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INTRODUCTION

This annotated bibliography is based upon a review of the published literature in support of the development of the Quality of HIV Care Consumer Training Workshop Curriculum, "**Making Sure Your HIV Care Is The Best It Can Be.**" The literature review was conducted as part of the needs assessment process for curriculum development.

Absent from this bibliography is any publication citation for a consumer training curriculum related to the use of quality of care data. None was found. It appears, based upon this review, that the curriculum to which this bibliography is a companion, is unique.

Lacking published literature on the development, utilization, and evaluation of similar curricula, the review of the literature was focused on publications that could be used to inform the curriculum development process. Publications were sought for their relevance to: identifying the need for consumer training in the use of quality of care performance data; describing potential target populations and guidance in tailoring the curriculum to meet the needs of those populations; describing factors found to influence consumer satisfaction with health care and consumer choices in health care decision making; identifying factors that specifically influence consumer assessment of the quality of HIV health care; self-advocacy education for people with HIV/AIDS; and, the relationship between health literacy and health care practices and health status in people with HIV/AIDS.

This annotated bibliography is limited to only those publications that were found to provide valuable insights and guidance in the curriculum development process. Not included is any reference to publications that were reviewed and found lacking specific relevance to the creation of the curriculum.

Annotations have been grouped in sections containing closely related citations. Each annotation consists of the following: Author and publication citation information (boldface type); a key quotation from the article cited (italicized type); a brief summary of the content and conclusions of the article; and, bulleted points that form the "take home message" of the article as interpreted by the reviewer and possible its application to the development of the curriculum.

QUALITY OF CARE DATA, REPORT CARDS AND PROCESSES

JENCKS S. CLINICAL PERFORMANCE MEASUREMENT: A HARD SELL.
JAMA 2000;283(15):2015-2016

A number of studies indicate that, in general, patients rank quality information far behind convenience, coverage, access, and cost in choosing health plans, and this likely holds for choice of provider organizations and practitioners.

An editorial accompanying the publication of an article by Erickson, et al., on the relationship between managed care insurance and the use of lower-mortality hospitals for CABG surgery, this article presents the arguments which are used to support the use of performance data in the health care marketplace. In each case, Jencks concludes that the actual use of performance data never measures up to the potential. His conclusion is that neither physician referral practices, managed care plan contracting practices, nor patient choices of providers are currently affected by the availability of performance data.

Nevertheless, Jencks argues that clinical performance data should continue to be collected and disseminated to the clinical and patient community. Anecdotal reports indicate that hospitals use the data internally to make improvements without market pressure. Patients have a right to know the information. And, performance data will be used to drive improvements in the market in the future as a result of both provider and consumer education efforts.

- Personal factors take precedence over institutional factors in the assessment of quality-of-care from the patient's perspective. The training workshop should recognize this and start with this approach to quality assessment and then move on to include clinical/institutional information as part of rating the quality of care.

LONGO DR, LAND G, SCHRAMM W ET AL. CONSUMER REPORTS IN HEALTH CARE: DO THEY MAKE A DIFFERENCE IN PATIENT CARE?
JAMA 1997;278(19):1579-1584.

The results reported here confirm that consumer reports are associated with changes in the quality of hospital care...It appears that although consumer reports were initially designed to assist patients in making better decisions about personal health care, they have been carefully evaluated by health care clinicians and delivery organizations.

One year following the 1993 release of the Missouri Department of Health obstetrics consumer report, "Show Me Buyer's Guide: Obstetrical Services," a retrospective study was conducted to assess the impact of the Guide on clinician practice behavior.

The results of the study show that consumer reports can change provider behavior. Hospitals with either low or average patient satisfaction quality indicators were more likely to have changed, or be planning to change, policies relating to those indicators than hospitals with high quality scores. Changes were most often seen in hospitals in areas where competition for patients existed.

Nevertheless, the authors of this report are concerned about the use of consumer guides by patients themselves. They write, "...while there appears to be a consensus that information facilitating patient participation in health care decision-making is in the best interest of the patient, an examination of how patients themselves use consumer reports and related information is still needed."

MARSHALL M, SHEKELLE P, LEATHERMAN S, ET AL. THE PUBLIC RELEASE OF PERFORMANCE DATA: WHAT DO WE EXPECT TO GAIN? A REVIEW OF THE EVIDENCE.

JAMA 2000;283:1866-1874.

The reasons for consumers' lack of interest in and use of performance data include difficulty in understanding the information, disinterest in the nature of the information available, lack of trust of the data, problems of timely access to the information, and lack of choice. There is evidence from descriptive studies that consumers rate anecdotal evidence from family and friends more highly than empirical evidence.

The peer-reviewed published literature on the public release of performance data was collected and reviewed for evidence of the utility of the data and the extent to which expectations of public disclosure have been realized. Publications in the U.S. from January 1986 through October 1999 were reviewed.

In answer to the question, "Do consumers use public reports?", the data reviewed show that consumers want more information about health care provider performance but that the information has only a limited impact on consumer decision-making.

- Many of the factors cited in this review of the literature have been confirmed in the consumer focus groups we have conducted. In particular, age of the data and the lack of personal relevance to them of the clinical indicators evaluated, have been routinely identified as criticism of the Consumer's Guide. If the data in the Guide is to prove useful to consumers, its relevance must be explained, they must have an opportunity to use the Guide in personally relevant ways, and they should have an opportunity to have their criticism of the Guide be acknowledged.

