

# Using outcome measures to provide excellence in Alzheimer care

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## Abstract

*Outcome measures have been widely touted as a valuable tool to guarantee quality assurance in healthcare settings. Recently, a number of factors have conspired to make outcome-based measurement more feasible. This paper describes the advantages of utilizing outcome measures, continuous quality improvement methods and consumer based input to ensure excellence in long term care.*

## Introduction

In *Guidelines for Dignity*, the Alzheimer's Association developed eight goals for which dementia care settings should strive. The last of these emphasized "success indicators." The authors stated that "programs will want to monitor some of the indicators that show benefit for the residents, for staff and for families...[However,] outcome measures for the care planning and implementation suggested in these guidelines do not yet exist."<sup>1</sup>

Since then, a number of factors have conspired to make outcome-based measurement possible. First, a standardized record keeping system, the Minimum Data Set,<sup>2</sup> has been implemented nationwide in virtually all nursing homes. Second, a group of 10 collaborating research projects sponsored by the National Institute on Aging validated a common core of data collection instruments.<sup>3</sup> And, most recently, researchers and providers,

including the authors of this paper, are refining these instruments not only for research purposes, but also for improving provider services. However, as we and others have attempted to use these measures to improve quality of care, we have found the relationships to be more complex and problematic than previously anticipated.

## Overview of measurement domains

To determine the excellence of a program or service there are a number of domains to be considered. Until recently most studies of provider excellence concentrated on structure and process measures. These measures examine factors that are thought to be related to good outcomes, such as amount and training of staff, rather than on the outcomes themselves.

Authors of the landmark 1986 Institute of Medicine (IoM) report argue that widely accepted criteria used in assessing quality of medical care can also be used for assessing quality of nursing home care.<sup>4-6</sup> These criteria have structural, process, and outcome components. The authors of the IoM report state that structure refers to a health care facility's capacity to provide good quality care. Structural criteria refer to training, experience, and number of caregivers; organizational arrangements, safety and appropriateness of the environment and the adequacy and appropriateness of equipment and technology used in providing care. The authors assert that structural factors have only a potential relationship to quality. The availability and capacity to provide good care don't necessarily mean that it is delivered to residents.

Studies on the association between structural measures and the process of care in nursing homes have not found them to be strong.<sup>7-9</sup> There is evidence, however, that environmental circumstances influence personal well-being. Studies have shown that nursing homes which

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**Table 1. Three measurement domains: Sample items**

Structure	Process	Outcomes
Physical environment	When garden is used, who uses it and what is done in the garden?	Resident satisfaction
Policies & procedures	What information is collected at intake?	Functional status
Equipment & technology	How a Hoyer lift is used.	Functional status
Staff training	How a staff member talks with a resident.	Quality of life
Staffing patterns	What staff are actually at work on a given day.	Mental status

support resident autonomy, integration, and personalized care promote better morale, life satisfaction, and adjustment. Process criteria assume that quality is related to services provided, the manner in which they are provided, and resources used. Summarizing the research findings, authors of the IoM report state that few studies have shown strong correlations between process measures and resident outcomes in nursing homes.

Outcomes are changes in a resident's functional or psychosocial status that are related to care provision. Outcome measures have been widely touted as the most direct way to guarantee quality assurance in nursing homes. Proponents of this approach believe that focusing on outcomes deflects arguments about the effectiveness of structure and process factors by allowing the results, resident outcomes, speak for themselves. Two kinds of outcomes may be measured—subjective and objective. For residents of nursing homes, subjective outcomes may include satisfaction with self and the environment as well as satisfaction with nursing home care. The objective components of outcomes include changes in functional and mental status.

