QUALITY OF CARE IMPLICATIONS OF SHIFT IN HEALTH CARE SERVICES TO HOME AND COMMUNITY-BASED SETTINGS

INSTITUTE OF MEDICINE WORKSHOP

SUMMARY

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MEMORANDUM

Memo No. HHC-12
June 26, 1991

TO: Members of the IOM Program Initiation Fund Workshop and Observers

FROM: Jo Harris-Wehling JHW
Kathy Lohr

SUBJECT: SUMMARY OF IOM WORKSHOP
QUALITY-OF-CARE IMPLICATIONS OF SHIFT IN HEALTH CARE SERVICES
TO HOME AND COMMUNITY-BASED SETTINGS

COPIES: Queta Bond, Karl Yordy, Bob Cook-Deegan, Polly Harrison, Gary Ellis, Ruth Bulger

Attached is the summary of the IOM workshop on quality-of-care implications of the shift in care settings to the home and community. This version reflects a few changes made in response to suggestions we received on the earlier draft. We received other suggestions that will be helpful to us as we develop one or more proposals.

We want to thank each of you for participating in the workshop. Additionally, many of you have been very helpful in providing additional comments, reference materials, or more general reflections and comments on the proposed project. We expect to followup with some of you as our plans move forward on seeking a sponsor (or two) for the project.

Should you have additional thoughts about potential sponsors or "best strategies" on proposal content, please give us a call.

QUALITY-OF-CARE IMPLICATIONS OF SHIFT IN HEALTH CARE SERVICES TO HOME AND COMMUNITY-BASED SETTINGS

SUMMARY OF AN INSTITUTE OF MEDICINE WORKSHOP

I. INTRODUCTION

This document reports on a one-day workshop held at the Institute of Medicine (IOM) in April 1991. The purposes of this workshop were threefold: (1) to develop a framework for addressing the key quality, appropriateness, and effectiveness issues related to the accelerating shift in the settings of health care delivery to home and community-based settings; (2) to articulate a strategy for addressing the information and methodological needs viewed as obstacles to confronting the policy issues; and (3) to recommend steps the IOM should take in this area. Invitees -- listed in the accompanying roster -- represented a broad sector of concerns from several disciplines.

This summary is intended to guide the Division of Health Care Services in detailed program planning in the area of assessing and assuring the quality of health care, with particular emphasis on care in settings other than hospitals. More specifically, it will provide the basis for proposal development for an IOM study.

Sections II and III below address the topics listed.

- An overview of the workshop (Part II); and
- The proposed study's framework (Part III), which consists of the following major sections:
  - -- the changing nature of community care;
  - -- major quality-of-care concepts and dimensions applicable to community care;
  - -- data acquisition, management, and technology; and
  - -- policy, implementation, and operational issues.

Section IV is a brief summary of this document.

II. OVERVIEW OF THE WORKSHOP

WORKSHOP DISCUSSIONS

IOM staff used a variety of mechanisms to share relevant information with workshop participants before the meeting and to help focus the discussion during the workshop. Several items were distributed as background material, including a paper commissioned from Robert Kane, M.D., entitled "The Implications for Quality Assurance of the Move to More Community-based Care." (Attachment 1 gives a bibliography that includes items sent to participants.) At the dinner on the eve of the workshop, Mary Mundinger, R.N., Dr.P.H.,

chairperson of the panel, gave a general overview of the workshop theme; she touched on the historical background of the IOM's interest in home and community care; information on utilization and cost of Medicare home health care; and proposed reasons for and implications of the shift to home and community care. Additionally, three participants served as lead discussants during the workshop on different facets of the topic under discussion (Attachment 2, Workshop Agenda).

CONCLUSIONS AND SUGGESTIONS FOR STUDY

The workshop participants reached three main conclusions. First, a study is needed on the "quality of community care"; second, the IOM should plan and conduct such a study, drawing on related work it has done in the past 5 to 10 years; and, third, the study design should be the "traditional" IOM study format, namely a committee-directed study of approximately 18 to 24 months. Because the group was not asked specifically to define home and community-based care (that is, to specify what types of care, what patient populations, and what settings were involved) and because discussion time did not permit elaboration of these issues, the group opted to refer to "community care," which is the broad term used henceforth in this summary.

To facilitate the framing of the proposed study, participants submitted written suggestions of priority topics and issues at the mid-point of the meeting. Kathleen Lohr converted these suggestions into a rough outline; further discussion led to some revisions, and a provisional study framework is discussed below. In addition, participants proposed an array of appropriate activities for the proposed study (e.g., workshops, site visits).

Several suggestions emerged that might serve as principles or guidelines to an IOM committee conducting the study:

- Avoid orthodoxy on standards;
- Support the importance of obtaining hard empirical data ("dogmas are hard to undo");
- Look to the future context in which care will be provided (e.g., more bundling, mini-capitation, linking quality and accountability, and collective responsibility of larger enterprises);
- Look to an increased role for information technology (e.g., information flow and transmission, monitoring of care, development of databases); and
- Do not compromise or underplay the importance of information acquisition needs as a trade-off to a focus on policy issues; a well-designed study (and committee) must address both.