HOCHHAUSER M. WHY PATIENTS HAVE LITTLE PATIENCE
FOR REPORT CARDS.

Managed Care 1998; MARCH: 31-34.

Policy makers believe that if consumers are given detailed information about the quality of health care plans available to them, they will choose an “above average” plan and reject a “below average” plan. That won’t happen...

The reason that consumers are not likely to use health plan performance data in the way that policy-makers expect them to is that policy-makers fail to take into account the way consumers think and behave. According to Hochhauser, people don't always make decisions rationally. In fact, most people do not rely on objective information to decide what to buy.

In support of this position, a 1996 Agency for Health Care Policy and Research survey found that most people relied on personal recommendations from doctors, family and friends to make health care decisions. While more than 80% who saw a report card thought it would be useful to someone trying to make decisions about health plans, only one third have actually used the information to make decisions.

The use of a worksheet to help consumers make use of the data in health plan report cards relies too heavily on the reading and thinking skills of the consumer. Additionally they are too data-heavy, too time-consuming, and not clearly linked to assistance in decision-making.

- Many of the issues raised in this article have been reiterated in our focus group and interview experience. Of particular similarity is the initial statement by interviewees that the Guide looks good and useful to consumers which is then taken back later when the actual data in the Guide is reviewed. On a conceptual, rational basis the Guide looks valuable but on a personal, practical basis, it loses value.

WICKS E AND MEYER J. MAKING REPORT CARDS WORK.

Health Affairs 1999;18(2):152-155

...our research suggests that present measurement and reporting initiatives have not yet had much impact on consumers or the choices they make.

Report cards can be effective at facilitating consumer decision-making only if: 1) consumers are willing to use them; 2) consumers can correctly interpret the performance comparisons; 3) performance measures measure the kinds of health plan and provider activities that purchasers want to influence; 4) quality data truly distinguishes high performance from lesser performance; 5) reported measures reflect outcomes that plans can significantly influence; and, 6) health organizations are convinced that good performance will be rewarded and poor performance penalized.

- From this it is clear that the consumer training workshop should provide consumers with the tools to critically assess the value of clinical performance data in order to benefit from the Consumer's Guide.

GUADAGNOLI E, EPSTEIN A, ZASLAVSKY A, ET AL.
PROVIDING CONSUMERS WITH INFORMATION ABOUT THE QUALITY OF
HEALTH PLANS: THE CONSUMER ASSESSMENT OF HEALTH PLANS
DEMONSTRATION IN WASHINGTON STATE.

***The Joint Commission Journal on Quality Improvement* 2000;26(7):410-420.**

...dissatisfaction is due, in part, to the fact that few available surveys were developed with the explicit goal of collecting information that would be useful to consumers and purchasers when selecting health plans.

Survey research was conducted in May-June 1997 with 1500 responses from consumers in Washington State regarding their use of the Washington State Health Care Authority health plan Report Card on health plans in the state. Nearly everyone who was mailed the report said they saw it. A large proportion said they read most or all of it and most thought it was easy to understand and was apparently useful. Those who used it said they felt confident it helped them to switch health plans. The value of the report to those not anticipating switching health plans is questionable.

- Since quality of health care report cards have many potential uses, and consumers have differing, though probably overlapping, data needs for determining the quality of health care from that of regulators and providers, the value of the report cards to consumers will depend upon the performance indicators for which data was collected and reported. Consumer training in the use of report cards (Consumer's Guide) should address the various uses of performance data and assist the consumer in making the best use of available data.

SMITH M, ATHERLY A, KANE R, ET AL. PEER REVIEW OF THE QUALITY OF CARE: RELIABILITY AND SOURCES OF VARIABILITY FOR OUTCOME AND PROCESS ASSESSMENTS. ***JAMA* 1997;278:1573-1578.**

Peer assessments can play an important role in characterizing the quality of care for complex patients with multiple interrelated chronic conditions, but reliability can be poor.

The poor reliability and significant variability of peer assessments of the quality of care provided for frail, elderly patients makes this form of quality assessment less valuable than other measures. Both systematic bias and inter-rater variability were deterrents to the use of peer assessments. Nevertheless, the potential value of the insightful and nuanced assessment of process that can be derived from peer assessments of the quality of care require that this form of quality evaluation be refined.

- Consumers may be interested in the quality of care ratings that other providers might give their doctors. The bias inherent in this form of assessment may make the information significantly less useful. It should be made clear in the workshop that alternative types of quality assessment could be done and that each has certain strengths and weaknesses.

VALENTI W. HIV, MANAGED CARE, AND OUTCOMES.
The AIDS Reader 2000;10(5):274-278.

HIV is first and foremost a medical issue, with the patient at the center of a series of steps that deliver complex health care, the standards for which change rapidly.

The transition from delivering HIV care in fee-for-service settings to managed care requires that the quality of care remain high. Focusing on outcome measures appears to be the most useful strategy for monitoring the quality of care. A variety of methods of data collection are reviewed, the most unique methods include: structured reports by standardized patients, abstraction of medical records from those same visits, and physician responses to clinical vignettes. Chart review appears to be the most often used method in HIV settings.

Patient satisfaction surveys provide valuable data as well. The Community Health Network, Rochester, NY, distributes patient questionnaires in the office and collects 100 surveys three times a year. The New York State Department of Health AIDS Institute has developed one of the surveys the office uses.

