Assuring the Quality of Home Care: The Challenge of Involving the Consumer

Introduction

“...The question of how to assure quality in long-term care is a vexing one, challenging regulators, frustrating families, and provoking providers for more than three decades...” (Hawes 1997-1998)

The use of home care services, particularly by older persons, has increased dramatically in recent years. This trend has been fueled by increased public funding for home care, shortened hospital stays that often result in a need for followup care, advances in medical technology that facilitate home care treatment, and the desire of individuals to continue living in their homes rather than move to get services.

Home care services include skilled nursing care and personal assistance with basic activities of daily living, such as bathing and dressing, or a combination of skilled and personal care. Millions of older Americans rely on these services to remain in their homes.

The growth in home care use has been accompanied by concerns about the quality of the care provided. Many untrained workers care for people in the isolation of the home with little or no supervision. Anecdotal reports or occasional media stories about fraud or abuse of home care recipients have raised fears about safety.

Quality-of-care questions go beyond safety and protection issues, however. Policymakers and regulators want to know if public monies are paying for effective services that result in better health or improved functioning for the consumer. Researchers question whether current quality assessment tools are capable of measuring quality of care. Consumers ask whether home care workers have been adequately trained for the services they provide. To the public and to policymakers, these are also quality-of-care considerations.

The extensive literature on quality of home care addresses these issues by examining the roles played by government regulators, researchers, home care workers, and consumers in assuring quality care. This report provides an overview of this literature to summarize the debate and discussion. An understanding of these issues can help educate the consumer, inform the policymaker, and guide future research.

The report begins with a background section (Section I) defining home care and describing the users, providers, and funding sources of home care services. Section II describes a quality assurance model upon which regulators and researchers have relied for years to provide a framework for their work. Section III discusses the federal and state regulatory roles, particularly under the Medicare and Medicaid programs.

Section IV summarizes the efforts of researchers to design outcome measures to assess the effects of home care services.
Section V examines the part that home care workers play in achieving quality care. Section VI reviews the consumer perspective on quality of the care. The report concludes with possibilities for greater consumer involvement.

I. Background

When researchers use the term “home health care,” they are generally referring to skilled medical services; when they say “home care,” they typically mean personal care or supportive services. These are services that assist people with activities of daily living, such as bathing, dressing, and eating. Supportive services help people “maintain functional abilities or compensate for impairments” (Eustis et al. 1993).

However, these definitions are not always so clear-cut. “Home care” for many researchers and other persons denotes a range of services provided in the home, including skilled nursing and therapies, personal care, and even social services, such as meals and home modifications. For example, Kane and her colleagues define home care as: “…any kind of health care, personal care, or assistance with independent living given to functionally impaired, disabled, or ill persons in their own homes” (Kane et al. 1994).

This paper uses the term “home care” as defined by Kane. The paper uses “home health care” only when referring to the Medicare and Medicaid Home Health programs, which fund medical services mainly.

During 1996, there were an estimated 2.5 million current patients and 8.2 million discharges from 13,500 home health and hospice care agencies in the United States (National Center for Health Statistics 1998). The clients for home health care services are largely older persons. (See Figure 1.)

The largest source of payment for home health services is the Medicare program. In fiscal 1997, Medicare payments to home health agencies totaled $17.2 billion, about 43 percent of total home health expenditures of $40 billion and a fourfold increase over the almost $4 billion of Medicare spending for home health in 1990. About 3.4 million Medicare beneficiaries received fee-for-service home health services in 1997, up from about 2 million Medicare recipients in 1990 (U.S. Health Care Financing Administration 1998).

The federal-state Medicaid program spent about $13.5 billion in 1997 in payments for the home health, personal care, and home and community-based care waiver programs, which provide either medical or
personal care services or a combination of both kinds of services (Burwell 1990).

