Perspectives on Home Care Quality

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Home care quality assurance (QA) must consider features inherent in home care, including: multiple goals, limited provider control, and unique family roles. Successive panels of stakeholders were asked to rate the importance of selected home care outcomes. Most highly rated outcomes were freedom from exploitation, satisfaction with care, physical safety, affordability, and physical functioning. Panelists preferred outcome indicators to process and structure, and all groups emphasized "enabling" criteria. Themes highlighted included: interpersonal components of care; normalizing life for clientele; balancing quality of life with safety; developing flexible, negotiated care plans; mechanisms for accountability and case management. These themes were formulated differently according to the stakeholders' role. Providers preferred intermediate outcomes, akin to process.

INTRODUCTION

Home care poses difficulties for QA because it encompasses a wide variety of procedures and services delivered to a diverse range of patients and clients by diverse health and social service agencies, independent vendors, and families. Before

elaborating a technology of QA in home care in response to the call for accountability, it is necessary to consider, in a more general way, what health and social goals home care should be expected to meet, and what will count as success or failure.

The information reported here on key stakeholder perspectives on the quality of home care is the first part of an ongoing HCFA-funded series of linked studies that were designed to examine quality issues with attention to socially oriented and non-skilled home care as well as Medicare-certified home care (Kane et al., 1991). Other tasks include development of a system for reliable measurement of quality for non-skilled home care; examining the adequacy of home care in late stages of Medicare coverage; analyzing issues regarding recruitment, retention, and quality of a paraprofessional workforce for home care; and identifying and describing best practices in QA for home care. The last task is further subdivided into examining consumer-protection mechanisms, agency-initiated QA practices, external case management as a QA tool, and State regulatory approaches. As a result of all these studies, a research and demonstration agenda on QA in home care will be proposed. Early reports of these approaches are found in Yee and Capitman (1994); Kane (1994); Crown, McAdam, and Sadowsky (1991); and Sabatino (1992).

This article describes the challenges of defining and achieving an acceptable quality of in-home services for older people, including ways of classifying different types of home care, possible goals for

home care, and ways that achievement of these goals might be or has been measured. It then identifies multiple perspectives on the quality of home care held by different stakeholders.

BACKGROUND

Home Care Defined

Home care, simply stated, is any kind of health care, personal care, or assistance with independent living given to functionally impaired, disabled, or ill persons in their own homes. Some expand this definition to include the assistance to family members who are caring for relatives in their homes and to care given to residents of other community home-like settings, such as assisted living (Russell, 1977). Home care may include modification of the home and provision of equipment so that a consumer may remain at home. Some argue that home care also includes a wider range of community services, such as delivered meals, adult day care, and transportation that may be organized for frail elderly persons living at home. Spokespersons for some younger disabled persons reject the term "home care" entirely, urging "personal assistance services" as the preferred term and concept. To them, "care" carries an affective rather than instrumental meaning, and "home" violates the principle that assistance should be extended to persons with functional disabilities regardless of whether they are at home, at their job, in school, or pursuing recreational or social activities outside their homes. Depending on the view of home care endorsed, the scope of QA activities may become very broad (Litvak, Zukas, and Heumann, 1987).

Home care falls in a gray zone of health and human services. It includes both acute-care services (some involving equipment and procedures that formerly were found only in hospitals [U.S. Congress, 1992]) and the more amorphous personal care services associated with long-term care. It is a social service that allows disabled persons to maintain more independent lifestyles or remain in the community. It draws upon the talents of a multidisciplinary range of professionals (for example, nurses, physical therapists, physicians, social workers), but it also is provided by paraprofessional home health aides, homemakers, attendants, personal assistants, and chore workers. It runs the gamut from a highly technical, health-related service that can be judged by explicit criteria, to a social service with broad, general, and sometimes individualized goals. Often, clients receive both extremes of services as part of their home care, either sequentially or simultaneously. The very alternation between the designation of "patient" and "client" reflects this dual sponsorship.

Home care is funded many ways— Medicare, Medicaid, title XX, title III of the Older Americans' Act, the Department of Veterans Affairs, and special State initiatives—as well as by direct consumer purchase of care. Again, clients may well receive services sequentially or simultaneously from more than one provider agency or independent vendor and under more than one payment source, all in addition to the services provided by family and friends.

Why Consider Home Care Quality Now?

Long-term care at home has been an ideal long advocated by older persons and their spokespersons, as well as by many professionals who serve the elderly. But home care is more than an ideal—it is also a rapidly expanding reality. The number of certified home health agencies (HHAs) has increased markedly over the past decade, increasing 43 percent from 1983 to

1989 and leveling off at 6,000 agencies in 1991 (Branch et al., 1993). The number of uncertified home care, homemaker, or personal care agencies also has increased markedly, although it is more difficult to enumerate the organizations, as Harrington and Grant (1990) attest from their work in California. Spending on the Medicare home health benefit increased from about $2 billion in 1988 to $10.5 billion in 1993, with a 96-percent increase in visits per beneficiary over the 3 years from 1989 to 1992 (Vladeck, 1994). Expenditures on home health as a total share of Medicare went from 2.4 percent in 1988 to 5.5 percent in 1992 (Arnold, Gage, and Harris, 1994). Given trends towards greater treatment of chronic disease in the home, interests in the integration of acute-care and long-term care, and interest in designing benefits that serve persons with disabilities with all ages (Vladeck, Miller, and Clauser, 1993), HCFA recently launched the Medicare Home Health Initiative (1994) to examine the extent to which this ever more costly benefit is designed to meet the needs of beneficiaries. Views are being sought on the extent to which the Medicare home health benefit meets goals of responsiveness to consumers, flexibility, and fiscal responsibility (Vladeck, 1994).