A list of types of quality-indicators for potential use in managed care settings is offered.

- There are a number of alternative quality-indicators that might provide information of value to consumers, in addition to the five clinical indicators presented in the **Consumer's Guide**. These should be provided to the facilitators for use in a possible expanded discussion of "other indicators" in Module Two.

OERMANN M. CONSUMERS' DESCRIPTIONS OF QUALITY OF HEALTH CARE.
J Nurs Care Qual 1999;14(1):47-55.

While consumers have reported an interest in having access to this information, how they actually define quality of care is not yet clear.

Providers' perceptions of quality often differ from patients' perceptions. The expectations of consumers influence their satisfaction with care. This study involved 239 (non-HIV) consumers in a convenience sample of patients in a general medical clinic population, in interviews using open-ended questions to determine their descriptions of quality health care (and quality nursing care). Consumers described quality health care in terms of access to care, followed by having competent and skilled providers, and receiving proper treatment. They defined quality nursing care as having nurses were concerned about them and demonstrated caring behaviors, were competent and skilled, communicated effectively with them, and taught them about their care.

- Competent providers who are able to communicate well with patients are considered to be essential components of quality health care. These qualities are echoed in studies of HIV-infected patients.

HIBBARD J AND JEWETT J. WILL QUALITY REPORT CARDS HELP CONSUMERS?

***Health Affairs* 1997;16(3):218-228.**

The findings show that poorly understood indicators are viewed as useful. Consumers often do not understand quality information because they do not understand the current health care context.

This survey study of 104 consumers assesses the relationship between the salience of quality information and how well it is understood by consumers. Though the study relates to health plans and not to providers, it finds that without an understanding of the indicators, ratings are not viewed as useful in decision-making. Some problems include: not understanding terms, not understanding whether high or low rates of an indicator show good performance, and not understanding what an indicator is supposed to tell about quality of care.

Prior research by this group showed that the indicators consumers rated as most useful did not match the ones they actually used in choosing a plan. This underscores the difference between stated preferences (salience) and actual choices. The findings also suggest that when risk is made explicit (and personal control is low), consumers will make a risk-averse choice.

- The understanding of terms that define quality indicators and the relevance of those indicators to actual concerns of consumers is essential to the usefulness of quality data to consumer choices.

LOUGHRAN S. HEALTHCAREREPORTCARDS.COM: VALUABLE CONSUMER INFORMATION. ***Health Care Strategic Management* 1999 JUNE:19-20.**

When it comes to information, the perfect should not be enemy of the good. Were one to keep consumers and others in the dark until "perfect" data were available, no light would ever be shed on differences in quality between U.S. hospitals.

This article critically reviews the website HealthCareReportCards.com. The site reportedly provides accurate and objective grading of the performance of every hospital in the United States. The need for this information is supported by the belief that historically, consumers have been able to get more performance information on a new car than on their own hospital.

The response to the site has been overwhelming. In its first five months, the site received more than 187,000 visitors, with slightly more than half being consumers.

- This demonstrates the health consumer desire for comparative data on health care facilities and providers. It also supports the belief that it is legitimate to bring quality performance data information to the attention of consumers, even though it may not be "perfect."

EDDY D. PERFORMANCE MEASUREMENT: PROBLEMS AND SOLUTIONS.
Health Affairs 1998;17(4):7-25.

Recent efforts to measure performance have established its feasibility and value. However, its full potential is currently limited by several problems...Solutions are to rely more on process measures...

This article reviews the problems and potential solutions associated with the measurement of health quality performance. One significant problem is related to the probability of health outcomes. Almost all health outcomes are highly probabilistic. They don't always occur when a plan or a provider does the right thing, and they can occur even when a plan or provider does the wrong thing. One solution is to measure processes rather than outcomes.

- The measurement of processes rather than outcomes is at the heart of the use of the five quality indicators used by the AIDS Institute Clinical Performance Quality Program. The curriculum should address, even if only in trainer notes, the validity and usefulness of process indicators as opposed to outcome measures (e.g., survival).

HIBBARD J, HARRIS-KOJETIN L, MULLIN P, ET AL.
INCREASING THE IMPACT OF HEALTH PLAN REPORT CARDS
BY ADDRESSING CONSUMERS' CONCERNS.
Health Affairs 2000;19(5):138-143.

Consumers understand report-card information best when it is succinct and conveys a message of risk, not benefit.

This article refers to the utilization of health plan report cards. Decision research has shown that although almost all health plan report cards present or frame decisions about plan choice as an opportunity to obtain better-quality care, framing a decision as a potential loss or risk has more impact. In addition, consumers are more likely to respond effectively if risk measures are accompanied by clear directions about how to reduce the potential risk.

- The potential application of these findings to the curriculum may be to frame the description of quality indicators in terms that make it clear that if the performance indicators are not provided, HIV care is less than adequate and can put the patient at risk of further disease progression.

ANONYMOUS. DOCTORS, NOT REPORT CARDS, SHAPE CONSUMER CHOICES. *Physician Relations Update* 1997

Despite the prevalence of ratings and report cards, physician recommendations about health plans, hospitals, or other providers continue to be patients' most valued resource...

A national telephone survey of 2,006 adults, conducted in 1996, found that consumers cited "a regular doctor" as the most influential source of recommendations on health plans, other doctors, or hospitals. The second most influential source was reported to be family and friends. The study was funded by the federal Agency for Health Care Policy and Research (AHCPR).

