generated from critical incident and person-focused interviews thus identify a larger range of needs and provide potential content for surveys that can be used to assess the importance and satisfaction of those needs. These techniques have been successfully used to develop a survey of AMI patients[26] that assesses both care delivery and information and support needs. The senior author identified these information and support needs by conducting telephone interviews with ten AMI patients, five spouses, and three young adult children. The interviews were based on the critical incident and person-focused strategies. Trigger questions included "What is it like to have had a myocardial infarction?" and "Think back to when you had the heart attack. What stands out in your mind about that experience? What fears and uncertainties did you have?" The same questions were repeated for the interviewees' time in the hospital, the immediate postrecovery period, and the current time. Similar questions were asked of spouses and children. These patients represented a random sample of patients discharged 5–7 months before the interviews from a large midwestern teaching hospital. Detailed notes from all interviews (which were not recorded) were used to generate a nonduplicated list of possible needs.

The study concluded that patients' perceptions of both quality of care and quality of life are associated with clinicians' ability to transfer key information. Similar surveys, which include information and support needs, along with the typically assessed care delivery needs, would help in presenting a broader picture of the total burden of illness.[20] For instance, in one of the interviews used to develop the surveys used in this study, an AMI patient described how his teenage son began to have panic attacks shortly after his father was admitted to the hospital.

Over time the boy (heretofore an honor student) became unable to attend classes because of the attacks and eventually dropped out of high school. Three years later (when the interview was conducted) the young man was still receiving medications and counseling for panic attacks, and he had not returned to school. If getting high-risk families into counseling after a heart attack had been seen as an important need (as it could be if such needs were included in patient surveys), a significant part of the total burden of illness could have been reduced.

Hypothesis 1

Information and support needs are important to patients, and because these needs are often overlooked by providers, patients will be less satisfied with how well information and support needs are met.

Measurement of Importance of Needs

Satisfaction surveys can help identify areas where improvement efforts may be focused. Satisfaction scores alone are not sufficient in identifying priority areas, as a number of needs could receive low satisfaction scores, and a need with a low satisfaction score may not necessarily be very important. A measure of importance would help identify needs where improvements would have the greatest effect. Rather than measure importance of needs directly, many patient survey analyses[17,27] treat the correlation or regression coefficient between global and individual need satisfaction as a measure of importance. Not only could these derived methods of assessing importance suffer from certain statistical limitations such as multicollinearity among satisfaction scores of individual needs[17] or high ceiling effects of global satisfaction scores,[15,28] but more importantly, they could also produce misleading results. When asked to rate global

satisfaction, patients base their evaluation on a mental model of needs they expect a health care provider to meet. Correlation-based analyses capture the association between global satisfaction and how well these expectations were met. They may not, however, reflect the needs the patient considers most important. For instance, if patients expected or hoped for a restful atmosphere, it would enter into their global satisfaction rating. If they did not expect the provider to help the family in role adaptations (a need they may consider very important), it would not influence their global satisfaction rating.

Hypothesis 2

Derived and direct measurements of importance yield different results, and direct measurement more accurately measures importance.

Methods

The surveys used in this study, which were developed using the critical incident and person-focused techniques, are more fully discussed elsewhere.[26]

Sample

We examined our hypotheses using data from a study conducted in 1992 on 258 consecutive AMI patients admitted to three community hospitals in the southeastern United States. Thirty-five percent of the patients were women, 54% were older than 65 years of age, and 60% were employed. The patients typically reported a history of cardiac problems (56%); 93% had abnormal EKG (electrocardiogram) findings on admission. Eligibility for this study was based on a discharge diagnosis of AMI and elevated enzymes or documented evidence of EKG abnormalities consistent with AMI.