Home care providers, both large and small, have taken initiatives to implement their own QA efforts (i.e., Daubert, 1977; Gould, 1985; Day, 1984; Daniels, 1986; Wagner, 1988; Peters and Regenstreiff, 1989). The National League for Nursing's Community Health Accreditation Program (1986), the Joint Commission on the Accreditation of Health Care Organizations (JCAHO) (1988), McCann and Rooney (1989), and the National HomeCaring Council (1981) have all promulgated standards for private voluntary accreditation of home care providers. For the most part,

these efforts apply to medically oriented programs, especially those affiliated with hospitals or Visiting Nurse Associations.

In general, QA in home care is at an early stage of development, comparable to QA in nursing home care about 15 years ago. However, in response to both public and professional pressure, States are moving with some rapidity toward licensure requirements for home health and homemaker agencies and even toward certification for paraprofessional home care providers who work for agencies or independently (Miller et al., 1989; Hankowitz, 1991). This approach to defining quality by setting standards for the organizations and individual providers who will be allowed to give the care is being pursued without an adequate body of evidence about the type of training, supervision, and qualifications actually needed for a good result in home care.

The following militate toward greater surveillance of home care:

- Public payments for home care are increasing, bringing in their wake an increased interest in accountability.
- Much anecdotal and some research evidence is appearing about defects in the quality of home care (American Bar Association, 1986; Harrington, 1988; Leader, 1986; U.S. Office of the Inspector General, 1987; Reif, 1987).
- Some evidence is appearing to suggest inadequacies of access to home care, either as a result of hospital prospective payment or early discharges (Estes, Swan, and Associates, 1993). Furthermore, Shaughnessy and colleagues (1994) report that HMO members receive less home care on discharge from hospital than their fee-for-service counterparts and have poorer results.

- Home care clients are perceived as particularly vulnerable. By definition, home care occurs much more privately than most health care. Clients who are extremely physically disabled or cognitively impaired (especially if they live alone) and those who simply live alone are viewed as unable to protect themselves against inadequate or abusive care.
- Home care is often perceived as an inherently desirable service that may be misused by clients and their families unless its appropriateness is monitored.
- Home care is increasingly emerging as feasible for persons disabled enough to qualify for publicly subsidized nursing home care. Because nursing homes are heavily regulated, nursing home leaders are calling for a "level playing field" with similar surveillance of quality in the home care sector.
- The growth of public programs that reimburse self-employed workers (Flanagan, 1994), including some that compensate relatives (Linsk et al., 1992), introduces new concerns about quality because of the lack of the oversight associated with formal agencies.
- Home care providers are also serving persons who live in group residential settings where clients have their own self-contained apartment units, like assisted living (Kane and Wilson, 1993), blurring cleancut distinctions between home and residential care and introducing additional quality concerns.

QA Technology

In the United States, QA in health services is: first, a discipline with its own language and techniques; second, a growth industry, with its panoply of consultants; and third, at least to some extent, a social movement. Since the enactment of Medicare and Medicaid, a technology has developed to examine both the appropriateness of care and the quality of the care rendered. Commonly, QA is seen as having three steps: establishing the definition of adequate and/or excellent quality; assessing care against those standards; and correcting identified problems. Criteria for defining quality are typically expressed according to Donabedian's classic threefold typology (1966): (1) structural criteria that pertain to the entire program—for example, buildings and equipment, staff credentials and ratios, record systems, and committee structures; (2) process criteria that pertain to treatment of particular problems; and (3) criteria for expected outcomes.

QA in health care as a science and as an industry developed largely in the acute hospital setting, where review tends to be done retrospectively, usually by examining the records of discharged patients. Well-established techniques have evolved to reach consensus on quality criteria, assess care according to protocol, develop management information systems for profiling care, and conduct medical care evaluation studies (which are retrospective audits of care, followed by systematic efforts to correct identified deficiencies, and re-audits). In addition to these techniques, the revisionist technology known as Total Quality Management (TQM) or Continuous Quality Improvement (CQI) has taken a hold on bureaucratic imaginations over the past decade. Now a new orthodoxy with overtones of social movement, TQM is a bottom-up process by which work groups are encouraged to define quality and suggest ways of improving it. In fact, the TQM approach is highly compatible with and can coexist with the older form of audits against specified criteria. If used thoughtfully, it offers a vehicle to continuously update criteria.

Nursing home QA has been acknowledged to be different from QA in hospitals because stays tend to be lengthy and perhaps

of indefinite duration. This has three implications for QA (Kane and Kane, 1988). First, defining events and attributing outcomes is difficult, particularly if the nursing home stay is punctuated by episodes of hospital care. Second, and perhaps more important, prospective review of ongoing care becomes feasible and, therefore, a moral imperative is created to provide feedback to improve care for particular persons in the present rather than merely using feedback to do a better job with the next group of patients. Third, because a nursing home is a living situation, sometimes of indeterminate length and sometimes for the remainder of the resident's life, the more complex issue of quality of life of the resident becomes, in part, the responsibility of the care setting. Conflicting goals are often held by and for nursing home residents. The definition of adequate quality of care may, therefore, depend on which medical, psychological, or social goals take priority. Fourth, though nursing home care often entails use of sophisticated technology, much of the service is provided by personnel with minimum training, and without professionally derived standards or codes. Review based on records is even less feasible than in hospital review.

In common with nursing home care, home care takes place over extended time periods, with current or periodic use of other services (e.g., adult day care, primary medical care, hospital care, and nursing home care) that renders attribution of outcomes difficult; serves clients whose problems are complex and multiply determined; includes both high and low technology services; requires setting priorities among conflicting goals for physical, psychological, and social outcomes; and is usually provided within a climate of resource constraints. The next section describes special features of home care that should be considered in defining and assessing its quality.

RELEVANT FEATURES OF HOME CARE

Home care takes place at multiple private locations, making overseeing difficult. Responsibility for quality of life, which is a salient aspect of the quality of nursing home care for which providers are held accountable, is more ambiguous in home care. In the nursing home, every aspect of the resident's life is governed by the care plan. Therefore, nursing homes should be properly accountable for positive and negative quality of life and should be required to explain on a case-by-case basis why negative outcomes were beyond their control.

