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CONSUMER SATISFACTION: MEASUREMENT TOOLS FOR

THE FRAIL AND COGNITIVELY IMPAIRED

A Thesis

Presented to

The Faculty of Health Science - Gerontology

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

by

L. Gail Dobell

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# ABSTRACT

## CONSUMER SATISFACTION: MEASUREMENT TOOLS FOR THE FRAIL AND COGNITIVELY IMPAIRED

by L. Gail Dobell

This study identified, analyzed, and evaluated 60 satisfaction measurement tools being used with very frail elder care service recipients. Satisfaction measurement tools were collected during interviews conducted with 21 different provider sites serving frail elders. Five additional tools were selected from the gerontological literature.

The tool analysis and evaluation indicated that many tools were suitable for measuring the satisfaction of very frail elders who are cognitively intact. However, few tools were suitable for measuring the satisfaction of cognitively impaired elders. Self-report methodologies were identified as a new and potentially successful way of understanding the care experiences of physically and cognitively frail elders.

This study represents the first of a two phase study that is being conducted by the National PACE Association. The goal of the second phase of the study is to develop a satisfaction measurement tool that is suitable for both physically and cognitively frail elders.

## ACKNOWLEDGMENTS

# TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Purpose

This study evaluates different tools currently used to measure the satisfaction of

frail or cognitively impaired clients with their elder care services. This study represents

the first phase of an effort conducted by the National PACE Association (NPA), a non-

profit membership organization that supports, maintains, and promotes the provision of

services through the Program of All-inclusive Care for the Elderly (PACE) (Appendix A)

and On Lok SeniorHealth, the original program model located in San Francisco

California. Phase two of the study, to be conducted from May 1999 to May 2001, will be

the development and testing of a client satisfaction measurement tool suitable for use

with all PACE clients across the United States.

Research Problem

Although the use and validity of consumer satisfaction information is still widely

debated, the trend to measure the satisfaction of health care consumers is well established

in our society. Client feedback, properly measured, is increasingly becoming recognized

as an important component of continuous quality improvement (CQI) (Owens &

Batchelor, 1996; Cleary & Edgeman-Levitan, 1997). Three factors have contributed to

the intense focus on satisfaction measurement: a) growing sophistication among health

care consumers; b) the increasing attentiveness of service providers; and c) intensifying

competition for pre-paid and fee-for service patients (Rosenthal & Shannon, 1997; Cleary

& McNeil, 1988). With the frail elderly, however, population characteristics can complicate the situation. Measuring the satisfaction of elders who are often seriously ill and/or cognitively impaired presents very special challenges. Hearing loss, difficulty with memory recall, and anxiety about being asked lots of questions about their care are just some of the issues that may be encountered when surveying the frail elderly.

While many tools exist for measuring the satisfaction of acute care consumers, few tools have been developed to measure the satisfaction of frail and cognitively impaired elders who utilize non-acute professional services. Lack of a satisfactory tool has been an obstacle in collecting and utilizing client feedback for the NPA and many other elder care organizations (Williams, 1994; M. L. Clark, personal communication, October 1, 1997).

The Health Care Financing Administration (HCFA), which sponsored the original PACE demonstration, did not require PACE programs to monitor customer satisfaction during the demonstration period. Therefore, a measurement tool suitable for use at all sites has not been developed (although some NPA member programs have been experimenting with different approaches to measuring client satisfaction). The Balanced Budget Act of 1997 has established PACE as a permanent provider under the Medicare and Medicaid programs (Appendix B). As it joins other managed care programs, there is likely to be increased demand for consumer satisfaction reporting as one facet of CQI (M. L. Clark, personal communication, October 1, 1997).

Given the structure of the PACE program and its participants, existing customer satisfaction measurement tools may not reflect the broad range of services offered as well as the cultural diversity and the high levels of cognitive impairment of the program participants. If future HCFA regulations do require PACE to monitor satisfaction, NPA member programs will benefit from this analysis of existing measurement instruments and the development of a tool more appropriate to the needs of their target populations.

## Research Objectives

There are 4 relevant questions related to this study.

1. What tools exist in the field and in gerontological literature that are being used to measure frail and cognitively impaired elders' satisfaction?

2. Of the tools identified, to what extent are they appropriate for measuring the satisfaction of this elder population?

3. To what extent are the identified tools sensitive enough to capture the satisfaction of a socio-demographically diverse population?

4. To what extent are the identified tools suitable for measuring client satisfaction at elder care organizations offering a broad range of care services?

To address these questions, this research identifies the common and important components of successful client satisfaction measurement tools used with frail and cognitively impaired elders. It then considers the strengths and weaknesses of existing tools in terms of process (the way in which the data was collected and analyzed) and content (the subject matter of the data collected) (Ejaz, Cohen-Mansfield, & Werner,

1996). Next, a list of elements deemed necessary (by this researcher) for use with this

client population is developed incorporating the strengths of successful tools previously

analyzed. This list is then re-examined for its applicability to a diverse socio-

demographic client population and those organizations that offer a wide range of elder

care services.

<div align="center">Research Definitions</div>

<div align="center">Conceptual</div>

## Consumer

For the purpose of this study, the consumer is defined as the elder individual

receiving care services. (A broader definition of consumer might include informal

caregivers who receive respite as a result of having their relation in an elder care program,

HCFA or any other funding or regulatory body which may have involvement with the

program, or even taxpayers who contribute to programs that receive government

funding.)

## Consumer Satisfaction

Evaluating and developing tools for measuring consumer satisfaction requires a

basic definition of what satisfaction is and means. However, research has shown, and

common sense tells us, that satisfaction means different things to different people

(Williams, 1994). The variability in definitions of satisfaction has led some to argue that

measures of this type are of no practical use (Williams, 1994). Others argue that the

criteria used to measure health care consumer satisfaction are based more on providers'

assumptions than on patients' values and experiences (Avis, Bond, & Arthur, 1997; Cleary & Edgeman-Levitan, 1997). From the literature, it appears that there are several core dimensions that are widely used in measuring an individual's satisfaction. These include: self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth (Ryff & Essex, 1991). Developing a list of core dimensions to describe satisfaction for cognitively impaired elders is more difficult. Satisfaction research with this target group often involves observational measures of positive and negative affect and social engagement (Mor et al., 1995; Lawton, Van Haitsma, & Klapper, 1996). Observations by third parties of facial expression, body movement, and relationships are used rather than self-reporting. The specific dimensions of consumer satisfaction used in this study will be explored further in Chapter 2.

Quality Care

Lohr cites the Institute of Medicine's (IOM) definition of quality as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (as cited in McGlynn, 1997, p. 8). However, this neat definition masks the complexity of measuring quality.

McGlynn identifies six objectives which need to be addressed when exploring and measuring quality within the context of a particular health care delivery system: 1) identifying and balancing the competing perspectives of the major participants in the delivery system in question; 2) developing an accountability framework; 3) establishing

the explicit criteria by which health care system performance will be judged; 4) selecting a subset of indicators for routine reporting; 5) minimizing the conflict between financial and non-financial incentives and quality-of-care objectives; and 6) facilitating the development of information systems necessary to support quality monitoring (McGlynn, 1997). Yet, strategic decisions about all of McGlynn's six objectives are proving difficult. For example, two of the objectives particularly appropriate to this study, numbers 1 and 4, continue to be debated. The competing perspectives of health care purchasers, patients, and health care providers are far from balanced. Purchasers remain intently focused on the financial cost of care, patients are concerned with having their needs met, and providers are caught somewhere in-between their professional standards, the patient's wishes, and accountability for cost of care.

Selecting a subset of indicators (objective 4) also remains unmet. As Cleary and Edgeman-Levitan (1997) point out "recent work on the definition and measurement of health care quality has resulted in the availability of a range of quality indicators that exceed, by a large factor, the number any existing health system could implement and use" (p. 1608).

The inconclusive results of even the most recent literature illustrate that a definitive methodology for assessing quality has not yet been achieved (Cleary & Edgeman-Levitan, 1997; Rosenthal & Shannon, 1997).

While the debate on how to measure quality continues, consumer satisfaction is increasingly being used as one indicator of quality. However, even this widely used methodology is under scrutiny. Explored in more detail in Chapter 2, the validity of consumer satisfaction ratings as a measure of health care quality is questioned on both conceptual and methodological grounds (Owens & Batchelor, 1996; Cleary & Edgeman-Levitan, 1997). As challenging as quality monitoring appears to be, it is critical for maintaining a balance between the financial and administrative mechanisms that attempt to control health care is rising costs and the delivery of services (McGlynn, 1997).

Quality Assurance (QA)

QA, CQI, and total quality management (TQM) are terms given to the strategic goals and management methods used by health care organizations to promote better quality health care delivery (McGlynn, 1997). Quality assurance, the more traditional term, is considered more oriented toward individual practitioners and facilities. It is usually imposed on organizations from outside regulatory bodies. In contrast, CQI and TQM strategies are data driven, focus on systems of care, encourage providers to work at continually improving their performance, and are considered more internally driven approaches to improving quality (Lohr, 1997). Although CQI and TQM strategies initially focused on the delivery of non-clinical services, since 1989 they have been increasingly applied to clinical and chronic disease management (Enthoven & Vorhaus, 1997).

Operational

## PACE

The Program of All Inclusive Care for the Elderly (PACE) is a nationwide effort

to replicate the service delivery and financing model of acute and long-term care created

by On Lok SeniorHealth in San Francisco, California. The goal of the program is to

maximize each enrollee's autonomy and continued community residence and to provide

quality care at lower cost to Medicare, Medicaid, and private-pay enrollees relative to

their payments in the traditional system (National PACE Association, 1997).

## On Lok SeniorHealth

Established in 1971, On Lok's goal is to prevent the institutionalization of frail

elders by providing comprehensive and consolidated medical and long-term care services.

Primary care, social work, and restorative therapy services are provided at one of five day

centers, in the participant's home, or in the hospital. Specialty and ancillary medical

services are provided, as are transportation, meals and personal care. Fully capitated, On

Lok receives both Medicare and Medicaid waivers allowing it to receive fixed monthly

per capita payments to provide care to its population.

## The National PACE Association (NPA)

NPA is a non-profit membership organization that promotes the PACE model of

care and encourages the development of similar models. With funding from membership

dues and conference registration fees, the NPA manages a variety of cross-site activities

including annual and special interest meetings, public policy and advocacy, research, quality assurance mechanisms and accreditation standards.

## Health Care Financing Administration (HCFA)

HCFA is an agency within the federal government's Department of Health and Human Services (DHHS) that is responsible for administering the Medicare and Medicaid programs (Common definitions in aging and health care, 1997).

## National Committee for Quality Assurance (NCQA)

The NCQA is a nonprofit organization committed to collecting and publicly reporting data on different managed care plans. The data reported allows for a comparative analysis of those plans (Common definitions in aging and health care, 1997).

## Health Plan Employer Data and Information Set (HEDIS)

HEDIS is a set of standardized performance measures designed to collect data so that purchasers and consumers can have some information to assist them in reliably comparing the performance of managed health care plans. Sponsored, supported and maintained by the NCQA, HEDIS provides the most complete view of health plan quality available to guide choice among competing health plans (National Committee for Quality Assurance [NCQA], 1997). HEDIS reports performance across eight domains

effectiveness of care

accessibility/ availability of care

consumer satisfaction with the experience of care

cost of care

stability of the health plan

informed health care choices

service utilization

health plan descriptive information

The data set that measures satisfaction with the experience of care has three components:

(a) Consumer Assessment of Health Plans Study (CAHPS); (b) disenrollment survey; and

(c) satisfaction with breast cancer treatment survey (NCQA).

Consumer Assessment of Health Plans Study (CAHPS)

CAHPS is a set of satisfaction surveys designed for use with consumers covered

by both public and private health insurance and different delivery systems (Agency for

Health Care Policy and Research [AHCPR], 1996). The CAHPS information is being

incorporated into the HEDIS measures of "satisfaction with the experience of care" noted

above (AHCPR, 1997, p. 2-3). The CAHPS project was designed to provide "an

integrated set of carefully tested and standardized questionnaires and report formats that

could be used to collect and report meaningful and reliable information about experiences

of consumers enrolled in health plans" (AHCPR, 1997, p. 2-3). The surveys have three

key areas of focus: rating of specific experiences rather than multiple experiences;

emphasis on patient-provider interaction; and the development of tailored approaches for

specific populations including children, people with chronic illness, Medicaid and

Medicare beneficiaries, and non-native speakers of English (AHCPR, 1996; NCQA,

1997). The development of CAHPS has been a five year collaborative effort between the

federal government's Agency for Health Care Policy and Research (AHCPR) and four

other organizations: Harvard Medical School, RAND, Research Triangle Institute, and

Westat.

Nursing Home Certifiable Elder

An individual is certified as eligible for Nursing Home care based on state criteria.

This certification allows those financially eligible to receive Medicare and/ or Medicaid

reimbursement for the nursing care they receive (M. L. Clark, personal communication,

September 10, 1998).

Significance of the Research

The identification, analysis, and evaluation of satisfaction measurement tools for

use with frail and cognitively impaired elders benefits two principle populations, the elder

care service recipient and the elder care service provider.

Care Recipients

As Chapter 2 of this report indicates, comparatively little effort to date has

focused on obtaining satisfaction with care information directly from frail populations.

Measurement studies traditionally conduct research using client samples of those

considered capable of responding to questions in existing tools rather than developing

measures that are suited to a wider, more representative client population. This study and

its planned continuation efforts are attempting to demonstrate that satisfaction

information can be obtained directly from clients previously considered uninterviewable.

New tools designed specifically for use with very frail and cognitively impaired do exist

and provide information that the traditional proxy and caregiver studies cannot. Giving voice to a population historically unrepresented can lead to a greater understanding of the experience of the very frail and cognitively impaired elder and, in turn, affect service delivery and client satisfaction in a profound way.

<div align="center">Service Providers</div>

The identification and analysis of a variety of satisfaction measurement tools for use with frail and cognitively impaired elders are stepping stones toward the development of a PACE-specific measurement tool. This tool is a top priority for PACE and other non-PACE elder care organizations. For PACE, an organization committed to self-evaluation and improvement, this project represents the first coordinated effort to understand how PACE sites can monitor elder consumer satisfaction. Non-PACE providers will also benefit from this research, which provides a foundation upon which smaller organizations can build. They rarely have the resources to develop and validate original tools.

Benefits to PACE Providers

PACE self-evaluation. A federally recognized leader in providing medical and social services to the most frail and economically challenged elderly, the PACE model constantly self-evaluates to ensure that the changing needs of existing and potential clients are met and to explore creative options for service delivery (Ansak & Zawadski, 1983). Complete and effective self-evaluation is now recognized as including both staff and client input.

Traditional measures of client satisfaction have relied on plan disenrollment as a signal of enrollee dissatisfaction (Newcomer, Preston, & Harrington, 1996). However, with frail or cognitively impaired elderly, disenrollment statistics cannot be used as a valid measure of satisfaction. These individuals are often unable to control or change their care situation, so disenrollment may be a poor indicator of client satisfaction (Newcomer et al.).

Recognizing the importance of accurately collecting client satisfaction information, several PACE sites across the country have already developed and field tested tools with the client populations at their own sites. However, very little, if any, effort has been made to coordinate these individual site studies. This project links these efforts for the benefit of the whole organization by identifying, analyzing and evaluating these and other tools.

PACE accreditation. In addition to the internal, self-motivated desire to better understand the satisfaction levels of its clients, the NPA is also being affected by external forces. Encouraged by the now recognized value in measuring consumers' satisfaction, accreditation bodies will likely require providers to document client satisfaction measures as a component of TQM (M. L. Clark, personal communication, October 20, 1997).

Using the assistance of several national bodies, including the American Association of Health Plans (AAHP), the NCQA, the AHCPR, the Centers for Disease Control and Prevention (CDC), and the DHHS, HCFA has a mission to "collect and disseminate information that will help beneficiaries choose among health plans and

contribute to improved quality of care through identification of quality improvement opportunities (U. S. Department of Health and Human Services, 1997). An important component of that evaluative information will be the consumer satisfaction reports measured by CAHPS (AHCPR, 1997).

As the only congressionally recognized at-risk integrated program for nursing home certifiable elders residing in the community, PACE represents an accreditation challenge for HCFA. HCFA must either adapt existing regulations used to monitor "traditional" providers or develop a new set of regulations applicable for monitoring the PACE program. At this time, HCFA is still working through the political process of developing those regulations (M. L. Clark, personal communication, February 18, 1999).

Although little is confirmed to date, the NPA is developing the administrative and structural processes to meet the expected requirements that will be imposed by HCFA and other governing bodies of managed health care providers. Anticipating that client satisfaction measurement will be mandatory for all HCFA managed care programs, PACE is attempting to better understand the likely requirements and then to advocate for a measurement methodology that is reflective of their unique program structure.

Benefits to Non-PACE Providers

As the number of satisfaction measurement studies and tools targeted specifically to frail elders increases, developing an annotated index of existing measurement tools becomes helpful. Trends and gaps in measurement can be more easily identified, comparisons between methodologies are feasible, and smaller long-term care

organizations can use the information as a resource guide to consumer satisfaction measurement. This project provides non-PACE elder care organizations a comprehensive overview of the elder consumer satisfaction measurement market, identifies a range of existing tools available for use with elder consumers, and will make available a new or adapted tool that may be even more applicable to their client population.

## Assumptions and Limitations

The sample populations, both PACE and non-PACE, used for the qualitative survey portion of this research do not represent randomly collected samples. All dual-capitated PACE sites (those receiving both Medicare and Medicaid capitation payments for eligible enrollees) were considered survey participants. As non-PACE survey participants were recruited from a small geographical area, it is not possible to generalize the survey findings to a larger population. Thus, the results of the qualitative survey are suggestive only.

The validity of the qualitative interview guide may be limited. The interview guide was evaluated for content validity by staff members of On Lok and PACE. However, as a tool designed specifically for this study, it was not subjected to pre and post tests.

The data collection process did not control for some types of bias. For example, interviews conducted earlier in the data collection phase tended to be longer than those conducted later in the process. With experience, the interview process became more efficient. Although the interview questions remained the same, greater detail was

recorded later in the data collection process. Interviewee bias was not controlled and may affect study results. Interviews were conducted with a number of different site personnel. Responses to interview questions may differ between executive directors, quality assurance staff, and social workers, the positions held by most interview respondents.

The validity of the methodology used to analyze the satisfaction measurement tools may be limited. The methodology used was designed specifically for this study, based on the learning of this researcher and others. The methodology was evaluated by different On Lok and PACE staff members but was not subjected to further scrutiny. Subjective opinion will play a role in the final results of this study.

CHAPTER 2

REVIEW OF THE LITERATURE

The Evolution of Satisfaction Measurement

Much of the current literature that explores consumer satisfaction measurement

refers to the work of Dr. Avedis Donabedian (Cleary & McNeil, 1988; Fletcher,

Dickinson, & Philp, 1992; Glass, 1991). His model for quality assessment, developed

through the late 1960's to the early 1980's, describes the need to observe structure,

process, and outcome of care to assess quality (Cleary & McNeil, 1988). Structure refers

to the institution's capacity to provide quality care, including its resources, physical

design, and settings in which the providers work (Cleary & McNeil, 1988; Glass, 1991).

Process is made up of the activities and services performed by the organization, evaluated

in terms of clinical protocols and the ethics and values of society. Outcomes are the

results of structure and process for the consumer. Primarily designed for assessing

quality in acute care environments, the first two approaches, structure and process, were

the primary foci of measurement efforts. As regulatory bodies intervened, the foci of

assessment began to change and include outcome measures. However, outcome measures

remained embedded in the medical model of care with little attention paid to consumers'

opinions regarding services they receive.

Today's health and social care environment is different. Health care organizations

increasingly compete for enrollees. Concern is being voiced about how cost containment

is affecting quality of care, and CQI is broadly encouraged. Providers are now

recognizing the value of monitoring customer satisfaction (Rosenthal & Shannon, 1997;

Newcomer et al., 1996). Led by acute care hospital chains and health maintenance

organizations (HMOs), CQI departments are aggressively seeking consumers' opinions

and using this information as one quality indicator for the care being provided (Uman &

Uman, 1996; Owens & Batchelor, 1996).