In choosing doctors, surveyed consumers said that they are most influenced by how well a doctor communicates with patients and shows a caring attitude. The majority of those surveyed believe that doctors have more influence over the quality of health care than do health insurance plans.

- The relationship between a consumer and physician is often a factor that confounds the usefulness of other forms of performance data. Loyalty to a physician and the value placed upon information and opinion received from a personal doctor can often override other sources of quality information. These personal and loyalty factors make the logical “exit” or “voice” choices less simple.

BATES D AND GAWANDE A. THE IMPACT OF THE INTERNET ON QUALITY MEASUREMENT. *Health Affairs* 2000;19(6):104-114.

Most people sought advice on specific medical conditions rather than to compare sources of care. However, as the volume and quality of health-related content grow and use of the Web increases, U.S. consumers inevitably will become more comfortable finding and using comparative information.

The extensive and growing diversity of health-related information in the internet is described in this review. Of great significance is the observation that “word-of-mouth” advice about providers is gaining respectability through the web.

- The power of personal recommendations in health care choice and decision-making (best exemplified by information from family, friends and doctors) can be derived through the impersonal internet.

THE KAISER FAMILY FOUNDATION/AGENCY FOR HEALTH CARE RESEARCH AND QUALITY. NATIONAL SURVEY ON AMERICANS AS HEALTH CARE CONSUMERS: AN UPDATE ON THE ROLE OF QUALITY INFORMATION. *Highlights and Chartpack*. DECEMBER 2000.

The public is still more likely to choose doctors and hospitals that they are familiar with, over those that are more highly rated, although this gap has narrowed over time. And, as in 1996, people are more likely to say they rely on recommendations of friends, family, and health professionals they know than on standardized quality indicators.

This highlights data collected in a survey conducted to learn more about the role of quality information in consumers’ health care decision-making, and to assess changes over time by making comparisons with a similar survey conducted in 1996.

The majority of people say that they felt confident that they had enough information to make the right choices the last time they decided on a treatment option (81%), a new prescription drug (79%), hospital (73%), or health plan (67%).

People seeking quality information are more likely to ask for recommendations from people they know instead of contacting official groups or looking at printed information.

Few Americans have actually used quality information to make their health care choices.

It may not be surprising that so few people have used this type of information given that less than 30% have seen quality information in the last year.

At the same time, 63% of the public says the government should be involved in promoting, monitoring, or providing information about quality of health care. And, nearly 75% favors mandatory reporting and public availability of medical error information.

- The value of personal recommendations in health care choice and decision-making (best exemplified by information from family, friends and doctors) over official sources of information is significant. This must be acknowledged in the curriculum. Nevertheless, the role of the government in making quality of care information available is also supported. It is likely that consumers will appreciate the intent, if not the information, of the Consumer's Guide.

COMMUNICATION AND THE DOCTOR-PATIENT RELATIONSHIP

SULLIVAN LM, STEIN MD, SAVETSKY JB, ET AL. THE DOCTOR-PATIENT RELATIONSHIP AND HIV-INFECTED PATIENTS' SATISFACTION WITH PRIMARY CARE PHYSICIANS.

***J Gen Intern Med* 2000;15:462-469.**

Specific aspects of the doctor-patient relationship were highly significantly associated with overall or global satisfaction. In particular, patients' perception of their physician's HIV knowledge was highly related to satisfaction as was patient's ratings of their physician's empathy.

The results of a longitudinal, observational study of 146 HIV-infected patient-satisfaction at two urban medical centers in the northeastern U.S. are presented.

Previously, satisfaction has been shown to be associated with adherence with treatment, utilization of services, continuity of care and improved clinical outcomes. Satisfaction with care reflects the extent to which patients' expectations have been met. Satisfaction with medical care in general and with primary care physicians, in particular, may promote continuity of care and adherence in HIV-infected patients.

Patients studied included a spectrum of asymptomatic and symptomatic HIV-infected and AIDS-diagnosed individuals. Patients were interviewed at enrollment as a new patient and then six months later. Patient satisfaction was found to be greatest among patients who were more comfortable discussing personal issues with their physicians, who perceived their primary care physicians as more empathetic, and those who perceived their physicians as more knowledgeable about HIV. Factors found not to be associated with patient satisfaction included sociodemographic characteristics of both patients and physicians, HIV risk characteristics, alcohol and drug use, quality of life, and concordance of patient-physician gender and racial matching.

- HIV Patient satisfaction with a primary care provider is largely determined by the quality of the interaction with physicians. Both physician- and patient-centered factors influence this interaction. Patient practice in techniques that initiate and personalize the interaction may enhance its quality.

BARTLETT E, GRAYSON M, BARKER R, ET AL.
THE EFFECTS OF PHYSICIAN COMMUNICATIONS SKILLS
ON PATIENT SATISFACTION, RECALL, AND ADHERENCE.
J Chron Dis 1984;37(9,10):755-764.

Nonetheless, the accumulated evidence indicates that the physician-patient relationship can play a crucial role in influencing patient satisfaction, adherence to the regimen, and even act as a therapeutic modality in itself.

This study examined the effects of physician interpersonal skills and teaching on patient satisfaction, recall, and adherence to a therapeutic regimen in 63 patient visits to five medical residents at a teaching hospital in Baltimore.

Verbal, nonverbal, and affective communication skills all influenced patient variables. All effects of interpersonal skills and teaching are mediated by patient satisfaction and recall.