The threefold purpose of the workshop (as stated in the Introduction) was overly ambitious. Participants did not explicitly discuss strategies for addressing the information and methodological needs (which had been viewed as

obstacles to confronting policy issues). The need for such strategies is reflected in the proposed study framework. Another IOM workshop, however, is being convened in the near future on a related subject -- database development to serve clinical evaluation needs -- and these issues may be dealt with to some degree there.

SUGGESTED SPONSORS

Finally, participants suggested several potential sponsors of an IOM study in this area. Within the private sector, several foundations were noted to have interests in this or related topics. Among them were the Robert Wood Johnson (RWJ) Foundation, the John A. Hartford Foundation (in relation to the National Demonstration Project for Quality Improvement in Health), the MacArthur Foundation (if wellness issues are emphasized), The Commonwealth Fund (risks in the community), and The Henry J. Kaiser Family Foundation. If the study were to include children (or a separate study on children were to be mounted), other foundations with a possible interest included the W.T. Grant Foundation and The Kellogg Foundation.

In addition, because community care (especially home health care) is increasingly concerned with high technology services (e.g., respiratory therapy, oxygen, intravenous medications, parenteral nutrition), some participants thought that the major manufacturers or suppliers of the pertinent drugs and devices might consider sponsorship of the study. The pharmaceutical industry was specifically mentioned, as was Baxter Travenol. Other possible funders might be the related trade and professional associations.

Various other private sector organizations came up as well. They included the American Association of Retired Persons, as well as various voluntary foundations and organizations, such as the United Way or the March of Dimes.

Several federal agencies were also mentioned as potential sources of support. These included the Health Care Financing Administration (because of its responsibilities for persons covered by the Medicare and Medicaid programs), the Social Security Administration (because of its responsibilities for persons with disabilities), and (within the Public Health Service) the Agency for Health Care Policy and Research, the Health Resources and Services Administration, the National Center on Health Statistics (insofar as data sets are of concern), and possibly one or more institutes of the National Institutes of Health. Specifically mentioned were the National Institute on Aging (because of its interests in basic data projections and demographics; qualitative studies on informal caregivers; and issues of quality of life for both patients and families) and the National Center for Nursing Research (especially relevant for their work on special populations and a particular focus on community care interventions and patient outcomes).

III. FRAMEWORK OF A PROPOSED STUDY

The following framework for a possible study by the IOM on quality implications of the shift to community care is the product of the workshop. Some of the elaboration of topics below is taken from Dr. Kane's commissioned paper, Dr. Mundinger's comments at the dinner preceding the workshop, and references included in the attached bibliography. The four main parts of a study -- the changing nature of community care, major quality-of-care concepts and dimensions; data acquisition, management, and technology; and policy and operational issues -- are taken up in turn in the remainder of this section.

THE CHANGING NATURE OF COMMUNITY CARE

Workshop participants debated the character of community care at some length, especially as it related to quality-of-care concerns. Among the issues were: whether a unifying construct might be found and usefully employed; whether community care has unique characteristics with ramifications for quality assessment and assurance; the advantages and disadvantages of focusing on specific settings or special populations in a study of community care; and the appropriateness of the shift to noninpatient settings, viewed in a context of technology assessment.

Community care involves numerous and diverse sites and thousands of health care providers representing multiple disciplines. Home health care probably is the best known and has the longest traditions. Newer types of care and social services (for instance, adult day care) that have a potential health component are rapidly emerging.

Existence of a Unifying Concept

Conceptually, two points crystalize the problem under discussion: first, the unit of analysis can be a single individual receiving care from diverse providers and settings; second, a considerable commonality unites of the types of care provided to different individuals among diverse settings. Kane proposes a useful taxonomy of two separate, although perhaps overlapping, modes of care that incorporates these two factors (the individual and the type of care) and that reflects the shift, beginning in the early 1980s, in the locus of care from hospitals to community settings. He calls these modes of care "hospital-displacement care" and "hospital-extension care."

Hospital-displacement care refers to activities that could be (and typically used to be) done as inpatient services in a hospital but are now delivered outside such settings. Locales for hospital-displacement care include ambulatory care settings such as physicians' offices and outpatient surgical centers, day care centers, patients' homes, and nursing homes.

Hospital displacement has occurred for two reasons. First, changes in payment policy have fostered service provision in settings of presumed lower

resource use, thus resulting in lower costs and lower charges. Second, technologic advances have occurred that presumably provide the necessary support for care delivery in the alternate settings. A third factor may have contributed to hospital displacement -- the preference of some patients for treatment settings other than the hospital -- but its effect on volume is probably less significant than the other reasons.

Hospital-extension care refers to services begun in the hospital setting and continued in nonhospital settings. Such services are likely to be acute or post-acute care in nature. The same forces propelling hospital displacement may be applicable here, in particular if health care needs are perceived as declining in intensity or changing in nature over time.