Measuring client satisfaction produces information that can a) be used as a

valuable marketing tool, b) fulfill accreditation requirements, and c) direct service

delivery change. Satisfaction measurement reports can identify areas where service

delivery is not meeting consumer expectations. For example, improving access to

physicians might lead to higher satisfaction ratings and reduced client disenrollment from

a particular health plan (Newcomer et al., 1996). Health care organizations that can

demonstrate higher customer satisfaction can market their services more successfully to

corporations and large purchasers of employee benefit plans who increasingly demand

data on patient satisfaction and value of services before purchasing (Enright, 1996). In

addition, the Joint Commission on Accreditation of Health Care Organizations (JCAHO),

the NCQA and other accreditation bodies now require providers to measure patient

satisfaction and address problem areas in order to receive or maintain accreditation (US

Department of Health and Human Services, 1997). In a report written for the President of

the United States, the Advisory Commission on Consumer Protection and Quality in the

Health care Industry wrote:

>The Commission believes that some of the most important types of information a
>consumer has a right to receive fall into the categories of consumer satisfaction

ratings and clinical quality performance measures for health plans, health care professionals, and facilities. (Advisory Commission on Consumer Protection and Quality in the Health Care Industry, 1997, p. 11).

<center>The Validity of Satisfaction Measurement</center>

The validity of satisfaction measurement continues to be debated despite its seemingly wide acceptance as a quality indicator for health care service delivery (Williams, 1994; Owens & Batchelor, 1996; Cleary & Edgeman-Levitan, 1997; Rosenthal & Shannon, 1997). Two fundamental questions fuel the debate: a) can valid and reliable satisfaction information be obtained from consumers, particularly frail and cognitively impaired elders? and b) are satisfaction reports valid measures of quality of care? Critics tend to question the validity of satisfaction measures on both conceptual and methodological grounds (Avis et al., 1997).

<center><u>Conceptual Criticism</u></center>

Criticism of the conceptual framework of satisfaction measurement is based on several arguments. Some research suggests that too little is known about the way individuals perceive and evaluate their care (Williams, 1994; Avis et al., 1997). Williams argues that before patient evaluations can be accurately collated and interpreted, we must improve our understanding of how each individual determines if they are satisfied. He cites an example of how three individuals, all of whom reported to be "very satisfied", evaluated their care:

> "I've evaluated the service and I'm happy with it."
> "I've evaluated the service and I'm unhappy with it, but I don't really think I have the ability to evaluate, but I do have confidence in the staff."

"The service was appalling, but I don't like to criticize, after all they're doing their best."(Williams, 1994, p. 514).

A common assumption in the literature is that patients evaluate satisfaction by comparing their experience of care with their prior expectations (La Monica, Oberst, Madea, & Wolf, 1986; Newcomer et al., 1996). However, in the few studies that control for these dimensions, patient expectations and satisfaction ratings were not consistently correlated (Cleary & McNeil, 1988; Williams, 1994; Owens & Batchelor, 1996).

> (E)xpectations account for only a small amount of the variance in patient reports of satisfaction with care, and there is little consistency in the way patient expectations have been studied or in the correlation with satisfaction (Cleary & McNeil, 1988, p. 28).

A second concern is that when making health care evaluations, patients may not be able to distinguish between the process and outcome of care (Avis et al., 1997). For example, a patient may rate a particular service as "poor" because their unrealistic outcome expectations were not met. Despite a situation where the service delivery was perfectly adequate or even better, one measure of the "quality" of the process of care would be recorded as unsatisfactory, which would be a false negative, because the difference between the process and outcome of care were not clearly understood. Cleary and McNeil (1988) note:

> Patients are certainly aware of whether or not the way care was delivered met their expectations and whether there was an acceptable outcome, but it is difficult for them to know whether they had reasonable expectations or whether any undesired outcomes were the result of poor care or unusual circumstances (p. 29).

Patients can too easily report to be satisfied with care that is not high quality and can be dissatisfied with quality care (Cleary & Edgeman-Levitan, 1997).

A third conceptual issue is that very little is known about how other variables may influence an individual's expression of satisfaction. Race, culture and ethnicity, economic status, and educational background may have an impact on ratings of satisfaction, as might a patient's health status, knowledge, and level of experience with health care services (Avis et al., 1997; Cleary & McNeil, 1988). Although very little research has been conducted that examines the impact of these factors, work done to date indicates that they do have an effect (Linn & Greenfield, 1982; Eleazer et al., 1996). Attempting to explain variance in patient satisfaction ratings, Linn and Greenfield (1982) examined chronically ill patients' perception of their health and social circumstances. Exploring a number of situational variables (including age, sex, educational background and racial/ethnic background) on patient satisfaction, the researchers found that race and ethnicity were significantly associated with patient satisfaction ratings. Although the sample population was not selected based on ethnic background, and was only reported in terms of three categories (white, black and Hispanic), the results indicated that chronically ill black and Hispanic individuals were more satisfied with their health services than white patients.

Newcomer et al. (1996) report that "satisfaction with the components of care (rather than overall satisfaction levels) have been found to be weighted differently by patients depending on their socio-demographic and personality status" (p. 146). They also report that consumer gender plays a role in care evaluation. Females place "particular value on continuity of care" (p. 146).

Research is emerging that examines how racial and ethnic backgrounds, financial and health status and gender affect values regarding health care. However, much more emphasis is required to better understand how broader and different subsets of health care consumers report satisfaction.

<div align="center">Technical Criticism</div>

The technical limitations of some satisfaction surveys have also led to questions about their value as a measure of health care quality (Avis et al., 1997; Rogers & Herzog, 1992). Guyatt et al. (1997) discuss the importance of having a measurement tool that is sensitive to "signal" (differences in score between survey respondents) and "noise" (variability within subjects over time). Tool reliability (the ratio of variability between patients to the total variability), and tool responsiveness (the ability to detect change over time), are often untested before a measurement tool is used with a target population (Guyatt et al., 1997; Avis et al., 1997). Thus, the satisfaction reported by some tools may be inaccurate or misleading.

Tool validity, which is whether an instrument is actually measuring what it claims to measure, is a common methodological issue with satisfaction measurement surveys (Guyatt et al., 1997). Tools often rely heavily on global measures of satisfaction, such as "Are you satisfied with your home care worker?" These broad or "cumulative" measures likely reflect "numerous features of the care received and not those aspects most closely related to quality of care" (Cleary & McNeil, 1988, p. 27).

The difficulty in defining the concept of satisfaction has often led to claims that the satisfaction being reported is based on providers' assumptions about what satisfaction means to consumers rather than consumer values and experiences. A tool may produce reports of high satisfaction but be measuring items that have little relevance to the consumer or to health care quality (La Monica et al., 1986; Avis et al., 1997). Although their research was conducted in acute care hospital settings, the Picker/Commonwealth Program for Patient-Centered Care concluded that what patients seem to care most about are not the things health professionals often think they care about (Gerteis, et al., 1993). Their research found that although patients expected access to up-to-date medical care, what concerned them most were feelings of vulnerability, helplessness, and dependency. While many satisfaction surveys have focused on amenities, e.g., food and cleanliness, having call lights answered in a timely fashion and getting the needed help with toileting were better indicators of satisfaction. To develop a more valid tool, specific dimensions of satisfaction relevant to consumers must be identified.

Using client focus groups to help pre-identify and confirm important indicators of satisfaction is becoming popular (Public Sector Contracting Report, 1997). Studies that use focus groups are doing so both as a means of identifying what dimensions of satisfaction are relevant to consumers and as a means of testing dimensions constructed from a literature review or provider assumptions (Zinn, Lavizzo-Mourey, & Taylor, 1993; Public Sector Contracting Report, 1997). Research that explores how consumers define satisfaction and quality of care reinforces the belief that some traditionally measured

dimensions of satisfaction may not be measuring what is really important to consumers. Cleary and Edgeman-Levitan (1997) note that the amenities of care which have been, and continue to be, a big part of satisfaction measurement, are perceived by consumers as "very distinct" from quality of care concerns. Instead, enabling them to become involved in their care planning and being treated with respect (which are not often measured) are considered extremely important to consumers (Cleary & Edgeman-Levitan, 1997).

The validity of a measure of consumer satisfaction will depend in part on the relevance of the satisfaction domains to the consumers being surveyed. However, the domains used to define satisfaction differ between providers and consumers and among consumers. As a result, there is variability in the domains found in satisfaction measurement tools. A review of different sets of domains (most tools use more than one domain) indicates that technical quality appears most consistently, despite concerns of relevancy and consumer ability to evaluate technical aspects of care (Case, 1996). Most, but not all, sets of dimensions have some measure of the relationship between the consumer and staff. After these, the variability between sets increases further. Other domains that appear include accessibility, environment (meals, physical surroundings, cleanliness), and cost. Very few include measures of how consumers feel they are treated, items such as autonomy, respect, and degree of involvement in care planning.

Satisfaction Measurement in an Elderly Population

The health care industry's effort to collect client satisfaction information has largely been concentrated on those who utilize in-patient and out-patient acute health care services. Few measurement tools have been developed specifically for use with very frail, long-term care populations and even fewer studies have attempted to measure the effect of age on the way individuals report their satisfaction with health care services. The research that has explored satisfaction with this target population consistently reports that age does affect the way individuals interpret and evaluate the services they receive (Newcomer et al., 1996; Owens & Batchelor, 1996; Linn & Greenfield, 1982). Explored in greater detail below, conditions associated with age such as declining health and physical and financial dependency appear to have an effect on levels of satisfaction.

## Measurement Obstacles

The rationale for why so little effort has been focused on frail elder satisfaction is twofold. First, the structure of the health care delivery and reimbursement systems have not motivated research with long-term care populations to the same extent as with acute care consumers. Second, the physical, cognitive, and psychological constraints characteristic of the very old represent very significant challenges to current satisfaction measurement technology (Owens & Batchelor, 1996).

The Structure of Health Care for the Elderly

Prior to 1992, the elderly were served primarily by providers reimbursed by and subject to the program regulations of Medicare, Medicaid, and the Older American's Act (OAA) (Moon, 1996). Health care consumers had some limitations of choice in care providers as not all physicians were willing to serve these beneficiaries. The concept of competition for elder consumers was non-existent; in fact, the reverse was sometimes true. These elders were an unwanted population in the sense that there was additional paperwork, regulatory oversight, and often limited reimbursement associated with Medicare and Medicaid beneficiaries (Moon, 1996). Since introduction of the Tax Equity and Fiscal Responsibility Act (TEFRA) in 1992, HMOs have increasingly competed to provide health care services to Medicare beneficiaries. As the competition for these consumers has intensified, the demand for some common evaluation–a report–has arisen. Measures of consumer satisfaction are one component of report card evaluations (Epstein, 1996).

However, the satisfaction of the very frail and cognitively impaired elderly population continues to be largely unmeasured for several reasons. The high cost of serving this dependent group makes them less profitable to managed care organizations. David J. Lothson, a financial analyst at Paine-Webber, states "HMOs have been financially successful in courting below-average and average-risk patients whose health care costs fell well below the premium paid annually–avoiding high cost patients is a strategy practiced by nearly every HMO" (cited in Herzlinger, 1997, p. 121).

The nature of frail elders' chronic conditions and unlikely prognosis for recovery make them less rewarding to serve, and their relatively small numbers (perhaps as few as 3,600,000) make them less of a priority (Appendix C).

Physical and Cognitive Impairment

The ability to communicate is basic to most efforts to assess satisfaction. Information must be effectively transmitted and effectively received for communication to take place (Henry & Capitman, 1995a). Physical and cognitive impairment can limit an elder individual's ability to understand and/or respond to inquiries about satisfaction with a program (Henry & Capitman, 1995a). Satisfaction surveys have traditionally relied heavily on an individual's memory. However, memory error such as underreporting bias (when a survey respondent forgets to report an event) or over-reporting bias (when an event is remembered having occurred more often or more recently than it actually did) can significantly affect survey results (Bradburn, 1983).

With approximately four million older adults now diagnosed with Alzheimer's disease (The Alzheimer's Association, personal communication, November 5, 1997) and over 70 percent of nursing home residents having some degree of cognitive impairment, the reliability of self-report survey methodologies have been challenged. Agraphia, aphasia, confabulation, and dysarthria (Appendix D)—conditions that are common in those suffering from cognitive impairment, stroke, and related illnesses, can severely limit an individual's ability to participate in a client satisfaction study (Butler, Lewis, & Sunderland, 1991). Sensory impairments also limit an elder individual's ability to

respond to questions concerning his/her satisfaction with services. Visual and hearing

impairments, the most prevalent sensory impairments among the elderly, mean that

compensatory action must be used (Henry & Capitman, 1995a). However, instead of

developing and utilizing more sensitive measurement techniques such as oral interviews

(a far more costly methodology than the usual written surveys), it is more common that

this large population of elders is ignored in satisfaction measurement studies (Henry &

Capitman, 1995a; Simmons et al., 1997).

Psychological Constraints

In addition to the physical and cognitive limitations that make satisfaction

measurement difficult, the vulnerability of some elders who use long-term care services

further complicates the collection of satisfaction measures. Eliciting critical responses

from the general population on questions of global satisfaction is often challenging.

Owens and Batchelor (1996) estimate that when asked, approximately 80% of consumers

will claim they are satisfied with the care they receive. However, obtaining evaluative

information from elderly consumers is even more difficult. Owens & Batchelor explore

two psycho-sociological explanations for why older individuals report higher satisfaction:

frail elderly have lower expectations about the care they will receive, and elder

consumers are reluctant to articulate their dissatisfaction.

Examining the issue of expectations, Owens and Batchelor (1996) conducted 60

qualitative interviews with elders using the United Kingdom's District Nurse Caregiving

services in the United Kingdom. The interviews began with a global question about the

client's satisfaction, to which 98% of respondents reported being satisfied. Respondents were then asked to describe first, what they had expected the District Nurses to do for them, and second, what the nurses had actually done for them. Three categories relating to expectations were identified. The first category of respondents knew what to expect of the nurses, having been informed by others or by having personal prior experience with the service. The second category was unfamiliar with the services and had no expectations about the care they would receive. The third category of respondents had misconceptions and false expectations about the services they were to receive. The research indicated that "high levels of satisfaction may not be directly related to the fulfillment of prior expectations" (p. 1486) and therefore, having lower expectations cannot, in isolation, explain the impact of age on elder consumer satisfaction reporting.

The reluctance of older consumers to report dissatisfaction may be a better explanation of high satisfaction ratings reported by the elderly. Owens and Batchelor (1996) used the same 60 interviews to explore reasons for failing to report dissatisfaction. Identified reasons included the client's fear that expressions of dissatisfaction might increase the workload for the already overworked nurses, that nothing would be done about the negative issues anyway, and that complaints about service might further compromise nursing care (Williams, 1994; Owens & Batchelor, 1996). Dependency on, and personal attachment to, caregivers may account for some of these sentiments. For example, Owens and Batchelor found that clients' level of dependence on District Nurses had a direct impact on satisfaction ratings: in high dependency cases, where District

Nurse care represented the difference between remaining at home or being institutionalized, greater satisfaction with District Nurse care was reported. Newcomer et al., (1996) found that patients with higher need for care services placed more value on continuity of the patient-caregiver relationship. In this case, complaints about service delivery may not be expressed for fear of an interruption in service continuity.

Elder consumers also seem less willing to criticize health professionals with whom they have developed a personal relationship (Owens & Batchelor, 1996). Patients, particularly those with chronic, long term care needs, may consider their professional caregivers friends and feel loyalty to them. Great care must therefore be taken in obtaining critical evaluations from clients who have been served by a particular caregiver for many months or years. Owens and Batchelor conclude that "personal interactions between nurses and patients appear to be significant predictors of patient satisfaction rather than patient approval of the actual care received" (p. 1488). Elderly consumers appear more willing to critically comment on areas unrelated to the performance of caregivers, such as the large caseloads and demanding schedules the nurses had to manage.

<u>Increasing Need for Better Measurement</u>

The changing demands on elder care service delivery intensify the need to develop measures that can assess frail and cognitively impaired elder satisfaction.

Concerns of Today

Increasing health care costs and demand for care have led to societal concerns

about the quality of elder care service provision (Murphy, Morris, Fries, & Zimmerman,

1996). Quality issues in residential facilities include inappropriate use of physical

restraints and psychotrophic drugs (Murphy et al., 1996). Adult daycare and day health

programs have been criticized for not providing enough stimulation and personal

attention to participants (Henry & Capitman, 1995b). Home care quality issues include

the high turnover rate of care providers and physical and fiduciary abuse of elder

consumers (Donaldson & Lohr, 1990). The reporting of such issues has relied heavily,

and unrealistically, upon mechanisms that may not be able to capture valid and reliable

data about elder consumers' values and experiences.

Concerns for the Future

Identifying valid, reliable, and easy to administer satisfaction measurement tools

becomes even more important when considering elder care needs of the future.

Demographic information and research on informal caregivers support the assumption

that there may be an increase in number and frailty of elders requiring professional care

services (Cantor, 1991). Demographic projections indicate that the fastest growing age

segment is the oldest-old, those 85 years of age and older. Research on the contemporary

American family reports that changes in mortality, fertility, marriage, and female

participation in the labor force will further strain informal caregivers (Stone, Cafferata, &

Sangl, 1987). An increasing proportion of the 85 and older population, rising health care

costs, and decreasing resources all reinforce the importance of developing reliable methods for monitoring health care quality.

## Procedures for Measuring Elder Client Satisfaction

Most efforts to measure the satisfaction of frail or cognitively impaired elders attempt to circumvent physical and/or psycho-social constraints by relying on proxy or caregiver reports and observations of affect and social engagement, rather than self-reports methodologies.

### Proxy and Caregiver Measures

Caregiver surveys measure the caregiver's own satisfaction with the services received by their parent, spouse, or other relation. The proxy survey asks the informal caregiver to evaluate the satisfaction of the care recipient. Although both provide some measure of client satisfaction, many researchers believe neither provides accurate enough information about client satisfaction.

Gerontological literature on the validity of proxy reporting of elder satisfaction is generally negative. Proxy measurements are criticized for negating the value of the life experiences of an individual with dementia and failing to recognize that perceptions of caregivers and patients often disagree (Henry & Capitman, 1995a). Caregiver bias may be based on their own depression, poor relations with the care recipient, or misinterpretation of patient behavior.

One recent study measured 152 nursing home resident-surrogates' perception of the residents' satisfaction with the quality of physician services, nursing care, and nursing

home environment. The surrogates' scores were recorded on a Likert scale similar to an instrument used by the residents themselves. The correlation of residents' satisfaction with surrogates' perception of residents' satisfaction was calculated. The study concluded that nursing home residents' surrogates cannot accurately express residents' satisfaction with nursing home care (Lavizzo-Mourey, Zinn, & Taylor, 1992).

Another study with similar conclusions found that the most significant differences in reporting were on the measures of health status and psychological dimensions (Berlowitz, Du, Kazis, & Lewis, 1995). The authors found that patient-surrogates who spend greater lengths of time with the patient report greater impairments and are more divergent from the patient's own perception of quality of life than do surrogates with less frequent contacts (Berlowitz et al., 1995).

Although most caregiver surveys will ask the caregiver proxy-type questions, these surveys focus more on the satisfaction of the well caregiver. Survey questions such as "Does the program make your job as caregiver less stressful?", "Do you have more time for yourself now that your parent/ spouse is in the program?" are common (Rodgers & Herzog, 1992). Although these questions can provide valuable information to service providers, they do not report on the care recipient's experience.

Observed Affect and Social Engagement

Two additional methods for measuring the satisfaction of elders who may not be able to self-report are observed affect and social engagement (Mor et al., 1995). Researchers observe and record signs of positive affect in a target client, such as

expressions of pleasure, interest, and contentment, and negative affect, such as sadness, worry, and anger (Lawton et al., 1996). They might also observe an individual's social interaction, recording how well and how long the individual engages with other program participants, staff, and family (Mor et al., 1995). Studies that report on the validity and reliability of these types of tools conclude that if the dimensions of satisfaction are well defined, affect and social engagement measures can provide valid and reliable client satisfaction information (Lawton et al., 1996; Mor et al., 1995). However, the research also points out that "considerably more research is needed before counted affects may be used in quality control" (Lawton et al., 1996, p. P13).

Self-report Methodologies

Self-report methodologies, such as care recipient surveys, have been widely used with the elder population. However, recent literature questions the validity of some self-report measures and practices currently in use.

The Nursing Home Reform Act in the Omnibus Reconciliation Act (OBRA) of 1987 formally introduced the concept of obtaining client satisfaction information from frail elders. Under OBRA, the Patients' Bill of Rights required nursing home administrators to survey residents to determine how to increase their quality of life (Ferrini & Ferrini, 1992). The legislation promoted the use of tools such as the Nottingham Health Profile (NHP), the Sickness Impact Profile (SIP), the Life Satisfaction Index (LSIA), the Philadelphia Geriatric Center Morale Scale (PGMS), and the Bradburn Affect Balance Scale (ABS) (Fletcher et al., 1992). Despite widespread recognition that

resident opinion is necessary to improve nursing home quality and regulation (Estes,

Swan, & Associates, 1993), many have since criticized the methodology used to measure

satisfaction (Simmons et al., 1997). Current literature points out that the majority of

nursing home patient satisfaction surveys collect their data from unrepresentative

samples. The HCFA survey procedures define an interviewable patient as:

> (A) resident who has sufficient memory and comprehension to be able to
> coherently answer the majority of questions contained in the Resident Interview.
> These residents can make day-to-day decisions in a fairly consistent and
> organized manner (Simmons et al., 1997, p. 544).