- One primary objective of the training should be to assist the participants in getting the most information, explanation, and advice directly from their physician. This will enhance the value and utility of that information.

WILSON I AND KAPLAN S. PHYSICIAN-PATIENT COMMUNICATION IN HIV DISEASE:
THE IMPORTANCE OF PATIENT, PHYSICIAN, AND VISIT CHARACTERISTICS.
JAIDS 2000;25:417-425.

...in our study the positive effects of female gender and gay/lesbian/ bisexual sexual preference in HIV-specific communication were present across relevant patient subgroups, including patient HIV risk factor, patient gender, and patient sexual preference.

The results of a cross-sectional survey of 69 HIV physicians and 264 of their patients are presented. In multivariable models relating patient and visit characteristics to general communication, longer reported visit length, longer duration of the physician-patient relationship, and female gender were significantly associated with better communication. The interaction of patient gender and visit length was also significant; longer visit length was more strongly associated with better general communication for male than female patients. Both female physician gender and gay/lesbian/bisexual sexual preference were significantly associated with better HIV-specific communication.

The pressure to shorten visit length may compromise physician-patient communication and this effect may be seen more with male patients. Women may be better able to “negotiate” the physician-patient relationship than men, perhaps as a result of the likelihood that they have more experience with that relationship.

- Training workshop activities should assist consumers in developing strategies which engage physicians in communication directed to solving patient-centered problems, with the possible consequence of lengthening the time of the visit, while being sensitive to physician/provider constraints.

GERBERT B, LOVE C, CASPERS N, ET AL. "MAKING ALL THE DIFFERENCE IN THE WORLD": HOW PHYSICIANS CAN HELP HIV-SEROPOSITIVE PATIENTS BECOME MORE INVOLVED IN THEIR HEALTHCARE. *AIDS Patient Care and STDs* 1999;13(1):29-39.

Persons who are more actively involved in their healthcare, who participate in making treatment decisions and plans, and who collaborate with their physicians to change their own health behaviors have improved health outcomes and greater satisfaction with their care...It really does matter when physicians take a few minutes to stroke a hand or just listen to what [patients] have to say.

The active, effective participation of HIV/AIDS patients in their health care improves both their satisfaction with the care they receive and health outcomes. This is consistent with the experience of patients with diabetes, breast cancer and heart disease. Physicians can and should help HIV patients become more involved in their health care.

This qualitative study, involving in-depth interviews with 64 HIV-infected patients in the San Francisco area, showed that involvement led to improved quality of life and health outcomes; increased involvement was most facilitated by using "opportune moments" (passages from one stage of HIV care to another) to effect change; and participants became more involved when their physicians used a "relationship-centered approach to care.

The results of the study suggest that physicians should be aware of and utilize opportune moments to enhance patient involvement in HIV care.

- A training workshop intervention which assists patients to create opportune moments by raising issues related to the interpretation of quality data may serve to enhance relationship-centered communication between physician and patient and increase patient involvement in health care.

KRAVITZ R, BELL R, AND FRANZ C. A TAXONOMY OF REQUESTS BY PATIENTS (TORP): A NEW SYSTEM FOR UNDERSTANDING CLINICAL NEGOTIATION IN OFFICE PRACTICE. *J Fam Pract* 1999;48:872-878.

Requests are the primary means of patient-initiated action in office practice. But these requests can be problematic because they consume time and resources...Patients who participate in their own care, however, often achieve better outcomes than those who do not...Patients are more than passive recipients of doctors' actions; they influence the clinical encounter through use of their own linguistic resources.

The Taxonomy of Requests by Patients (TORP) was developed to provide a standardized and valid tool for the identifying and categorizing patient "requests." In this study of the reliability and validity of TORP, in 1994, 139 patients made 772 requests of six physicians in a community-based university-affiliated general internal medicine practice.

There were 619 requests for information and 153 requests for physician action. The majority of both information and action requests were related to treatment and medications.

Physicians viewed visits with a high relative number of patient requests as both demanding and of longer duration. Patients with better health status made fewer requests. Having more chronic disease was associated with more requests for physician action. Patients with more unfulfilled requests had lower visit satisfaction.

- Training workshop activities should assist consumers in developing techniques that directly communicate the need for information or physician action.

PATIENT SATISFACTION

TSASIS P, TSOUKAS C AND DEUTSCH G. EVALUATION OF PATIENT SATISFACTION IN A SPECIALIZED HIV/AIDS CARE UNIT OF A MAJOR HOSPITAL.

AIDS Patient Care STDs 2000;14(7):347-9.

...the overall satisfaction of quality of care of HIV/AIDS patients in a dedicated HIV/AIDS unit is affected mainly by the patient's perception of his/her health status, level of professional or family support, and the patient's involvement in treatment decisions.

Quality of care was measured in terms of patient satisfaction. Overall satisfaction with the quality of care of patients in a dedicated HIV/AIDS unit was found to be correlated with the patient's perception of their health status, level of professional or family support, and the patient's level of involvement in treatment decisions.

- These factors correlated with a rating of quality of care reflect the concerns of hospitalized patients and may not be as relevant to a training in which non-hospitalized and relatively healthy people will participate. There are enough similarities to support emphasis on the personal aspects of satisfaction as indicators of quality of care.