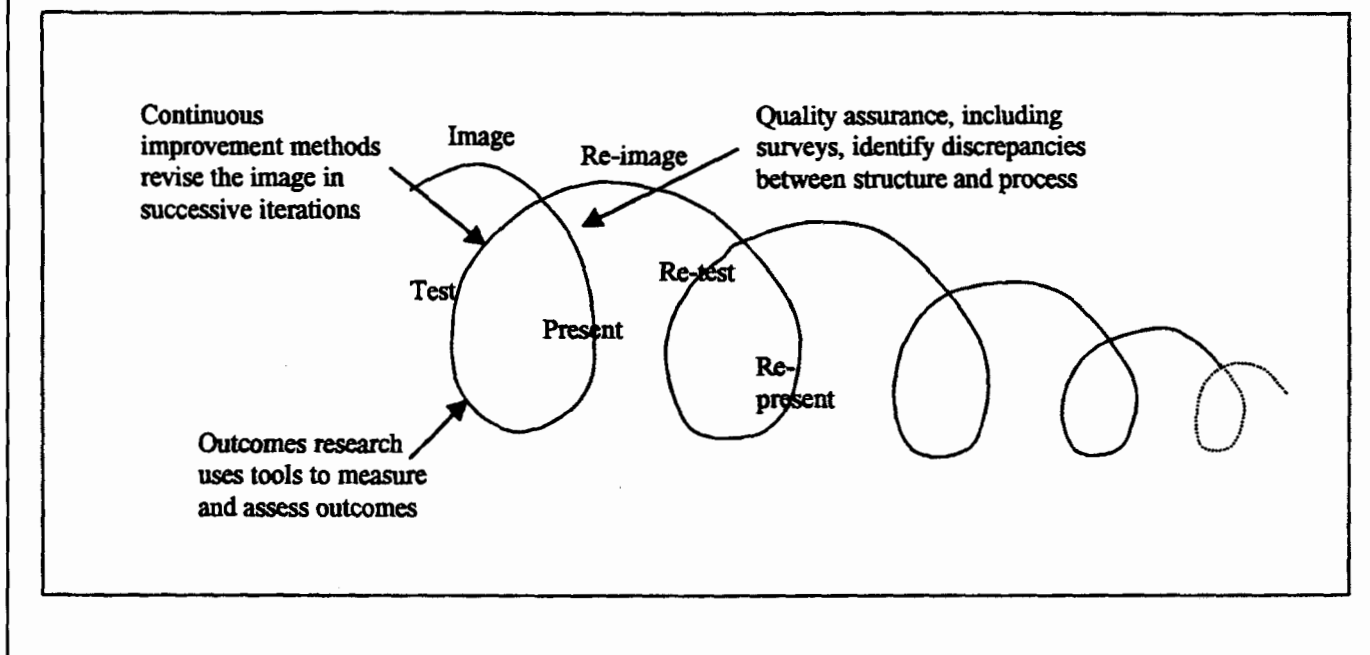
### Outcome measures in long term and dementia care

Outcomes fall into several domains. Most commonly measured is health status, including both morbidity and mortality. A related and equally important domain is "functional status." Measures in this domain assess the number of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) that a person can perform independently, and how much

assistance is needed, if any. However, these domains are limited by instruments that are based on provider/management definitions of quality rather than ever-changing consumer definitions.

Several recent studies have begun to focus additional attention on the definition of quality of care. One study gathered health status measures from elderly members of an HMO and examined the relationship among these measures by asking patients to rate factors of overall health. Patients included functional, physiologic, and emotional health factors. In contrast, physicians did not include emotional health as a factor.<sup>10</sup> This suggests that patients may have additional references to gauge overall health that physicians overlook. In a study of pain management in the elderly, it was revealed that patient beliefs act as barriers to effective pain management.<sup>11</sup> These beliefs concern issues about self-concepts and the aging process; patient and health professional roles; pain; consequences of treatment, including addiction, falls, constipation, and sexual and personality problems. Therefore, optimal pain management in the elderly needs to be based on a complete assessment with intensive patient interviews. In a third study, it was shown that rural elderly participants relied on their own appraisal and resources to manage health problems, rather than those of a health care professional.<sup>12</sup> These findings point to the importance of understanding and eliciting elders' self-assessments, in order to provide appropriate interventions which adequately address their perceived needs. The Medical Outcomes Study<sup>13</sup> reported that patient-defined determinants of medical treatment compliance included interpersonal quality and financial aspects. However, satisfaction with the technical quality

Figure 1. Iterative model



of care was reported to be negatively associated with adherence by patients. This casts doubt on a professionally driven model of outcomes research, with its overemphasis on the technical aspects of care.

Another key domain of outcome measurement is usually referred to as "quality of life." There are many definitions of this domain. In fact, many researchers and practitioners use the term without defining it at all.<sup>14</sup> In a comprehensive review, these authors concluded that quality of life measures were made without taking patient perspectives into consideration. Quality of life, the authors assert, can only be suitably measured by determining the opinions of patients and incorporating their definitions into instruments developed by the so-called experts. Elders were rarely asked to give a subjective account of their quality of life, from their own perspective. Definition is particularly difficult for this population because people with dementia are less able to articulate what "quality of life" means for them. Another domain that can be measured is "quality of circumstance."<sup>15</sup> These are factors that directly affect individuals, such as access to the out-of-doors, or time spent with friends and family, that would be considered by most people to be relevant to quality of life.