Medical records were reviewed to collect data on patient age, sex, angina level, comorbidities, and AMI severity. Mailed surveys were sent 2 and 8 weeks postdischarge, followed by a postcard reminder to those who did not respond within 3 weeks. Sixty-two patients were excluded because of death ($n = 32$), severe incapacitation ($n = 9$), rehospitalization ($n = 8$), and lack of information on contact address or phone number ($n = 13$). Forty-nine of the remaining 196 subjects were further excluded, as they were recruited after the 2-week postdischarge, resulting in a final eligible sample of 147 patients. Response rate for the two-week survey was 71% (105/147). Ninety-two

patients (63%) also completed the eight-week survey. Exclusion of 1 outlying patient from the analysis, as suggested by Hartwig and Dearing,[29] resulted in a final sample size of 91.

Surveys

The 2-week survey was used to collect data on education, living arrangement, marital status, and race. Global satisfaction was measured by two items addressing likelihood of recommending the hospital (four options, from "definitely recommend" to "definitely not recommend"), and likelihood of returning (seven options from "100% sure to return" to "very unlikely to return").[30] Five-point scales (excellent to poor and not important to essential) were used to rate satisfaction and importance of 18 *information and support needs* (such as "knowing how to maximize recovery") and 12 *care delivery needs* (such as coordination of care). While some care delivery needs were identified during the person-focused and critical incident sessions, we wanted this study to compare the information and support needs to care delivery needs included in surveys used in patient satisfaction studies, such as the Patient Judgments of Hospital Quality (PJHQ) study.[31]

As with all such surveys, there were more information and support needs and more care delivery needs than could be included in this one survey. The study team set a limit on the number of questions that could be asked. The senior developer of the PJHQ survey from which the care delivery needs were selected nominated a subset of care delivery needs. The senior author of this article nominated a subset of information needs and support needs. The study team jointly made the final selection.

The primary focus of the 2-week questionnaire was to gather perceptions regarding experience at this hospital. Since care delivery needs are experienced during the hospital stay, questions concerning satisfaction were asked on that two-week postdischarge survey. The 8-week survey assessed patients' functional health status, perceptions of the overall quality of their life, and the helpfulness of information and support provided to them by their "doctors, nurses and other health professionals during your hospitalization and after you returned home." Questions about satisfaction of information and support needs (for example, dealing with family finances, family role adjustment) were asked on that 8-week postdischarge survey

because they typically arise after the patient has been discharged.

Questions about global satisfaction and importance of both information/support and care delivery needs were asked on the 2-week survey. Surveys were pilot tested for understandability, variability, and face validity.

Importance and satisfaction scores were transformed to a 0–100 scale, with 0 representing the theoretical low point of satisfaction and importance, and 100 the highest. The outcome metric used in our analyses was an index of unmet need (importance score minus satisfaction score). Correlation analyses and *t*-tests were conducted for testing our hypotheses, with a two-tailed *p* value at the 0.05 level of statistical significance.

Results

Patient Characteristics

Patients had a mean age of 65 years (range, 37–100 years), 71% were men, 95% were Caucasian, 79% were married, 76% had completed high school, and 18% lived alone. Clinically, 19% had AMI of medium/high severity, 40% reported medium/high levels of comorbidities, and 31% suffered from medium/high levels of angina.

Test of Study Hypotheses

Hypothesis 1. Information and support needs are important to patients, and because these needs are often overlooked by providers, patients will be less satisfied with how well information and support needs are met.

In this study, 18 different information and support needs identified by patients were included in the surveys, as were 12 care delivery needs used in a typical patient satisfaction survey. Table 1 (p 86) presents the importance, satisfaction, and unmet need scores of these care delivery and information and support needs assessed in our surveys. Twelve of the 14 most important items were information and support needs, while 18 of the 20 lowest satisfaction scores were also given to information and support needs. Only one care delivery need had a positive (that is, importance greater than satisfaction) unmet need score, and none of the information and support needs had a negative unmet need score. The information and support item with the lowest unmet need score was "getting help dealing

with changes in family roles" at 3.5, while the highest unmet need score in care delivery needs was restfulness of atmosphere, at 0.2. Overall, unmet need scores for information and support needs were significantly higher ($p < 0.0001$) than those for care delivery needs.