II. The Donabedian Model

The quality assurance work of regulators and researchers has been built on a foundation laid by Avis Donabedian in the 1960s. The Donabedian model consists of three components: structure, process, and outcomes (Donabedian 1980). Simply put, “structure” refers to general administrative standards for the organizations and people providing the care; “process” refers to the delivery of care; and “outcome” is the result of care.

The following are examples of each component:

- **Structure**: types of personnel required, staff qualifications and training needs, licensing for staff, record-keeping, staffing and supervisory ratios, physical plant and equipment, and general administrative policies.

- **Process**: the process through which care is delivered, including the kind of services provided and treatment procedures.

- **Outcomes**: the set of expected or desirable results for clients: positive outcomes sought (improvements in function or in quality of life) or negative outcomes to be avoided (hospitalization or emergency room visits, nursing home admittance, death).

III. Federal and State Regulation

Government regulators have relied for years on structure and process standards to help achieve basic goals of protecting the public’s health and safety. For example, states have established licensing laws and regulations to assure that providers possess the minimum level of competence to guarantee the public’s safety.

One of the main advantages of using structural criteria in particular is ease of administration. As one researcher notes, structural standards are “generally straightforward and easiest to define and measure” (Applebaum 1989).

A regulatory approach that relies on structure and process standards realistically has its limits, however, in helping to determine outcomes of care, in assessing a consumer’s satisfaction with services, or in ascertaining whether a person’s quality of life has been maintained or improved.

Another difficulty with evaluating the impact of regulation on quality of care is the multiplicity of standards under federal and state regulations and licensing. For example, the federal government regulates *home health* care providers who provide skilled nursing and other services under the Medicare and Medicaid Home Health programs. Many states license *home health* and *home care* agencies that provide medical services and/or personal care or nonmedical home care services under other Medicaid or state-funded programs. States that do not have their own licensing laws may require providers to be Medicare certified to be reimbursed by the state for delivering state-funded personal care services.

As the U. S. General Accounting Office (GAO) says, the result is a “complex financing structure” with different quality assurance requirements for similar services based on the source of payment for the services (GAO 1994).
Medicare and Medicaid certification under the Home Health programs requires home health agencies to meet minimum federal standards (called Conditions of Participation), which cover measures “considered necessary to assure patients’ health and safety” (42 C.F.R. 484). (See Table 1.) These standards were mainly structural in nature until passage of the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987). The law added patient rights, home health aide training and competency evaluations, more frequent surveys of providers, evaluations of individual clients, stronger enforcement tools, and complaint hotlines (Harrington et al. 1991).

The legislation also provided the impetus for development of a federal outcomes measurement system called “Outcome-Based Quality Improvement (OBQI)” to be used by Medicare-certified home health care agencies to measure patient outcomes. The basis of the system is an Outcome and Assessment Information Set (OASIS) that represents core items of a comprehensive assessment for a home care patient. The objective is to find out what happens to consumers as a result of the care they receive. Do they benefit from the care, and if not, why not? (Shaughnessy and Crisler 1995).

Many state licensing laws for home health agencies mirror the Medicare standards. A few states go beyond these requirements to include provisions on consumer rights or consumer complaint mechanisms or to impose intermediate sanctions for noncompliance, such as prohibiting agencies from accepting new clients or reassigning caseloads to other agencies (Riley 1989). A number of states also have developed separate quality assurance standards for programs such as the Medicaid Home and Community-Based Waiver program or state-funded programs that reimburse agencies for providing personal care services in the home.

The result is that agencies may be delivering services to individuals under a variety of different federal and state programs, each with its own rules relating to quality assurance. To be reimbursed by Medicare for providing nursing services to an individual, for example, an agency would have to be Medicare-certified. If the agency was also providing personal care services to the individual under a state-funded program, the agency might also have to meet specific state standards for those services.

Differences also exist among the states in regard to the types of providers who come under a state’s scrutiny, the workers employed by the agencies, and the sanctions or penalties a state might impose for noncompliance with standards. Within the same state, several government agencies might be involved in regulating or contracting for services in the home. Each state agency might have its own regulations and procedures for monitoring home care providers.