Related to but distinct from quality of life and quality of circumstance, are measures of customer satisfaction. While residents of a care facility are the primary customers,

families also receive services and may be acting as proxies. Regulators, referral sources such as hospitals, and others in the aging network also function as customers. Finally, staff are affected by facility practices, and may provide service information in ways directly related to the overall quality of the facility.

### Quality assurance and quality improvement

Quality assurance and improvement have typically been perceived as a closed system. We are positing the case for an open, continuously improving system. A closed model assumes that if structure and process are consistent, the system will produce desired outcomes. A "continuous improvement" model constantly evaluates the value of outcomes to consumers, and tests the relationship of structure to process and process to outcomes creating opportunities to favorably modify these relationships. A model for this process was developed by Zeisel.<sup>16</sup>

In this model, time is used to test the multiple relationships of structure to process and process to outcomes. Any aspect of the system may be improved in subsequent iterations.

By comparison, most surveys and standards, even those developed by non-governmental groups such as the Joint Commission on Accreditation of Health Care Organizations (JCHO) are primarily interested in the

**Table 2. Comparison of quality models**

Quality assurance model	Continuous quality improvement
Assumes that provider, consumer and regulator agree about what we mean by quality	Assumes that quality means different things to different people at different times
Assumes that structure is closely related to process	Tests relationship of structure to process
Assumes process is closely related to outcomes	Tests relationship of process to outcomes
Quality is in the realm of management or QA staff	Involves those workers closest to an issue by providing them with information and empowering them to make changes in structure and process

consistency of process with structure. They also assume that desirable outcomes are stable and can be adequately defined by the provider. In fact, a study funded by the Alzheimer's Association found that family definition of quality in SCUs changes.<sup>17</sup>

## Measurement instruments and tools

Traditionally, outcome assessment focuses on parameters defined by health care professionals. These typically include domains such as ADL's, IADL's, physical and cognitive function, and quality of life. The following domains are most typically measured in outcome assessment of the demented elderly:

- Physical functioning;
- Mental functioning;
- Social functioning, including subjective well being, and;
- Coping.

### *Physical health*

Indicators to assess general health status rely on various methods of input such as self-evaluations, caregiver assessments and evaluations from medical professionals. Different indicators usually do not yield similar results. For example, individuals usually rate their own health more positively than physicians do. This is particularly true with the elderly. Although people have different criteria

for evaluating their health, self-evaluations are important. Self-identified health helps to predict number of medications, number of physician visits, number of diagnoses and even longevity. Even though objective health measures, such as laboratory tests for cholesterol, tend to be poor predictors of functional ability, these measures are also important — especially in demented populations that may have trouble giving accurate self-reports. Ideally, health measures should be derived from a combination of physician reports, medical records, patients and their caregivers.

### *Activities of Daily Living*

General health measures have limited value in determining the degree of independence an individual can attain. ADL measures tap the practical dimensions of functionality. ADL measures commonly include dressing, bathing, toileting, transfer, feeding, continence and sometimes mobility. These instruments are almost always completed by a caregiver or health professional. The scales differ in how they assess independence. For example, the original version of the Katz Index<sup>18</sup> offered dichotomous ratings about whether an individual can or cannot perform an activity. A more recent version of this scale gives intermediate scores if activities can be performed with assistance from another person or device. Other factors such as time to complete a task or whether performance scales are averaged should also be considered. Ideally ADL scales used in institutions will consider if some activities are not applicable. For example, the Patient Appraisal and Care Evaluation (PACE II)<sup>19</sup> allows "against nursing home policy" as a category

**Table 3. Outcome measures as feedback**

Individual resident	Residence
Intake and ongoing assessment	MDS type standardized measures
Service plan meetings	Obtain comparison and longitudinal data
Grand rounds	Identify challenges and opportunities for improvement
Train staff to use assessment techniques	Provide staff with aggregated data for use in quality improvement

Once the incidence of incontinence is determined, facilities rating higher than others may use this information to develop structures and processes to minimize incontinence. This information should be reinforced by individual assessments that may be generalized to systemic changes thereby ensuring excellence in Alzheimer care.

since many institutions prohibit unsupervised bathing.