In home care, the caregiver's responsibility is less direct. Although insensitive, incompetent, exploitive, or abusive home care could certainly diminish the quality of the client's life in measurable ways, the clients themselves are generally responsible for many of the psychological and social outcomes of home care. Unless they are "live-in" personal assistants, home care providers have only periodic contact with the clients and subsequently may or may not have a pervasive effect on their social and psychological well-being. Nevertheless, the one-on-one nature of home care can provide a unique opportunity for the client and provider to form a close relationship. No doubt the interpersonal components of care are often prime determinants of a patient's perception of quality (Gubrium and Sankar, 1990). When a home care plan has the expressed goal of providing companionship and social contact to mitigate loneliness and isolation, the achievement of that goal should be measurable and measured. But whether the effects of home care can be reflected in general measures of positive well-being is unclear and a matter for study.

Heterogeneity of Programs, Goals, and Clientele

Home care is hardly monolithic; it serves differing clientele with different health conditions and prognoses. Home care providers differ, therefore, in the goals they have for their interventions. We propose a classification relevant to defining quality of home care that cuts across arbitrary distinctions based on categorical payment programs. We suggest that, based on general goals, at least five types of home care can be identified: post-hospital convalescence; rehabilitation; hospice; in-home maintenance; and home respite care. Each of these types emphasizes different goals.

- *Convalescence from Acute Illness:* goals emphasize stability of medical condition; patient and family knowledge about the condition and its proper care; limiting complications; rapid attention for complications; goals for disease-specific recovery; and limiting rehospitalizations.
- *Rehabilitation:* goals emphasize physical functioning; self-care abilities; mobility; communication ability; and patient and client knowledge about how to compensate for disabilities.
- *Terminal Care:* goals emphasize pain control; psychological well-being of patients and families; patient's self control; and "good deaths."
- *In-Home Maintenance:* goals emphasize minimized unmet need; reduced rate of deterioration; social well-being; psychological well-being; prompt identification of and attention to changes in health status; perceived sense of safety and security; client satisfaction; and reduced use of nursing homes.
- *Respite Care:* goals emphasize psychological and social well-being of family caregivers; continuation of family caregivers in their roles; and reduced use of nursing homes.

When outcome criteria are specified, they should match the goals of the enterprise, regardless of the payment program. Similarly, structure and process criteria that are promulgated should be logically related to the particular outcomes desired.

Lack of Provider Control

The nature of home care implies a sharing of power between provider and client. Because home care occurs on the client's turf, providers have much less control over outcomes than for hospital care or nursing home care. (In this sense, home care is analogous to ambulatory care.) Clients and family members have rightful expectations for how and when things are done in their own homes, and professional standards of sanitation, efficiency, and optimal routines are inevitably compromised by the give and take of a household (Riley, Fortinsky, and Coburn, 1992). This shift in the balance of power is, one can argue, highly desirable, but it has made some home care organizations leery of accepting responsibility for outcomes.

A related issue is the adequacy of a given home setting as an environment for specific care or as a working setting for personnel. For example, can a home care provider function capably in the absence of plumbing and electricity? Must a home care program send its workers into dangerous neighborhoods or buildings with drug traffic in the stairwells? Or, if home care providers are subject to disrespectful treatment at the hands of clients or their relatives, are they obliged to continue giving care?

Specific lines of organizational accountability for home care are likewise difficult to pinpoint. Perhaps, responsibility is clearest when a client is referred for Medicare-funded home health care, and this is the only source

of payment for services received. Then a registered nurse or, when no nurse is involved, a physical therapist, has overall responsibility for coordinating care and supervising paraprofessional home health aides. Even then, issues arise about the responsibility of the physician who technically has ordered the care and oversees it, about how responsibilities are shared when more than one home health professional is in the case, and about the adequacy of any home care plan after the client is no longer eligible for Medicare.

Beyond Medicare, accountability becomes more diffuse. A case manager who is independent of a provider may have responsibility for assessing need, purchasing services, and monitoring the quality of care, but home care agencies may also retain or be designated some of these functions under various public programs (Applebaum and McGinnis, 1992). Moreover, clients may well receive care and services from multiple agencies and self-employed workers as well as from family. Thus, an external case manager and several provider agencies or independently employed providers may be active in a single case. Even legal responsibility is unclear (Johnson, 1989). Although private tort action in home care is rare, relevant precedents point to confusion about the responsibility of HHAs to supervise paraprofessional workers employed by other agencies or directly by the consumer. One response to such confusion is to hold home care providers responsible for only a narrow set of goals related to their own services. A different approach is to hold a lead provider, all providers, or a case management provider responsible for the cumulative effects of all home care.

Family Involvement

Most non-skilled home care, and indeed substantial care that would be considered "skilled," if provided by an agency, that is received by functionally impaired older persons is given on a voluntary basis by family members—i.e., the uncompensated help and care labelled as "informal care" by professionals. Home care under Medicaid waiver or State-funded programs is typically designed to supplement, not supplant, informal home care. When families are expected to be active partners in care, QA is complicated in three ways:

- Definitions of appropriateness and need for care must be grappled with when family care is or is not appropriate for the condition or circumstances and, therefore, formal care is indicated.
- Assessments of quality of care must take into account the quality of the care given by family members, and some would argue that formal caregivers have a legitimate role in instructing and monitoring informal caregivers.
- To some extent, the goals for home care include goals related to family members, particularly when the home care is construed as respite care designed to relieve family burden.

Unfortunately, these complications generate confusion about whether and when family members are perceived as providers of care or as receivers of care. The role definitions are made even more complex when a public program compensates family members for some of the care they provide, thus blurring the distinctions between formal and informal care.

ESTABLISHING CRITERIA

Home care can be examined according to Donabedian's three types of criteria: structure, process, and outcome. Structural criteria would apply to staff qualifications, staffing levels, supervisory practices, record-keeping, equipment, and administrative policies (including having a QA program).