In practice, nursing home or survey staff make a subjective determination about which

residents qualify to participate in a satisfaction study. They generally exclude all those

with advanced dementia and a large majority of those with mild to moderate cognitive

dysfunction (Simmons et al., 1997). In a literature review conducted by Simmons et al.,

the authors cite nursing home satisfaction ratings based on sample populations as low as

8% of the nursing home's total population. As more organizations who serve the elderly

attempt to measure their customers' satisfaction, the danger associated with

unrepresentative samples will grow. Without tools that are more inclusive of the very

frail and those with dementia, this population will continue to be excluded from

satisfaction studies.

## A New Trend

Recent evidence suggests there is a "shift toward including other, more vulnerable groups, such as the elderly, the mentally ill, and those with learning disabilities" (Owens & Batchelor, 1996, p. 1484) in self-report studies of consumer satisfaction. Where historically this population was considered ineligible, or was measured by proxy or observation methods, recent studies have demonstrated success in directly assessing patients (M. Brod, personal communication, January 15, 1998). The ability of some newer tools to directly assess vulnerable populations appears attributable to the increased research and effort applied to tool development. More tools are being designed for very specific populations, and are sensitive to the unique characteristics and challenges of the survey respondents. Focus group research is providing a better understanding of how vulnerable clients define terms such as quality, personal satisfaction, and contentment (Cleary & Edgeman-Levitan, 1997; Geron, 1997). This produces more relevant survey questions and increases tool validity. Greater attention is being focused on identifying methodologies that allow individuals to communicate their experiences more openly and easily (Henry & Capitman, 1995a). Examples of self-report tools designed specifically for vulnerable populations include the Dementia Quality of Life tool (DQoL) (Brod, Stewart, Sands, & Walton, 1998), the Nursing Home Resident Satisfaction Scale (NHRSS) (Zinn et al., 1993), and the Alternative Communication Device (ACD) (Oklahoma State University, Department of Sociology, 1996).

Adults with Developmental Disabilities

Measuring the satisfaction of adults with developmental disabilities involves

many of the same challenges faced with the very old cognitively impaired. Although this

link is rarely discussed in the gerontological literature, there is an opportunity for shared

learning, according to the Human Services Research Institute, an organization which

consults and develops satisfaction and quality of life measurement tools for both

population groups (M. Kimmich, personal communication, November 17, 1997).

Oklahoma State University and the Oklahoma Department of Health and Human Services

is currently using a unique approach to measuring the satisfaction of adults with

developmental disabilities.

Oklahoma's Alternative Communication Device

The 1987 amendments to the Developmental Disabilities Act identified positive

outcomes for this population as independence, productivity, integration and satisfaction

(Murray & Boose, 1997). Based on that framework, Oklahoma State University

developed a project to determine dimensions of quality of life and consumer outcomes

that are most important and valued by individuals with developmental disabilities–the

Developmental Disabilities Quality Assurance Project. In field-testing their project, the

University was able to assess all but the participants' satisfaction by conducting

interviews with each individual's primary caretaker (Murray & Boose, 1997). However,

to obtain valid measures of satisfaction, the program participant had to be interviewed.

The project found that more than half of the target population were unable to respond to

one-to-one interview questions about satisfaction because of communication, physical, and cognitive disabilities. Motivated by this high non-response rate, the University contracted with a speech-language pathologist to develop an alternative communication device based on the consumer satisfaction survey they were currently using.

The resulting tool, the Alternative Communication Device (ACD) adapted the consumer satisfaction survey to an alternative format featuring pictorial representations of the twenty-four scaled survey questions (Murray & Boose, 1997). For example, the question "Is the food good or bad" is represented by two pictures on facing pages. One side features a consumer model eating a sandwich with a pleased look on her face. The opposing picture shows the same person eating a sandwich with a pained look on her face, which clearly indicates dislike of the food being eaten. Under each picture are the corresponding words, FOOD is GOOD, and FOOD is BAD. Interview staff are trained to simultaneously verbalize the question, sign the question, and show the pictorial representation of the question, thus utilizing as many models of communication as possible (Oklahoma State University, undated). Consumers can use many methods to respond to the question, depending on their abilities. Some may point to the representative picture, some may use eye gaze, some may nod.

Initial research with the ACD indicated that the "unable to respond" rate dropped from 54% of the target population to 32% (Murray & Boose, 1997). In order to ensure validity of the tool, the University completed follow-up work to modify the instrument "promoting attention and response from individuals with limited communication

capabilities" and developed a training program for interview staff (Murray & Boose, p. 2). Through on-going modifications, the ACD tool has now reduced the "unable to respond" rate to 29% and is increasingly being recognized as a valid and reliable method of obtaining satisfaction information for those with developmental disabilities.

The ACD tool represents a creative approach to overcoming the cognitive and communication challenges of potential survey respondents. Given some of the overlap in interview obstacles presented by adults with developmental disabilities and very frail and cognitively impaired elders, the ACD tool methodology should be considered as a methodology suitable for use with the elder population.

<div align="center">Summary</div>

While the value of consumer satisfaction measurement is still being debated, the practice of using these measures as quality indicators in health care is widespread. However, the challenges of obtaining valid and reliable information from populations who can easily self-report are compounded by additional issues involved in collecting satisfaction information from very frail or cognitively impaired elders. Measures with this population must address not only physical and cognitive limitations but commonly must also accommodate for psychological constraints.

New studies and measures attempt to address the communication issues that are present with frail elder populations. Although a perfect tool is yet to emerge, each advances our knowledge about how to measure satisfaction with this population and is

another piece of the overall puzzle of understanding the experience of frail and

cognitively impaired elders.

CHAPTER 3

METHODOLOGY

Purpose

This study identified, analyzed, and evaluated tools currently used to measure the

satisfaction of frail or cognitively impaired clients who use professional elder care

services.

Design

This study had two phases: first, the identification of different tools currently

being used to measure frail and cognitively impaired elder satisfaction; second, the

analysis and evaluation of those tools.

Phase One: Tool Identification

Satisfaction measurement tools were identified by approaching two sources, elder

care service providers and the gerontological literature. The service provider category

was divided into two sub-categories: I) PACE programs, and II) non-PACE elder care

organizations. In-depth qualitative interviews were conducted with staff representatives

from both of these categories. Tools from the second source were identified by reviewing

the gerontological literature and interviewing individuals who are currently researching

different approaches to measuring the satisfaction of frail and cognitively impaired elders.

Phase 1: Sampling

PACE providers. All dual capitated PACE sites (those receiving both Medicare and Medicaid waivers) currently using some type of client satisfaction measure were recruited for this study. All twelve eligible organizations willingly participated in the study. The twelve sites are located in nine states across the country (Appendix E). The measurement tools provided by the PACE population did not constitute a random sample.

Non-PACE providers. Organizations that qualified for the non-PACE sample were those who have conducted some measure of client satisfaction within the past twelve months and were willing to participate in the study. The list of these organizations was developed based on recommendations of gerontological professionals who have knowledge in this area and by prescreening organizations listed by local information and referral agencies.

Three organizations from the three categories of community care, residential care, and adult day care, were recruited for a total of nine non-PACE respondents. All but one organization was located in one of Santa Clara, San Mateo, San Francisco, or Alameda counties (Appendix F). The one other organization was located in Fairfax County, Virginia.

The measurement tools provided by the non-PACE population did not constitute a random sample, but rather an available geographic-based, purposive sample.

Tools from the literature. The first priority in identifying tools from the literature and research in progress was to locate those which have been developed specifically for

use with frail and cognitively impaired elders. Additional effort was made to locate tools

that were designed for three elder care service categories: community care (specifically

home care), residential care, and adult day care. Tools from the literature were collected

from the following data bases: Ageline, ERIC, and PsycLit. Tools that were provided by

professional organizations and individuals researching satisfaction measurement

methodologies were identified through a process of word of mouth, conference

presentations, and contacts made through the literature review.

Phase 1: Procedure

PACE providers. All twelve dual capitated PACE sites received an information

package introducing them to the study. The introduction package described the purpose

and procedure of the research and clearly outlined their participation requirements. A

follow-up telephone contact initiated by the researcher prompted agencies to send any

written documentation they had available about satisfaction measures being used at the

site and samples of measurement tools used. It also confirmed the date and time for the

qualitative interview. Eleven of twelve PACE interviews were conducted by telephone.

One PACE interview was conducted in-person. All interviews were with a senior

administrator from each organization and were conducted by this researcher. All were

conducted in English and followed the Qualitative Interview Guide (Appendix G). The

PACE tools identified for Phase two of this study are listed in Appendix H. Thirty-one

PACE tools were identified.

Non-PACE providers. The non-PACE participant list was compiled by contacting potential participant agencies listed by information and referral services and sites recommended by professionals in the field. A prescreen was done on the first contact to determine if the contacted agency currently conducted client satisfaction surveys, and if so, to determine their willingness to participate in a survey sponsored by On Lok SeniorHealth and the National PACE Association. After agreement to participate in the survey, all participant organizations received an information package similar to the one given to PACE providers detailed above. The same follow-up telephone contact was initiated by the researcher that prompted agencies to send any written documentation they had available about satisfaction measures being used at the site and samples of measurement tools used. Six of nine non-PACE interviews were conducted in-person. Telephone interviews were completed for the remaining organizations, due to geographic or scheduling constraints. All interviews were with a senior administrator from the organization and were conducted by this researcher. All were conducted in English and followed the Qualitative Interview Guide (Appendix G). The non-PACE tools identified for Phase two of this study are listed in Appendix I. Twenty-four non-PACE provider tools were identified.

Tools from the literature. After initial identification, effort was made to contact the research authors to get additional information about the tools that were selected from the literature. Information about the development process of the tool, scope and frequency of use of the tool, revisions made to the tool, and qualitative information about

the strengths and weaknesses of the tool was sought. The discussions with the authors of the tools were open-ended and varied in length and content depending on the willingness of the interview subject, and the amount of prior information collected about the tool. Of the five tools selected from the literature and individual researchers, four author interviews were conducted. Three of four were conducted by telephone; one was conducted in-person. All interviews were in English. The tools from the literature identified for Phase two of this study include:

1. Nursing Home Resident Satisfaction Scale (NHRSS)

    Authors: Zinn, Lavizzo-Mourey, and Taylor, 1993

2. The Dementia - QoL Instrument (DQoL)

    Authors: Brod, Stewart, Sands, and Walton 1998

3. Home Care Satisfaction Measures (HCSM)

    Author: Geron, 1997

4. Home Care Satisfaction

    Author: The Picker Institute, 1997

5. Alternative Communication Device (ACD)

    Author: Oklahoma State University, Department of Sociology, 1996

Interview Instrument

The Qualitative Interview Guide was developed specifically for this study and was adapted from the model provided by Lo-Biondo-Wood & Haber (1994). The guide covered three domains: information about the provider organization, their clients, and the

organization's satisfaction measurement efforts. Interviews were generally very structured through the first two domains. However, due to the variation in responses to questions in the third domain, the guide was directional only. It served as a checklist of discussion topics. Interviews ran approximately one hour in length.

<div align="center">Phase Two: Tool Analysis and Evaluation</div>

The tool analysis and evaluation was based on a multi-step process. At the completion of an interview, information was summarized in a data package (Appendix J). Data packages covered three areas: the provider organization, the clients, and the organization's satisfaction measurement efforts.

The third area required a detailed breakdown of the tool(s) identified. An adaptation of two models (those of Ejaz et al. and Fletcher et al.) for assessing measurement tools produced a framework that examined the tools on two domains, process and content (Ejaz et al., 1996; Fletcher et al., 1992) (Appendix K). The process subdomains are methodology and development, reliability, validity, and data analysis, question structure, and confidentiality. Content reports on two issues: the topics covered and the length of the instrument.

Analysis and Evaluation of Tool Process

Each of the 60 tools identified was analyzed and evaluated based on the subdomains of process outlined above. Tools were first categorized based on the methodology used to collect the data. The Methodology Grids illustrate this categorization (Fink, 1995a, 1995b) (Appendix J). Tool development examined the

creation of the tool. Was it developed by the provider alone? If not, what and how much outside assistance received? Tool reliability, validity, and data analysis considered what type and how much pre and post-testing was conducted on the tool and resulting data. A score between 0 and 5 was then given for each tool. Question structure considered two factors: whether survey questions required an evaluative or factual report response, and whether questions were open-ended or closed-ended. If closed-ended, question structure also distinguished between questions that required a Likert-type scale, yes/ no, or categorical response. Confidentiality with regard to the respondent was the last process evaluation. Confidentiality was reported as being optional or not optional. A rating of moderately optional was recorded in cases where individuals were told their responses were confidential but the interviewer was known to the interviewee. All process analysis and evaluation information was recorded in the Tool Summary tables (Appendix L).

Analysis and Evaluation of Tool Content

All tools were categorized for overall content. A measure that probed all services was considered a general measure. Examples of more specific measures included enrollment follow-up, transportation, dental, and disenrollment surveys.

The literature review (Chapter 2) was then used to develop a list of all satisfaction domains that appeared in measures of frail elder satisfaction (Appendix M). Every question of every tool identified in this study was then categorized according to which dimension of satisfaction it belonged. This was accomplished by completing the Content Evaluation tables (Appendix N), then summarized in the Content Summary tables

(Appendix O). A second list of satisfaction domains was then created that better reflected this researcher's interpretation of consumer rather than other stakeholder interests (Appendix P). This list was based on the knowledge gained throughout the course of this study. The number of content dimensions found in each tool was summarized in the Tool Summary tables (Appendix L). The second subdomain of tool content, tool length, considered how many questions were included on the tool and, when possible, the length of time required to complete the survey.

A summary of tool strengths and weaknesses was then developed. This summary was the foundation of the criteria list for tools intended for use with very frail or cognitively impaired elders (Appendix Q).

CHAPTER 4

RESULTS

Main Findings

This study identified, analyzed, and evaluated different satisfaction measurement instruments used with frail and cognitively impaired elders. The results indicate that there is significant diversity in the measurement tools being used with this population. Many of the identified tools appeared suitable for measuring the satisfaction of very frail elders who are cognitively intact, but very few tools were suitable for measuring the satisfaction of cognitively impaired frail elders.

Phase one of this study identified 60 satisfaction measurement tools. Interviews that were conducted with agency representatives from the 12 PACE and 9 non-PACE elder care organizations revealed 55 tools. The remaining five tools included in the analysis were selected from the satisfaction measurement literature.

Phase two of this study analyzed the tools identified in Phase one. Results indicated that service providers and researchers were committed to identifying and using self report methodologies for measuring participant satisfaction, despite the measurement challenges encountered with this methodology that were identified in Chapter 2.

Almost 70% of the total 21 provider sites surveyed were attempting to measure client satisfaction by using some type of self report methodology. Of the measurement instruments identified in the literature, four out of five focused on identifying ways of

obtaining direct client reports rather than conducting research with the traditional caregiver or proxy measurement methodologies.

The tool analysis indicated that few of the self report tools were being used with cognitively impaired program participants. Instead, agency staff screened out the cognitively impaired when using such tools. Therefore, agencies serving a population with a significant proportion of dementia enrollees risked reporting results that were not representative of their entire caseload.

The study indicated that both agency representatives and researchers in the measurement field were concerned about the validity and reliability of measurement tools used with frail elder populations. Providers voiced concern that many tools may not probe the aspects of service delivery that are most important to their consumer population, that many tools were not sensitive enough to identify valid service delivery problems, and that some tools overemphasized the impact of isolated incidents.

Furthermore, existing tools did not account for the unreliability of elder consumer responses which can fluctuate from day to day, even moment to moment. Most providers agreed that while current satisfaction measurement efforts were better than none, a great deal more research was required to develop a mechanism that would provide accurate and reliable satisfaction information that could then be translated into improvements in service delivery.

Detailed Findings

Research Sample Characteristics

PACE

Site profile. The services provided at each PACE program were consistent, all

providing integrated acute and long-term care services (Appendix R). The size of PACE

programs varied considerably with the smallest and largest reporting 93 and 693 program

participants respectively. The mean site size was 329 program participants. Appendix S

provides cross-site summary information about the twelve PACE programs included in

the study.

Participant profile. The typical PACE enrollee was similar to many recipients of

long-term care services: an 80 year old widow, living alone, with several chronic medical

conditions and, more likely than not, suffering some degree of cognitive impairment.

Appendix S illustrates the physical and cognitive frailty of the PACE population.

Evident from the table, 58% of the total PACE population was dependent in three or

more activities of daily living. Approximately 68% of the total PACE population were

either diagnosed with or suspected of having some type of dementia (based on a mental

status questionnaire).

Other Providers

Site profiles. The range in services offered by the non-PACE research sites fell

into three categories. Three sites provided adult day care services only, three provided

home-care services only and the remaining three were residential facilities that provided

skilled nursing, rehabilitative, and independent or assisted living services. The size of these programs varied considerably. The smallest site was a rehabilitative nursing facility with an average monthly census of 36. The largest program was offered by a home-care provider network with sites across all of northern California. Their average monthly census was 3,900 enrollees. Appendix T and U provide descriptions and cross site summaries of the non-PACE programs included in the study.

Participant profiles. Appendix U provides information on the physical and cognitive frailty of the non-PACE participants. Similar to those in PACE programs, the average age of non-PACE participants was 80 years old. The percent of participants dependent in three or more ADLs ranged between 20% at the independent/assisted living facility and 95% at the Veterans center. The range in the number of program participants with some degree of cognitive impairment also varied more than in the PACE sites. The lowest incidence of cognitive frailty was 10% (at an assisted living facility), the highest incidence was 90%, reported at a nursing/rehabilitative residential nursing center. Many non-PACE sites do not report the number of ADL dependencies or diagnosis of dementia, therefore, average scores for these indices may be misleading.

Phase One: Tool Identification

Sixty tools were identified by the study. Organized by the method of data collection, three basic categories of tools were identified: tools that were administered by an interviewer, tools that were self administered by the respondent, and group meetings.

<u>Interviewer Administered Tools</u>

Of the 60 tools identified, 27 (44.9%) were interviewer administered tools. Of these interviewer administered tools, two sub-categories were identified. The first sub-category included interviews that were conducted in-person with a single respondent (22, or 36.6% of all tools). The second sub-category was telephone interview tools (5, or 8.3% of all tools were telephone interview tools.

<u>Respondent Administered Tools</u>

Only one type of respondent-administered tool was identified by the research. This type of tool was a written survey, usually mailed, that the respondent completed at home then mailed back to the provider agency or a contracted data collection organization. Twenty-two (36.6% of all tools) written surveys were identified by the research.

<u>Group Meetings</u>

The third category was a group meeting format where assembled groups of individuals could provide feedback, ask questions, or raise concerns with a staff representative(s). The remaining 11 (18.3% of all tools) tools identified by the research were group meetings, all following a forum-type format that encouraged open-ended discussions. Structured, formal tools were not used in the forum measurement process.

Figure 1 provides a summary of the tools identified by the method of data collection.

Figure 1

Tool Methodologies Identified by the Research
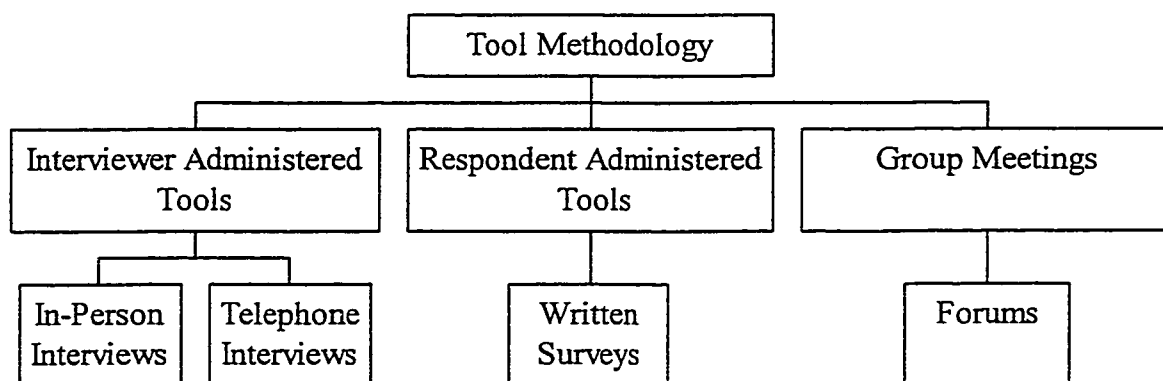
## Respondent Identity

The organizations included in this research were similar in that they served participants with high levels of physical and cognitive frailty. Consequently, the questions asked for determining participant satisfaction were often asked of an indirect source, such as a relative or staff member, rather than directly asking the program participant. Thus, an additional way of categorizing the measurement tools is based on the identity of the respondent. Three categories of tools emerged based on respondent identity: tools that were designed specifically for use with frail elders, tools that were designed specifically for caregivers, and tools that were used interchangeably with both. The tools that were used interchangeably with participants and caregivers were usually intended for the frail elder but, in the event that individual was unable to self-report, the same tool was then administered to the caregiver.