STEIN M, FLEISHMAN J, MOR V, ET AL. FACTORS ASSOCIATED WITH PATIENT SATISFACTION AMONG SYMPTOMATIC HIV-INFECTED PERSONS.
Medical Care 1993;31(2):182-188.

Patient satisfaction has been defined as "the ultimate validator of quality of care..."

Patient satisfaction with medical care is an important outcome in evaluating the quality of medical care. A total of 1,031 HIV/AIDS patients, recruited from community-based organizations, were surveyed between 1988 and 1989. At that time, overall level of satisfaction with care was high. Satisfaction was negatively affected by frequency of HIV-related symptoms and limited access to care. Interpersonal relationships with providers was the most important quality of care factor.

STONE V, WEISSMAN J, AND CLEARY P. SATISFACTION WITH AMBULATORY CARE OF PERSONS WITH AIDS.

J Gen Intern Med 1995;10:239-245.

...the patients who were black or who were injection drug-users rated the quality of their care significantly lower than did the other patients with AIDS.

Patient surveys (N=305) and medical records review were used to determine the perceptions of PWAs of the quality of their care. The primary outcome measure was a six-item scale of patient-rated quality of care (PRQC). Patients with a primary nurse were least likely to have low PRQC ratings. Low perceived health status, black race and injection drug use were associated with lower PRQC scores.

- This study is the only one reviewed to show a correlation between race and injection drug use and quality of care satisfaction ratings.

MARQUIS M, DAVIES A, AND WARE J. PATIENT SATISFACTION AND CHANGE IN MEDICAL CARE PROVIDER: A LONGITUDINAL STUDY. *Medical Care* 1983;21(8):821-829.

Consumer satisfaction with medical care does predict subsequent changes in the medical care provider.

Using longitudinal data from the Rand Corporation's Health Insurance Experiment, the hypothesis that provider continuity is a behavioral consequence of patient satisfaction was tested. The study sample included 279 adults who used physician services in Dayton, Ohio. Patients were interviewed twice, one year apart to determine satisfaction and provider continuity. Consumer satisfaction was found to be a predictor of subsequent changes in medical care provider. The data suggests that the probability of provider change increases evenly as satisfaction decreases.

- The relevance of this study is that it demonstrates that under some circumstances patients will "exit" and find a new provider if they are sufficiently dissatisfied with the quality of care they are receiving.

HECKMAN T, SOMLAI A, KALICHMAN S, ET AL. PSYCHOSOCIAL DIFFERENCES BETWEEN URBAN AND RURAL PEOPLE LIVING WITH HIV/AIDS.

***J Rural Health* 1998;14(2):138-145.**

Compared with their urban counterparts, rural people with HIV reported significantly lower satisfaction with life...reduced access to medical and mental health care...and more maladaptive coping strategies.

Anonymous, self-administered surveys were completed by 276 people with HIV/AIDS in a mid-western state. Compared with their urban counterparts, rural people with HIV reported a significantly lower satisfaction with life, lower perceptions of social support from family members and friends, reduced access to medical and mental health care, elevated levels of loneliness, more community stigma, heightened personal fear that their HIV status would be learned by others, and more maladaptive coping strategies.

- Flexibility must be built into the training curriculum to allow for a range of behavioral options in response to varying levels of satisfaction with care and estimates of both the quality of care and the health care choices available to the consumer. This will account for the significant differences in both perceptions of self-efficacy and access to services in rural and urban areas of the state.

SELF-ADVOCACY TRAINING PROGRAMS

DAVIDS J, MASKOVSKY J, HARLEY A, ET AL. ADAPTING TREATMENT EDUCATION TRAININGS FOR THREE POPULATIONS OF PEOPLE WITH HIV/AIDS. 12TH WORLD AIDS CONFERENCE, GENEVA, JUNE 28-JULY 3, 1998. ABSTRACT 60292.

Treatment education programs are successful in reaching HIV positive low-income people with HIV, including women, the working poor, and injection drug-users, if they are tailored to meet the needs of the target population.

Project TEACH (Treatment Education Activists Combating HIV) is a training program that trains primarily low income people of color living with HIV/AIDS on subjects including secondary prevention, "good medical care" for HIV, peer education and communication skills, and AIDS activism. The training involve 48 hours of instruction, homework, field trips, and a graduation ceremony. Trainees reported a high level of satisfaction with the program. Pre- and post-program tests indicated a significant increase in trainee knowledge. No description of training methods are provided. Peer educators were trained to deliver the trainings.

- The use of peer educators/facilitators in the delivery of the training workshops would be consistent with Project TEACH and should be considered.

PLEASANT K, DAVIDS J, GOLD R, ET AL. PROJECT TEACH (TREATMENT EDUCATION ACTIVISTS COMBATting HIV). 11TH WORLD AIDS CONFERENCE, VANCOUVER, JULY 6-12, 1996. ABSTRACT WE.D.3784.

Low-income people of color living with HIV have demanded and begun to serve in positions peer education and treatment advocacy. However, a lack of prior experience, education, and support can impair their capabilities to be accurate, effective educators and advocates.

Project TEACH (Treatment Education Activists Combating HIV) is an interactive training program for people living with HIV who demonstrate an interest in peer education and advocacy. The five-week long training program includes ten three-hour sessions covering a broad range of topics from basic science to research and teaching methods and treatment activism.