Hypothesis 2. Derived and direct measurements of importance yield different results, and direct measurement more accurately measures importance.

Figure 1 (p 87) plots the importance of need scores calculated by direct assessment against those calculated as correlation coefficients of satisfaction of individual needs against global satisfaction. The correlation between derived weights and direct assessment of importance for care delivery needs was 0.28 ($p > 0.3$). The correlation between derived weights and direct assessment of the information and support needs was –0.17 ($p > 0.4$). The negative correlation suggests that while information and support needs may be important, the patient may not expect the health care provider to meet them. Although some have expressed concern that patients would rate everything as important when asked directly,[17] our data suggest the contrary. As can be seen from Table 1, importance scores ranged from 52.8 to 82.9, a variation that was similar to that found for the satisfaction scores (range, 44.6–88.5). A similar variation in importance scores, when assessed directly, has been reported by Rubin et al.[32] Thus, we feel that patients can accurately assess a significant range of importance in their needs and that direct measurement importance more accurately reflects this than do derived measures.

Identification of Areas for Performance Improvement

The index of unmet need (importance minus satisfaction) helps identify opportunities for improvement. However, prioritizing on the basis of the unmet need scores alone has limitations. For instance, an unmet need score of 5 could be obtained from a need that has an importance score of 95 and a satisfaction score of 90, as well as from a need with an importance score of 20 and a satisfaction score of 15.

We propose a two-step process to overcome this limitation. First, we plot the importance scores versus the satisfaction scores for the various needs. The satisfaction and importance scores obtained from the 5-point rating scales are dichotomized such that mean

Table 1. Importance, Satisfaction, and Unmet Need Index Scores for Patient Needs (N = 91)*

Care Delivery Needs	Importance Mean (SD)	Satisfaction Mean (SD)	Unmet Need Index*
D1: Attention of physicians to patient condition	77.0 (26.4)	83.0 (23.2)	−6.0
D2: Coordination of care	75.3 (25.4)	88.3 (16.4)	−13.0
D3: Attention of nurses to patient condition	74.7 (25.3)	88.5 (18.4)	−13.8
D4: Skill of staff who start IVs	73.6 (24.5)	81.1 (22.3)	−7.5
D5: Pain management	72.8 (26.4)	86.8 (18.5)	−14.0
D6: Discharge instructions	71.9 (23.4)	78.7 (23.7)	−6.8
D7: Ease of obtaining information	70.8 (24.6)	80.3 (23.8)	−9.5
D8: Restfulness of atmosphere	68.6 (23.0)	68.4 (28.3)	0.2
D9: Coordination of transfers	66.1 (27.6)	82.7 (21.2)	−16.6
D10: Efficiency of admitting procedure	64.0 (25.5)	85.5 (22.5)	−21.5
D11: Explanation of costs and bills	59.1 (29.3)	66.5 (30.2)	−7.4
D12: Housekeeping	55.1 (24.9)	77.2 (20.7)	−22.1
Information and Support Needs			
I1: Getting help with treatment decisions	82.9 (17.8)	73.1 (24.3)	9.8
I2: Knowing how to maximize recovery	81.5 (18.0)	71.0 (23.9)	10.5
I3: Understanding the treatment regimen	81.3 (15.4)	74.4 (23.4)	6.9
I4: Understanding implications of heart attack	80.4 (16.3)	73.3 (23.9)	7.1
I5: Knowing what questions to ask the doctor	80.1 (16.9)	66.9 (24.9)	13.2
I6: Knowing the chances of another heart attack	79.5 (20.1)	64.2 (25.1)	15.3
I7: Having the ability to recognize another heart attack	79.0 (21.5)	64.9 (25.4)	14.1
I8: Understanding side effects of treatments	78.7 (20.4)	68.9 (25.0)	9.8
I9: Knowing where best medicine is practiced	76.4 (22.4)	59.8 (29.9)	16.6
I10: Understanding insurance coverage issues	75.3 (18.6)	53.8 (27.1)	21.5
I11: Understanding impact of attack on future	75.3 (24.2)	63.9 (24.0)	11.4
I12: Prospects for regaining previous health	75.3 (20.1)	68.2 (21.7)	7.1
I13: Knowing how to locate sources of information	74.2 (19.7)	67.1 (25.1)	7.1
I14: Coping with family and business finances	72.3 (22.3)	44.6 (25.9)	27.7
I15: Getting help in stopping depression	70.5 (25.2)	56.6 (25.5)	13.9
I16: Ensuring that family doesn't feel shut out	68.8 (24.0)	60.1 (26.7)	8.7
I17: Dealing with changes in family roles	62.5 (27.2)	59.0 (26.1)	3.5
I18: Finding counseling program for family	52.8 (32.3)	48.7 (26.9)	4.1