Under either of these constructs, the purpose or objective of care delivered outside of the hospital is assumed to be the same as it would have been had care been delivered in the hospital. Whether one can also assume that the quality of that care (or the methods by which it is measured or improved) are the same as those applied to the hospital setting is problematic.

Unique Aspects of Community Care

The workshop participants identified several critical, and perhaps unique, aspects of community care, among them the "moving target" of accountability for outcomes of care and the interrelatedness of health care with the culture and environment. More generally, unique or supposedly unique aspects of community care were proposed from both conceptual and a practical point of view.

Conceptual framework. Community care might be defined, conceptually, as care provided to an individual in situations influenced simultaneously by four factors: the time horizon for needing and receiving care; the technologies involved (that is, the services, personnel, financing and delivery schemes, and organizations); the sites and environment of care; and goals of care. Exploring the factors of time, technology, site and environment, and goals of care, both singly and in combinations, within a conceptual definition of quality is a critical step that must take place before identifying quality assessment measurements and assurance strategies.

The interrelatedness of these four factors determines the dimensions of appropriate care for different types of individuals. The constructs of hospital displacement and extension focus on a particular segment of the community-care population that is perhaps more vulnerable to receiving poor quality or inappropriate care. Further quality issues can be seen in the complexity of determining what is appropriate care for a population identified by an external occurrence (e.g., one who is discharged from a hospital, or one who has received care in a setting other than as a hospital admission) rather than by clinical data or demographic characteristics.

Practical aspects. Operating in a more pragmatic perspective, workshop participants noted the following elements of community care as important for any proposed IOM study to address:

- Diversity of patient types by clinical, social, and situational factors;
- Special populations (e.g., children with special home care needs; the elderly; and underserved persons who face financial and other access problems);
- The relevance of and accounting for cultural and environmental factors;
- Conceptualizations of a unit of service, an episode of care, and the spectrum of care;
- Multiple, varied goals of care;
- The multiplicity of formal health care providers, who differ in terms of disciplines, type (e.g., individuals, institutions), and sheer numbers;
- The role of the physician as the principal care provider, as the coordinator of care, or as both;
- The interrelationship of formal and informal care providers;
- Infrastructure of care settings, for safety and effectiveness in particular; among the wide-ranging examples offered were electrical power, individuals trained in technical aspects of using and maintaining devices and equipment, capacity of informal caregivers to cope with stress, and motivations of informal caregivers that may be detrimental to or work against decisionmaking that promotes quality care;
- The balancing of needs and quality of life of family and informal support groups with those of the patient;
- Management of care (e.g., less "control" over the patient and environment than in the hospital setting; accountability; information acquisition and availability);
- A focus on the elements of care rather than on the setting per se (for instance, "assistance with personal care" rather than "home care" or "nursing home care"), which leads to a separation (in terminology) between the type of care and the site of care; and
- Fragmented responsibilities across the full spectrum of care.

Advantages and Disadvantages of Focusing on Specific Settings or Special Populations

The multiple dimensions and complexities both of the concept of community care and its unique aspects -- within the context of a shift away from inpatient care -- present challenges in articulating a reasonable and manageable scope of a potential study. One choice concerns how broad or narrow a study might be in terms of its focus on specific settings and on special populations.

Setting constraints. The major reason for imminent concern about the quality of community care appears to be the current nature of and reason for that care. That is, the multiple dimensions of community care and the forces driving growth in such care are perceived as primarily financial incentives for a perhaps inappropriately aggressive transfer policy. This perspective (which many participants in the workshop appeared to share) dictates a very broad scope of work for any IOM study. It suggests, for instance, that the project should not be limited to only home health care or even to all community care except nursing homes. To do so would exacerbate existing problems both of comprehending the interrelatedness of the issues and of addressing them in a timely and orderly fashion.

An alternate suggestion -- that the scope be limited by boundaries of sites -- is nonetheless appealing. For instance, the study might center on only home health care. Or, it might be broadened to noninstitutional care short of nursing home populations, on the grounds that the nursing home environment provides structure and supervision that eliminates or, at a minimum, decreases some of the concerns applicable to care provided in non-institutional settings). A "setting-specific constraint" -- specifically, one that excludes nursing home care per se -- might be more manageable for an IOM study; from the perspective of some, it has greater potential for producing meaningful conclusions and recommendations that would be, in turn, more likely to be implemented.[1]

Several arguments can be made against adopting this seemingly narrower approach:

o Major issues such as continuity of care, appropriateness of the match between patient need, elements of care, and site of care, and appropriateness of the hospital discharge plan could not be explored in full.