## Participant Only Methodologies

The largest of the three tool categories, 30 (50%) of the total 60 tools identified in this study, were used with the participant only. Of the 30, half used interviewer administered methodologies to collect data. Fourteen (46.6%) were one to one, in-person interviews and one (3.3%) was administered over the telephone. Six tools (19.9%) were self-administered, written surveys and the remaining nine (29.9%) were participant forums with one or more clients.

## Caregiver Methodologies

Of the remaining 30 instruments, 16 (26.6%) were focused on the caregiver alone. Of these, three (18.7%) were in-person interviews, one (6.2%) was a telephone interview, and 11 (68.7%) were self-administered written surveys. The remaining methodology (6.2%) was a forum meeting.

## Participant or Caregiver Methodologies

The third and smallest respondent category was tools that were used interchangeably with participants and caregivers. Fourteen (23.3%) instruments were identified. Of those, eight (57.1%) were interviewer administered (five were in-person interviews and three were conducted on the telephone), and five (35.7%) were written surveys. The remaining interchangeable methodology was a forum meeting (7.1%).

Using the two organizational categories: method of data collection and respondent identity, Table 1 summarizes the tools identified by the research.

Table 1

Respondent Identity and Methodology

| Category | Methodology | Participant only | Caregiver only | Participant or Caregiver |
|---|---|---|---|---|
| Interviewer Administered Tools | In-person | 14 | 3 | 5 |
| | Telephone | 1 | 1 | 3 |
| Respondent Administered Tools | Written | 6 | 11 | 5 |
| Group Meetings | Forum | 9 | 1 | 1 |
| **Total** | | **30** | **16** | **14** |

Phase Two: Tool Analysis

Methodology One: Interviewer Administered Tools

Mode A: In-person Interviews

A total of 22 (36.6%) in-person interview tools were identified by the research. Fourteen (63.6%) were designed for use with the participant alone, five (22.7%) were used interchangeably with the participant or caregiver, and the remaining three (13.6%) were designed for use with the caregiver alone.

Using the dimensions of process and content, the following compares and contrasts the 22 in-person interview tools identified by the study.

Tool development. Most in-person interviews tools were developed by site staff with some degree of assistance from an outside consultant or research firm. Outside assistance was sought by provider agencies that believed they lacked the technical expertise to develop a tool independently. Tools designed for use with participant only tended to receive a greater amount of outside assistance in their development than those tools that were used interchangeably with participants or caregivers or those used with caregivers alone.

Few sites had the time or resources to fully investigate the tools they developed. On a scale of 1 to 5, the only tools to receive the top score (5) for reliability and validity testing were those identified in the literature. Of those sites that did test their tools, focus group research was a common method to confirm that their instrument was actually measuring the dimensions of satisfaction it was purported to measure. One site used a

methodology called back-translation and had participants view visual representations of the response options and respond with the questions the picture represents (Howard Eells, Fouquet Stinnett, & Dodder, 1997). Very little was known about the reliability of most of the tools used. Again, lack of resources and knowledge about how to measure reliability with a largely demented population was the major challenge.

Reports that did go into greater depth about tool reliability were those identified in the gerontological literature. Tool responses were analyzed for internal consistency and reliability, using standard statistical analysis. Tests of Cronbach's alpha, Pearson's product-moment correlation, Cohen percent agreement coefficients, and Kendall's tau were observed. Few sites had a well developed technique for conducting content analysis on open-ended questions. One site did informally code key words recorded during open-ended interviews.

Frequency of tool administration. The intended frequency of the in-person interview tools varied significantly. Of the 14 participant only tools, five (35.7%) were conducted annually, two (14.2%) were used as one-time-only tools (one time per participant) as they related to single occurrence issues such as enrollment, one (7.1%) was conducted quarterly, one (7.1%) was intended as an "as needed" measure, and the remaining five (35.7%) were experimental tools that had not yet been administered at regular intervals.

Of the 5 in-person interview tools used interchangeably with either the participant or caregiver, the range in frequency of use was broader. Only one tool was being used on

an annual basis, one bi-annually, one quarterly, one monthly, and one as a one-time only (disenrollment survey) tool.

Within the caregiver only category, one in-person interview tool was used annually, one bi-annually, and the third was a one-time only measure that followed up on enrollment.

Tool content. Patterns in the content of the in-person interview tools tended to follow frequency of use patterns of the tools. The annual tools tended to cover a broader range of topics and probed multiple dimensions of satisfaction. These tools generally probed at least five content areas: the interviewees' global satisfaction, the art of care of the staff, the accessibility of staff, the technical quality of services provided, and the facility infrastructure, including meal and transportation services.

Tools that were used with greater frequency such as quarterly or monthly tools were more limited in what they intended to measure. Where annual tools tended to ask questions about overall satisfaction with a program, more frequently-used tools followed up on specific experiences with care. Quarterly and monthly tools tended to probe recreation, transportation, and meal services. These tools generally probed five or fewer dimensions of satisfaction.

The relationship between the frequency of administration of a tool and the number of content dimensions was not consistent for the one-time only tools. Usually very specific in their purpose—to measure the experience of enrollment into the program or to

understand disenrollment for reasons other than death—these tools generally probed multiple dimensions of satisfaction.

The experimental tools—those that had been administered only once—tended to follow the same content patterns as the annual and one time only tools. Most of the experimental tools asked questions from five or more content areas.

Tool length. Tool length was measured by two factors: the number of questions asked and the amount of time respondents needed to complete the survey. Of the 22 in-person interview instruments, the shortest tool asked seven questions. This instrument was designed for use directly with program participants and asked only open-ended questions. The longest instrument, also intended for use with participants, asked 72 closed-ended questions. This was an experimental tool that was not scheduled to be re-used as it was considered too lengthy for frail elders. The average number of questions on an in-person measurement tool was 24.5. It is important to note that the instruments with greater numbers of questions tended to be experimental tools, those being used with client populations for the first time.

Two of the 22 in-person interview instruments were unstructured interviews where the process and content of the interviews varied from respondent to respondent. These tools were not included in the calculation of the average number of questions per tool.

The average length of time it took an individual to complete an in-person interview was 25 minutes. The range for this measure varied between 10 minutes to 1

hour. Despite this range, almost all providers and researchers agreed that self-report measures of satisfaction should require no more than a half hour to complete.

Question structure. Two components of question structure were identified in the analysis of the tools. The first component distinguished between questions that required an evaluative and those that required a factual report response. For example the question "Are you satisfied with the transportation service at [site name]" requires the individual to make an evaluation about the quality of the transportation service they receive. The question "How often is your van more than 30 minutes late?" requires the individual to make a factual report. For the latter question, the determination of whether or not the service is satisfactory is the responsibility of the provider based on the factual reports they receive from participants.

The second component of question structure distinguished between questions that required the respondents to answer in their own words or choose from a pre-selected or fixed response option list. Fixed response questions required the individual to rate their responses on a scale (e.g., excellent, very good, good, fair, poor), respond with yes or no answers, or choose categorical responses.

The research results indicated that the most common type of question required the respondent to provide an evaluative response to survey questions. Of the in-person tools that followed a structured set of questions, approximately 302 of those questions were evaluative versus the 188 that were factual report questions. However, this researcher found the consistency of this dimension was the lowest of all analyses completed. A

large proportion of tool questions clearly fell into either the evaluative or factual report question category. However, about 20% of all questions could belong to either category. The ambiguous questions were analyzed on at least three separate occasions, and the category to which they were appointed after each round of analysis changed. The final allocation of ambiguous questions was made according to the category each question was placed on two of the three three occasions it was analyzed.

The research confirmed that the number of closed-ended questions far outweighed the number of open-ended questions. Of the total 491 in-person interview questions identified, 424 of those required the respondent to choose his/ her responses from a fixed number of alternative options rather than use his/ her own words. Of the 20 structured tools, eight asked only closed questions, nine asked a combination of open and closed questions, and only three tools asked open-ended questions exclusively.

The most frequently identified type of response mechanism for a closed question was an ordinal scale. Of the 424 closed-ended questions asked, 311 of those required the individual to rate their response on a Likert-type scale. Most scales ranged from a three point scale to a five point scale and covered intensity (strongly disagree, disagree, neutral, agree, strongly agree) and frequency (always, very often, sometimes, almost never, never). One interview provided a six point scale. Most scales included a "don't know" or neutral response option.

Yes or no options and categorical responses were used as alternatives to the Likert-type type scale response options, but with less frequency. Approximately 102 (of

the total 424 closed questions) provided a yes or no option. Several yes or no questions also provided a "don't know" or neutral response options. Eleven questions provided a categorical or nominal set of response options. These questions often probed the amount of care services an individual received (from once weekly through daily), gender, and their living situation (own home, home of a relative, home of a friend, assisted living home, nursing home). The individual was required to choose the option that best suited him or her.

Confidentiality. Most providers reported that their tools granted the survey respondent confidentiality. A statement, such as the one that follows (taken from IP-PO Tool 11), was usually read at the beginning of the interviews.

I will be asking questions about how you feel about specific services provided by [site name]. There are no right or wrong answers; your answers will be kept confidential. Only a summary of the combined results from the surveys of all program participants will be shared with the [site name] staff.

Despite having their confidentially assured, sites reported that in-person interviewees were skeptical about the confidentiality of their responses. This might be more pronounced in situations where the interviewer was known to the interviewee. The design of this research did not include a comparison of the quality of confidential responses versus the quality of responses made when confidentially was not assured.

In-person Interview Tool Evaluation

More than any other category identified by the study, the in-person interview tool category received the greatest amount of outside assistance for tool development and testing and contained the greatest number of experimental or first time used measures.

Almost all this new development activity was focused on the participant only, rather than the participant or caregiver or the caregiver only respondent categories.

Providers new to using in-person interview tools for participants were committed to identifying new and better ways of collecting information directly from the source, rather than relying on proxy reports. The providers more familiar with participant self-report measures reported that they were able to obtain valuable information from program participants. However, the analysis of the tools revealed that, while these measures were certainly increasing the percent of consumers self-reporting, the existing tools still fell short of what would be ideal for measuring the satisfaction of very frail elders (Appendix Q). Most tools were still too sophisticated for individuals with even mild levels of dementia. For example, responses relied on memory recall and required the individual to distinguish between different types of care providers (e.g., doctor, nurse, social worker, activities director).

The risk of obtaining unrepresentative results was high because participant samples were not randomly selected. The tool analysis indicated that the participant samples were often purposive, individuals were hand-picked to be survey respondents based on their level of cognitive function. Generally, most individuals with a diagnosis of cognitive impairment were not selected as survey respondents. Therefore, the tools used were still unable to accommodate the range of cognitive abilities of the total participant group.

The tool analysis also revealed that the level of testing of many tools was limited and that little was known about the reliability and validity of the information collected by the measures. Many providers support the observation that satisfaction ratings were "erroneously" influenced by issues unrelated to the delivery of care. For example, one provider suspected that a relationship problem at home was negatively affecting one client's evaluation of care provided at the site. Providers also commented that a participant's response to the same question differed from one day to the next, or that conversely, participant responses were too consistent and did not reveal any deficiencies other than isolated episodic incidents.

The tool analysis also found fault with the measures that were used interchangeably with participants or their caregivers. Interchangeable respondent measures raised questions about how well a single tool can provide valuable, relevant information from either a very frail elder consumer or their caregiver. How can a tool that is well designed for use with a very frail or cognitively impaired elder be the same as one that is well designed for a caregiver?

The tools identified by this research as interchangeable were often too long for a very frail or cognitively impaired elder. They required respondents to make evaluations which might have left one who is very frail feeling exhausted, frustrated, or confused at the conclusion of the interview.

In-person measures designed for use with the caregiver alone do not encourage elder participant self-reports. However, in cases where communication with program

participants is prohibitively difficult, such as those with advanced dementia, caregiver proxy reports can provide valuable information about the experience of the frail elder. This study identified 3 in-person interview tools designed to be used with the caregivers alone. More common methodologies with this population were written surveys, telephone interviews or forum meetings.

Sites that did use in-person interviews with caregivers reported advantages over other methods of data collection. A generally low response rate to written or mailed surveys can be overcome by conducting interviews. In-person interviews rather than telephone or forum meetings allowed for a greater connection between interviewer and interviewee. In-person interviews were also reported to enrich the caregiver responses to open-ended questions.

If the goal of a satisfaction measure is to understand each participant's level of satisfaction with care, then it follows that a tool should be designed to enable the elder individual to self-report. Of the three types of in-person interview tools identified by the research, those designed for use with the frail elder service recipient are the most likely to reflect that individuals level of satisfaction with care. Those designed for the caregiver have value (e.g., reporting for those who cannot self-report or for cross referencing reports of a participant and their caregiver) but as proxies, may miss nuances of the recipient's care experience. Measures designed for use with either the participant or caregiver likely miss important information from each possible respondent by attempting to accommodate both.

Mode B: Telephone Interviews

The second category of one-to-one interviews, telephone interviews, was considerably smaller than the in-person interview category. Only five telephone interview tools were identified by the research: one tool was designed for use with participants, one for caregivers, and the remaining three tools were those that were used interchangeably with participants or caregivers.

Tool development. The patient only and caregiver only telephone interview tools (used at the same provider site) were developed with the assistance of an outside researcher and were "experimental" tools. At the time of the data collection for this project, each tool had been used only once and there were no plans for further use in the near future. This was due in part to the high cost of executing the interviews and organizational changes at the site.

The remaining three telephone interview tools were all used interchangeably with patients or caregivers. Two of the three were developed by staff at the provider site and the "informality" of the development of these tools was consistent with their purpose. One tool was used as a weekly follow up on home care service delivery and did not follow a specific format. The questions and content changed weekly, depending on the respondent and the care services provided that week. The second tool was an ad hoc transportation survey used to obtain more detail about complaints site staff received about the van service.

The third interchangeable telephone interview tool used the services of a research consulting firm to help in the development and testing of the tool. The purpose of the tool was complex: it was designed to measure the overall satisfaction of survey respondents (participants or caregivers) and was also used as a disenrollment tool for participants (or family members) leaving the program for reasons other than death.

Tool validity and reliability testing were conducted on the two experimental tools and on the tool that was developed with the assistance of the research consulting firm. Focus group research and pre-testing results were used for all three tools. As in the case of the in-person interview tools, sites had difficulty measuring the reliability of the tools used with the frail elder respondents.

Statistical data programs that measured frequency distribution, central tendency, and cross tabulations were used to analyze closed-ended questions. Response themes and codes were developed for responses to open-ended questions.

The remaining two telephone interview tools conducted little formal data analysis.

Frequency of tool administration. The patient only and caregiver only interview tools were two of a set of measures designed to be used together at the same site (a third, provider tool, completed the set). The scope of the total measurement project was enormous and used considerable time and financial resources of the site. Consequently, there were no plans to repeat the effort in the near future, although the site did intend to use the package again at some point. The frequency of these tools was therefore undetermined.

Of the three tools used interchangeably with participants and caregivers, one was intended as an annual tool, one was a weekly, and the remaining was planned as an "as needed" tool with no scheduled pattern of use.

Tool content. As one telephone interview tool did not follow a consistent format, only four data points on the content of telephone interviews were obtained. So few a number makes patterns difficult to observe. However, as was the case with the in-person interviews, the tool that was used less frequently tended to ask questions from a greater number of dimensions and provided a broader interpretation of satisfaction. The annual tool asked questions from six dimensions: staff accessibility, art of care, technical quality, infrastructure, education and information, and global satisfaction.

The patient only and caregiver only tools probed fewer dimensions, despite the fact they were also general satisfaction measures. However, in both cases, the bulk of the questions on these tools were from the global satisfaction dimension and probed few if any specifics about the delivery or quality of care services received.

The remaining tool, the "as needed" transportation measure, was very specific and included only questions that dealt specifically with aspects of the transportation service delivered.

Tool length. Again, based on four tools, the length of the telephone interviews ranged from 5 to 46 questions with three of the four having less than 20 questions (5, 8, and 19 questions each). A pattern did not emerge between the ability of the respondent to communicate (assuming caregivers can communicate more easily than the frail or

cognitively impaired elder) and the number of questions on the survey tool. The shortest and longest tools (5 and 46 questions each) were used with either the elder program participant or their caregivers. Of the remaining tools, the shorter one (eight questions) was a patient only tool, the longer one (19 questions) was developed for caregivers.

The time needed to complete the telephone interviews varied from participant to participant and ranged from 5 to 45 minutes. The unstructured weekly interviews conducted by the home care agency were reported to take, on average, 5 to 10 minutes, although no formal documentation of duration was made.

Question structure. Survey questions were framed in such as way as to require an evaluative response more than twice as often as factual report response. This finding is consistent with the in-person interview questions. However, unlike the in-person interviews, a greater proportion of telephone interview questions were open-ended. Only 16% of in-person interview questions were open-ended questions compared to 27% of telephone interview questions. However, the vast majority of questions still required a closed-ended response (61 closed-ended versus 17 open-ended). One tool required exclusively open-ended responses (the unstructured interview), three tools produced a balance between open-ended and closed-ended responses, and the remaining tool used a closed-ended only response format.

The most common type of response mechanism for closed-ended questions was a Likert-type scale. Fifty-four of the total 61 closed-ended questions required the respondents to rate their answer on a scale. Three of the four tools that asked closed-

ended questions used a 5 point scale, the fourth a 4 point scale. Only one tool provided a "don't know" option on scaled responses.

Yes or no and categorical responses were used infrequently in telephone interviews. Only five yes/no and two categorical questions were asked. This was a considerably smaller proportion than was identified in the in-person interviews.

Confidentiality. Four of the five telephone interview tools used an interviewer who was either unknown (someone outside of the agency) or only remotely known to the individual being interviewed. In each of the four cases, the interviewer informed the respondent that their answers would be kept confidential and that they could refuse to answer any questions that made them feel uncomfortable. Several tools also informed the individual that if they wished to have a staff member answer any questions or concerns that arose during the interview they could forfeit their confidentiality.

Telephone Interview Tool Evaluation

The telephone interview category was small compared to the number of in-person and forum measures identified by the research. And, unlike the other aforementioned categories, the respondent focus of the telephone interview tools was not weighted towards tools for frail elders alone. Of the five tools in this category, one was for the frail elder alone, one was for the caregiver alone, and three were used interchangeably with both.

The information collected from the providers and the tool analysis indicated that telephone interviews were a good "half-way" approach to communicating with

participants. Telephone interviews provided an opportunity for greater feedback than written surveys and were able to better include those with communication challenges than a written survey. However, telephone interviews may not enrich the communication between interviewer and interviewee as much as in-person interviews. For caregivers, the telephone interviews, like the in-person interviews, encouraged a greater number of completed responses than written surveys.

<p style="text-align:center;">Methodology Two: Respondent Administered Tools</p>

Written Surveys

A total of 22 respondent or self-administered tools were identified by this study. All were written surveys, some to be completed at the site, others requiring the respondent to mail back the finished survey.

Of the 22, six measures were designed for use with the participant alone, five were being used interchangeably with participants or their informal caregivers, and the remaining 11 were designed specifically for use with the informal caregiver.

Based on the dimensions of process and content, a comparison of the written tools illustrates their similarities and differences.

Tool development. Almost all sites had some degree of outside assistance when developing their written survey tools. In many of these cases, the assisting organization also issued and collected the surveys and provided data summary reports to the provider agency.

Two tools were developed independently, without outside assistance. Both had been used for over 10 years and were frequently revised and updated based on the learning derived from their previous use.

The high level of outside assistance used in developing and conducting the written measures may have led to greater amount of data analysis. Organizations that specialize in satisfaction measurement are often able to test the reliability and validity survey questions to a greater extent than smaller provider organizations who have developed their own surveys. Also, written measures appear to have been used on more occasions than the interviewer administered tools thus many sites were able to improve problematic questions over several years of use.

Frequency of tool administration. The majority of the written surveys identified were conducted annually. Fifteen of the 22 were annual measures, two were designed for use twice yearly, and two were quarterly instruments. The remaining three measures were experimental and the frequency with which they would be used in the future had not yet determined. The experimental tools were intended for use with the patient only, supporting the observation that efforts to tap into the experiences of frail elder participants is a new and developing area. The tools that were used more than annually were those designed for use with the patient alone or the patient or caregiver interchangeably.