Process criteria could be directed toward the appropriateness of various types and intensity of care for specific conditions. Several problems complicate the development of criteria for appropriateness of home care:

- More than one plan can lead to a good result, and considerable interchangeability is possible in the use of, say, in-home services, home-delivered meals, and adult day care.
- Clients have opinions about how much home care they desire, often selecting less care than professionals deem optimal (Lawton et al., 1989).
- The need for home care will depend on the amount and adequacy of family care.
- Little is known about the results of offering care of different intensity from care providers with different levels of formal training; reliance on expert judgment of professionals tends to perpetuate an orthodoxy that drives up costs and, thus, reduces availability.

Process criteria also refer to general or problem-specific protocols for the adequacy of care. The former could include general processes for maintaining hygienic conditions, whereas the latter could include, say, protocols to prevent skin breakdown in the event of immobility or to care for catheters. There is some disagreement about whether such process criteria should differ according to the setting where the client is found. Kramer and colleagues (1990) developed a series of quality indicator groups (QUIGs) to classify home care clients into groups that pose similar quality challenges and develop "focused" process indicators for Medicare-funded clientele.

A wide range of outcome criteria could be suggested, linked in part to the goals associated with the type of home care and the individual goals and preferences of the clients. To use outcomes in QA, one must develop data about groups of clients so as to compare actual average outcomes for one group with actual average outcomes for another group, taking into account expected outcomes given baseline status. However, demanding responsibility for outcomes in a situation where providers do not have control poses serious difficulties.

Finally, we argue for a fourth type of criteria, which we call "enabling criteria," to take into account some non-technical preconditions for a satisfactory result when care occurs in the intimacy of a private home. These could include courtesy, punctuality, reliability, and honesty of the in-home workers and compatibility between home care providers and clients (Eustis, Kane, and Fischer, 1993). Focus groups and surveys of consumers repeatedly point to the importance of these factors as contributors to client satisfaction (Applebaum et al., 1988; Caro, 1988; Riley, 1989). Table 1 displays problems in home care quality identified in the literature for each type of criteria. The table documents the course of the allegations for each quality problem; the presence of these problems is based more on anecdotal than solid evidence.

PERSPECTIVES OF MULTIPLE STAKEHOLDERS

Method of Study

In January and February 1990, the University of Minnesota research staff conducted six structured panel discussions to identify the most salient outcomes of home care as perceived by six different constituencies: (1) actual users of home care; (2) consumer representatives; (3) home care providers of different disciplines

Table 1

Suspected Home Care Quality Problems, by Type of Criteria

Structure	Providers with criminal convictions.[1]
	Home health aides deficient in basic knowledge.[2]
	Essential services not available in community.[3]
	Not enough qualified personnel to meet demand.[3]
	Inappropriate match of personnel and client.[4]
	Care too expensive, insufficiently reimbursed.[5]
Process	Case managers not seeking to remedy remediable conditions.[4]
	Rough care.[4]
	Failure to perform or complete tasks adequately.[4,6,10]
	Failure to conform to physician orders.[4,7]
	Worker insensitivity, disrespect, or intimidation of client.[4]
	Inadequate plan of treatment.[7]
	Inadequate coordination of patient services.[7]
	Inadequate clinical care.[7]
	Post-hospital care not received according to guidelines for time of initial visit and intensity of service.[8]
Outcome	Unintentional physical injury of clients.[8]
	Intentional injury or abuse of clients.[8]
Enabling	Theft and financial exploitation.[4,8]
	Worker tardiness, no-shows, or early departures.[4,8]
	Attendants not available at hours needed or long enough.[5]
	User has insufficient control over selection, training, job definition, supervision, and firing of home attendant.[5]
	Clients not confident workers will be available as long as they will be needed.[9]

[1]Harrington, 1988.
[2]A 1987 survey by the National League of Nursing of Home Health Aides found 46 percent did not know how to monitor fluids; 45 percent did not know proper diabetic care; 40 percent could not safely assist a stroke victim in walking; 30 percent could not identify low-salt foods; 30 percent did not know what to do if a patient stopped breathing; and 4 percent could not read a thermometer.
[3]Relf, 1987.
[4]Phillips et al., 1989.
[5]Litvak, Zukas, and Heumann, 1987, referring particularly to personal assistance for independent living.
[6]American Bar Association, 1986. Data came from testimony of interested parties, including consumers.
[7]Leader, 1986, reporting 1985 Health Care Financing Administration surveys in New Jersey and in Region 2 (New York, Puerto Rico, Virgin Islands). Data came from record reviews.
[8]Phillips, 1989.
[9]Fischer and Eustis, 1988.
[10]In a 1987 survey by the U.S. Office of Inspector General, aides failed to document or perform one-half of all prescribed tasks that were needed to support the duties of skilled nurses or physical therapists. One hundred percent of all personal care duties were performed.

SOURCE: (Kane et al., 1991).

and sponsorship; (4) paraprofessional personnel; (5) payers and insurers of home care; and (6) regulators, accrediting bodies, and government officials overseeing publicly financed home care. The home care consumer and paraprofessional provider meetings were limited to attendees from the Twin Cities area, whereas the other four panels were national in scope. Each panel included six to eight participants.

The agenda of each panel meeting included: informal reaction to prepared material; iteration of the goals of home care held by group members; rating the importance of the resultant list of outcome goals; generation of indicators that in the opinion of panelists would signify goals had been achieved; and a general discussion of quality and QA as perceived by group members. This procedure allowed us to examine within-panel and across-panel points of consensus and disagreement. To further explore the issues, we convened selected participants from previous groups for a final panel meeting. Although we by no means suggest that the panels were representative of their particular constituencies (and indeed each panel was far from homogeneous), the points of difference that emerged were suggestive, and the general areas of agreement were illuminating.