* Unmet need score = Importance minus satisfaction. A negative unmet need score means that satisfaction was rated higher than importance. Importance and satisfaction scores were transformed to a 0–100 scale. Needs are arranged in descending order of their importance scores. SD, standard deviation.

scores of 4 or more represent high satisfaction or high importance, and mean scores below 4 represent low satisfaction or low importance. Since we transformed the raw scores from the 1–5 scale to a 0–100 scale, high importance and high satisfaction were represented by mean scores of 75 or greater. Other organizations might choose a cut-off different from 75, depending on resources available for improvement.

The plot of the importance and satisfaction scores could thus be divided into four quadrants[33] (Figure 2, p 88). Needs in the high importance–low satisfaction quadrant represent high-priority areas for

improvement. Needs in the high importance–high satisfaction quadrant represent areas where the provider is currently doing a good job; these areas need continued monitoring. Needs in the low importance–low satisfaction quadrant may also present opportunities for improvement after the high importance–low satisfaction needs have been addressed. Needs in the low importance-high satisfaction quadrant represent areas where a provider with limited resources might reasonably choose to devote relatively less attention.

In Figure 2, points marked I1–I18 represent the 18 information and support needs, and points marked
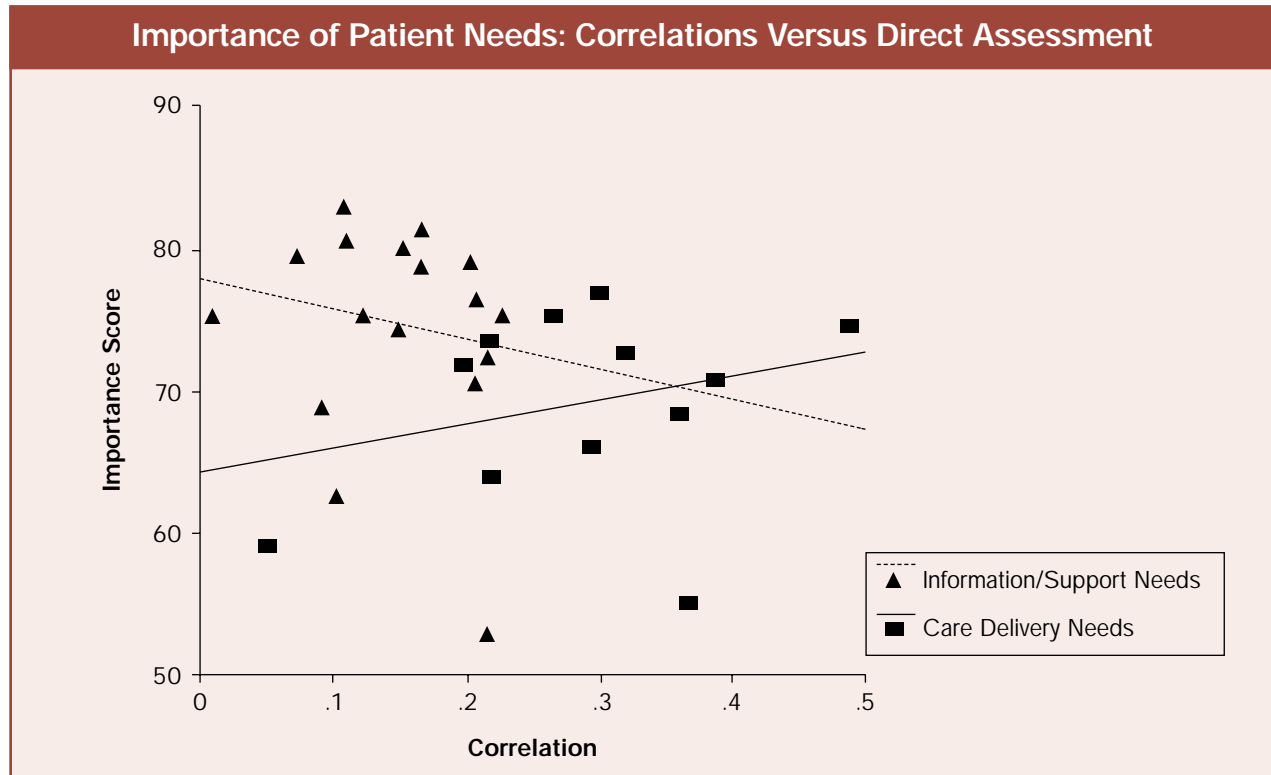
Figure 1. *This figure plots the importance of need scores calculated by direct assessment against those calculated as correlation coefficients of satisfaction of individual needs against global satisfaction. Importance ratings scale: 0–100. Straight lines represent lines of best fit via linear regression.*