Tool content. Patterns in the content of the written tools were more difficult to identify than in the interviewer administered measures. Unlike the interviewer

administered tools where more frequently used tools were generally less inclusive, there was no association between frequency of use and the number of dimensions covered by written surveys. Almost all probed five or more dimensions.

Again, a consistent pattern did not emerge when the number of dimensions probed in each written measure was matched with the identity of the respondent. Written surveys intended for use with the frail elder alone did probe fewer dimensions. However, the tools that were used interchangeably with the patient or caregiver probed more dimensions than those intended for the caregiver only population, a group that could be assumed to have greater cognitive abilities.

Tool length. The number of questions on the written surveys ranged between 2 and 72, with a mean of 28.7 questions. The shortest was an open-ended survey that asked the respondents to evaluate the performance of a particular staff member. The longest was an all-inclusive closed-ended measure that probed every aspect of service provided at a PACE site.

A pattern in the number of questions paralleled the number of dimensions probed. Tools intended for use with the participants were the shortest, with an average 12.8 questions. Tools that were used with either the participant or the caregiver were the longest, with an average 43.0 questions per tool. Tools used with just the caregiver had an average of 28.3 questions.

The length of time to complete the tools was unknown as most were completed in private and none required the respondent to indicate the length of time it took him/ her to complete the survey.

Question structure. Six hundred and four written survey questions were examined by this research and, like the interview tools discussed above, most questions were structured to produce evaluative rather than factual report responses (71.9% versus 28.1%).

Even more distinct, only 35 of the 604 questions, or 5.8%, were open-ended. Like the in-person and telephone interview tools, closed-ended questions were the most common.

Of the closed-ended questions, the majority (82.9%) required the individual to respond using a Likert-type type scale. Approximately 10.5% of questions required a yes/no response and the remaining 6.5 % were categorical response type questions.

Confidentiality. Of all the tool methodologies analyzed, written surveys provided the most secure confidentiality. As many tools were completed in the respondents' homes then mailed to an independent data collection source, the identity of the respondent was never known to the provider.

Some sites did code the surveys when they were distributed to the respondents. Coding was done to identify how long a participant had been with the program. For example, yellow surveys were distributed to individuals who had been affiliated with a

program for less than 6 months and green surveys distributed to those affiliated for longer than 6 months.

<u>Written Survey Evaluation</u>

Providers conducted written surveys as a low cost way of gathering consumer feedback about their care programs. However, as a method of obtaining self-reported information from the very frail and cognitively impaired, written surveys were unlikely to provide reliable or valid information. Most written surveys intended for use with the very frail and especially the cognitively impaired were far too sophisticated for this population. Many required the individual to recall specific episodes of care or to distinguish between and report on the abilities of various care providers. For example, individuals were asked to report their satisfaction with the social worker, the health aides, the nurses, and the doctors. These tasks would likely be challenging to someone with even a mild level of dementia.

Another concern with the written surveys was the length. Particularly with the interchangeable tools, where some of the respondents were the program participants, the length of some measures was long: 49, 59, and 68 questions. Providers' intentions were to collect as much information as possible but did not consider the "wear out factor" of lengthy tools. Although formal data was not collected, the number of surveys actually completed may have been lower than for those measures that were less demanding.

## Methodology Three: Group Meetings

### Forums

The last methodology identified by the research was the group meeting. All the group meetings identified by the research involved more than one participant and followed a forum-type format that encouraged open discussion and consumer participation.

Forums were formative and, unlike the tools discussed previously that provided definitive assessments of satisfaction, forums were an opportunity to introduce and qualitatively discuss topics of importance to consumers. Although consumer satisfaction could only be loosely judged based on the verbalized opinion of meeting attendees, providers reported that forums were a good way to cost effectively "take the pulse" of the assembled group. Many providers reported becoming aware of issues or complaints for the first time in a forum meeting.

Eleven forums were identified by the research: 9 were conducted with frail elders, one included both elders and some family caregivers, and the last was for family caregivers alone.

As 10 of the 11 forums reviewed did not use formal tools to structure the group meetings, a tool analysis is not applicable. However, an analysis of the process of the forums is important to understanding their value as a method for assessing consumer satisfaction. The following is a summary of the process and content of the forums reviewed.

<u>Forum process</u>. Lack of a specific tool meant forums differed not only between sites but within an individual site, from one meeting to the next. Despite this, a pattern in the way these meetings were conducted did emerge. Most forums were led by a staff representative who first provided an update of site events or happenings. This often led to attendee questions or comments about the updates. In many cases a pre-determined topic was then introduced for discussion. Other sites did not pre-determine topics but encouraged attendees to raise issues particular to them during the course of the meeting.

The process by which meeting attendees were determined also varied; however, random selection was not used at any of the sites. Most providers encouraged all participants (or their caregivers) to attend, others pre-selected attendees, looking for specific attributes. For example, sites selected participants who were willing and able to communicate well, and those from different ethnic or cultural backgrounds.

When necessary, language barriers were overcome in many forum meetings by using translators. Translators were identified as staff, non-agency individuals hired specifically for their translation services, or in one case, a particularly capable participant.

The degree to which forum discussions were documented also varied. Some sites followed a formal system of taking meeting notes, posting them, and documenting any required and taken follow-up measures. Other forums were less well documented. Individuals with specific questions or concerns may have been addressed after the meetings but in most cases, staff used the forum feedback to help guide further discussions about the issues that were raised.

Forum meetings were also used by some sites to entertain and educate meeting attendees. Visiting school children and choir performances were common; some sites also offered health lectures.

Frequency of forums. A monthly meeting was the most common frequency (6 of 11 meetings) followed by quarterly (3 of 11 meetings). One site conducted weekly forums and the last did so annually. The annual forum, described more like a focus group, was conducted with caregivers and followed a more structured format.

Forum content. As a result of the open agenda typical of most forums, the topics discussed were reported to vary. One location reported that at one meeting, several topics were discussed—the introduction of a new recreation activity, complaints about the transportation service, and a welcome to a new participant. The following month's meeting focused almost entirely on the transportation service.

The discussion topics were more frequently introduced by the staff representatives at the meetings, but many sites reported that attendees did often introduce issues that staff would not have introduced themselves. Meal and transportation services were reported as frequently recurring issues introduced by program participants.

Forum length. The length of most forum meetings ranged between 30 minutes and one hour. Sites with greater numbers of dementia clients found shorter session more appropriate. The assisted living facility, where dementia was less of an issue, reported that some meetings exceeded one hour when particularly contentious issues were being discussed.

Question structure. An analysis of question structure is not relevant for forums because questions were not documented and likely changed from meeting to meeting. However, to encourage feedback, most questions were presented as open-ended.

It is unclear if questions were asked in such a way as to eliminate any staff or moderator bias.

Confidentiality. The open nature of the meetings meant that confidentiality was not assured. As a staff representative was often present in these meetings, the comfort level of forum attendees to discuss issues related to staff members (and other sensitive topics) was unknown.

## Forum Evaluation

Forum meetings are a creative means of collecting satisfaction information as they encourage participants to self-report issues important to them. However, these meetings should not be relied upon as the only means for collecting satisfaction data as several challenges to their validity and reliability exist. There is a strong possibility that the most vocal participants will "control" forum meetings. An issue presented may be important to the most vocal few, but not to the whole population. Further, if dissenting opinions exists, some participants may be reluctant to voice an opinion counter to another meeting attendee. The ability of those with dementia to communicate in participant forums is also questioned. The distracting environment, larger numbers of individuals, and "speak-out" nature of these meetings may not be conducive to those with cognitive impairment.

<u>Satisfaction Measurement Criteria List</u>

From the tool strengths identified by this research, a criteria list for successful satisfaction measurement for frail and cognitively impaired elders was developed (Appendix Q). This list stresses the need for tool development that includes provider and outside consultant involvement. It encourages increased validity and reliability testing, greater attention to tool length and participant-verified indicators of satisfaction.

This is a pragmatic criteria list, one based on an analysis of components of several tools that currently exist. Used as a guide for future tool development, this criteria list could help to produce tools that can ultimately provide more accurate and valid satisfaction data.

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

This research identified, analyzed and evaluated satisfaction measurement tools

that have been used with very frail elder care consumers. A comprehensive review of the

literature and discussions with providers caring for this population revealed two factors.

First, it became evident that very few tools exist that can effectively measure the

satisfaction of this frail elder population. Second, little work has been done that analyzes

and evaluates the tools that do exist and are currently being used with the very frail and

cognitively impaired.

The commitment and enthusiasm of providers involved in this project is a

testament to the desire and need for this type of research. This study has identified and

evaluated existing tools to add one more piece of knowledge in the puzzle of how best to

measure frail elder client satisfaction–knowledge that may lead to further research and

ultimately policy that will direct better service provision.

Identification, Analysis and Evaluation Results

Components of Successful Satisfaction Measurement Tools

One of the challenges of this research was to identify the common and important

components of successful satisfaction measurement tools for the frail elderly. However,

the tool analysis revealed that, of the 60 tools identified, no one tool could alone measure

the satisfaction of the average enrollee at the sites that participated in the study. Many

tools were able to measure the satisfaction of the frail elderly to varying degrees,

however, very few were capable of including those with dementia. Most often, these latter individuals were excluded from participating in surveys that used self-report methodologies of data collection. Instead, providers used caregiver or proxy methodologies if any measurement was taken.

Although no one tool emerged as *the* satisfaction measure that was suitable for the very frail or cognitively impaired client, many components of the tools identified advanced our understanding of what criteria would produce a good measure of satisfaction for this population. Tool strengths were identified by examining both the process (the way in which data was collected and analyzed) and the content (the subject matter of the data collected). The criteria list was constructed using the identified tool strengths.

<u>Strengths of Measures Identified</u>

<u>Methodology</u>

This research examined tool methodology on two axes. Tools were identified based on the method used to collect data. Three methodologies were found: tools that were administered by an interviewer (in-person and telephone interviews), self administered tools (written surveys), and group meetings (forums). Tool methodology also identified the respondent. Three categories of respondents were found: tools designed for use with the participant only, tools for the caregiver only, and tools that were used interchangeably with either participant or caregiver.

It is this researcher's belief that the best approach for determining the satisfaction of a very frail or cognitively impaired individual is to first ask that individual to self-report his or her experience, rather than collect information from a secondary source. Therefore, self-report rather than proxy methodology was favored. However, for some individuals (e.g. those with severe dementia), self-reporting is not an option. In these cases, a secondary respondent such as a caregiver must be used.

Focusing on consumer self-reporting, in-person interviews provided the optimal environment for addressing the communication challenges faced by the very frail and cognitively impaired. Interviews conducted in a quiet, familiar, distraction-free location facilitated respondent concentration and comfort and gave the interviewer visual cues regarding the status of interviewee (e.g. agitated, confused, or guarded). Telephone interviews did not permit the same valuable eye-to-eye contact as in-person interviews but still provided a more direct connection between interviewer and interviewee than written surveys. Forums were not optimal for data collection with the very frail or cognitively impaired as the meetings were distracting and became confusing when more than one individual was speaking.

Tool Development

Tool development was most effective when providers and measurement consultants worked together to develop the tool. Tools developed by the site alone often lacked the validity and reliability testing necessary to ensure the tools produced accurate results. Tools developed by consultants alone were often too long and too complex for

participants to complete and neglected to probe for elements specific to the service program.

## Frequency

The frequency with which a tool was used was often associated with the purpose of the tool. Therefore, the frequency of use could not be considered as an indicator of tool success. However, as the purpose of the measures identified was to determine participant satisfaction, one-time only and infrequently used tools may be missing opportunities to obtain participant feedback. Tools that were used repeatedly also had the advantage of providing longitudinal results that allowed comparisons to be made over time.

## Length

Discussions with providers and evaluations of tool length revealed that a satisfaction survey should not take more than 30 minutes to complete. Many providers recommended (in hindsight) that 20 minutes was optimal, though few of the tools identified adhered to this recommendation.

## Question Structure

Evaluative versus factual report. The factors that contribute to a satisfied (versus dissatisfied) evaluation are different for every individual. Even a well designed evaluative question can produce a response that is affected by factors uncontrolled by the provider. However, asking a mildly cognitively impaired elder to provide a factual report response, such as how many times they had to wait more than 30 minutes for a van, is

also unreliable. The best tools were those that structured the questions specific to the client's capabilities and limited the need for memory recall for those more cognitively impaired.

Open-ended versus closed-ended questions. Most tools used closed-ended questions. Though easier to answer and tabulate results, open-ended questions provided much more qualitative detail. A combination of open-ended and closed-ended questions may be optimal, depending on the communication capabilities of the sample population.

Response mechanism. Most closed-ended questions used a Likert-type type scale. More than a yes or no answer, a scaled response provided information about the respondents' feeling of intensity to survey questions. Though many measures had a "don't know" option, some tools eliminated this, encouraging respondents to choose the response that best reflected their feelings.

Confidentiality

Providers differed on the best approach to confidentiality. Some believed that confidentiality must be ensured to get an authentic response, particularly with questions about program staff. The study results showed that most tools did provide respondent confidentiality. However, many who worked with the very frail or cognitively impaired observed that these individuals get flustered or wary of strangers asking them questions about their care. The tools that did interview participants with known dementia used an interviewer who was known to the individual.

Three sites used a unique approach to balance the issues of respondent confidentiality and comfort (familiarity with the interviewer). Their solution was to use a staff member who did not provide direct care services to participants, such as an intake coordinator.

Content

Depending on the intent of the tool, a measure of overall satisfaction or a specific aspect of care, the content of the questions will vary. However, the literature review and discussions with providers indicated that some dimensions are more important to the very frail and cognitively impaired than others. The relationship between the client and certain staff appeared to be very important. Accessibility to staff members (e.g. ease in making appointments) and level of involvement in making decisions about their care was also reported as being very important to very frail elders.

Comparing the content of all the questions identified by the research, much of it was evenly distributed across 6 of the 10 dimensions. Those 6 dimensions were infrastructure (13.0% of all questions), global satisfaction (12.6%), art of care (11.47%), accessibility of staff (11.39%), education and information (10.5%), and demographic questions (10.26%).

The content dimension least frequently probed was cost and value (2% of all questions). The content dimension most frequently probed was technical care (17% of all questions). These questions asked the individual to rate the skillfulness and thoroughness of the provider staff.

Exactly what indicators of satisfaction should be included in a survey will vary depending on the service provider and the individuals receiving care. The strongest tools will conduct preliminary research, such as focus groups, to ensure the dimensions included in the survey reflect what is important for measuring the satisfaction of their client population.

## Directions for Future Research

This study did not identify any one tool that could successfully measure the satisfaction of very frail and cognitively impaired elders, raising critical questions. Was the inability of this research to identify a successful tool for this population because such a tool is yet to be developed, or because there cannot be such a tool? Is the criteria list for measuring the satisfaction of physically frail elders sufficiently different from the list measuring the satisfaction of cognitively impaired elders that a second tool is required? If the criteria list for each population is different, what are the factors that make that so? How do the differences in criteria affect existing or future measures?

The tool analysis revealed that few of the identified measures were suitable for use with cognitively impaired program participants. However, systematically excluding subsets of the frail elder population from survey participation because of impairment is no longer acceptable. Future research must find ways of including the cognitively impaired in satisfaction studies.

One approach to including a broader range of participants in satisfaction studies is to develop a set of measures rather than using just a single measure. A set of measures

with a sliding degree of sophistication could allow matching participants to the tool that best meets their cognitive and communication capabilities. This strategy increases the probability of obtaining responses from more frail interviewees. For example, one version of a tool could be for those with no cognitive dysfunction. A simpler version of the same tool could be for those with mild levels of dementia. If possible, an even more simplified version could be for those suffering more dysfunction. Preliminary research that confirms the indicators of satisfaction for each population subset would be very important.

Another avenue for future research is to improve the knowledge of existing and future tool reliability and validity. The amount of validity and reliability testing conducted on the identified tools was limited. Future efforts with these and other tools must incorporate more testing to ensure they are measuring what they report to measure and that they will produce consistent results. How much consistency can be expected with frail and/or cognitively impaired respondents is unknown. Future research efforts will need to establish benchmarks that are applicable to this population.

Another challenge is to explore the effect of race and ethnicity on satisfaction reporting. Several of the sites involved in this research provide services to minority elder populations. Providers assumed that ethnicity had an effect on the way some ethnic groups reported satisfaction. Unfortunately, very little research has been conducted that could either prove or disprove these assumptions.

The impact of economic and educational status on satisfaction reporting is yet another issue to explore. The majority of providers involved in this study served low income, urban elders. Again, many providers held assumptions that these factors, like ethnicity, affected they way individuals reported their satisfaction. Little research has been done that could shed light on the impact of economic and educational status on satisfaction with care.

## Looking to the Future

Very few measures have been developed to date that use self-report methodologies for data collection with frail elder populations. This is understandable given the numerous and complex obstacles encountered when surveying this group. Rather than deconstructing these obstacles, most measures have continued to rely on caregiver and/or proxy reports to ascertain client satisfaction.

The intersection of several factors has created an environment that demands the development of tools that are suitable for a broader range of frail elders. An increasing number of seniors are requiring professional elder care services, the level of physical and cognitive functioning of the individuals seeking care services is lower, and the health care industry is becoming increasingly consumer driven.

More active consumer interest in health care has led to policy that demands providers measure client satisfaction with care. Though debate continues on the extent to which consumers are capable of evaluating some aspects of care, requirements such as

CAHPS and other report card type evaluations will become increasingly necessary to attract the much sought-after clients, external funding and accreditation.

Initially motivated by their desire to provide quality services to frail elders, long-term care providers now face regulations that will require them to conduct measures of client satisfaction. The provider's notion of quality service will be augmented by the consumer's notion of quality. Lacking a widely accepted, or truly relevant tool, providers have been attempting to develop measures suitable for their individual populations.

This research identified 60 satisfaction measurement tools, 30 of which were designed to be self-report measures used with frail elder participants alone. Many of the tools were being used for the first time. This is a clear indication that there is an increasing amount of activity in the area of satisfaction measurement with the very frail. However, the research also indicated that while these tools represent some very creative approaches to overcoming the challenges faced when measuring this population, there are several areas where future research can expand our knowledge.

Continuation of the Research

This study represents the first phase of a two part effort conducted by the National PACE Association. Phase two of the study will develop and test a client satisfaction measurement tool or set of tools suitable for use with both the very frail and cognitively impaired elderly.

Phase two of the research was designed to fill in some of the research gaps identified in Phase one of the study. Participating sites were chosen to allow exploration

of satisfaction measurement with individuals from different ethnic groups and geographical areas of the United States. Eight PACE sites serving Chinese, African-American, Hispanic, Russian, Italian, and Caucasian populations from seven states were selected for the study.

To ensure applicability of the developed tool(s), focus group research with both very frail and cognitively impaired consumers will be conducted. Two review panels, one staffed by care providers, the other with a group of individuals assembled from the fields of gerontology, statistical measurement, and policy, will provide input throughout the tool development and testing phases.

The goal of Phase two of the research is to produce a measurement tool that enables the very frail and cognitively impaired to self-report their satisfaction, improving our knowledge of their care experiences and preferences. Our hope is to have that knowledge reflected in better care for this population.

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APPENDIX A

PACE OVERVIEW

## Pace Overview

The Program of All-Inclusive Care for the Elderly (PACE) is a nationwide effort to replicate the comprehensive service delivery and financing model of acute and long-term care created by On Lok SeniorHealth Services in San Francisco. The PACE model integrates the provision and financing of medical and long-term care services, both in-patient and out-patient. Enrollees must be at least 55 years of age, live in the catchment area of the PACE program, and be certified as eligible for nursing home care by the appropriate state agency. The goal of the program is to maximize each enrollee's autonomy and continued community residence and to provide quality care at lower cost to Medicare, Medicaid and private pay enrollees relative to payments in the traditional system.

APPENDIX B

THE BALANCED BUDGET ACT

# The Balanced Budget Act

The Balanced Budget Act of 1997 established the PACE model of care as a permanent entity within the Medicare program and enabled the States to provide PACE services to Medicaid beneficiaries as a State option (HCFA web site).

The legislation authorized expansion of the program by 40 sites within the first year after enactment and an additional 20 sites in each succeeding year (Judith Baskins, President, National PACE Association).