Preference for Outcomes as Quality Indicators

Panel members were asked to rank, in order of importance, the four kinds of quality indicators: structure, process, outcome, and enabling. The provider, insurer/payer, and government overseeing official panels all rated outcome indicators the most important. (The consumer group found enabling indicators the most compelling.) The regulators indicated that focusing on outcome measures is especially important when comparisons are being done. Outcome measures, however, were seen to have some limitations. Two perceived disadvantages to using outcome measures are: the belief that providers have incomplete control over outcomes; and the concern that outcome measures may not identify care of questionable quality until it is too late to make changes.

Outcome indicators were followed in order of preference by process, enabling, and structural indicators. Within each of these types of measures participants found certain specific ideas they felt were important. For example, although structural indicators were the least preferred among the four types of indicators, training of care providers was still favorably endorsed by all groups.

Several panels suggested that the caveats associated with these rankings needed to be understood. For one, it was widely acknowledged that none of the types of indicators should be used alone. Additionally, some panelists (particularly the professional providers) thought there should be a different set of criteria for medically oriented home care and more socially oriented home care. Consequently, certain indicators may be preferred over others, depending on the nature of care. Professional standards (process indicators

of quality) already exist for acute medical care while there are no community standards for chronic care. And, as several participants pointed out, clients feel unqualified to evaluate appropriate care, but believe they can evaluate such attributes as courtesy, promptness, and responsiveness, making them keen on enabling quality for the less technical aspects of care.

The consensus around the value of outcomes was marred by the different ways outcomes were interpreted. Providers tended to define outcomes in terms of what others might consider process. For example, they cited gains in family member knowledge about how to provide specific services, rather than improvements in function. When pressed, the providers were willing to accept responsibility for activities they viewed as intrinsic to their services, such as education, but were reluctant to accept more global outcomes that required active patient participation.

Rating Home Care Outcomes

We asked each participant to rate the importance of 21 home care outcomes by assigning each a score from 0 to 100. The exercise was performed with reference to three different types of clients: those who need help with instrumental activities of daily living with no more than need for minimal personal care (Table 2); those with heavy personal care needs and/or need for medical monitoring (Table 3); and those with moderate or severe cognitive impairments (Table 4).

In assigning scores, panelists were asked to consider the extent to which home care providers should be held responsible for, on average, achieving positive outcomes or slowing down or preventing negative outcomes on each item for groups of clients. The whole task was done

Table 2

Relative Importance of Home Care Outcomes, as Perceived by Multiple Constituencies, for a Client With Homemaking Needs and Minimal Needs for Personal Care[1]

Home Care Outcomes	Consumer Representatives n=9	Professional Providers n=9	Insurers/ Payers n=6	Regulators n=11	Paraprofessional Providers n=6	Home Care Users n=4
Physical Functioning	68	49	83	81	63	40
Cognitive Functioning	68	31	53	58	54	51
Symptom Control	64	33	28	67	64	75
Physiological Functioning	51	32	45	66	64	64
Psychological Functioning	65	45	56	66	62	68
Social Activity	48	35	42	56	52	53
Compliance With Regimen	39	44	69	67	59	78
Client Knowledge	82	63	65	72	70	70
Physical Safety	36	66	90	78	69	75
Freedom From Abuse	93	76	83	91	91	98
Satisfaction With Care	93	68	72	92	88	80
Satisfaction With Life	72	56	32	69	68	65
Client Choice	88	68	56	96	71	73
Hospitalization	43	36	83	48	87	49
Nursing Home Admission	49	43	86	51	90	70
Other Congregate Setting	41	39	65	52	86	60
Death	29	41	49	43	88	79
Morbidity	45	52	80	74	83	68
Family Stress	53	56	66	54	63	63
Family Knowledge	64	61	56	61	58	73
Affordability	88	54	93	71	53	58

[1]Importance score from 100 (most important) to 0 (least important).

NOTE: All scores were assigned by considering the extent to which home care providers should be held responsible for achieving positive outcomes or slowing down or preventing negative outcomes, with the understanding that average achieved outcomes would be compared with expected outcomes for groups of clients.

SOURCE: (Kane et al., 1991).

Table 3

Relative Importance of Home Care Outcomes, as Perceived by Multiple Constituencies, for a Client With Heavy Personal Care Needs and/or Medical Needs[1]

Home Care Outcomes	Consumer Representatives n=9	Professional Providers n=9	Insurers/ Payers n=6	Regulators n=11	Paraprofessional Providers n=6	Home Care Users n=4
Physical Functioning	82	74	87	92	73	81
Cognitive Functioning	75	50	74	63	68	79
Symptom Control	81	73	74	94	60	70
Physiological Functioning	73	79	73	96	78	69
Psychological Functioning	69	63	59	66	70	59
Social Activity	55	30	62	47	66	43
Compliance With Regimen	68	62	88	77	63	83
Client Knowledge	83	84	80	86	74	84
Physical Safety	46	79	87	81	88	73
Freedom From Abuse	92	84	97	91	93	81
Satisfaction With Care	82	73	80	90	86	88
Satisfaction With Life	68	59	42	65	66	59
Client Choice	83	70	59	87	68	68
Hospitalization	55	58	87	59	80	48
Nursing Home Admission	59	51	89	57	78	66
Other Congregate Setting	45	52	62	53	72	74
Death	37	53	69	51	67	73
Morbidity	68	74	82	92	85	80
Family Stress	61	57	72	66	63	71
Family Knowledge	62	71	58	74	63	84
Affordability	88	59	93	69	60	73

[1]Importance score from 100 (most important) to 0 (least important).

NOTE: All scores were assigned by considering the extent to which home care providers should be held responsible for achieving positive outcomes or slowing down or preventing negative outcomes, with the understanding that average achieved outcomes would be compared with expected outcomes for groups of clients.

SOURCE: (Kane et al., 1991).