D1–D12 represent the 12 care delivery needs. All 12 needs in the high importance–low satisfaction quadrant (high priority) were information and support needs. All 8 needs in the low importance–high satisfaction quadrant were care delivery needs. Thus, 67% (12 out of 18) of all the information and support needs were high priority for improvement, whereas 67% (8 out of 12) of the care delivery needs did not warrant much attention. When a set of needs in the high-priority quadrant are identified, the next step is to further prioritize among them by calculating their unmet need index scores. Table 2 (p 89) presents the 12 priority needs, in decreasing order of their index scores.

Discussion

As predicted by the hypotheses, we found that when asked critical incident and person-focused questions, patients identified many information and support needs not commonly addressed in patient satisfaction surveys. Patients considered these needs to be important, and they were less satisfied with how well these needs were met than they were with the care delivery needs typically assessed by patient satisfaction surveys. Indeed, all the identified priority areas for improvement comprised information and support needs. Although these data were obtained in 1992, additional work by our team, using this methodology, has confirmed that information and support needs are both important and among the needs least well met in a variety of health conditions, including breast cancer,[22] asthma,[34] and HIV/AIDS.[35]

We also found that correlation-based analyses produce very different importance scores than did direct importance assessment. Furthermore, we found that patients did distinguish significant differences in importance between items. Thus, we conclude that direct measurement of importance more accurately reflects the true feelings of the patient than do derived measures.

Recommendations

First, information and support needs should be identified and included in customer assessments. Studies