The complexity of this regulatory system increases the difficulties for consumers in understanding the protections of laws and regulations. Licensing, accreditation, and certification can suggest government “seals of approval” that consumers mistake for signs of excellence rather than as minimal government standards.
Table 1. Medicare’s Conditions of Participation and Associated Standards for Home Health Agencies

<table>
<thead>
<tr>
<th>CONDITIONS OF PARTICIPATION</th>
<th>STANDARDS</th>
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<tbody>
<tr>
<td>Patient Rights</td>
<td>• Notice of rights</td>
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<td></td>
<td>• Exercise of rights and respect for property and person</td>
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<td></td>
<td>• Right to be informed and to participate in planning care and treatment</td>
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<td></td>
<td>• Confidentiality of medical records</td>
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<td></td>
<td>• Patient liability for payment</td>
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<td></td>
<td>• Home health hotline</td>
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<tr>
<td>Acceptance of patients, plan of care, and medical supervision</td>
<td>• Plan of care</td>
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<tr>
<td></td>
<td>• Periodic review of plan of care</td>
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<td></td>
<td>• Conformance with physician orders</td>
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<tr>
<td>Skilled nursing services</td>
<td>• Duties of the registered nurse</td>
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<td></td>
<td>• Duties of the licensed practical nurse</td>
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<tr>
<td>Therapy services</td>
<td>• Supervision of physical therapy assistant and occupational therapy assistant</td>
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<td></td>
<td>• Supervision of speech therapy services</td>
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<tr>
<td>Home health aide services</td>
<td>• Home health aide training</td>
</tr>
<tr>
<td></td>
<td>• Competency evaluation and in-service training</td>
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<td></td>
<td>• Assignment and duties of the home health aide</td>
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<td></td>
<td>• Supervision</td>
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<td></td>
<td>• Personal care attendant: evaluation requirements</td>
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<tr>
<td>Clinical records</td>
<td>• Retention of records</td>
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<td></td>
<td>• Protection of records</td>
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<tr>
<td>Evaluation of the agency’s program</td>
<td>• Policy and administrative review</td>
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<tr>
<td></td>
<td>• Clinical record review</td>
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There are also hundreds of agencies in every state that do not seek or qualify for licensure, such as registry agencies that provide temporary home care workers for private-paying consumers. Researchers who studied California agencies speculated that unlicensed and temporary personnel agencies might outnumber licensed providers by two to three times. The researchers found that public officials rarely compared licensed and unlicensed agencies and services in terms of the quality of the care provided by the two types of agencies (Harrington and Grant 1990).

Many researchers are skeptical that this fragmented state regulatory system can be very effective at enforcing quality home care. For example, Harrington et al. contend that state licensing standards for home care agencies “are relatively weak or nonexistent.” These researchers question whether “state regulation has a direct effect” on the quality of home care services (Harrington et al. 1991).

Several researchers have selected a few states for detailed review. Applebaum and his colleagues examined the quality
assurance systems of Massachusetts, South Carolina, and Washington, named by long-term care experts as having exemplary systems. The study found that these states were using structural standards, such as licensing providers and requiring training, and process criteria, such as state audits of service providers.

Two of the three study states designate a state office for quality of care activities. At the time of the review, the study states had begun to develop outcome-based performance measures (Applebaum et al. 1997-98).

The researchers conclude that states in general use the following broad quality assurance strategies:

- Development of standards - requirements for worker training, agency certification, and criminal background checks on workers.
- Monitoring activities - supervision of workers, supervisory home visits, case management, contract reviews, and provider visits and audits.
- Enforcement - withholding contracts or reimbursement, use of criminal penalties.

In another study, the GAO analyzed the quality assurance systems of state home and community-based care programs that provide a range of personal care and other supportive services. The GAO report outlines key questions that should underpin state quality assurance systems as well as possible performance indicators states might use to reach quality care goals. The GAO’s framework includes a focus on outcomes. Table 2 summarizes several elements of the GAO-suggested framework.