Table 4

Table 4

Relative Importance of Home Care Outcomes, as Perceived by Multiple Constituencies, for a Client Who is Moderately or Severely Cognitively Impaired[1]

Home Care Outcomes	Consumer Representatives $n=9$	Professional Providers $n=9$	Insurers/ Payers $n=6$	Regulators $n=11$	Paraprofessional Providers $n=6$	Home Care Users $n=4$
Physical Functioning	75	44	82	80	76	68
Cognitive Functioning	71	34	70	58	55	53
Symptom Control	76	41	41	78	61	95
Physiological Functioning	53	41	64	76	73	85
Psychological Functioning	73	44	47	60	49	80
Social Activity	59	34	57	48	57	47
Compliance With Regimen	41	30	77	62	65	90
Client Knowledge	59	15	51	36	51	79
Physical Safety	52	62	75	81	95	58
Freedom From Abuse	92	79	92	93	97	71
Satisfaction With Care	77	35	55	58	73	65
Satisfaction With Life	52	35	28	40	71	58
Client Choice	72	36	50	46	42	60
Hospitalization	42	53	73	43	62	53
Nursing Home Admission	53	44	78	43	60	50
Other Congregate Setting	38	46	57	41	50	49
Death	31	34	65	42	49	60
Morbidity	46	46	70	69	93	96
Family Stress	83	53	79	63	64	91
Family Knowledge	77	75	70	77	71	93
Affordability	91	43	93	71	66	97

[1]Importance score from 100 (most important) to 0 (least important).

NOTE: All scores were assigned by considering the extent to which home care providers should be held responsible for achieving positive outcomes or slowing down or preventing negative outcomes, with the understanding that average achieved outcomes would be compared with expected outcomes for groups of clients.

SOURCE: (Kane et al., 1991).

twice. The first ratings were calculated, shared with the groups, and used as a basis for discussion. Thus, the ratings in the tables reflect each panelist's more considered opinion. Panelists from the final panel consisting of representatives from each of the original six panels were also asked to perform the exercise though on a simplified Likert-style rating (not shown). Table 5 summarizes the outcomes seen at the extremes of most important and least important by each group for each type of home care client, based on the final round of ratings after group discussions.

Based on the rankings from six role-specific panels and the final cross-cutting panel, five goals were consistently reported to be important: freedom from exploitation and abuse, satisfaction with care, physical safety, affordability, and maintenance or improvement of physical functioning.

Freedom from exploitation was the universally accepted goal for all panels and for all types of clients, whereas satisfaction with care (for the two cognitively intact groups only) was important to all panels except the insurers. The consumer representatives and the paraprofessional providers did not consider physical safety to be as important a goal as the other panels did (including the actual users of services). Physical safety was considered less important for clients with heavy care and medical needs.

Although mentioned less often by the six role-specific panels than the first three goals, the fourth goal—affordability—was ranked among the top three goals by the final panel. Only the consumer representatives and insurers ranked affordability as an important goal for all three types of clients, whereas actual home care

Table 5

Relative Importance of Home Care Outcomes, as Perceived by Multiple Constituencies (Consumers, Providers, Insurers/Payers, and Regulators), for Different Types of Clients[1]

Home Care Outcomes	Client With Homemaking Needs and Minimal Needs for Personal Care	Client With Heavy Personal Care and/or Medical Needs	Client Who is Moderately or Severely Cognitively Impaired
Physical Functioning	68	83	70
Cognitive Functioning	54	66	58
Symptom Control	52	81	65
Physiological Functioning	52	81	60
Psychological Functioning	57	63	56
Social Activity	47	49	50
Compliance With Regimen	52	71	50
Client Knowledge	69	82	42
Physical Safety	65	72	68
Freedom Fom Abuse	85	89	88
Satisfaction With Care	82	82	58
Satisfaction With Life	58	58	39
Client Choice	79	75	50
Hospitalization	52	64	53
Nursing Home Admission	56	62	53
Other Congregate Setting	52	56	47
Death	43	53	42
Morbidity	60	78	59
Family Stress	57	63	69
Family Knowledge	62	69	77
Affordability	71	74	72

[1]Importance score from 100 (most important) to 0 (least important).

NOTE: All scores were assigned by considering the extent to which home care providers should be held responsible for achieving positive outcomes or slowing down or preventing negative outcomes, with the understanding that average achieved outcomes would be compared with expected outcomes for groups of clients.

SOURCE: (Kane et al., 1991).

consumers included affordability among their top goals for the cognitively impaired clients only. Physical functioning was not among the top goals cited by the final cross-cutting panel, although several of the other panels considered it important. The insurer/payer and government overseeing panels considered physical functioning a goal for all three clients types, the consumers and consumer representatives considered it an important goal only for the heavy care client, and paraprofessional providers considered it important only for the cognitively impaired client.

Beyond these five goals, the other 16 goals were dispersed across the spectrum between important and unimportant although there were subtle differences among rankings for the three types of clients. For example, panels tended to give more importance to family-related goals for the cognitively impaired client (because respite for family is embedded in the care) and consistently ranked the goals of symptom and pain control higher for the heavy physical need client (presumably because this is more relevant to that group).

The results of this exercise in quality rating are presented not as hard data representing the constituent groups, but as illustration of the process and the complexity involved in considering and prioritizing outcomes.

Key Themes

Although differences in emphasis exist, several themes consistently emerged from all panels except the group of insurers, which tended not to be concerned about the quality of care except in certain narrow parameters.

The Interpersonal Component of Home Care

In keeping with the mutual dependency between the providers of home care and their clients that prevails in home care and the blurring of the boundaries of a paid care provider's duties, the panelists emphasized the importance of the "human element" of care. Consumers, providers (particularly home health aides), and regulators and government officials alike emphasized the importance of compatibility between the home care worker and client as a goal for home care. Some home care users, while not minimizing the importance of the skills of the worker, went so far as to prefer adequate care from a worker with whom they enjoyed a genial relationship over excellent care given by an unpleasant worker. Similarly, maintaining the personal autonomy and choice of the consumer was a widely held goal. To this end, there was an interest in mechanisms for consumers to complain and make changes when their home care worker proved unsatisfactory.