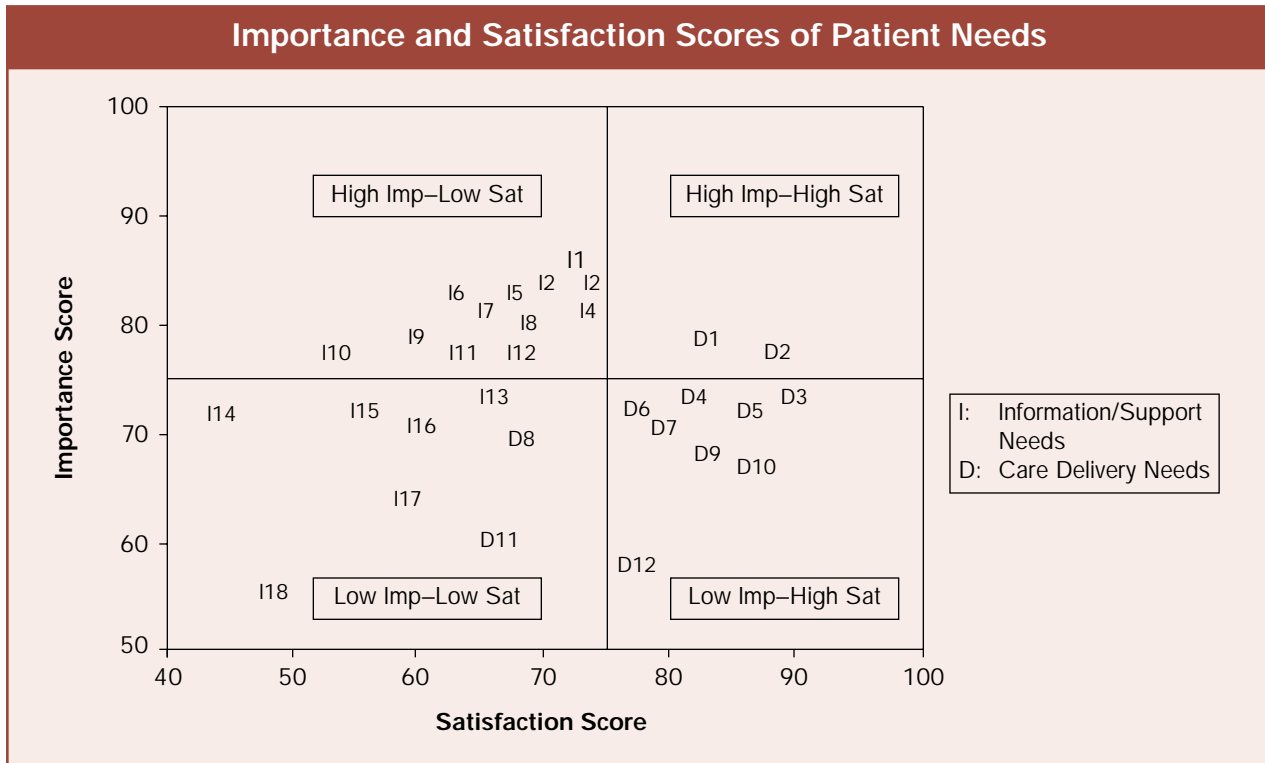## Importance and Satisfaction Scores of Patient Needs

Figure 2. *The plot of the importance (IMP) and satisfaction (SAT) scores were divided into four quadrants; scores were transformed to a 0–100 scale. The labels for the 18 information and support needs (I1–I18) and the 12 care delivery needs (D1–D12) are presented in Table 1.*

of patient experience typically include only care delivery needs and ignore information and support needs. Many information and support needs could easily be met, and if met, could reduce the total burden of illness by reducing readmissions and other long-term demands on the health system.[36,37] For instance, it would not be difficult to refer to vocational counselors patients whose income production capacity will drastically change after a heart attack. To do so makes economic sense in an environment of capitation and managed care where readmissions produce costs rather than revenues for providers. But more importantly, it is the right thing to do.

Second, critical incident and person-focused strategies should be used in telephone interviews and group sessions with patients to identify needs.[21] Both strategies avoid "what do you need" kinds of questions because neither patients nor providers may know everything the patient needs. Patients can describe critical incidents and tell what their lives are like. Analyzing these stories can uncover unexpected qualities, and telling those stories to staff can be a powerful motivator for change.

Person-focused questions could easily be part of a focus group, probably placed early in the set of probes used to initiate discussion to ensure that a broad focus is taken. Critical incident questions are probably more effective in one-on-one interviews because they focus on one person's experiences and follow that experience through time.

While not directly addressed by the data presented in this study, we also feel that it is critically important to consider the needs of patients' families. A significant body of research demonstrates the impact of family support on illness.[38–40]

Research is now being done to better understand the needs of patients' families.[22,41,42] The techniques used to improve understanding of patient needs, as described in this article, can and should be used to better understand family and caregiver needs as well.