Table 2
FRAMEWORK OF A SYSTEM TO IMPROVE THE QUALITY OF HOME AND COMMUNITY-BASED CARE

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>KEY QUESTIONS</th>
<th>POSSIBLE MEASURES</th>
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<tbody>
<tr>
<td>Define quality</td>
<td>What goals and outcomes can be identified?</td>
<td>Maintain functional capacity</td>
</tr>
<tr>
<td>Identify indicators of quality</td>
<td>Based on the goals and outcomes identified, what indicators of program</td>
<td>Optimize autonomy and mobility</td>
</tr>
<tr>
<td></td>
<td>implementation or performance can be identified?</td>
<td>Satisfy clients</td>
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<tr>
<td></td>
<td></td>
<td>Improve quality of life</td>
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<tr>
<td></td>
<td><strong>Structural indicators</strong></td>
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<td></td>
<td>Caseload per worker per day</td>
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<td></td>
<td>Staff knowledge</td>
<td></td>
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<tr>
<td></td>
<td><strong>Process indicators</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Frequency of supervision</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Appropriateness of care plan</td>
<td></td>
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<tr>
<td></td>
<td><strong>Outcome Indicators</strong></td>
<td></td>
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<tr>
<td></td>
<td>Functioning</td>
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<td></td>
<td>Change in ADL &amp; IADL status</td>
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<td></td>
<td>Safety</td>
<td></td>
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<tr>
<td></td>
<td>Health</td>
<td></td>
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<td></td>
<td>Client Satisfaction</td>
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</table>

The limitations of government regulation notwithstanding, most experts agree that “government clearly has a role to play” in assuring quality of home care. “Federal and state governments have continuing responsibilities,” says Kane, “for establishing and enforcing a minimum definition of quality and for fostering the conditions under which programs can be innovative, responsive to consumer preferences, and encouraged to exceed minimum standards” (Kane 1995a).

IV. The Research Focus on Outcomes

Many researchers have been frustrated with the structure-and-process approach, which they see as largely “paper compliance” with “management, staffing, and …policies and procedures” (Kramer et al 1990). They view the use of structure- and-process criteria as a reaction to failings, rather than as an active approach to promoting quality of care. Clients presumably care more about outcomes and less about the structure and process that support the outcomes.

As a result, researchers have turned their attention to defining the goals of care services for each client and to measuring or evaluating the results (outcomes). The goals of care can range from maintenance of or improvement in health or functioning to greater satisfaction with one’s quality of life.

What happens to an individual when he or she receives home care services? Does care result in improved functioning or, at a minimum, is further deterioration halted? Is quality of life improved?

A definition of quality care proposed by the U.S. General Accounting Office speaks of “the extent to which service increases the probability of desired outcomes and reduces the probability of undesired outcomes given the constraints of existing knowledge” (GAO 1994). Researcher William Weissert says that a “reasonable starting point” is the question: “Has home care succeeded in improving outcomes, including increased longevity, improved physical or mental functioning, or increased satisfaction or morale of the patient or informal caregiver?” (Weissert 1991).

Researchers agree that in actual practice defining “desired outcomes” and measuring the results of specific care services can be very difficult. The long-term care population is heterogeneous. The health and functioning of many people may diminish regardless of a specific intervention. For some people, the quality outcome may very well be to assure their comfort as much as possible. Therefore, appropriate, desirable, and realistic outcomes vary enormously. As one group of researchers says, “attributing patient outcomes to care provided is not straightforward” (Shaughnessy et al. 1996).

Several researchers have suggested that for outcome measures to be meaningful, the measures need to be related to specific conditions of individuals (Kramer et al. 1990, Weissert 1991). Weissert says “we have not appropriately matched patients to appropriate outcome expectations.” Instead, he says, individuals are treated as if they need “pretty much the same thing and are likely to improve in pretty much the same way regardless of important differences in the specific health risks which they may face at a given point in time” (Weissert 1991).