Functional ability in dementia is most often related to cognitive ability. Weaverdyk has developed a methodology for assessing the individual in the context of task and environment to give caregivers the information they need to restructure tasks to improve success.<sup>20</sup>

### Instrumental Activities of Daily Living

IADL scales evaluate more complex activities such as self-care, cooking, cleaning and shopping. Problematic issues in assessing IADLs include:

- Activities may be more susceptible than ADLs to variations in mood and emotional health; a person suffering from depression may be more likely to neglect cleaning than more basic self-care activities such as toileting. Thus, IADLs should be evaluated in relation to the individual's mental health.
- IADLs are difficult to measure in institutionalized individuals. Even when kitchens and laundries are available, residents usually are not given an opportunity to demonstrate IADLs. In some cases individuals lose the ability to perform IADLs because they become dependent on others. IADLs may be evaluated in institutionalized elders by taking them on a

trial home visit.

- There is a great deal of variation in how tasks can be performed. Cooking for example, may be as simple as microwaving a frozen meal or as complicated as following elaborate recipes.
- Assessed activities are traditionally performed by women rather than men.

### Mental status

Mental status measures are particularly important with elders with dementia. Often the most telling sign of dementia is a change in intellectual functioning. Three primary areas are evaluated—cognitive functioning, affective functioning and general mental health. The instrument most extensively used is the Mini-Mental State Examination (MMSE).<sup>21</sup> The results of this measure have been shown to change with disease progression. Mental status is evaluated in a variety of ways, including: unstructured "mental status examinations," in which mental health professionals evaluate functioning through observations; self-report, which is used widely for measures of depression and anxiety; and semi-structured interviews combining professional observations with a list of topics to be covered in the interview. For example, the FROMAJE<sup>22,23</sup> asks that the interviewer collect information about certain physical

and social problems that could influence mental health. Mental status measures that assess small increments of deterioration or improvement can be important in measuring the effects of care.

### *Social functioning*

Social functioning is a broad concept that "embraces all human relationships and activities in society." Research has demonstrated that social support has profound implications for health and illness recovery. There are three components of social functioning:

- Social interactions and resources;
- Personal coping and subjective well being; and
- Environmental fit.

Social interactions are typically assessed with measures of the existence, frequency and nature of social interactions. These measures are complicated because social interactions vary by stage of the life cycle, culture, social class and personal inclination. Environmental fit combines environmental and resident satisfaction assessments. These measures may be particularly important with institutionalized elderly because behaviors that are considered bizarre and disruptive may abate if activities are individually structured.

### *Multidimensional measures*

These measures, usually assessed by a multidisciplinary team, are attractive because of the frequent co-morbidity in this group. These measures provide a snapshot of the individual's current status across many domains. For example, the Older American Research and Service Center Instrument (OARS)<sup>24</sup> measures functioning in five domains:

- Social resources;
- Economic resources;
- Mental health;
- Physical health; and
- ADLs.

There are a growing number of comprehensive measures that are designed for individuals with dementia, such as the Global Deterioration Scale.<sup>25</sup>

### *Behavior and affect*

The NIA Collaborative Study of Dementia Special Care Units used a number of instruments designed to assess resident behavior and affect. These include the Cohen-Mansfield Agitation Inventory,<sup>26</sup> Behavioral Pathology in Alzheimer's Disease (BEHAVE-AD),<sup>27</sup> and the Multidimensional Observation Scale for Elderly Subjects (MOSES).<sup>28</sup> In addition, there is a measure developed by Lawton, the Philadelphia Geriatric Center Affect Rating Scale,<sup>29</sup> which was utilized in our study on the effect of environmental design on health outcomes.

### *History*

Needs assessment for clinical populations is still driven by the agendas and priorities of health care professionals. In non-clinical populations, needs assessment is aimed at epidemiological considerations, where the focus is almost exclusively on the functional status instead of subjective accounts from elders themselves about factors that influence their functional states. The World Health Organization (WHO) defines health as a "state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."<sup>30</sup> Dictionary definitions identify both physical and mental dimensions of health and suggests "well-being" to include soundness and vitality. Clear precedents for the dimensionality of health and distinguishing between physical and mental health along with empirical evidence becomes convincing.

Yet this multidimensionality of health is not adequately measured. A recent review of needs assessment articles revealed that primary attention is given to the utility of quantitative instruments for assessing the demand for various types of clinical services. Few studies focused on prevention with non-clinical populations and even fewer were developed with extensive input from the very elders whom the studies were attempting to characterize and inform. Very rarely was patient or family participation included in the formation of outcome measurements.<sup>31</sup>

These findings are somewhat startling and point to the necessity of including consumer input when designing strategies to measure and reduce negative outcomes. The following reasons outline the importance of incorporating consumer-generated input:

- Health care professionals, with their emphasis of biologic factors that influence functional decline, often focus attention on functioning only after it has begun to deteriorate;<sup>32</sup>
- Providers often underestimate the problems

with measuring functionality;

- Consumers themselves are the best sources for precisely describing the factors and circumstances that impede their functioning and for outlining the health beliefs that most influence their health maintenance behaviors.