Finally, importance should be measured directly, not by correlating or regressing global satisfaction scores against satisfaction scores on individual aspects of care. Correlation-based analyses treat factors with the largest correlation or regression coefficients as most important. A patient's expectations about the

Table 2. Unmet Need Index Scores for Patient Needs in the "High Importance–Low Satisfaction" Quadrant (Priorities for Improvement) of Figure 2*

Patient Need	Index Score
1. Understanding insurance coverage issues (I10)	21.5
2. Knowing where the best medicine is practiced (I9)	16.6
3. Knowing the chances of another heart attack (I6)	15.3
4. Having the ability to recognize another heart attack (I7)	14.1
5. Knowing what questions to ask the doctor (I5)	13.2
6. Understanding the impact of the attack on the future (I11)	11.4
7. Knowing how to maximize recovery (I2)	10.5
8. Getting help with treatment decisions (I1)	9.8
9. Understanding side effects of treatments (I8)	9.8
10. Understanding the implications of the heart attack (I4)	7.1
11. Knowing the prospects of regaining the previous state of health (I12)	7.1
12. Understanding the treatment regimen (I3)	6.9

* Needs are arranged in descending order of the Unmet Need Index score.

provider's role drives global satisfaction ratings and may not include many of the most important needs. Thus patients might recommend or return to a physician who offers no help in meeting crucial needs such as dealing with depression, changes in family and vocation roles, self-image, stress, or financial difficulties, if they don't see it as the physician's job to help meet those needs.

Comment on Methodology

Although survey response rates in this AMI study were adequate, the sample size was small, with 91 patients responding to both surveys. Our decision to measure satisfaction of information and support needs on the 8-week but not the 2-week survey (when care delivery satisfaction was measured) should not limit the validity of our conclusions. Other investigators found that patients reported lower satisfaction in the second-week postdischarge than in the eighth week.[43] This suggests that our findings of lower satisfaction scores for information and support needs are conservative because a greater difference may have been found between care delivery and information and support satisfaction scores, if both were measured during the second week.

Implications

Most patient surveys study the wrong issues if their goal is to find where improvement is most needed. Those surveys that include some information and support needs do so at such a general level of detail that

they offer little guidance for improvement. We hope that patient surveys will be refocused to include needs covering the total burden of illness, not just short-term needs associated with a narrow definition of episodic health care. Critical incident and person-focused surveys may lead providers to adopt new roles and/or find other ways of meeting these needs.

Our results indicate that while patients see information and support needs as very important, the health care system does little to meet those needs. Yet there is growing evidence that psychosocial functioning (anxiety and depression) predicts rehospitalization.[44] If lack of information and support contributes to anxiety and depression, which in turn lead to readmission, then addressing those needs could significantly decrease the total burden of illness. Information and support have also been found to reduce the demand for and costs of care[45–52] and to improve health status and recovery from illness.[53–60] Other studies report that actively involved patients experience better outcomes.[61,62]

We foresee an emerging role for future physicians, with less emphasis on "healing" (although this will always be important) and more on "coaching" the patient and family on their choices and how they can play an active, informed role in prevention and managing their own care. Indeed, the model for successful care of people with some chronic problems, such as diabetes, is already moving away from physician-based treatment to patient-based self-management with the physician, and other health professionals coaching the patient and those closest to them.

There is reason to believe that innovations meeting information and support can reduce both the short-term and the long-term burden on the health care system. As mentioned earlier, we realize that health care providers are being asked to see more patients in less time. Hence it will be difficult to ask them to meet the information and support needs

identified in this research using strategies in use today. Partly in recognition of this problem, we developed a computer-based interactive health communication system—the Comprehensive Health Enhancement Support System (CHESS)—to be placed in patient homes following the diagnosis of ten different serious diseases such as coronary artery disease and breast and prostate cancer. CHESS provides information, decision-making tools, and support services (see chess.chsra.wisc.edu). Some clinicians ask patients to review CHESS in preparation for clinic visits as a way to prepare them and make the visit more efficient (see Sidebar, p 91).