Weissert contends that there is a greater potential for improved outcomes “by separating the home care population into groups of individuals who face different risks,” such as chronic physical function decline, mental decline, or hospital
readmission. Care plans can then be tailored to those specific needs; outcomes would be evaluated in terms of ameliorating the risks for each type of impairment or disorder.

Many researchers suggest that outcomes should also encompass psychosocial objectives, such as social well-being, particularly in situations where improvements in physical functioning are not possible. Rosalie and Robert Kane contend, for example, that “consumer satisfaction should always be considered as one important outcome” (Kane and Kane 1989). Capitman and his colleagues say that measurable outcomes could include “changes in morale, anxiety, and other indicators of the quality of life” (Capitman et al. 1997).

For example, Capitman says, minimum standards might call for the care recipient to be able to move in and out of bed on a daily basis to perform an essential task such as toileting. An “adverse outcome” would be a fall and/or injuries. But these events might also trigger increased anxiety and a decline in morale that would also be considered adverse outcomes (Capitman et al. 1997).

Many researchers have also examined quality-of-home-care issues from the perspective of the home care worker in her relationship to the care recipient. To some researchers, the concept of quality care embraces “punctuality, courtesy, kindness, and honesty” of home care workers (Kane et al. 1991).

V. The “Hands-on” Home Care Worker

“When aides do good work, consumers get good care” (Feldman, Generations, 1994).

Home care is unique because it “relies primarily on paraprofessional care delivered by a home care aide working alone, essentially as a guest in the client’s home” (United Hospital Fund 1994). Paraprofessional workers provide the hands-on care that is the core of supportive home care services. These workers have been called “the backbone of home care” (Eustis et al. 1993).

Paraprofessional home care workers (called personal care aides, home health aides, or personal care attendants) work for a home care agency or can be self employed. If an individual is employed by a Medicare-certified agency, she will be required to complete certain training or pass a competency test; if she works for a state-licensed agency, she may have to meet other requirements.

Many researchers say that the relationship between the individual receiving care and the home care worker is the key to defining quality home health care (Eustis et al. 1993, Eustis et al. 1994). The quality of home care services will be ensured, one report says, “only if the paraprofessional is a caring, competent, and responsible adult” (United Hospital Fund 1994).

In regard to worker-client relationships, the researchers say that home care clients judge the quality of their workers in a “much broader context than task performance.” Clients “value reliable, honest, and compatible people who genuinely care about them and with whom they get along” (Eustis et al. 1993).
According to researchers, home care workers will be caring and competent if they are paid decent wages and given adequate training and respect for their roles (Eustis et al., 1993, Eustis et al., 1994, Feldman et al. 1994). The industry is characterized, however, by low pay; few benefits such as health insurance or pensions; little or no training, support, or supervision; and high turnover.

Eustis et al. (1993) examined the paraprofessional home care job itself and the relationships between workers and clients to assess the impact these two factors have on quality of care. The authors conclude that home care jobs would be “more intrinsically rewarding and offer better conditions for high-quality care if the workers had more contact with supervisors and peers, more information about clients and care plans, clearer accountability, and more authority.”

A very different type of worker — the care manager — is increasingly assuming a quality-control role in home care, according to several researchers (Riley 1989, Riley et al. 1992, Quinn 1995, Kane 1995, and Kane and Degenholtz 1997). Care managers in publicly funded home care programs generally determine a person’s need for home care services and then authorize, coordinate, and monitor the services. Thus, care managers are “well-positioned to be a force for QA (quality assurance) in home care,” Kane and Degenholtz say, “and to serve as a point of accountability.” Another researcher found that many state officials view care management as a quality assurance mechanism because care managers are “in direct, personal communication with consumers,” and have “oversight for an entire plan of care” (Riley 1989).

VI. The Consumer Perspective

“...the ultimate test of quality must come from the perspective of consumers...”