- While no educational methods are presented, the use of interactive methods are likely to be effective for the purposes of the Quality of Care training curriculum. Interactive methods are favored because they can be effective with participants who may have lower reading levels and less understanding of clinical terms. These methods, however, work best when used by more experienced facilitators, since much of the benefit of the activities comes as a result of participant interaction which is enhanced by the trainer's ability to give up a measure of "control" (a skill that comes with experience).

SHOUTEN J, HUBERT J, AND COPPEDGE B. (STEP) EVALUATING TREATMENT OPTION AND HEALTH CARE PROVIDERS: STRATEGIES FOR SELF-ADVOCACY. *STEP Perspective* 1996;8(3)-WINTER.

The bottom line in insuring the best treatment possible is the combination of an educated client and a knowledgeable and experienced health care provider.

According to STEP, the Seattle Treatment Education Project, the most important factor in choosing a health care provider is the level of clinical experience of the provider. All HIV/AIDS care providers are equally experienced. Consumers must be prepared to take action to insist that their health care provider and health plan provide them with the opportunity to receive the best possible care. Consumers must advocate on their own behalf to obtain quality care. Their first option is to discuss their care with their health care providers and, if necessary provide them with information to help raise their understanding of treatment options. If the health care provider has not been responsive, a second option is to request to talk with the patient care representative. Lastly, consumers can form an advocacy group and lobby for change.

- The stepwise approach to advocacy provides a starting point for our consideration of a simple, effective set of steps to self-advocacy.

JAMES J. TREATMENT ADVOCACY PROGRAM TRAINS 200: INTERVIEW WITH MATT SHARP. *AIDS Treatment News*. 1999; ISSUE 326.

We start with a discussion of health care and people's experiences with the medical system.

The curriculum for a three-day treatment advocacy training program which had trained 200 people when this article was published, was developed by Judy Leahy of Project Inform. It is designed for case managers, treatment advocates, peer advocates and counselors. The program is called Treatment Education Certification Program (TECP). One of the goals of the program is to help patients understand the complexities of HIV treatment and help guide them in working with their doctor.

- The program has a post-program certification test. While certification is a possible incentive for participation, basing it on an exam may not be consistent with the timeframe and tone of the anticipated training.

HIV AND HEALTH LITERACY

KALICHMAN S, RAMACHANDRAN B, CATZ S. ADHERENCE TO COMBINATION ANTIRETROVIRAL THERAPIES IN HIV PATIENTS OF LOW HEALTH LITERACY. *J Gen Intern Med* 1999;14:267-273.

Health literacy is frequently below functional levels in medical populations, and people with lower health literacy often experience poor health and negative treatment outcomes.

HIV-infected men and women (N=318) were recruited for this study from community based health care and social services agencies. Questionnaires and interview instruments were used to assess health literacy, HIV treatment status, health status, perceived barriers to treatment and reasons for non-adherence.

Both univariate and multivariate analyses showed that the only significant predictors of treatment adherence were years of education and health literacy. People with lower health literacy and lower education level were 4 and 3 times, respectively, more likely to have missed a dose of antiretroviral medication in the last two days. Income level, ethnic background, and HIV disease progression did not account for these associations. People of lower literacy were more likely to have missed a dose of their medications because they were confused about their treatment regimen, were depressed, or desired to cleanse their body of treatments.

- The relationship between low education and low literacy and the ability to understand and adhere with treatment information, suggests the importance of including concrete practice exercises with lots of repetition in interventions designed to improve health behaviors.

KALICHMAN S AND ROMPA D. FUNCTIONAL HEALTH LITERACY IS ASSOCIATED WITH HEALTH STATUS AND HEALTH-RELATED KNOWLEDGE IN PEOPLE LIVING WITH HIV-AIDS. *JAIDS* 2000;25:337-344.

We found that lower literacy participants were less likely to be taking antiretroviral medications despite their poorer health status, and this difference was not accounted for by years of living with HIV infection or income level. Lower health literacy participants were also more likely to doubt the potential benefits of medical treatment and were more likely to distrust their health care providers.

HIV-infected men and women (N=339) were recruited for this study from community-based health care and social services agencies. Surveys and interview instruments were used to assess health literacy, HIV treatment status, health status, HIV-AIDS treatment knowledge, health care perceptions, and experiences.

Twenty-five percent of patients sampled demonstrated difficulty comprehending simple medical instructions (lower health literacy). Lower health literacy in this sample was associated with lower health status and lower treatment adherence, as well as, lower HIV-AIDS treatment knowledge, and more negative health care perceptions and experiences.

- The relationship between low education and low literacy and the ability to understand and adhere with treatment information, suggests the importance of including nonverbal forms of communications and pictographs in delivering medical information. These should be considered for inclusion in workshop activities.

THEORIES OF DECISION MAKING

KLEIN R. MODELS OF MAN AND MODELS OF POLICY: REFLECTIONS ON EXIT, VOICE, AND LOYALTY TEN YEARS LATER.

Milbank Memorial Fund Quarterly/Health and Society 1980;58(3):416-429.

...the question of how to assess the quality of medical care is notoriously contentious. There is little agreement even among the experts, so that equipping the consumer with adequate information is no easy task. More centrally still, it is not self-evident that exit is necessarily an effective corrective mechanism...A consumer might well be satisfied with the technical treatment provided, but highly incensed about the quality of the environment in which it has been provided.