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[1]Conceptually it is possible to think of including nursing homes in the broader framework of hospital displacement and extension. This would have the effect of defining the scope of concern as including a shift in the setting of care from both hospital and nursing home settings. In other words, the issue of whether to include nursing home care within the rubric of community care may turn on whether one is concerned about nursing home care per se or about home and other forms of community-based care delivered to residents of nursing homes -- residents who may be there temporarily or permanently.

o The quality of care provided in nursing homes remains a concern to many, and this issue should not be dodged. Several recent events in this arena would argue for including the care provided in nursing homes in the scope: (1) the advent of a mandated minimum data set for all nursing home residents and promotion of the Nursing Minimum Data Set (NMDS) across several settings including nursing homes; (2) HCFA's "practice guidelines" that are used by surveyors of long-term care facilities; (3) preadmission screening of Medicaid patients; and (4) the implementation by HCFA of the use of resident assessment protocols on certain nursing home patients.

o Recent evidence suggests the prevalence of medical problems and problems requiring skilled nursing among Medicare patients in some nursing homes (referred to as "high-Medicare nursing homes" by Shaughnessy and Kramer [1990]) has increased substantially. These data and inferences are based on clinical profiles constructed in 1982 and 1986 and the potential link between this finding and the implementation of Medicare's Prospective Payment System.

o Access to skilled nursing homes by Medicaid patients may have been reduced inappropriately because of increases in Medicare admissions secondary to hospital policies that have led to the discharge of more "medically needy" Medicare patients (Morrisey et al., 1988). The ramifications of this pattern for equitable distribution of health care resources deserve attention.

o Some findings indicate that Medicare clientele have increased need for skilled nursing care in these settings where, in many instances, additional resources are unavailable. These data underscore the need to be concerned about poorer patient care in Medicare home health and nursing homes.

o Recent evidence suggest some increase in the use of tube feeding and urinary catheters in home health, which may reflect a trend to use technologies in home care rather than more labor-intensive services (for instance in this case, less-skilled personnel to feed patients). Such evidence may indicate inappropriate, premature discharge from nursing homes or access problems in nursing home admissions; conversely, the home setting may be more appropriate than the nursing home for individuals needing tube feedings and urinary catheters.

Special populations. The workshop participants considered whether the proposed study should look at the special needs of the developmentally disabled, physically disabled adults, and various other special populations. There was general agreement that these groups should be included to the extent that they are among the more broadly defined populations receiving community care. Comments at the workshop suggested, however, that the IOM might be well advised to consider another study on the special needs of these populations (particularly the developmentally disabled and disabled adults).

After the workshop, Henry Ireys, Ph.D., suggested that the forces leading to home care for children and the expectations regarding outcomes of such care are critically different from those for other community-care populations. Consequently, the quality assessment and assurance strategies for addressing care to children might (and perhaps should) be different. Additionally, trends in the development and use of technology, issues of

program implementation, and funding patterns for child health care have quality implications that are not common to other populations. Dr. Ireys thus argued that the IOM ought to undertake a separate effort on quality of community-based care for children.

To accommodate these divergent views, IOM staff suggest that an IOM committee embarked on a study in this area should explore, very early in its work, the question of whether community-based care for children has unique aspects and, if so, whether these are of the number, nature, and importance to warrant a different conceptualization and methodology -- in short, a separate study.

Patient care needs. Dr. Mundinger proposed an additional construct related to special populations (in her presentation at dinner and in follow-up correspondence). This concerned categories of patient care needs and the goals of care. Using this construct, the scope of an IOM study might be defined in the following manner:

- Acute or unstable care with the goals of cure and maintenance;
- Chronic or disability needs with the goal of rehabilitation (and maintenance); and
- Frail and vulnerable subgroups with the goal of prevention of deterioration in health status.

Technology and Technology Assessment

A major issue for the proposed study is the appropriateness of the shift in settings; this appropriateness cannot be assumed and must be examined directly. Although this subject has clear quality-of-care implications, it can also be dissected in the context of technology and technology assessment.

Health care technology, commonly understood to refer to drugs, devices, and procedures, can be (and often is) defined to include the organizational and supportive systems within which care is provided. Technology assessment, broadly defined, subsumes issues of safety, efficacy, effectiveness, cost-effectiveness, and even questions of the social, ethical, and legal aspects of the use of health care technologies. In this broad conceptualization, technology assessment can easily be seen to include how to anticipate or effect changes in the site of delivery of technologies.

From some perspectives, home and community settings have served historically to protect patients from technological interventions. As the use of these technologies in these settings becomes more common and as financing systems encourage that movement further, the need increases better to understand their effectiveness and the risks and benefits to the patient. Formal technology assessment is not done setting by setting; thus, transfers of a given technology to "new" settings may have significant implications for the effectiveness of that technology in terms of safety, adequacy of support systems, and training of personnel.

Assessing home and community care technologies (from the point of view of quality of care) in the absence of clearly stated, scientifically based rules or principles for guiding users and practitioners is unrealistic. A more serious problem than the lack of basic information on home care technologies is the absence of any logical, systematic approach to technology assessment in home and community-based care. Many of the same technologies (drugs, devices, procedures) used in institutional setting are found in the home or community setting. Assessments of these technologies could be done using common criteria (i.e., irrespective of the setting). Even technologies that have been formally assessed are not likely to have been so assessed in home and community settings, meaning that lessons about effectiveness, appropriateness, personnel, and quality of care learned for the hospital environment may not be relevant for the noninpatient environment.