Given this agreement about the salience of the social aspect of home care, debate arose over whether the practical translation of this would necessarily encourage a home care worker to socialize in a familiar sense (e.g., sit around and chat or watch TV) with the client. Home health aides saw socializing as part of the care even if it was not specifically written into the care plan. In contrast, some consumers of home care indicated that having a good relationship with the worker did not entail workers spending their limited service time socializing with the client. Rather, they preferred workers to use their time doing "things with a purpose."

Normalization

Consumer advocates (particularly for the younger disabled) emphasize the idea that home care should allow persons with limitations to live as normal a life as possible. For younger disabled persons who are receiving home care, there are a myriad of programs set up to normalize their lives. At least one State aging director suggested that special consideration be given to programs that promote normal living for the elderly and that any biases against these programs should be consciously minimized. For example, a State's willingness to make public funds available to transport an elderly client to adult day care for socialization but not to take them to a friend's home to play bridge (an activity that most would consider "normal") would reflect such bias. Similarly, a normalizing approach to home care would permit home care workers to perform a variety of tasks that the client deems important to sustaining his or her independence and values but that do not constitute care in the traditional sense.

Normalization has been emphasized by disability activists, who have asserted the importance of client control over the details of the care plan and the performance of the paraprofessional workers. In the extremes of the position, it is argued that the disabled person should be taught how to select and supervise the worker and then given that responsibility. Another theme, as mentioned previously, is that care should be offered outside the home, as well as inside, to promote normalization, dignity, and an optimal quality of life. Ignoring issues of cost associated with large numbers of potential clients, it was argued that, if desired, older disabled persons should have personal assistance

services available in places other than their own homes. The extent to which older persons desire full control over activities of the personal assistants is less clear. Some panelists thought that many older clients, perhaps because of ill health or because of expectations attributable to their previous life experience, would prefer that an agency hire, supervise, pay, and fire their workers. However, it was also thought that some older clients who preferred to forego direct supervision of care personnel may well want to control specific details of routines and schedules and have the prerogative to complain about poor care. Some spokespersons for younger disabled groups pointed out that older persons have rarely been given a chance to exercise direct control and that some age stereotyping may underlie the assumption that they do not want it. The preferences of older persons in this regard and the outcomes from offering them enhanced control have not been adequately studied.

Balancing Quality of Life With Safety

"Quality of life" is an often-used term that encompasses but transcends ideas of interpersonal relationships with caregivers, normalization, client choice, and client control as goals of home care. To be held responsible for the quality of life of the client is to approach the goal of psychological and social well-being.

Some discussion emerged about whether home care should take on goals of maintaining or increasing a client's social involvement and participation, especially if this means that agencies whose clients are, on average, more socially involved or happier would be deemed better home care providers. This is an issue flagged for further examination, and its resolution requires determining the scope of the home care provider's mission.

Our panelists' hesitation to embrace quality of life as a goal reflects more than just the desire to stick to more readily attainable goals. Most providers and many consumers and their representatives thought quality of life should be balanced against the safety of the client. Although both consumers and providers consider safety an appropriate goal for home care, each emphasized different aspects of safety. Consumers expressed a desire to feel safe with both the living situation and the care provider. Few consumers were concerned with the risks associated with receiving high-tech care in the home, though some actual users of home care wanted assurance that knowledgeable health professionals were monitoring the status and performance of their hands-on providers. In contrast, providers viewed safety in terms of minimizing the risks associated with providing care to a frail and often cognitively impaired population in their homes as well as minimizing their own liability. Consequently, issues such as risk management pervade their discussion of safety. The regulator and government oversight panel suggested that the client and family be involved as much as possible in developing a plan of care that spells out the acceptable risks associated with their care. This was usually couched as "informed choice," a concept that merits further attention. For example, how should clients be informed, can mentally impaired clients really make choices, and should respect for informed choice be a valid defense for a provider faced with litigation?

When framing the discussion of personal autonomy and choice, the professional providers preferred to differentiate between technically complex medical procedures performed at home and ongoing low-tech personal care and homemaking. Personal autonomy and client choice, they argued,

pertain mostly to the latter, whereas the professional must control the former to ensure that procedures are performed correctly and safely.

Flexible, Negotiated Care Plans

Among many panel participants, much faith has been placed in the care plan and its role in improving the quality of home care. It has been touted as the instrument by which providers and consumers can establish and negotiate priorities, expectations, and responsibilities, as well as serve as an avenue for articulating client values. For socially-oriented home care, the plan is usually provided and monitored by a case manager external to the agency or agencies providing services (Kane, 1993). A number of criticisms were made about the way care plans are presently developed and utilized.

Members of the government oversight panel indicated that what is written in the care plan is often driven by reimbursement and does not necessarily reflect what can reasonably be achieved. Nor does the care plan generally reflect goals agreed upon by the provider, consumer, physician, and family, for both the medical and social needs of the client. (Often these details are negotiated by provider and consumer after the formal care plan is completed and once care has begun.) Home care workers suggested that the care plan does not undergo enough revisions throughout the course of care; therefore, changes in client status and preference are not adequately captured. Home health aides stated that care plans often included more time than they deemed necessary to complete the designated tasks. At the same time, caution was voiced over giving a level of detail in the care plan that would compromise flexibility.

Both consumers and government officials perceived flexibility in the care plan, including flexibility in who can perform what tasks, as highly desirable if not absolutely necessary, considering current and predicted future labor force shortages. However, professional providers were generally reluctant to sanction lesser trained persons to perform certain procedures.

Affordability

In addition to service supply and service accessibility, panel members suggested several other global or system-design issues that deserve explicit attention. Closely related to accessibility, for example, is affordability. Affordability, particularly for the chronically ill client, was a universal concern. Understanding that the more costly the service, the less care would be available, users of home care and consumer representatives were concerned about the general affordability of care, even publicly subsidized care.