(Kane 1995)

In an increasingly consumer-driven health care system, it is unfortunate that only limited research has been undertaken on the consumer’s perspective on the quality of home care services. “The importance of the client’s perspective [generally has] not been acknowledged,” say Woodruff and Applebaum (1996). “Attempts to obtain feedback from consumers have been extremely rare.”

Some states have experimented with ways to test consumer satisfaction with the services they receive — telephone or mail surveys, report cards or scorecards, or in-home interviews. A two-year demonstration project in Ohio, the Ohio Quality Assurance Project, illustrates the use of these strategies. The project sought the opinions of home care recipients through postcards, in-home visits, a “Nielsen” approach that used logs on which clients registered comments, a telephone survey, and six in-depth case studies.

More than 90 percent of the telephone survey respondents responded affirmatively when asked if the home care workers “performed the job properly and were kind and courteous.” However, when consumers were asked more specific questions about services, their responses varied. About one fifth of the respondents said workers did not arrive on time, and about 17 percent reported that they were not notified when a worker was unable to arrive at all. “When given the opportunity,” the study notes, consumers have a “great deal to say” about the quality of the services they received (Applebaum et al. 1993).
Indiana researchers have developed another approach to evaluating quality of home care through consumer feedback. One component of this statewide demonstration project involves a Client Feedback System under which consumers evaluate the services they receive and provide comments to a local area agency on aging. These agencies pass on the evaluations to the home care agencies, making it easier for the consumers to be candid about their care without fear of jeopardizing their relationship with the provider (Kinney et al. 1994, Kinney et al. 1997).

For all services, the Client Feedback System included several questions on the following quality indicators: (1) degree of choice and autonomy, (2) consistency of services and workers, (3) respectfulness and trustworthiness of workers, (4) timeliness of workers, and (5) quality of task performance. Questions required clients to indicate “how often” workers met quality indicators, with clients having five choices: “Always, Usually, Half the Time, Occasionally, Never.”

While clients gave high marks to workers on survey questions, they also reported serious deficiencies in worker performance when surveyors probed for specific comments about services (Kinney et al. 1997).

Table 3

<table>
<thead>
<tr>
<th>SELECTED CLIENT OUTCOME MEASURES</th>
<th>CLIENT SATISFACTION WITH SERVICES</th>
<th>FOR CHOICE AND MEDICAID AGED AND DISABLED WAIVER CLIENTS IN EIGHT AAA’S</th>
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<tbody>
<tr>
<td>Quality Component</td>
<td>Number of Responses Included</td>
<td>Outcome Score*</td>
</tr>
<tr>
<td>Satisfaction with Attendant Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and/or Homemaker Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Degree of Choice and Autonomy</td>
<td>3809</td>
<td>4.75</td>
</tr>
<tr>
<td>2. Consistency of Services and</td>
<td>1906</td>
<td>3.95</td>
</tr>
<tr>
<td>Workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Respectfulness and Trustworth-</td>
<td>6222</td>
<td>4.91</td>
</tr>
<tr>
<td>iness of Workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Timeliness of Workers</td>
<td>2886</td>
<td>4.55</td>
</tr>
<tr>
<td>5. Quality of Task Performance</td>
<td>4327</td>
<td>4.68</td>
</tr>
</tbody>
</table>

*The score was derived from averaging the average of responses to each question for each domain of quality. Questions were posed in terms of “how often” services met specific conditions of importance to a domain of quality. The response set was: “never(1),” “occasionally(2),” “half of the time(3),” “usually(4),” “always(5).”


Researchers have been cautious about placing too much faith in the results of consumer surveys. In the Applebaum three-state study, satisfaction surveys conducted by both case management and provider agencies in all three states generally showed high levels of satisfaction with services. Case managers were concerned, however, that clients might be overstating their levels of satisfaction. Although the states also provide complaint mechanisms, administrators believed that most clients are “reluctant to complain about their workers or case managers” (Applebaum et al. 1997-1998).
In the Ohio study, although 95 percent of the clients said they would recommend the service, 14 percent reported that a worker had been verbally abusive, and 5 percent reported physical abuse from a worker. The researchers suggest that these inconsistent findings could indicate several things: “consumers often may have mixed feelings about the services, consumers may be dependent on a service and feel that anything is better than nothing, or data collection and measurement problems may result in invalid or unreliable findings” (Woodruff and Applebaum 1996).