A review of the then-current thinking about consumer options in the marketplace with emphasis on the health care consumer in 1980. The contrasting (or, better, complementary) views of humans as consumers: homo economicus and homo politicus exemplify the options of exit (in a competitive marketplace) and voice (advocacy) are tempered by the recognition of the role of loyalty. Klein states that, "decisions by individuals as to whether to employ the exit or the voice option will depend on the degree of loyalty that they feel to the firm or organization [clinic or provider] in question: a high degree of loyalty is likely to inhibit exit and may encourage voice." Both options, however, carry with them costs.

In addition, the health care market is characterized by a high degree of uncertainty about the product ("about which diagnostic and treatment procedures are most apt to prove efficacious.")

The problem of finding an appropriate balance between exit and voice in health care spring from the fact that consumers are not purchasing a product but a complex and heterogeneous package of services.

- The complexity of the "options" facing HIV/AIDS patients is great. The workshop curriculum should address the options of exit and voice in the context of the strength of the physician-patient relationship and its inherent loyalty.

TVERSKY A. AND KAHNEMAN D. THE FRAMING OF DECISIONS AND THE PSYCHOLOGY OF CHOICE. *Science* 1981;211:453-458.

...people exhibit patterns of preference which appear incompatible with expected utility theory.

When faced with a choice, a rational decision-maker will prefer the prospect that offers the highest expected utility. However, people systematically violate the elementary requirements of consistency and coherence of rational choices. This is because the framing of the choice and the value placed upon the outcomes alters the perception of the probability and desirability of the outcomes. In general, the response to losses is more extreme than the response to gains; most people are risk-averse; people evaluate acts in terms of a minimal account generally accounting for a loss or gain in a situation at hand rather than as a sum of all previous acts

Framing problems in terms of risks or gains, losses, probability, etc. all effect the decision outcome.

- The performance data provided in the **Consumer's Guide** can be described in a number of ways. Framing the data and presenting a positive value to it can influence the perception of its utility to the consumer. The curriculum should provide a frame for the quality-of-care data that enhances rather than detracts from its perceived utility.

KAHNEMAN D AND TVERSKY A. CHOICES, VALUES AND FRAMES.
American Psychologist 1984;39(4):341-350.

An objective improvement can be experienced as a loss, for example, when an employee receives a smaller raise than everyone else in the office.

The cognitive and psychophysical determinants of choice are described. The psychophysics of value induce risk-aversion in the domain of gains and risk-seeking in the domain of losses. The psychophysics of chance induce overweighting of sure things and of improbable events, relative to events of moderate probability. The process of mental accounting, in which people organize the outcomes of choices, explains some anomalies in consumer behavior. In particular, the acceptability of an option can depend upon whether a negative outcome is evaluated as a cost or as an uncompensated loss.

- People do not evaluate prospects by the expectation of an objective outcome but rather by the expectation of the subjective value of these outcomes. In describing the "objective" data in quality of care reports, they can be made more valuable to the consumer by providing an opportunity to workshop participants to add a subjective assessment of the data, adding value to the usefulness of the data beyond its numerical characterization.

SHAFIR E, SIMONSON I, AND TVERSKY A. REASON-BASED CHOICE.
Cognition 1993;49:11-36.

It is proposed that, when faced with the need to choose, decision-makers often seek and construct reasons in order to resolve the conflict and justify their choice, to themselves and to others.

An alternative theory of decision-making, in comparison with the "prospect theory" of Kahneman and Tversky, is reason-based analysis. This approach identifies various reasons and arguments that are offered as explanations of the factors ("reasons for and against") that influence decisions. Although the reasons identified by researchers may not always correspond to those that actually motivated a decision, it is believed that the process of reasoning out a decision may help to explain the decision, especially where value-based models are difficult to apply. A focus on reasons seems closer to the way we normally think and talk about choices.

People's choices may stem from affective judgments that preclude a thorough evaluation of the options. However, in most cases, people claim to carefully evaluate options, discarding the less attractive ones and, faced with a choice of remaining options that is hard to resolve, they often search for a compelling rationale for choosing one alternative over another. It seems that people, contrary to classical decision theory, often do not have well-established values, and they construct preferences while in the process of rationalizing a decision.

- Since values are sometimes revealed during the process of decision-making (rather than having been identified before a decision and then applied to the decision), the process of acting out a decision may help participants come to understand and then explain what is important to them. The use of role play can help participants to gain self awareness and use that in becoming a self-advocate.

ANNAS G. PATIENTS' RIGHTS IN MANAGED CARE – EXIT, VOICE, AND CHOICE. *NEJM* 1997;337(3):210-215.

Supplementing the ability to exit with the ability to have an effective voice can foster and enhance patients' rights.

Providing patients, who depend upon physicians for expert advice, with an effective voice is a long-standing problem that has been highlighted, but not caused, by managed care. The backlash against managed care may provide an opportunity to develop options for patients to find a voice in the health care marketplace. The role of physicians as patient advocates, one of their historical roles, is being altered by the demands and constraints of managed care. If physicians cannot or will not act as their patients' advocates, some other party will have to assume that role. At best, an independent organization should fill that role. Alternatively, patients may need to become their own advocates, and may need to be supported by the legal system in conflicts.

Relying solely on the ability of patients to leave one health plan and move to another is not sufficient to ensure either the rights of patients in managed care plans or improvement in the quality of care.

- Patients will need to be supported in the development of effective strategies and tactics to ensure the quality of their care. These tactics cannot only depend upon the options of exit and voice. Self- and group- advocacy skills–development may be necessary to move a system in which their exit is of no consequence and their voice will not be heard.