Special elements of assessment in the home setting may be of equal importance, however; these include considerations of safety in an environment without immediate back-up and training of both professional and informal care providers in intervention procedures. Additionally, many devices and medical technologies whose primary application is in the home are now being marketed or are under development; questions remain as to the assessments these devices have undergone or will be subject to before widespread use occurs.

MAJOR QUALITY-OF-CARE CONCEPTS AND DIMENSIONS

Addressing Quality Issues in a "New" Setting

Quality assessment and assurance concepts and methods have evolved in the context of care provided in hospital settings. Thus, they tend to focus primarily on acute care within an episode of care (e.g., the period of a patient's hospitalization). Efforts to assess and assure quality in other settings, such as nursing homes, or for care provided in a particular health care delivery system, such as care provided by health maintenance organizations, are patterned after the concepts and methods used for inpatient hospital care.

Hospital-based methods are known, however, not to generalize completely successfully to these other kinds of care (for example, physician office-based care). As implied in the previous section, one needs to understand the nature of community care before concluding that a transfer of slightly modified quality assessment and assurance concepts and methods to community-care settings is appropriate.

Addressing Quality Issues in Community Settings

Home care. Little is known about several key quality-related dimensions of community care that might be used in articulating a meaningful framework

for assessing and assuring its quality. State licensure and Medicaid and Medicare certification are the fundamental systems used for quality assurance in home care. These systems focus heavily on structural aspects of quality. Home care agencies for the most part acknowledge the structural elements as essential, but they encounter serious and fundamental obstacles, such as the nursing shortage, in their efforts to meet the structural standards or criteria. The role of new directions such as consumer-focused decisionmaking and outcomes measures in quality assessment and assurance in home settings remains unclear.

The 1990 IOM report Medicare: A Strategy for Quality Assurance noted four issues associated with assessing the quality of home care: (1) the importance of the family and social environment; (2) the potentially conflicting or duplicatory roles of many caregivers (which may still leave gaps of care or knowledge); (3) the multiplicity of funding sources and programs; and (4) the lack of integrated financing or record systems that span ambulatory, acute hospital, and home health care. All these points apply also to community care (broadly defined).

Setting-specific problems include the "invisibility" of care, lack of constant (or even adequate) "peer" supervision, and only a sparse selection of fully tested measures of functional outcomes and health status that can easily be applied in these settings. Poor study design (for projects in nontraditional settings) and a lack of common terminology and minimum data sets are frequently cited as obstacles to both health services and policy research and practical quality measurement and assurance activities. Additionally, data are very limited about the safety, effectiveness, and efficiency of modalities of care given primarily in the home and about technologies now diffused to noninstitutional settings. These factors all impede the development of quality-of-care criteria. Finally, even technologies that have been formally assessed are not likely to have been so assessed in the home or similar settings. This means that lessons about effectiveness, appropriateness, personnel, and quality of care learned for, e.g., the hospital environment may not be relevant for the non-inpatient environment.

The community care taxonomy. Within the taxonomy proposed by Dr. Kane (discussed earlier), several questions can be raised with regard to hospital displacement and hospital extension. As to the former:

- Can one logically conclude that the same standards of care and, thus, the same approaches to assessing quality used in the hospital setting are applicable to the alternate settings?

- Are new standards and assessment approaches needed for technologies that have been developed specifically and uniquely for the nonhospital setting?

- What evidence supports the (evident) assumptions that alternate settings need lower levels of resources or that technologic advances will, in fact, provide adequate support in alternate settings?

Similarly, the hospital-extension construct presents challenges of its own:

- What methods and mechanisms are used to determine that patients' health care needs have declined in intensity or changed in nature sufficient to warrant continuation in nonhospital settings? How effective are these mechanisms?

- What methods and mechanisms exist to identify the appropriate setting for meeting these needs, once the decision is made that the hospital is no longer the most appropriate? How effective are these?

- Who is responsible for monitoring the effect of the hospital discharge? Who is held accountable for the outcomes of care related to an episode of care that begins with hospitalization but continues with treatment in another setting? Are these responsibilities being met effectively?

Regardless of whether the phenomenon under observation is hospital displacement or hospital extension, broader issues warrant attention as well. Two questions warrant special attention. First, what mechanisms exist to determine if the quality of care is being compromised when changes in settings are (postulated to be) driven by cost containment? Second, what balancing of incentives exists to give equal value to the appropriateness and effectiveness of discharge planning (e.g., the timing of that discharge; the setting to which the patient is "launched") or of service planning more broadly conceived as to the appropriate and effectiveness of cost-containment measures?

Patient Autonomy, Choice, and Control

The concepts of patient choice and patient control have not been integrated into quality assessment and assurance concepts, methods, or analyses for any setting, let alone community care. Patient satisfaction measures approach some of these questions, but only insofar as they are concerned with the humanistic or interpersonal skills of practitioners. Far more exploration is needed that delves into areas such as:

- A better understanding of the concepts of patient autonomy, personal dignity, and sense of independence; passivity (for example, a trait shown in some elderly female patients); and aggressiveness (for example, a trait shown in some renal dialysis patients).