Major goals of consumer-focused outcomes research include the following:

- To improve the understanding of the wants and needs of elders and their families in order to prevent physical, social, role, and psychological declines;
- To help set priorities for new research on the factors which affect functional decline and to design consumer-dictated programs that have the potential of preventing such decline;
- To identify and remove system-wide barriers that impede provision of appropriate services; and finally,
- By using the input of consumers themselves, to develop models of community care that directly address the needs, worries, and issues that the elders themselves have identified and expressed.

In terms of cost-benefit analysis, involving consumers in the design and assessment of prevention programs can have immense benefit. Input of consumers provides more finely tuned, appropriately targeted interventions that presumably will result in improved outcomes. It is widely acknowledged that though prevention services are not cost-effective in younger populations, they are extremely effective in the elderly population, given that the likelihood and ensuing financial burden of functional impairment is so high within this population.<sup>33</sup> Elder focused intervention may demonstrate the following benefits: prevention of functional decline; improved quality of life; and decreased cost, which is linked to the treatment of preventable problems and focused on primary, as opposed to secondary prevention. This change in emphasizing the prevention of functional decline before an individual has had an illness or injury requiring treatment in an institution, is seen as a major benefit of the consumer-focused approach. In summary, there are two steps involved in the process of transitioning to a more elder-centered focus for outcomes research—the first is to switch emphasis from a secondary to a primary prevention model—and the second is to develop

assessments from the perspective of the elders and their families, rather than relying on the more removed view of the “experts” or professionals who are merely anticipating the elders’ needs.

Identifying ways of providing better elder-focused services would have substantial impact on the field, in terms of cost savings and increasing the range of services currently available. Within the managed care system, with its expanding responsibility and liability for the complete health care of its individuals, primary prevention is assuming greater and greater significance and priority. Accordingly, effective strategies for primary care prevention require the input of non-clinical groups. The absence of patient-centered input renders managed care organizations unable to develop efficient and effective intervention programs and priorities. The overall benefit of utilizing patient-centered outcomes is two-fold: decreased risk of functional decline and improved quality of life, as well as economic and practical benefits for managed care systems.

Although most research does not yet incorporate elder input, Ruta *et al* constructed a patient-generated index and concluded that it is feasible to construct a questionnaire that quantifies the effect of a medical condition on patients’ quality of life in a meaningful and relevant manner.<sup>34</sup> In a recent American Association of Homes and Services for the Aging Preview, a new model of care provision and assessment of consumer satisfaction was presented.<sup>35</sup> This model of measuring consumer satisfaction in long term care involves identifying resident “requirements” for satisfaction and quality of life in the nursing facility setting. It measures resident satisfaction across all possible levels of cognitive function. The overall philosophy includes an “ask the resident” premise that focuses on the quality of daily life experiences in the nursing facility. The resident “requirement” becomes a standard to be met or exceeded by the facility, and creates satisfaction/quality of life items that are as concrete and behavioral as possible. Specific methods used to develop the measurements include open-ended informant interviews to determine resident requirements, with questions tailored to individual levels of physical ability and cognitive status. It also includes distribution of a family satisfaction survey, which will be compared to resident satisfaction. These promising data suggest that more patient-centered outcome research is indeed possible.

## Issues in utilizing outcome data

Once a long term care facility has collected outcome data, they are faced with how to use that information to improve services and programs. This can be done in two ways. The primary method is to use this information to



improve outcomes on an individual basis. Thus, once a resident has been assessed using some of the tools described above, an individualized care plan can be developed. A number of mechanisms have been used to ensure that this plan is understood by the direct care staff and implemented correctly. One successful methodology includes key staff in the assessment and service planning process thereby ensuring that staff have the information they need to translate the plan (structure) into actual interventions (process). Staff are more committed and can intervene if the plan is not yielding the desired outcomes.

Alternatively, special care units may review aggregate resident outcome data. However, due to the small and unique sample, these data are difficult to use effectively. Each SCU has a unique and transient case mix making it difficult to compare any but the most obvious outcomes with the general dementia population or even within the facility population over time. However, as more data from standardized instruments are collected, such comparisons will become more practical. Some facility-wide data that has been successfully used for comparison include: falls, incontinence, and incidence of agitation.

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