APPENDIX C

CALCULATION OF FRAIL ELDER POPULATION SIZE

# Calculation of Frail Elder Population Size

The estimated number of very frail elders (3,600,000) is based on an often-used calculation to determine the prevalence of extreme frailty in the general Medicare population. This number was reached by multiplying the total number of Medicare eligible participants (36,000,000) by the percent of elders residing in nursing homes (at any one time) 5%, and the percent of elders residing in the community, 5%. The calculation is as follows: 36,000,000 x (5% + 5%) = 3,600,000. (The exact percent of very frail elders residing in the community is unknown, 5% is again a commonly used estimate).

APPENDIX D

GLOSSARY

# Glossary

Agraphia: Loss of a previously possessed facility for writing.

Aphasia: Loss of a previously possessed facility for language comprehension or production that cannot be explained by sensory or motor defects or diffuse cerebral dysfunction.

Anomic or Amnestic Aphasia: Loss of the ability to name objects.

> Broc's Aphasia: Loss of ability to produce spoken and (usually) written language with comprehension retained.

> Wernicke's Aphasia: Loss of the ability to comprehend language, coupled with the production of inappropriate language.

Confabulation: Fabrication of stories in response to questions about situations or events that are recalled.

Dysarthria: Difficulty in speech production as a result of uncoordinated speech apparatus. (From Butler, Lewis, & Sunderland, 1991).

APPENDIX E

PACE SITES

# PACE Sites

| Site Name (Site Acronym) | City / State |
| --- | --- |
| Bienvivir Senior Health Services (BSHS) | El Paso, TX |
| Center for Elders Independence (CEI) | Oakland, CA |
| Center for Senior Independence (CSI) | Detroit, MI |
| Community Care For the Elderly (CCE) | Milwaukee, WI |
| Comprehensive Care Management (CCM) | Bronx, NY |
| Elder Service Plan (ESP) | East Boston, MA |
| Independent Living for Seniors (ILS) | Rochester, NY |
| On Lok SeniorHealth (OL) | San Francisco, CA |
| Palmetto SeniorCare (PSC) | Columbia, SC |
| Providence ElderPlace (PEP) | Portland, OR |
| Sutter SeniorCare (SSC) | Sacramento, CA |
| Total Longterm Care (TLC) | Denver, CO |

APPENDIX F

NON-PACE SITES

## Non-PACE Sites

| Site Name (Site Acronym) | County / State |
| --- | --- |
| Bethany Center (BC) | San Francisco County, CA |
| Care Network For Seniors (CNS) | Fairfax County, VA |
| Live Oak Adult Day Services (LO) | Santa Clara County, CA |
| MidPeninsula Continuous Care Services (MCCS) | Santa Clara County, CA |
| Nob Hill Healthcare Center (NHHC) | San Francisco County, CA |
| Oak Park Convalescent Hospital (OPCH) | Alameda County, CA |
| Rosener House (RH) | San Mateo County, CA |
| Veterans Administration Healthcare System (VA) | San Mateo County, CA |
| Visiting Nurse Association and Hospice of Northern California (VNA) | Alameda County, CA |

APPENDIX G

QUALITATIVE INTERVIEW GUIDE

## Qualitative Interview Guide

<u>General Information</u>

1. Name of organization:

2. Number of years in operation:

3. Agency mission/ description:

4. Service category:

   • Residential

   • Adult Day Care

   • Community Care (list services)

6. Interviewee position:

<u>Client Information</u>

7. Number of clients in program:

8. Average age of clients in program:

9. Ethnic and gender composition:

10. Percent of population receiving SSI/ Medicaid:

11. Physical limitations of clients (average number of ADL difficulties):

12. Cognitive limitations of clients (number of individuals with dementia):

<u>Client Satisfaction Measurement Information</u>

13. How often do you measure client satisfaction?

**Qualitative Interview Guide Continued**

14. Service category:

- Observational

- Interviews

- Written Surveys

- Other

15. How did you develop your tool for measuring client satisfaction?

16. For observational methods:

- Who does the observing?

- Were the observers trained to minimize bias?

- Was there an observational guide?

- Were the observers required to make inferences about what they saw?

- Is there any reason to believe that the presence of observers affected subject behavior?

- Was informed consent given before observations began?

17. For Interviews:

- Is there clear indication that the subjects understood the questions?

- Who were the interviewers and how were they trained?

- Was there any evidence of interviewer bias?

## Qualitative Interview Guide Continued

18. For written surveys:

- Was there evidence that the subjects were able to perform the task?

- Was there evidence that subjects were able to fully understand the questions asked?

Additional Questions

19. Have you always used the same tool for measuring satisfaction?

20. If not, why did you change?

21. When was the last time you measured client satisfaction?

22. How have you used the information collected from the last measurement taken?

23. What features/ question of the tool gave you the best information?

24. What features/ questions of the tool did not work as well as you might have hoped?

25. Approximately how much time was required of clients for participation?

26. How many/ what percent of clients completed the process?

27. Of those that did not complete the process, why did they not?

28. In what setting did the clients complete the process?

29. Where there any particular features of the setting that may have helped or hindered the information collection process?

30. Any other comments to pass along to an individual developing a satisfaction measurement tool?

APPENDIX H

PACE TOOLS

**PACE Tools**

| Site Name | Tools |
| --- | --- |
| Bienvivir Senior Health Services | IP-PC-1, IP-C-1, F-PO-2 |
| Center for Elders Independence | IP-PO-2, F-PO-5, W-C-3 |
| Center for Senior Independence | IP-PO-3, W-C-4 |
| Community Care For the Elderly | IP-PO-6, IP-PO-10, F-PC-1 |
| Comprehensive Care Management | W-PC-1 |
| Elder Service Plan | W-PO-1, W-C-1 |
| Independent Living for Seniors | IP-PO-7, IP-PO-11, W-C-9, W-C-10 |
| On Lok SeniorHealth | No tools submitted |
| Palmetto SeniorCare | IP-PC-2, IP-C-3, F-PO-3, T-PC-3 |
| Providence ElderPlace | IP-C-2, F-PO-1 |
| Sutter SeniorCare | IP-PO-9, F-PO-2, T-PC-1 |
| Total Longterm Care | IP-PO-1, F-PO-4, W-C-2, IP-PC-5 |

IP = In-person Interview       T = Telephone Interview

W = Written Survey       F = Forum

PO = Patient Only       C = Caregiver Only       PC = Patient or Caregiver

APPENDIX I

NON-PACE TOOLS

# Non-PACE Tools

| Site Name | Tools |
|---|---|
| Bethany Center | F-PO-8, W-PO-2, W-PO-3 |
| Care Network For Seniors | T-PO-1, T-C-1 |
| Live Oak Adult Day Services | F-C-1, W-C-6, W-C-7 |
| MidPeninsula Continuous Care Services | IP-PC-4, T-PC-2, W-PC-4 |
| Nob Hill Healthcare Center | IP-PO-8, IP-PC-3, F-PO-6, W-PO-5, W-PO-6, W-C-4 |
| Oak Park Convalescent Hospital | F-PO-7, W-PC-2 |
| Rosener House Adult Day Support Center | W-C-5 |
| Veteran Affairs Extended Care | IP-PO-4, F-PO-9, W-C-8 |
| Visiting Nurse Association of Northern California | W-PC-3 |

IP = In-person Interview     T = Telephone Interview

W = Written Survey     F = Forum

PO = Patient Only     C = Caregiver Only     PC = Patient or Caregiver

APPENDIX J

SAMPLE DATA PACKAGE FOR TOOL ANALYSIS

Agency and Client Information

Process and Content Checklists

Methodology Grid

**Agency and Client Information (Sample)**

| Agency Information | Client Information |
| --- | --- |
| Site name | Number of clients in program |
| Number of sites | |
| Association with other organizations | Average age of clients |
| Number of years in service | Ethnic composition |
| Contact person | Economic information |
| Contact information | Service Payment |
| Position at organization | - Fee for service |
| Services provided | - Medicare A & B |
| | - Medicare A |
| | - Medicare B |
| | - Not entitled to Medicare |
| | - Medicaid |
| | Physical limitations |
| | Cognitive impairment |

**Data Package:  Process and Content Checklists (Sample)**

| Process Checklist | Content Checklist |
| --- | --- |
| 1. Methodology | 1. Length |
| 2. Tool Development | 2. Topics Covered |
|   - Reliability | |
|   - Validity | 3. Number of items |
| 3. Frequency of Administration | |
| 4. Question Structure | |
| 5. Confidentiality | |

## Methodology Grid

| Method of Data Collection | Telephone | Mailed | Personal One to One | Personal Small Group | Personal Focus Group | Personal Forum | Observa-tional |
|---|---|---|---|---|---|---|---|
| Frequency | | | | | | | |
| Completed by | | | | | | | |
| Cognitive Impairment | | | | | | | |
| Location Completed | | | | | | | |
| Length Questions / Items | | | | | | | |
| Format of Question | | | | | | | |
| Language | | | | | | | |

APPENDIX K

TOOL ASSESSMENT MODELS

Fletcher's Model

Ejaz's Model

**Fletcher's Model**

(Fletcher, Dickinson, & Philp, 1992)

Framework for Assessing a Quality of Life Measurement

| Feature / Dimension | Notes |
| --- | --- |
| Development | Characteristics of source population |
| - Conceptual basis | |
| - Source of items | |
| - Methods used | |
| Description | Open / closed, visual, analogue scale, etc. |
| - Format | Number of questions, etc. |
| - Administration | |
| - Method | Can sections be used separately |
| - Time taken | |
| - Acceptability | Interview / self-filled |
| | Expected response rates |
| | Overall score / sub-scales |
| Scoring | |
| - How scored | |
| - Ceiling / floor effect | |
| - Weighting | |
| - Norms available | Continued... |

**Fletcher's Model Continued**

Framework for Assessing a Quality of Life Measurement

| Feature / Dimension | Notes |
| --- | --- |
| Validity | |
|   - Test / retest | |
|   - Interview / self-filled | |
|   - Between interviews | |
|   - Statistical methods used | |
| Reliability | |
|   - Test / retest | |
|   - Interview / self-filled | |
|   - Between interviews | |
|   - Statistical methods used | |
| Responsiveness | |
|   - Type of study / trial | |
| Experience of use | |
|   - Previous studies / trials | |
| Intended use | |
|   - Appropriate content | |

**Ejaz's Model**

(Ejaz, Cohen-Mansfield, & Werner, 1996)

Framework for Assessing a Satisfaction Measurement

| Process | Content |
| --- | --- |
| Methodology | Length |
| Reliability | Number of Items |
| Validity | Organization |
| Data Analysis | Topics Covered |
| Cost | |
| Confidentiality | |

APPENDIX L

TOOL SUMMARY TABLES

Table L-1

Tool Summary Table

In-Person Interviews: Patient Only (IP-PO)

|  | IP-PO Tool 1 | IP-PO Tool 2 | IP-PO Tool 3 | IP-PO Tool 4 | IP-PO Tool 5 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | Annual | Annual | Annual | Annual | Annual |
| Development | Site & Consult | Site & Consult | Site & Consult | Site & Consult | Research |
| Data Analysis | 3 | 2 | 2 | 4 | 5 |
| Length | 23 | 7 | 13 | 13 | 31 |
| Question Structure | | | | | |
| -Open/Closed | 4/19 | 7/0 | 0/13 | 3/10 | 5/26 |
| -Scales/Yes-No | 14/5 | 0/0 | 3/8/2 | 0/10 | 24/2 |
| -Evaluative/ Factual Report | 14/9 | 0/7 | 7/5 | 10/3 | 6/25 |
| Confidentiality | Not Opt. | Optional | Moderate | Optional | Optional |
| **CONTENT:** | | | | | |
| Type of Measure | General | General | General | General | General |
| Dimensions | 6 | 4 | 6 | 5 | 6 |

Table L-2

Tool Summary Table

In-Person Interviews: Patient Only (IP-PO)

| | IP-PO<br>Tool 6 | IP-PO<br>Tool 7 | IP-PO<br>Tool 8 | IP-PO<br>Tool 9 | IP-PO<br>Tool 10 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | 1 x only | 1 x only | Quarterly | Ad Hoc | Exp. |
| Development | Site | Consult | Site &<br>Consult | Site | Site &<br>Consult |
| Data Analysis | 3 | 4 | 4 | 3 | 4 |
| Length | 7 | 35 | 12 | 10 | 8 |
| Question Structure | | | | | |
| -Open/Closed | 3/4 | 0/35 | 0/12 | 0/10 | 8/0 |
| -Scales/Yes-No | 1/3 | 35/0 | 0/12 | 0/10 | 0 |
| -Evaluative/<br>Factual Report | 3/4 | 31/4 | 6/6 | 10/0 | 8/0 |
| Confidentiality | Not Opt. | Optional | Not Opt. | Optional | Not Opt. |
| **CONTENT:** | | | | | |
| Type of Measure | Enroll F/U | Enroll F/U | Pt. free choice<br>& rights | Dental | General |
| Dimensions | 4 | 9 | 3 | 5 | 1 |

Table L-3

Tool Summary Table

In-Person Interviews: Patient Only (IP-PO)

| | IP-PO Tool 11 | IP-PO Tool 12 | IP-PO Tool 13 | IP-PO Tool 14 |
|---|---|---|---|---|
| **PROCESS:** | | | | |
| Frequency | Exp. | Research | Research | Research |
| Development | Consult | Research | Research | Research |
| Data Analysis | 4 | 5 | 5 | 5 |
| Length | 72 | 21 | 56 | 61 |
| Question Structure | | | | |
| -Open/Closed | 0/72 | 0/21 | 0/56 | 0/61 |
| -Scales/Yes-No | 68/0/4 | 11/10 | 56/0 | 61/0 |
| -Evaluative/ | 39/33 | 21/0 | 56/0 | 23/38 |
| Factual Report | | | | |
| Confidentiality | Optional | Optional | Not Opt. | Optional |
| **CONTENT:** | | | | |
| Type of Measure | General | General | General | General |
| Dimensions | 10 | 5 | 3 | 7 |

Table L-4

Tool Summary Table

In-Person Interviews: Caregiver Only (IP-C)

| | IP-C | IP-C | IP-C |
| --- | --- | --- | --- |
| | Tool 1 | Tool 2 | Tool 3 |
| **PROCESS:** | | | |
| Frequency | Annual | 1 x only | Bi-Annual |
| Development | Site | Not Structured | Site |
| Data Analysis | 3 | Not Structured | 4 |
| Length | 7 | Not Structured | 11 |
| Question Structure | | | |
| -Open/Closed | 1/6 | Not Structured | 4/7 |
| -Scales/Yes-No | 0/1/5 | Not Structured | 6/1 |
| -Evaluative/ | 4/3 | Not Structured | 8/3 |
| Factual Report | | | |
| Confidentiality | Optional | Not Structured | Optional |
| **CONTENT:** | | | |
| Type of Measure | General | Not Structured | General |
| Dimensions | 2 | 4 | 4 |

Table L-5

Tool Summary Table

In-Person Interviews: Patient or Caregiver (IP-PC)

| | IP-PC Tool 1 | IP-PC Tool 2 | IP-PC Tool 3 | IP-PC Tool 4 | IP-PC Tool 5 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | Annual | Bi-Annual | Quarterly | Monthly | 1x only |
| Development | Site | Site & Consult | Site & Consult | Site | Site |
| Data Analysis | 3 | 4 | 4 | Not Structured | 3 |
| Length | 31 | 53 | 6 | Not Structured | 14 |
| Question Structure | | | | | |
| -Open/Closed | 2/29 | 16/37 | 0/6 | Not Structured | 14/0 |
| -Scales/Yes-No | 18/11 | 14/23 | 0/60 | Not Structured | N/A |
| -Evaluative/ Factual Report | 12/19 | 32/21 | 6/0 | Not Structured | 6/8 |
| Confidentiality | Optional | Optional | Optional | Not Opt. | Not Opt. |
| **CONTENT:** | | | | | |
| Type of Measure | General | General | Nutrition | Home Visits | Disenroll |
| Dimensions | 8 | 9 | 1 | * | 7 |

* Open Interview - No content analysis possible.

Table L-6

Tool Summary Table

Telephone: Patient Only, Caregiver Only, and Patient or Caregiver (T-PO, T-C, & T-PC)

|  | T-PO Tool 1 | T-C Tool 1 | T-PC Tool 1 | T-PC Tool 2 | T-PC Tool 3 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | Exp. | Exp. | Annual | Weekly | Ad Hoc |
| Development | Site & Consult | Site & Consult | Consult | Site | Site |
| Data Analysis | 4 | 4 | 4 | 2 | 2 |
| Length | 8 | 19 | 46 | Varied | 5 |
| Question Structure | | | | | |
| -Open/Closed | 4/4 | 9/10 | 0/46 | 100/0 | 4/1 |
| -Scales/Yes-No | 3/1 | 4/4/2 | 46/0 | N/A | 1/0 |
| -Evaluative/ Factual Report | 3/5 | 4/15 | 46/0 | N/A | 1/4 |
| Confidentiality | Optional | Optional | Optional | Not Opt. | Optional |
| **CONTENT:** | | | | | |
| Type of Measure | General | General | General | General | Transport |
| Dimensions | 2 | 5 | 6 | * | 1 |

* Open Interview - No content analysis possible.

Table L-7

Tool Summary Table

Written: Patient Only (W-PO)

|  | W-PO Tool 1 | W-PO Tool 2 | W-PO Tool 3 | W-PO Tool 4 | W-PO Tool 5 | W-PO Tool 6 |
|---|---|---|---|---|---|---|
| **PROCESS:** | | | | | | |
| Frequency | Annual | Annual | Annual | Bi-Annual | 1x only | 1x only |
| Development | Other PACE | Site | Site | Site | Site & consult | Site & consult |
| Data Analysis | 3 | 2 | 2 | 2 | 3 | 4 |
| Length | 16 | 2 | 12 | 6 | 6 | 35 |
| Question Structure | | | | | | |
| -Open/Closed | 2/14 | 2/0 | 0/12 | 1/5 | 0/6 | 0/35 |
| -Scales/Yes-No | 12/2 | N/A | 10/2 | 5/0 | 6/0 | 35/0 |
| -Evaluative/ Factual Report | 11/5 | 2/0 | 10/2 | 4/2 | 6/0 | 33/2 |
| Confidentiality | Optional | Optional | Optional | Optional | Optional | Not Opt. |
| **CONTENT:** | | | | | | |
| Type of Measure | General | Staff Eval. | Nutrition | Recreation | Rehab. | General |
| Dimensions | 6 | 1 | 4 | 5 | 5 | 7 |

Table L-8

Tool Summary Table

Written: Caregiver Only (W-C)

| | W-C Tool 1 | W-C Tool 2 | W-C Tool 3 | W-C Tool 4 | W-C Tool 5 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | Annual | Annual | Annual | Annual | Annual |
| Development | Other PACE | Site & Consult | Site & Consult | Other PACE | Other ADC |
| Data Analysis | 3 | 3 | 3 | 3 | 3 |
| Length | 16 | 41 | 13 | 13 | 29 |
| Question Structure | | | | | |
| -Open/Closed | 1/15 | 2/39 | 0/13 | 0/13 | 1/28 |
| -Scales/Yes-No | 15/0 | 32/2/5 | 3/8/2 | 3/8/2 | 23/2/3 |
| -Evaluative/ Factual Report | 12/4 | 33/8 | 9/4 | 9/4 | 22/7 |
| Confidentiality | Optional | Optional | Optional | Optional | Optional |
| **CONTENT:** | | | | | |
| Type of Measure | General | General | General | General | General |
| Dimensions | 6 | 6 | 6 | 6 | 8 |

Table L-9

Tool Summary Table

Written: Caregiver Only (W-C)

|  | W-C Tool 6 | W-C Tool 7 | W-C Tool 8 | W-C Tool 9 | W-C Tool 10 | W-C Tool 11 |
|---|---|---|---|---|---|---|
| **PROCESS:** | | | | | | |
| Frequency | Annual | Annual | Annual | Exp. | Exp. | Annual |
| Development | Site | Site | Site & Consult | Consult | Consult | Site & consult |
| Data Analysis | 3 | 3 | 4 | 4 | 4 | 4 |
| Length | 8 | 16 | 26 | 32 | 72 | 46 |
| Question Structure | | | | | | |
| -Open/Closed | 3/5 | 3/5 | 2/24 | 0/32 | 0/72 | 1/45 |
| -Scales/Yes-No | 0/4/1 | 0/5/6 | 24/0 | 32/0 | 70/0/2 | 40/1/4 |
| -Evaluative/ Factual Report | 2/6 | 5/11 | 24/2 | 20/12 | 43/29 | 39/7 |
| Confidentiality | Optional | Optional | Optional | Optional | Optional | Optional |
| **CONTENT:** | | | | | | |
| Type of Measure | General Caregiver | General Proxy | General | Enroll F/U | General | General |
| Dimensions | 4 | 8 | 6 | 7 | 9 | 7 |