- Quality implications of the natural progression toward independence in young adulthood in settings such as community-based group residences;

- Patient (client, consumer) choice versus health and safety issues defined from a provider perspective;

- The meaning and interpretation of different kinds of risk (e.g., death, loss of bladder control, drop in public image); values attributed to these risks and the tradeoffs among them; understanding of degrees of risk

(e.g., a 5-percent probability; two-to-one odds); and the levels of discomfort, stress, or even anxiety about coping with unknowns and uncertainty); and the scope of benefit-versus-risk determinations from the perceptions of the various interested parties (insurers, individual and institutional health care providers, patients, and patients' families). Additionally, more study is needed on the forces that shape risk perceptions, how information about risks can be more effectively communicated, and effective methods for multiple interested parties to collaborate on benefit-risk determinations.

- Physician-patient interactions; this can include the significance of the content of the interaction, the context of the interaction, patterns of communication; patients' perceptions of the amount of control they have over the engagement; and extent to which emotion is expressed during the encounter by either party.

- Potential effects of shifting risk to patients on physicians' practice patterns (e.g., use of diagnostic procedures and therapeutic interventions; referrals), on clinicians' levels of comfort with patients who choose options of care regarded by professionals as entailing risk, on clinicians' levels of satisfaction and enjoyment of their profession, and finally on possible ethical dilemmas that clinicians' may have to confront.

- From a quality assurance perspective, the policy implications of honoring patient choices in high-risk situations, in particular when their preferences result in an increase in the types and degrees of risks for which others may be held accountable or liable; and

- Factors, characteristics, and skills of formal health care providers that contribute to their effectiveness in (1) communicating information to patients; (2) motivating patients to assume responsibility for self-care; (3) working with other providers in a cooperative and coordinated manner; and (4) serving as primary care managers. Measurement and analytical tools are needed to assess the degree of effectiveness in these areas.

General Issues of Quality Assessment and Assurance

As noted earlier, the focus of quality assurance systems has been the hospital. However, episodes of care are increasingly nonmedical (and nonhospital) in nature. The settings in which care is provided and the manner in which the quality of that care is measured and evaluated are all changing.

Cutting across the concepts of episodes of care is the question of the conceptual framework within which health care professionals and institutions function. Practitioners generally have been trained in a "medical model," and the institutions in which they practice reinforce that model. Few psychosocial models (for instance, for rehabilitative care) have been integrated into the health care system.

For many, the nonbiologic environment plays a major role in health maintenance or rehabilitation; deficits in the environment affect health

status, in some circumstances even more than the underlying pathologic phenomena. Additionally, the interrelationship between traditional medical diagnoses or underlying diseases or conditions (on the one hand) and comprehensive multidisciplinary needs assessment and health status assessment focusing on personal functioning and quality of life (on the other hand) presents new challenges to the traditional quality assessment construct of structure, process, and outcomes.

Appropriate balancing of nursing initiative and physician responsibility is exacerbated in the home setting. Other questions regarding physician and nurse participation in case management and role resocialization among team members in home and community settings have evolved from demonstration projects such as the National Channeling Demonstration.

Measuring the quality, effectiveness, and appropriateness of care all involve personal and professional values. In community care, the values of many parties must be considered, more so, perhaps, than in traditional or inpatient care. For example, the (presumed) efficiency and productivity of centralized community-based services (day care, clinics) might be laid against the (presumed) personalized, individualized home-based modality of care, and all of these must be weighed against values of cost-effectiveness.

The workshop participants stressed the importance of conceptualizing quality from a perspective appropriate to community care rather than the traditional structure, process, and outcomes paradigm that tends to drive the hospital (acute care) model of care. Additionally, the study should look ahead and take into consideration the health care delivery organizations (structure, financing, etc.) that may exist by the middle or end of the decade. In particular, changes in the payment system (e.g., bundling of services, mini-capitation) and changes in the legal and corporate structure of health care entities (e.g., increased vertical integration of organization and systems; physician-owned diagnostic facilities) call for new thinking in quality assessment and assurance constructs.

Institutional features of health systems, at both the macro and micro levels, may need to be reviewed from a fresh perspective. The science of technology assessment has advanced far more in assessing medical devices and procedures than in assessing health care organization and financing structures. The popularity of the "outcomes movement" should not overshadow the importance of identifying measurable elements of this "technology" of community care and of developing analytical tools to understand their importance. Progress in these areas will be needed to make reliable and valid comparisons among settings and patient management models about questions such as the quality of the process of care, the satisfaction of health care providers and patients, and the efficiency with which care is delivered. The characteristics of community care, i.e., an individual receiving elements or units of care from multiple settings, and multiple settings providing a common element or unit of care, reflect a highly fruitful environment for such review.

Although much rhetoric is given to a patient-focused quality assurance system, many aspects of "patient-focused" remain to be defined, let alone

explored. Little is known about the specific needs, expectations, and goals of patients (or their families) seeking this particular form of health care. Why do they choose to go to one provider instead of another? For example, patients place different values on convenience, participating in the decisionmaking, and understanding the diagnosis and prognosis of their illness. As one workshop participant pointed out, many older women are uncomfortable actively engaging in health care decisionmaking with male physicians. For some patients a high "quality" of care, as defined by a regulatory agency or other distant monitoring group, is valued less than other attributes of care, such as care that allows the patient to remain in his or her own home or be cared for by an individual selected by the patient.