CHESS has been studied in three randomized clinical trials and several field tests. During the past 8 years positive effects have been found on user participation in health care, information seeking, social support, negative emotions, and disease-specific concerns. These effects were particularly positive among underserved populations. Studies with HIV and coronary artery disease patients also suggest that CHESS shifts health care utilization to less costly care providers.[63–66] For instance, while HIV patients visit their physicians as frequently as the control group, they report spending 11% less time in the physician's office. They also have fewer hospital days.[66] There is reason to believe that innovations meeting information and support can reduce both the short-term and long-term burden on the health care system.

Interactive health communication systems such as CHESS have the potential to reduce the burden on providers and at the same time meet the information and support needs identified in this article.[67,68] The Internet is used by 67% of American adults,[69] and this number is increasing constantly; health information and support is reported to be the most common reason for using the Internet.[70]

While the Internet has great potential to help people,[70–73] it is also the source of false, deceptive, and misleading information, and puts at risk the privacy and confidentiality of its users.[74–79] Health care providers could lead the development and diffusion of these technologies not only because of their revenue potential, but also because high-quality systems can reduce the total burden of illness.[20]

Although we see these as positive and exciting opportunities, some people may resist expanding their roles to meet needs such as teaching patients how to cope with financial problems, providing asthmatic patients with access to alternative therapies, or helping gym teachers work with students with asthma. Our educational system, for the most part, does not recognize these as being part of the physician's role and does not incorporate the diagnosis of things like this in training programs. We believe the physician should be trained to identify these needs. Most information and support needs can be met by referring patients and families to other resources such as a financial counselor, providing a personalized form letter to the gym teacher, or suggesting a high-quality Web site on alternative therapies. Physicians may not meet these needs directly, but they should identify when the needs exist and help find ways to meet them.

It should be pointed out that since these data were collected—even with the advent of managed care and the anticipated increase in collaboration between patient and provider—information and support needs are still largely unmet. For instance, in a study of adults with asthma conducted in 1997, we found that the greatest unmet needs were knowing the long-term effects of asthma, having information on alternative treatments, having access to alternative treatments, knowing how to minimize the impact of asthma on other illnesses, having support to pay for alternative treatments, knowing the side effects of medication, and knowing which environmental factors bring on asthma. Many of these needs are related to information transmission.[34]

Final Comments

A growing trend in health care is to focus on service improvements as a way of differentiating an organization from its competitors. This is leading to large investments in efforts such as teaching staff to be courteous and to improve patient and family convenience. We applaud these efforts because in a time of high stress (as health problems almost always are), kindness and helpfulness are deeply appreciated. However, in this study patients had the opportunity to identify service as items of high concern. They didn't. We hope that this laudable focus on service will not detract from meeting the additional needs that can reduce total burden of illness: the information and support needs of patients and families. **J**

Sidebar. The Comprehensive Health Enhancement Support System (CHESS)

Information services include Questions & Answers (short answers to hundreds of frequently asked questions about their disease), Instant Library (full articles on a broad range of topics drawn from the scientific and popular press), Consumer Guide (descriptions of health services, how to identify a good provider and how to be an effective consumer), and Referral Directory (descriptions of and ways to contact local and national services).

Support services include Discussion Groups (limited access, facilitated bulletin boards where small groups of patients and families share information and support), Ask an Expert (patients write questions and receive a confiden-

tial response from experts), and Personal Stories (representative, real-life accounts of how other patients and families coped).

Decision services include Assessment (measures a person's emotional status and offers advice on how to cope), Health Charts (patients record and track health changes and link to CHESS material addressing specific health concerns), Decision Aid (patients learn about their options, clarify values, and understand consequences of choices), and Action Plan (users plan successful behavior changes by identifying goals, resources, and ways to overcome obstacles).

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