Table L-10

Tool Summary Table

Written: Patient or Caregiver (W-PC)

| | W-PC Tool 1 | W-PC Tool 2 | W-PC Tool 3 | W-PC Tool 4 | W-PC Tool 5 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | Annual | Annual | Bi-Annual | Quarterly | Quarterly |
| Development | Site | Consult | Consult | Consult | Consult |
| Data Analysis | 3 | 4 | 4 | 3 | 4 |
| Length | 14 | 49 | 59 | 25 | 68 |
| Question Structure | | | | | |
| -Open/Closed | 0/14 | 5/44 | 2/57 | 5/20 | 3/65 |
| -Scales/Yes-No | 12/2 | 43/1 | 48/3/6 | 11/3/6 | 48/17 |
| -Evaluative/ | 13/1 | 43/6 | 50/9 | 11/14 | 33/35 |
| Factual Report | | | | | |
| Confidentiality | Optional | Optional | Optional | Optional | Optional |
| **CONTENT:** | | | | | |
| Type of Measure | General | General | General | General | General |
| Dimensions | 8 | 8 | 8 | 5 | 9 |

Table L-11

Tool Summary Table

Forum: Patient Only (F-PO)

|  | F-PO Tool 1 | F-PO Tool 2 | F-PO Tool 3 | F-PO Tool 4 | F-PO Tool 5 | F-PO Tool 6 |
|---|---|---|---|---|---|---|
| **PROCESS:** | | | | | | |
| Frequency | Quarterly | Quarterly | Monthly | Monthly | Monthly | Monthly |
| Development | Site | Site | Site | Site | Site | Site & Consult |
| Info. Analysis | 1 | 1 | 1 | 1 | 1 | 3 |
| Length | Varied | Varied | Varied | Varied | Varied | Varied |
| Question Structure | | | | | | |
| -Open/Closed | N/A | N/A | N/A | N/A | N/A | N/A |
| -Scales/Yes-No | N/A | N/A | N/A | N/A | N/A | N/A |
| -Evaluative/ Factual Report | N/A | N/A | N/A | N/A | N/A | N/A |
| Confidentiality | Not Opt. | Not Opt. | Not Opt. | Not Opt. | Not Opt. | Not Opt. |
| **CONTENT:** | | | | | | |
| Type of Measure | General | General | General | General | General | General |
| Dimensions | ** | ** | ** | ** | ** | ** |

** Forum - No content analysis possible.          N/A - Not applicable.

Table L-12

Tool Summary Table

Forum: Patient Only, Caregiver Only, and Patient or Caregiver (F-PO, F-C, & F-PC)

|  | F-PO<br>Tool 7 | F-PO<br>Tool 8 | F-PO<br>Tool 9 | F-C<br>Tool 1 | F-PC<br>Tool 1 |
|---|---|---|---|---|---|
| **PROCESS:** | | | | | |
| Frequency | Monthly | Monthly | Weekly | Annual | Quarterly |
| Development | Site | Site | Site &<br>Consult | Site | Site |
| Info. Analysis | 1 | 1 | 1 | 2 | 1 |
| Length | Varied | Varied | Varied | Varied | Varied |
| Question Structure | | | | | |
| -Open/Closed | N/A | N/A | N/A | N/A | N/A |
| -Scales/Yes-No | N/A | N/A | N/A | N/A | N/A |
| -Evaluative/<br>Factual Report | N/A | N/A | N/A | N/A | N/A |
| Confidentiality | Not Opt. | Not Opt. | Not Opt. | Not Opt. | Not Opt. |
| **CONTENT:** | | | | | |
| Type of Measure | General | General | General | General | General |
| Dimensions | ** | ** | ** | ** | ** |

** Forum - No content analysis possible.          N/A - Not applicable.

APPENDIX M

CONCEPTUALIZATION OF DIMENSIONS OF SATISFACTION

**Conceptualization of Dimensions of Satisfaction**

| Dimension | Subdimension |
| --- | --- |
| Demographics | Age |
| | Gender |
| | Ethnicity |
| | Payment Structure |
| | Living Arrangement |
| | Care Arrangement |
| Accessibility | Primary Medical |
| | Special Medical |
| | Rehabilitation |
| | Social Work |
| | Personal Case |
| Art of Care | Friendliness and Courtesy of Staff |
| | Regard for Privacy and Dignity |
| | Regard for Autonomy |
| Technical Care | Thoroughness |
| | Skillfulness |
| Efficacy | Degree of Help in Feeling Better |
| | Degree of Help in Feeling Comfortable |

## Conceptualization of Dimensions of Satisfaction Continued

| Dimension | Subdimension |
| --- | --- |
| Infrastructure | Meals |
| | Transportation |
| | Recreational Activities |
| | Physical Environment |
| Global Satisfaction | Overall Satisfaction |
| Cost and Value | Cost of Care |
| | Value of Care |
| Education and Information | Choices and Options |
| | Involved In and About Care |
| Psycho-Social Well-being | Relationships and Interactions |
| | Positive and Negative Emotional Status |

APPENDIX N

CONTENT EVALUATION TABLE (SAMPLE)

## Content Evaluation Table (Sample)

| Question Number | Evaluative | Factual Report | Dimension |
|---|---|---|---|
| | | | |
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APPENDIX O

CONTENT SUMMARY TABLES

Table O-1

Content Summary Table

In-Person Interviews: Patient Only (IP-PO)

|  | IP-PO Tool 1 | IP-PO Tool 2 | IP-PO Tool 3 | IP-PO Tool 4 | IP-PO Tool 5 |
|---|---|---|---|---|---|
| Demographics | 0 | 0 | 2 | 0 | 1 |
| Accessibility | 2 | 0 | 4 | 0 | 2 |
| Art of Care | 0 | 1 | 0 | 6 | 9 |
| Technical Care | 6 | 2 | 1 | 1 | 0 |
| Efficacy | 1 | 0 | 1 | 1 | 0 |
| Infrastructure | 5 | 0 | 0 | 2 | 5 |
| Global Satisfaction | 4 | 6 | 2 | 2 | 9 |
| Cost and Value | 0 | 0 | 0 | 0 | 0 |
| Education and Information | 4 | 1 | 3 | 0 | 0 |
| Psycho-Social Well Being | 0 | 0 | 0 | 0 | 5 |
| **TOTAL NUMBER OF QUESTIONS** | **22** | **10** | **13** | **12** | **31** |

Table O-2

<u>Content Summary Table</u>

<u>In-Person Interviews: Patient Only (IP-PO)</u>

|  | IP-PO Tool 6 | IP-PO Tool 7 | IP-PO Tool 8 | IP-PO Tool 9 | IP-PO Tool 10 |
|---|---|---|---|---|---|
| Demographics | 1 | 0 | 0 | 0 | 0 |
| Accessibility | 0 | 3 | 2 | 3 | 0 |
| Art of Care | 3 | 5 | 0 | 2 | 0 |
| Technical Care | 0 | 7 | 2 | 2 | 0 |
| Efficacy | 0 | 2 | 0 | 1 | 0 |
| Infrastructure | 1 | 2 | 0 | 0 | 0 |
| Global Satisfaction | 2 | 2 | 0 | 0 | 8 |
| Cost and Value | 0 | 3 | 8 | 0 | 0 |
| Education and Information | 0 | 5 | 0 | 2 | 0 |
| Psycho-Social Well Being | 0 | 6 | 0 | 0 | 0 |
| **TOTAL NUMBER OF QUESTIONS** | 7 | 35 | 12 | 10 | 8 |

Table O-3

Content Summary Table

In-Person Interviews: Patient Only (IP-PO)

|  | IP-PO Tool 11 | IP-PO Tool 12 | IP-PO Tool 13 | IP-PO Tool 14 |
|---|---|---|---|---|
| Demographics | 4 | 0 | 5 | 6 |
| Accessibility | 12 | 4 | 0 | 16 |
| Art of Care | 9 | 6 | 0 | 11 |
| Technical Care | 20 | 4 | 0 | 12 |
| Efficacy | 4 | 0 | 0 | 1 |
| Infrastructure | 8 | 6 | 0 | 13 |
| Global Satisfaction | 1 | 1 | 10 | 0 |
| Cost and Value | 4 | 0 | 0 | 0 |
| Education and Information | 6 | 0 | 0 | 2 |
| Psycho-Social Well Being | 4 | 0 | 41 | 0 |
| **TOTAL NUMBER OF QUESTIONS** | **72** | **21** | **56** | **61** |

Table O-4

Content Summary Table

In-Person Interviews: Caregiver Only (IP-C)

|                          | IP-C<br>Tool 1 | IP-C<br>Tool 2 | IP-C<br>Tool 3 |
|--------------------------|:----:|:----:|:----:|
| Demographics             | 2    | 0    | 2    |
| Accessibility            | 0    | 0    | 0    |
| Art of Care              | 0    | 2    | 0    |
| Technical Care           | 0    | 0    | 0    |
| Efficacy                 | 5    | 0    | 0    |
| Infrastructure           | 0    | 0    | 0    |
| Global Satisfaction      | 0    | 6    | 7    |
| Cost and Value           | 0    | 0    | 0    |
| Education and Information| 0    | 1    | 1    |
| Psycho-Social Well-Being | 0    | 1    | 1    |
| **TOTAL NUMBER OF QUESTIONS** | **7** | **10** | **11** |

Table O-5

Content Summary Table

In-Person Interviews: Patient or Caregiver (IP-PC)

| | IP-PC Tool 1 | IP-PC Tool 2 | IP-PC Tool 3 | IP-PC Tool 4 | IP-PC Tool 5 |
|---|---|---|---|---|---|
| Demographics | 3 | 8 | 0 | * | 2 |
| Accessibility | 2 | 1 | 0 | * | 1 |
| Art of Care | 2 | 3 | 0 | * | 3 |
| Technical Care | 11 | 7 | 0 | * | 1 |
| Efficacy | 5 | 4 | 0 | * | 1 |
| Infrastructure | 2 | 8 | 6 | * | 0 |
| Global Satisfaction | 1 | 3 | 0 | * | 4 |
| Cost and Value | 0 | 0 | 0 | * | 0 |
| Education and Information | 5 | 18 | 0 | * | 2 |
| Psycho-Social Well Being | 0 | 1 | 0 | * | 0 |
| **TOTAL NUMBER OF QUESTIONS** | **31** | **53** | **6** | * | **14** |

* Open Interview - No content analysis possible

Table O-6

Content Summary Table

Telephone: Patient Only, Caregiver Only, and Patient or Caregiver (T-PO, T-C, & T-PC)

|  | T-PO Tool 1 | T-C Tool 1 | T-PC Tool 1 | T-PC Tool 2 | T-PC Tool 3 |
|---|---|---|---|---|---|
| Demographics | 0 | 4 | 0 | * | 0 |
| Accessibility | 2 | 2 | 5 | * | 0 |
| Art of Care | 0 | 0 | 17 | * | 0 |
| Technical Care | 0 | 1 | 12 | * | 0 |
| Efficacy | 0 | 4 | 0 | * | 0 |
| Infrastructure | 0 | 0 | 5 | * | 5 |
| Global Satisfaction | 6 | 8 | 2 | * | 0 |
| Cost and Value | 0 | 0 | 0 | * | 0 |
| Education and Information | 0 | 0 | 5 | * | 0 |
| Psycho-Social Well Being | 0 | 0 | 0 | * | 0 |
| **TOTAL NUMBER OF QUESTIONS** | **8** | **19** | **46** | * | **5** |

* Open Interview - No content analysis possible

Table O-7

Content Summary Table

Written: Patient Only (W-PO)

|  | W-PO Tool 1 | W-PO Tool 2 | W-PO Tool 3 | W-PO Tool 4 | W-PO Tool 5 | W-PO Tool 6 |
|---|---|---|---|---|---|---|
| Demographics | 0 | 0 | 2 | 0 | 0 | 0 |
| Accessibility | 1 | 0 | 0 | 0 | 0 | 2 |
| Art of Care | 2 | 0 | 1 | 1 | 1 | 4 |
| Technical Care | 4 | 0 | 0 | 0 | 1 | 9 |
| Efficacy | 0 | 0 | 0 | 0 | 2 | 0 |
| Infrastructure | 2 | 0 | 8 | 1 | 0 | 9 |
| Global Satisfaction | 6 | 2 | 0 | 1 | 1 | 4 |
| Cost and Value | 0 | 0 | 1 | 0 | 0 | 0 |
| Education and Information | 1 | 0 | 0 | 1 | 1 | 5 |
| Psycho-Social Well Being | 0 | 0 | 0 | 2 | 0 | 2 |
| **TOTAL NUMBER OF QUESTIONS** | **16** | **2** | **12** | **6** | **6** | **35** |

Table O-8

Content Summary Table

Written: Caregiver Only (W-C)

| | W-C Tool 1 | W-C Tool 2 | W-C Tool 3 | W-C Tool 4 | W-C Tool 5 |
|---|---|---|---|---|---|
| Demographics | 0 | 5 | 2 | 2 | 5 |
| Accessibility | 3 | 10 | 4 | 3 | 0 |
| Art of Care | 1 | 0 | 0 | 0 | 3 |
| Technical Care | 4 | 6 | 1 | 2 | 3 |
| Efficacy | 0 | 12 | 1 | 2 | 6 |
| Infrastructure | 2 | 4 | 0 | 0 | 6 |
| Global Satisfaction | 5 | 4 | 2 | 2 | 4 |
| Cost and Value | 0 | 0 | 0 | 2 | 1 |
| Education and Information | 1 | 0 | 3 | 0 | 1 |
| Psycho-Social Well Being | 0 | 0 | 0 | 0 | 0 |
| **TOTAL NUMBER OF QUESTIONS** | **16** | **41** | **13** | **13** | **29** |

Table O-9

<u>Content Summary Table</u>

<u>Written: Caregiver Only (W-C)</u>

| | W-C Tool 6 | W-C Tool 7 | W-C Tool 8 | W-C Tool 9 | W-C Tool 10 | W-C Tool 11 |
|---|---|---|---|---|---|---|
| Demographics | 5 | 3 | 0 | 0 | 3 | 5 |
| Accessibility | 0 | 1 | 4 | 2 | 12 | 1 |
| Art of Care | 0 | 0 | 3 | 9 | 12 | 3 |
| Technical Care | 0 | 1 | 11 | 4 | 15 | 17 |
| Efficacy | 0 | 1 | 0 | 4 | 5 | 0 |
| Infrastructure | 0 | 3 | 3 | 2 | 7 | 16 |
| Global Satisfaction | 2 | 3 | 2 | 3 | 4 | 3 |
| Cost and Value | 0 | 0 | 0 | 0 | 3 | 0 |
| Education and Information | 0 | 2 | 3 | 8 | 11 | 1 |
| Psycho-Social Well Being | 1 | 2 | 0 | 0 | 0 | 0 |
| **TOTAL NUMBER OF QUESTIONS** | 8 | 16 | 26 | 32 | 72 | 46 |

Table O-10

Content Summary Table

Written: Patient or Caregiver (W-PC)

| | W-PC Tool 1 | W-PC Tool 2 | W-PC Tool 3 | W-PC Tool 4 | W-PC Tool 5 |
|---|---|---|---|---|---|
| Demographics | 1 | 1 | 7 | 8 | 29 |
| Accessibility | 2 | 4 | 7 | 4 | 11 |
| Art of Care | 1 | 3 | 2 | 0 | 11 |
| Technical Care | 5 | 14 | 16 | 2 | 2 |
| Efficacy | 1 | 0 | 5 | 0 | 1 |
| Infrastructure | 3 | 24 | 0 | 0 | 1 |
| Global Satisfaction | 1 | 1 | 6 | 6 | 3 |
| Cost and Value | 0 | 1 | 2 | 0 | 1 |
| Education and Information | 1 | 1 | 14 | 5 | 9 |
| Psycho-Social Well Being | 0 | 0 | 0 | 0 | 0 |
| **TOTAL NUMBER OF QUESTIONS** | **15** | **49** | **59** | **25** | **68** |

Table O-11

Content Summary Table

Forum: Patient Only (F-PO)

| | F-PO Tool 1 | F-PO Tool 2 | F-PO Tool 3 | F-PO Tool 4 | F-PO Tool 5 | F-PO Tool 6 |
|---|---|---|---|---|---|---|
| Demographics | ** | ** | ** | ** | ** | ** |
| Accessibility | ** | ** | ** | ** | ** | ** |
| Art of Care | ** | ** | ** | ** | ** | ** |
| Technical Care | ** | ** | ** | ** | ** | ** |
| Efficacy | ** | ** | ** | ** | ** | ** |
| Infrastructure | ** | ** | ** | ** | ** | ** |
| Global Satisfaction | ** | ** | ** | ** | ** | ** |
| Cost and Value | ** | ** | ** | ** | ** | ** |
| Education and Information | ** | ** | ** | ** | ** | ** |
| Psycho-Social Well Being | ** | ** | ** | ** | ** | ** |
| **TOTAL NUMBER OF QUESTIONS** | ** | ** | ** | ** | ** | ** |

** Forum - No content analysis possible

Table O-12

Content Summary Table

Forum: Patient Only, Caregiver Only, and Patient or Caregiver (F-PO, F-C, & F-PC)

|  | F-PO | F-PO | F-PO | F-C | F-PC |
|---|---|---|---|---|---|
|  | Tool 7 | Tool 8 | Tool 9 | Tool 1 | Tool 1 |
| Demographics | ** | ** | ** | ** | ** |
| Accessibility | ** | ** | ** | ** | ** |
| Art of Care | ** | ** | ** | ** | ** |
| Technical Care | ** | ** | ** | ** | ** |
| Efficacy | ** | ** | ** | ** | ** |
| Infrastructure | ** | ** | ** | ** | ** |
| Global Satisfaction | ** | ** | ** | ** | ** |
| Cost and Value | ** | ** | ** | ** | ** |
| Education and Information | ** | ** | ** | ** | ** |
| Psycho-Social Well Being | ** | ** | ** | ** | ** |
| **TOTAL NUMBER OF QUESTIONS** | ** | ** | ** | ** | ** |

** Forum - No content analysis possible

APPENDIX P

MODIFIED CONCEPTUALIZATION OF DIMENSIONS OF SATISFACTION

## Modified Conceptualization of Dimensions of Satisfaction

| Dimension | Subdimension | |
|---|---|---|
| System Adequacy | Accessibility of the staff | |
| | Complaint management | |
| | Infrastructure | - Meals |
| | | - Recreation |
| | | - Transportation |
| | | - Physical Environment |
| Staff Competency | Technical elements | - Thoroughness |
| | | - Skillfulness |
| | Interpersonal and | - Education and information |
| | communication elements | - Regard for privacy and dignity |
| | | - Friendliness and courtesy |
| Social Well-Being | Sense of self in the | - Relationships |
| | environment | - Emotional status |
| | Sense of control and | |
| | autonomy in the | |
| | environment | |
| Global Satisfaction | Open questions about | |
| | preferences | |

APPENDIX Q

CRITICAL CRITERIA LIST

## Critical Criteria List

| Process | Recommendation |
| --- | --- |
| Methodology: | • Use tools that randomly select respondents for survey participation. <br><br> • Use tools that attempt to obtain client self-reports of satisfaction through in-person interviews. <br><br> • Use tools tailored to the communication capabilities of the client population being surveyed. <br><br> • Provide visual element to response options (e.g. ACD tool) |
| Tool Development | • Conduct client focus groups. <br><br> • Have providers and measurement specialists collaboratively develop tools. <br><br> • Test tools for validity and reliability. |
| Frequency | • Will depend on type of measure. |

## Critical Criteria List Continued

| Process | Recommendation |
|---|---|
| Length | • Tools should not take longer than 30 minutes to complete. (Aim for 20 minute length). |
| Question Structure: Evaluative versus factual report | • Ask subjective questions that limit the need for memory recall.<br>• Do not ask for or use specific time references.<br>• Do not ask for comparisons.<br>• Ask singular questions. |
| Question Structure: Open-ended versus closed-ended | • Use more closed-ended than open-ended questions.<br>• Use scales appropriate to the questions and population. |
| Confidentiality | • Use an interviewer who is introduced to the respondent by a staff member but not known to the respondent. |

**Critical Criteria List Continued**

| Content | Recommendation |
| --- | --- |
| Dimensions | <ul><li>Ask questions specific to the services offered.</li><li>Ask questions from each of the four dimensions listed below:<ul><li>System adequacy</li><li>Staff competency</li><li>Social well-being</li><li>Global satisfaction</li></ul></li></ul>(Detailed list found in Appendix P) |

APPENDIX R

PACE PROFILE:  SERVICES OFFERED

# Pace Profile: Services Offered

The following is a list of services offered at most PACE sites across the United States. This list is divided into 5 service categories: Day Center Services, In-home Services, Specialist Services, other Medical Services, and Inpatient Services.