Quality from the patient's perspective, in these examples, is thus defined within a much broader context than simply the health care intervention. The standard of quality desired from the health care intervention may be low or high, depending on the trade-offs of other, perhaps nonhealth-related factors valued by a patient at a given point in time. As explained by one of the workshop participants, "Quality is very much the making of choices among a range of choices and having knowledge about the alternatives."

Special Slants on the Processes and Outcomes of Care

Processes of care. Instead of focusing on processes of care as traditionally defined and measured, a more appropriate construct for community care might be a detailed taxonomy of the elements and types of care delivered in diverse settings. For example, many of the same elements of care are provided both in private residential settings and nursing homes. Thus, the meaning of global terms such as "home care" and "nursing home care" becomes clouded; for example, all health care that is provided in the home setting is also available in nursing homes.

Outcomes of care. Several measurable aspects of an individual's health provide some insight on the benefits of community care: physiologic status, functional status, health-related knowledge, compliance, and satisfaction (Kramer et al., 1990). The challenges occur in linking these outcome measures to the health care interventions and the more structural factors influencing health outcomes -- a challenge that is greater in community care than in inpatient care

Several outcome-related measures have potential significance for application to community care: focused measures and condition- or treatment-specific measures; midpoint clinical indicators that have been considered more process than outcome measures; measures focusing on "caring about the patient" (the interpersonal aspects of care and the amenities of care) in contrast to "curing the illness or disease"; transmittal of knowledge between formal and informal providers and from those providers to patients; and increase in coping skills of patients and family or other informal providers. Many methodological concerns may no longer dominate as progress is made in conceptualizing quality.

Moving from Quality Assessment to Quality Assurance

Ultimately, the purpose of assessing outcomes (or structure, or process dimensions of health care) is to use the information to improve the quality of care. As in more traditional settings, however, critical gaps remain in how to transfer the quality assessment information to the next step of quality assurance. As documented in the IOM report on quality assurance in Medicare, we know much more about how to measures quality of care than we do about how to improve it -- i.e., to foster those changes in practitioner, institutional, and patient behaviors that will enhance care. Furthermore, issues of case mix, continuity of care, and "who is in charge" exacerbate the problems facing those who work to improve quality of care.

DATA ACQUISITION, MANAGEMENT, AND TECHNOLOGY

Workshop participants almost unanimously agreed that the primary, and most critical, issue in assessing and assuring quality in community care is data acquisition. Occupying a close second place were issues of information management and the related information sciences and technologies. They expressed, however, much caution about moving too quickly in defining what data elements were important or in adopting standards of practice based upon current, and limited, data analyses.

Historically, data collection has been driven by regulatory and financing forces rather than by what is useful to providers in improving quality. More thought must be given to what information is needed to evaluate quality of care across settings. A compendium of data sets that either already exist or are being developed would be a beginning step to identify information gaps. Developing common terminologies and units of measure will be necessary.

Information technologies should facilitate both the flow of patient-level data from acute settings to other settings and the accurate recording of pertinent information by the diverse and disparate parties involved in community care (including the patient). Electronic records may provide opportunities for off-site, instantaneous monitoring of care providers. Algorithms to help guide care can be used by patients and both formal and informal care providers.

Information management should facilitate the monitoring and management of the patient's episode of care, not just a unit of service. All care providers need to understand the purpose of data collection and analyses within the context of their role and performance in patient care.

Workshop participants argued that any IOM study in this area should attempt to identify the information needed to address the following questions:

- What services can safely be delivered to patients in which settings?

- What services and technologies can be appropriately delivered, again in which settings?

- What systems must be in place to shift patient care from hospital to private homes? to other types of community settings?

The study committee should turn to the pediatric, child health, handicapped children, vocational rehabilitation, Alzheimer patient, and independent living (disabled adults) sectors for potentially transferable models in "team management," interventions for lowering stress of care providers and parents, identification of points of stress and levels of stress.

POLICY, IMPLEMENTATION, AND OPERATIONAL ISSUES

Methods issues tend to cloud the clear identification of policy issues. Nevertheless, a strong indication from the workshop deliberations was that several policy issues should be explored by the IOM study. The typical IOM committee-based study was seen as an appropriate mechanism for deliberating these kinds of questions.

The workgroup identified several policy issues that might be addressed.

- As patients' choices and preferences are given more weight in decisionmaking, what are the changing patient and provider responsibilities for a care plan and (to some extent) for the outcomes of care?

- Is it appropriate that quality assessment strategies include measures to assess health care providers' roles in educating patients about care alternatives and the risks and benefits of each alternative?

- In the context of patients' making more choices and assuming more risk of outcomes, what are the appropriate relationships of risk taking and quality assurance? What implications do these have for monitoring quality of care (e.g., quality assurance models based on market forces versus those based on regulatory oversight)?