Appropriateness

Given that home care is a highly desirable service, funding sources for it diffuse, and funds limited, it stands to reason that the demand for home care exceeds the availability. Government oversight officials, management for provider organizations, and insurers and payers are all faced with the issue of appropriateness of services with an eye towards overmet need rather than unmet need, i.e., making sure that those who are receiving benefits are eligible rather than making sure that those who are eligible have access to services. Eligibility in these cases must also include differentiation between those for whom services are a necessity and those for whom services are a nicety. Even once this is accomplished, the issue remains that, with limited resources (financial and staff), often a decision has to

be made between serving fewer clients better and serving all clients with less than optimal amounts and types of services.

Case Management

Most panelists thought service coordination and case management were effective mechanisms toward assuring quality in home care. Even so, payers and insurers of home care were mixed in their enthusiasm for these concepts. This lack of enthusiasm was due, in part, to the questionable cost effectiveness (a crucial element in developing an insurance product) of case management and, in part, to the difficulty large national companies have in setting up case management networks. Some caution was expressed about viewing external case management as a guarantor of quality, because decisions by case managers can easily be affected by financial constraints, and caseloads are often burdensome, leading to fewer cases being managed well.

Accountability

Related to case management is the issue of finding a vehicle for pinpointing responsibility for quality, particularly in complex cases. The highly fragmented system of home care confounds establishing accountability. Providers were especially concerned about drawing very specific lines of accountability to their agencies. Other panels saw the need for some general perspective on quality that transcends the activities of a caregiver or even an agency. Consequently, panelists urged that quality not be forced in narrow bureaucratic jurisdictional pigeonholes, even though the system is fragmented.

Insurers and Payers

Our panel meeting and related discussions with insurers and payers were different in kind from input from other informants. Insurers were largely concerned with defining an insurable event. Quality standards were largely viewed as an issue for the provider agencies. Insurers marketing a comprehensive insurance product that includes home care defined one goal of home care to be the decreased use of expensive nursing home, hospital, or emergency room services. With a typical business orientation toward maintaining the reputation of the product, consumer satisfaction was another desired goal. Those insurers working through case-managed networks thought that coordination and communication was a hallmark of high quality of care, whereas those whose benefits were in the form of annuities were not concerned with this issue.

We attempted to get input from large employers as purchasers of home care benefit packages; however, at the time of our study, relatively few employers (mostly very large ones) had benefits of this nature. For example, in a 1987 survey of 210 large corporations, the Washington Business Group on Health reported that more than three-fourths of their respondents had a strong interest in offering an employee long-term care benefit, but only on an employee-pay-all basis. Employers' criteria for quality seemed to emphasize maximizing employee satisfaction at the least cost. For that reason, such employers tended to favor purchasing a high visibility benefit that would give their employees expert but time-limited advice from case managers and other care coordinators in the communities where their elderly parents or relatives live.

IMPLICATIONS

QA in home care is not business as usual. Fresh approaches may be needed to substitute for or complement review of

each provider agency. Moreover, the overall program to enhance quality recognizes the varied nature of home care programs and home care clients and the intimacy of the setting. Our exercise in involving constituent groups not only revealed possible differences in outlooks based on roles, but showed that all stakeholders were able to differentiate desired outcomes based on different descriptions of client characteristics.

In an era when outcomes are being used to judge quality of care across a wide range of settings, it is attractive to think in outcome terms for assessing the quality of home care. Outcomes measures are conceptually appealing because they permit comparisons across modalities whose effectiveness and target populations seem to overlap. They focus attention on the impact of care of the person rather than on a single parameter and encourage the use of functional assessment and quality-of-life concerns. However, there are serious obstacles to overcome in this quest. Before a provider agency can be held accountable for the outcomes of care, it must have some degree of control over what care is given. The current system allows for great fragmentation. More than one agency may be involved in a case. The primary care physician may have only the loosest relationship to the home care agency. Some jurisdictional span of control must accompany efforts to use outcome measures.

We also see diminishing returns from asking provider agencies to develop a system for measuring ever more detailed outcomes. It may be important to examine the extent to which external case managers can develop a program for monitoring client satisfaction and other outcomes that are the products of all home care inputs. Such a strategy probably needs to be accompanied by an internal QA capacity for the technical home health care such as is delivered by certified HHAs.

Even if responsibility can be affixed among providers, they are likely still to be reluctant to accept an outcomes approach, as were many of those polled in this study, because they perceived a lack of control over those outcomes. The very nature of home care—indeed, one of its assets—is the potential for preservation of client autonomy. Home care providers must negotiate with clients and their families if their care plans are to succeed. An outcomes approach must then begin with a reconceptualization of the provider's responsibility for home care. Just as with ambulatory medical care, the provider's role includes educating the client and family and engaging them in cooperative approaches. In some cases, the level of compromise needed to satisfy the client may undermine achieving the ideal result from a professional perspective. Outcome measurement approaches must walk the fine line of recognizing the effects of client attitudes and behavior and allowing clients to choose to take risks without absolving the providers of all responsibility for those behaviors that interfere with giving good care.

The lack of enthusiasm for structural criteria among all stakeholders encourages demonstrations of home care arrangements that minimize supervision and training requirements to concentrate on demonstrated competence and outcomes. The stakeholders in home care were keenly conscious of tradeoffs between unit costs and amounts of service and were eager to avoid regulations for top-heavy programs. There is also a need to explore ways to get more money to those who actually deliver personal care and homemaking to entice and retain a committed labor force (Feldman, 1993).

To summarize, in the intimacy of home care, standard regulatory approaches should be augmented and at times should be

replaced by other approaches: efforts to activate consumers as arbiters of quality; efforts to promote active QA approaches by providers; and development of case management as a point of accountability in the system of care. Another phase of our project is examining best practices in QA on all of these dimensions. Meanwhile, work on developing criteria and standards must proceed, regardless of the mix of consumer-directed, provider-initiated, regulatory, and case management approaches that are used. Furthermore, our approach to outcomes of home care should not be sideswiped by efforts to carve out narrow areas of responsibility; surely, all professional agencies and case managers alike should share interest in and responsibility for outcomes.

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