---

| Day Center Services: | In-Home Services: | Other Medical Services: |
|---|---|---|
| Physician/ Nurse practitioner | Health Care | Prescriptions |
| Nursing | Personal Care | Lab tests/procedures |
| Social Work | Homemaker/chore services | Durable medical equipment |
| Physical Therapy | Meals | Outpatient Surgery |
| Occupational Therapy | **Specialist Services:** | Emergency Room Care |
| Speech Therapy | Audiology | Medical Transportation |
| Recreational Therapy | Dentistry | |
| Nutrition Counseling | Optometry | |
| Personal Care | Podiatry | |
| Chore Services | Psychiatry | |
| Transportation | **Inpatient Services:** | |
| Meals | Hospital | |
| Escort Services | Nursing Home | |
| | Inpatient Specialists | |

APPENDIX S

PACE PROVIDER CROSS-SITE SUMMARY - AS OF 12/31/97

PACE ETHNICITY BAR GRAPH

PACE ETHNICITY TABLE

**PACE Provider Cross-Site Summary – as of 12/31/97**

| Site Acronym | Number of Participants | Average Age of Participants | % Requiring Assistance with 3 + ADLs | % with Cognitive Impairment |
|---|---|---|---|---|
| BSHS | 277 | 80 | 64 | 74 |
| CEI | 132 | 78 | 67 | 65 |
| CSI | 93 | 82 | 40 | 60 |
| CCE | 417 | 80 | 53 | 70 |
| CCM | 468 | 77 | 57 | 32 |
| ESP | 356 | 80 | 51 | 65 |
| ILS | 353 | 80 | 74 | 71 |
| OL | 693 | 82 | 53 | 70 |
| PSC | 348 | 78 | 71 | 84 |
| PEP | 409 | 81 | 54 | 75 |
| SSC | 168 | 80 | 61 | 73 |
| TLC | 232 | 82 | 52 | 84 |

## PACE Ethnicity Bar Graph
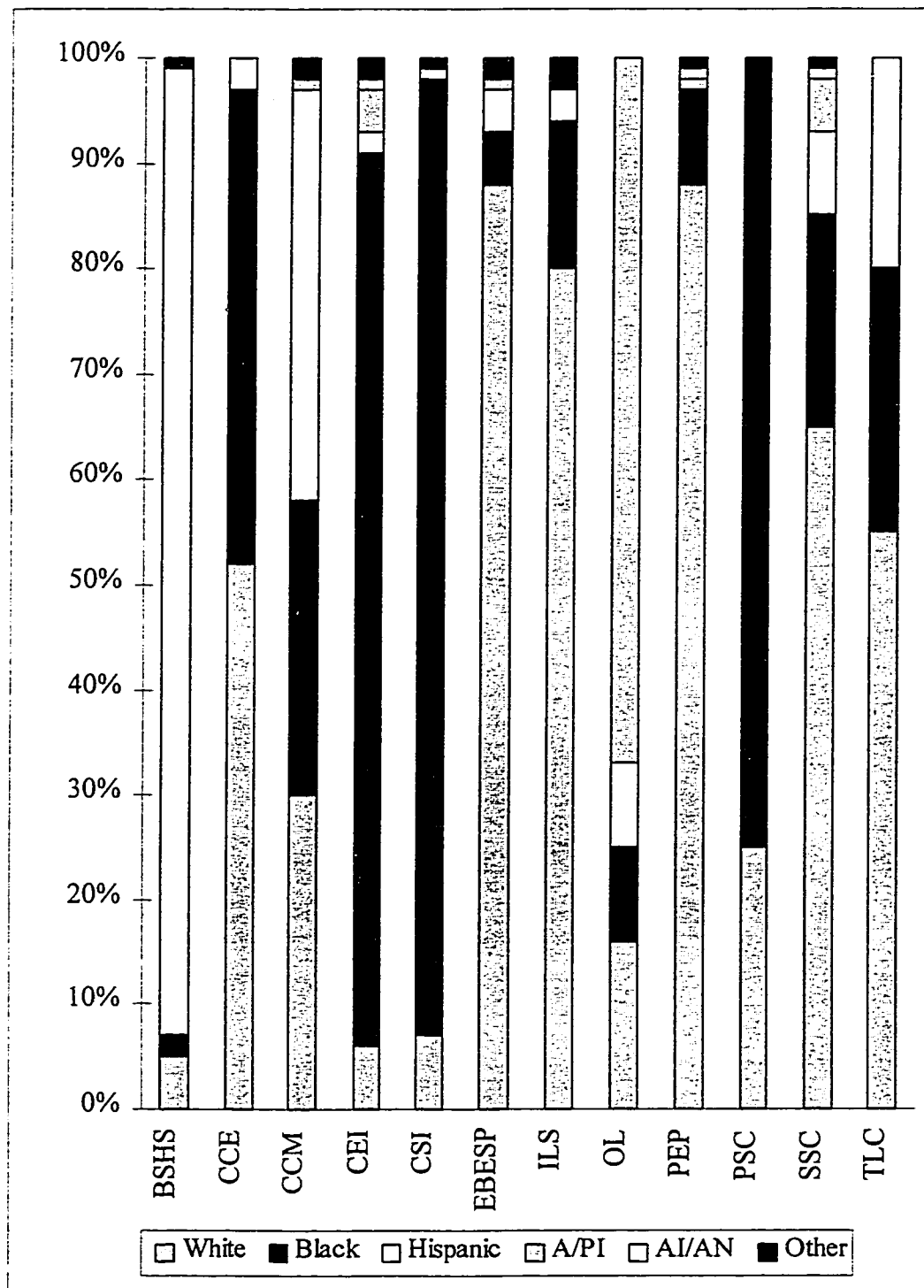
## PACE Ethnicity Table

|  | White | Black | Hispanic | Asian / PI | American Indian / AN | Other |
|---|---|---|---|---|---|---|
| BSHS | 5 | 2 | 92 | 0 | 0 | 1 |
| CCE | 52 | 45 | 3 | 0 | 0 | 0 |
| CCM | 30 | 28 | 39 | 1 | 0 | 2 |
| CEI | 6 | 85 | 2 | 4 | 1 | 2 |
| CSI | 7 | 91 | 1 | 0 | 0 | 1 |
| ESP | 88 | 5 | 4 | 1 | 0 | 2 |
| ILS | 80 | 14 | 3 | 0 | 0 | 3 |
| OL | 16 | 9 | 8 | 67 | 0 | 0 |
| PEP | 88 | 9 | 0 | 1 | 1 | 1 |
| PSC | 25 | 74 | 0 | 0 | 0 | 1 |
| SSC | 65 | 20 | 8 | 5 | 1 | 1 |
| TLC | 55 | 25 | 20 | 0 | 0 | 0 |

APPENDIX T

NON-PACE AGENCY PROFILES

**Non-PACE Agency Profiles**

**Bethany Center** is a non-profit Housing and Urban Development (HUD) complex for low-income elderly (and younger people with disabilities) located in San Francisco (CA). Bethany Center offers a wide range of services including community nurse, social worker, evening and weekend meals, shopping assistance, social and educational activities. Bethany has recently entered a partnership with On Lok to provide more extensive elder care services to clients requiring greater assistance. Bethany has been providing services for 30 years and enjoys a connection with Bethany United Methodist Church.

**Care Network For Seniors** (CNS) is a collaborative effort of Fairfax County's (VA) Department of Family Services, the Fairfax-Falls Church Community Services Board, the Department of Health, and the Office of Human Services Systems Management. CNS is designed to help older persons and their family caregivers determine, plan for, and obtain the in-home and community based services and assistance needed to remain as independent as possible, living in the community rather than in an institutional setting. The program targets people age 60 and older who need assistance in performing activities of daily living.

**Live Oak Adult Day Services** is a nonprofit, community service agency serving frail and dependent seniors in Santa Clara County (CA). Services are designed to prevent or delay the institutionalization of participants and include specialized recreation and socialization opportunities including adaptive physical exercise, music, and multigenerational events. Meals and transportation are also provided to the 100 participants that are divided across the organization's three sites. A second priority of Live Oak is to provide respite and

support services to the informal caregivers of participants through support groups and counseling.

**MidPeninsula Continuous Care Services** is a non-profit home care agency that has over 11 years experience in providing private duty licensed nursing, personal care, and supportive services to frail elder seniors. Home health, continuous and hospice services are offered on an hourly or live-in basis and coverage is by private insurance or a sliding scale fee based on income. MidPeninsula Continuous Care is affiliated with Camino Healthcare and Sequoia Hospital District. The organization's two administrative offices are located in Palo Alto and Cupertino, CA.

**Nob Hill Healthcare Center** offers skilled nursing and sub-acute rehabilitation services to frail elders. Approximately 90% of Nob Hill's 160 patients are long-term care residents, the remaining 10% are shorter term rehabilitation clients. In addition to the services provided to clients, Nob Hill also provides supportive services to informal caregivers including support groups and counseling. Nob Hill Healthcare Center is located in San Francisco (CA) and is owned by Vencor, an organization operating numerous nursing centers in Northern California.

**Oak Park Convalescent Hospital** is a small facility offering 24 hour, long and short term skilled nursing services. Oak Park offers specialized Alzheimer's and dementia care, social work, activities, respite, sub-acute care, rehabilitative, and hospice services. The low patient census, a maximum 36, allows for highly individualized care. Owned by Paracelsus Convalescent Hospitals Inc., Oak Park is located in Pleasant Hill, CA and is one of four sites in the geographical area.

**Rosener House** offers a therapeutic day program for older adults who have memory or sensory loss, mobility limitations, and who may be lonely and in need of socialization. Services include physical and speech therapy, health monitoring, social worker counseling, meals, transportation, and numerous activities. Support groups and other programs are also designed for family caregivers. Rosener House, located in San Mateo County (CA), can accommodate approximately fifty participants daily and develops care plans for each individual according to their interests and needs. Rosener House is one of four programs sponsored by Peninsula Volunteers, Inc., a nonprofit charitable corporation dedicated to serving older adults.

**The Veterans Administration** Healthcare System's (VA) Nursing Home Care Units (NHCU) provide both long-term skilled nursing and short term services. Short term services include hospice, respite, and transitional care for patients with post hospital needs that require skilled care before discharge. The VA's NHCU serve approximately 250 participants in two locations, Menlo Park, located in San Mateo county, and Livermore, located in Alameda county. Although slightly younger than community nursing home residents, the most frequently occurring diagnoses in the VA NHCUs is dementia (including Alzheimer's) and "other psychoses."

**The Visiting Nurse Association** (VNA) and Hospice of Northern California is a non-profit home care organization offering case management, home nursing and hospice services. Extensive care including IV therapy, home infusion therapy, and wound care, along with community education and nutritionist services are offered. Affiliated with Sutter Health (Home Health Division), VNA provides care services to 3900 individuals each month. The VNA accepts Medicare and private insurance.

APPENDIX U

NON-PACE PROVIDER CROSS-SITE SUMMARY

NON-PACE ETHNICITY BAR GRAPH
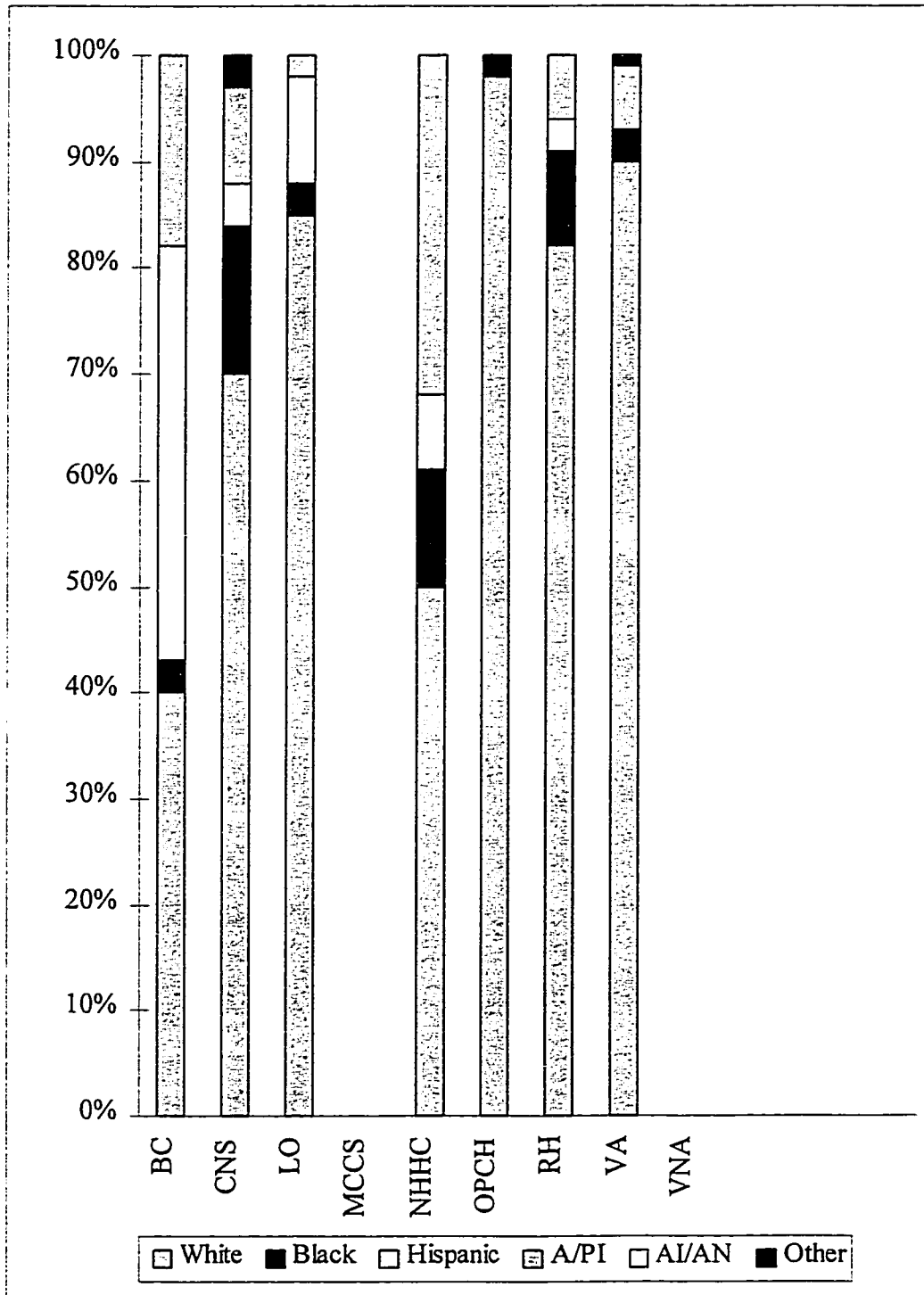
NON-PACE ETHNICITY TABLE

**Non-PACE Provider Cross-Site Summary - as of 12/31/97**

| Site Acronym | Number of Participants | Average Age of Participants | % Requiring Assistance with 3 + ADLs | % with Cognitive Impairment |
|---|---|---|---|---|
| BC | 162 | 81 | 20 | 10 |
| CNS | 210 | 81 | >50* | >50* |
| LO | 269 | 85 | N/A | 80 |
| MCCS | 215 | >75* | 90 | >50* |
| NHHC | 160 | >80* | 91 | 15 |
| OPCH | 36 | >80* | 95 | 90 |
| RH | 100 | 75 | 15 | 85 |
| VA | 484 | 73 | 95 | 66 |
| VNA | 3900 | N/A | N/A | N/A |

N/A = No data available from provider        * Provider estimate

**Non-PACE Ethnicity Bar Graph**

**Non-PACE Ethnicity Table**

|  | White | Black | Hispanic | Asian / PI | American Indian / AN | Other |
|---|---|---|---|---|---|---|
| BC | 40 | 3 | 39 | 18 | 0 | 0 |
| CNS | 70 | 14 | 4 | 9 | 0 | 3 |
| LO | 85 | 3 | 10 | 2 | 0 | 0 |
| MCCS | 0 | 0 | 0 | 0 | 0 | 0 |
| NHHC | 50 | 11 | 7 | 32 | 0 | 0 |
| OPCH | 98 | 0 | 0 | 0 | 0 | 2 |
| RH | 82 | 9 | 3 | 6 | 0 | 0 |
| VA | 90 | 3 | 0 | 6 | 0 | 1 |
| VNA | 0 | 0 | 0 | 0 | 0 | 0 |

# IMAGE EVALUATION
# TEST TARGET (QA-3)



150mm

6″
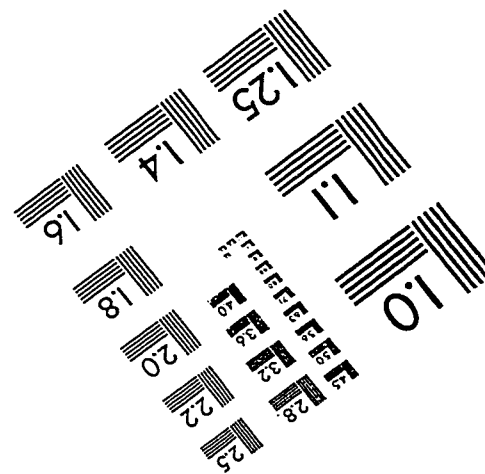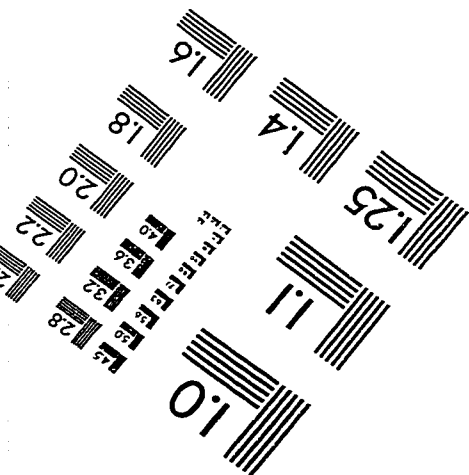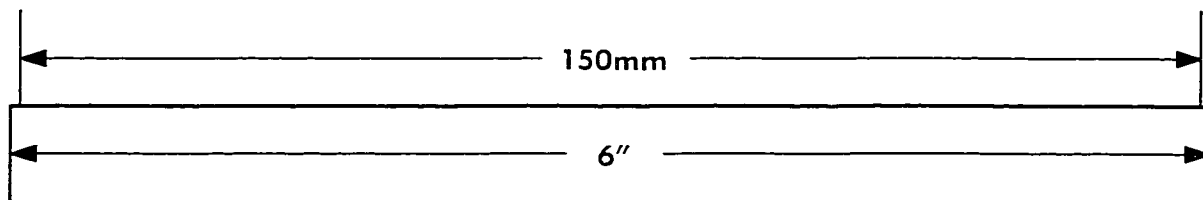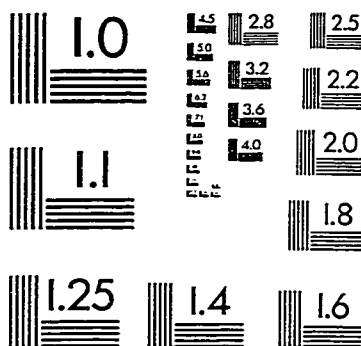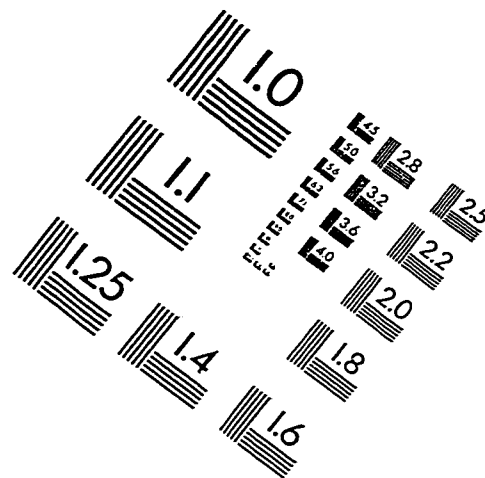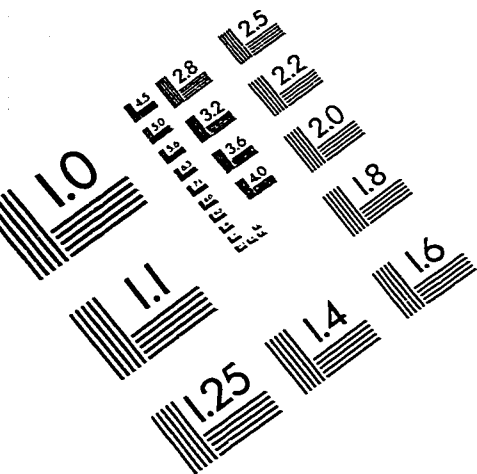
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