The 1994 GAO study listed the factors that consumers most frequently cite when asked about their criteria for quality service: (1) the arrival of a worker on the scheduled day and at the scheduled time and working for the scheduled amount of time, (2) completion of work, (3) service consistency, (4) neat and clean appearance, (5) honesty and trustworthiness, and (6) courtesy and respect” (US General Accounting Office 1994).

Sabatino and Litvak (1992) discuss the use of a client “statement of rights” that can serve, they said, as a useful teaching tool and standard for both providers and consumers.” However, they say many people “are reluctant to bite the hands they depend upon for day-to-day help, because finding a replacement is so difficult.”

Another researcher contends that a quality improvement program “should empower consumers to have a stake in the quality of services they receive by encouraging them to make choices about their care, educating them about their rights, establishing procedures to make complaints about services and to notify case managers of problems” (Quinn 1995).

To place more control in the hands of individuals for managing their own care, a movement called “consumer-directed care” has emerged. Many publicly funded programs today offer care recipients an opportunity to choose their own personal care assistants and to manage their plan of care. The thrust for this movement has come from working-age adults with disabilities who want to maximize autonomy, live in the least restrictive environment, and manage their own care (Institute of Medicine 1996, Tilly 1999). While many advocates of consumer-directed care contend that autonomy and control improve quality, others point to potential risks to health and safety.

For example, Kane asks: “What constitutes informed risk-taking” (Kane 1995)? Is there a tradeoff between assuring a person’s safety and health and providing maximum independence and autonomy so that a person can manage his or her own care? Rosalie and Robert Kane say that long-term care often involves choosing between issues of autonomy and safety. They conclude that there is “no clear standard for which is best” (Kane and Kane 1989).

Conclusion

Assuring quality of home care is a complex undertaking. Although researchers have developed or identified a variety of approaches for determining quality of home care services, no method has yet been judged entirely adequate.

Consumers are at the center of the debate about quality of care. The challenge for regulators and researchers is to create a
mechanism through which the “consumer voice can be heard and incorporated into an overall effort to achieve” the goal of quality care (Woodruff and Applebaum 1996).

Kane and Kane say that the purpose of a quality assurance system is to make sure that services “meet the needs of the …people they purport to serve.” This means examining those outcomes that older persons themselves say are important and getting information about a program and its impact “by speaking to those served,” not by having professionals “rate the happiness…or state of mind of older people” (Kane and Kane 1989).

States could take a number of steps to help improve the quality of home care services:

• Provide greater information to consumers about how to assess quality of home care.

• Make information available about providers, particularly agencies against which the state has levied fines or taken other punitive actions.

• Provide direct counseling for consumers on quality care issues, such as educating consumers about developing their care plans and providing information about licensing and training requirements for agencies and workers.

• Support payment reform and the provision of adequate health benefits, educational opportunities, and career ladders to encourage recruitment and retention of qualified home care workers.

• Conduct further study of the effectiveness of such consumer feedback strategies as report cards, consumer satisfaction surveys, and individual in-home interviews.

• Experiment with consumer-directed home care programs that provide consumers with direct payments to purchase services and allow the consumer to manage care providers.

Quality of home care involves the provision of appropriate and competent medical and personal care services. But quality of home care also incorporates values of significance to consumers: independence, control, choice, dignity, and privacy.

Regulation and research help guide the process of assuring quality of home care. As the focus of that process, the consumer can ultimately define quality of care if he or she is more knowledgeable about government standards for providers and a more involved participant in the process of care.
REFERENCE LIST

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