- Is it appropriate to have patients sign waivers of accountability, and if so under what circumstances?

- What are the roles and responsibilities of "society" in ensuring that <u>informed</u> choices are made and in determining the boundaries of acceptable options?

- Are there "Catch 22" implications for patients with strong family ties? For example, does eligibility for certain types of care depend on

having someone (informal caregiver) available to assist? Does assisting with care expose that caregiver not only to stress but also to liability should something go wrong? What happens when consensus does not exist among family members? How can abusive or fraudulent informal caregivers be identified and removed and, similarly, how can decisionmaking that is detrimental to the patient but provides financial or other rewards to the caregiver be detected and avoided or overcome?

- Will efforts under way to develop or implement standards of practice in community care produce relevant criteria that consider the importance of informed patient decisionmaking as well as medical theory?

IV. SUMMARY

MAIN ASPECTS OF THE WORKSHOP DISCUSSIONS

The workshop discussions produced clear guidance for the Institute of Medicine in the area under discussion (quality-of-care implications of the shift to home and community-based settings): plan and conduct a formal, committee-based study of the quality of "community care" and the means by which it might be assessed and improved. Workshop participants highlighted the many conceptual and practical obstacles to a successful exploration of these issues, not the least of which is the still-murky definition of community care.

Four main topics and a cluster of subtopics emerged as important for the study to address. First, with respect to the changing nature of community care, the topics that emerged from the discussion included the following: whether a unifying construct might be found and usefully employed; whether community care has unique characteristics with ramifications for quality assessment and assurance; the advantages and disadvantages of focusing on specific settings or special populations in a study of community care; and the appropriateness of the shift to noninpatient settings, viewed in a context of technology assessment.

A taxonomy was proposed to help clarify the shift in locus of care from hospitals to community settings: "hospital-displacement care" and "hospital-extension care." Hospital-displacement care refers to activities that could be (and typically used to be) done as inpatient services in a hospital but are now delivered outside such settings. Locales for hospital-displacement care include ambulatory care settings such as physicians' offices and outpatient surgical centers, day care centers, patients' homes, and nursing homes. Hospital-extension care refers to services begun in the hospital setting and continued in nonhospital settings. Such services are likely to be acute or post-acute care in nature.

Second, regarding major quality-of-care concepts and dimensions applicable to community care, a large number of questions surfaced. They involved: addressing quality issues in a "new" setting; addressing quality

issues in community settings; patient autonomy, choice, and control; general issues of quality assessment and assurance; special slants on the processes and outcomes of care; and moving from quality assessment to quality assurance.

Third, data acquisition and information management and information services technology were seen as critical aspects of the assessment and assurance of the quality of community care. Avoiding premature closure on definitions of data elements and fostering the use of electronic (e.g., computer-based) data systems were among the specific points emphasized.

Finally, policy and operational issues with a particular community-care slant were also brought up. Among the more difficult were those relating to patient choice (e.g., among settings and services that offer different kinds of benefits and risks) and problems of abuse, fraudulent, or self-interested informal caregivers (e.g., family and friends) in "invisible" home and community-based settings.

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QUALITY OF CARE IMPLICATIONS OF SHIFT IN HEALTH CARE TO HOME AND COMMUNITY SETTINGS
April 8-9, 1991
Provisional Agenda

MONDAY, APRIL 8, 1991 ROOM 110, 2001 Wisconsin Avenue, NW

6:30 p.m. RECEPTION

7:15 p.m. DINNER
Introductions of Planning Group and Staff
Overview of Workshop and Opening Discussions
Mary Mundinger, Chair
Kathleen Lohr, Deputy Director
Division of Health Care Services

TUESDAY, APRIL 9, 1991 ROOM 120, 2001 Wisconsin Avenue, NW

8:00 a.m. CONTINENTAL BREAKFAST

8:30 a.m. INTRODUCTIONS
OVERVIEW AND PURPOSE OF WORKSHOP
Mary Mundinger, Chair

WELCOME
Karl Yordy or Kathleen Lohr
Division of Health Care Services

8:50 a.m. MAPPING THE ISSUES
Robert Kane, Lead Discussant

10:00 a.m. BREAK

10:15 a.m. NARROWING AND CLARIFYING THE ISSUES
Ruth Galten, Lead Discussant

11:00 a.m. FRAMING THE ISSUES INTO STRATEGIES APPROPRIATE FOR IOM
Peter Shaughnessy, Lead Discussant

12:00 noon LUNCH

12:45 p.m. REACTIONS AND SUGGESTIONS FROM OBSERVERS

1:45 p.m. CONTINUATION OF DISCUSSION ON DEFINING AN IOM-SPECIFIC ROLE
Types of activities, short and long range, sources of funding

3:00 p.m. SUMMARY AND NEXT STEPS

3:30 p.m. ADJOURN

INSTITUTE OF MEDICINE WORKSHOP ON
QUALITY OF CARE IMPLICATIONS OF SHIFT IN CARE
TO HOME AND COMMUNITY SETTINGS
Meeting on April 8 - 9, 1991

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