ELSEVIER
SAUNDERS

Clin Geriatr Med 21 (2005) 121–146

CLINICS IN
GERIATRIC
MEDICINE

Assessment Instruments

Adnan Arseven, MD*, Chih-Hung Chang, PhD,
Onur K. Arseven, MD, Linda L. Emanuel, MD, PhD

*The Buehler Center on Aging, Northwestern University Feinberg School of Medicine,
750 North Lake Shore Drive, Chicago, IL 60611, USA*

This article examines question-based assessment instruments in palliative care for elders. Important in all aspects of medicine, reliance on verbal assessments is of special importance in palliative care. This is so partly because of the global nature of the assessments that undergird palliative care and geriatrics. Verbal assessments also take on more importance when the physical exam and tests are reduced in scope, which often occurs for patients in fragile states for whom the burden to benefit ratio is high.

Clinicians need to start with a set of screening questions so that an overall picture of patient needs is possible. The domains to be covered with these questions have been empirically derived in palliative care and have considerable although not complete overlap with those that are traditionally assessed in geriatrics. This article includes a comprehensive set of domains and identifies short instruments that can be used for the purpose.

When the clinician detects need, it is then necessary to use questions that are aimed at a deeper level of evaluation. Long forms, from which the short forms were derived, can provide some of these questions. Alternatively, short forms for the specific area in question may be relevant. Often these short forms are aimed more toward measurement than evaluation, so the clinician should take this into account. For each domain of assessment in palliative and geriatrics care, a definition, a statement of its importance or purpose, and a selection of assessment instruments that could most easily be used by the clinician are provided.

* Corresponding author.
E-mail address: a-arseven@northwestern.edu (A. Arseven).

0749-0690/05/$ – see front matter © 2004 Elsevier Inc. All rights reserved.
doi:10.1016/j.cger.2004.10.002

Physical examinations and test

Tests and evaluations based on physical examination, performance, visualization, or sampling fall mostly beyond the scope of this article. The methods of physical examination and the tests available for evaluation are not different in palliative care from other branches of medicine. However, one feature is distinctly characteristic for palliative care. That is, physical examination and tests should be selected based on the question Will the information help with management of suffering? as opposed to Will the information help with diagnosis and cure? Physical examination can foster a therapeutic alliance between the clinician and patient, and is often helpful in diagnosing sources of suffering. It is therefore an essential part of palliative care, but uncomfortable aspects of the examination should be avoided if the information is not expected to alter the care plan. Tests, even noninvasive tests, can be uncomfortable and practically challenging for older patients in need of palliative care and therefore should be used sparingly.

The varied purposes for question-based assessments

Assessment can be thought of as having three types: screening, evaluation, and measurement. Each type of instrument has different purposes and different desirable features. Each type is used by clinicians and researchers, although their desirable characteristics differ in either case.

Clinicians use screening instruments to detect conditions in need of medical attention among individuals. Researchers use screening instruments to detect conditions in a population, whether to select subjects for a study or to determine incidence of a condition in a defined population for a public health study. Screening instruments need to have high sensitivity rather than specificity. That is, they may sometimes detect conditions that look like but are not the condition in question, but they should rarely fail to detect the condition's presence.

Evaluation aims to provide a deeper description of a detected condition to confirm its existence and define subtypes, duration, and specific features. Evaluation instruments require higher specificity than sensitivity; that is, once a condition is detected, the more specific instrument should determine if the condition is what was sought and if so, what other characteristics can be identified.

Measurement, for a clinician, aims to quantitate the severity of a given condition. Clinicians need measurement instruments to follow a condition over time and to have definable thresholds for intervention. These thresholds are often referred to as cut-off scores on a scaled measurement. For a researcher, measurement allows determinations of prevalence and correlations among conditions. Prevalence findings and correlation analysis also commonly make use of defined points on a scaled measurement to identify when, for the purposes of the analysis, a condition exists.

All instruments should be validated, although many in use are not. Validation means that the instruments have been shown to measure what they are intended to

measure (have face validity), get the same results when the test is repeated (have test-retest reliability), and show sensible relationships to other related validated scales and among the component items of the instrument (have external and internal or construct validity).

Clinicians need instruments that are as short as possible while still being sufficiently valid so that they can be used efficiently in the busy clinical setting. Researchers need instruments that are highly valid even if their use requires more time.

Challenges of comprehensive assessment

The key feature of geriatrics and palliative care is something they hold in common and also something that presents a challenge for assessment. That is, the comprehensive nature of the assessments used. As noted in the article in this issue by DellaSantina on whole-patient assessment palliative care properly insists on organizing care according to a comprehensive assessment of all the dimensions of a person's illness experience, including the role and condition of the family and social context. Geriatrics also insists on the central role of a comprehensive assessment in developing a care plan.

As essential as this form of assessment is, it also presents a serious practical challenge: how to get it done. Its breadth of scope seems to demand inordinate amounts of time and attention, which is not compatible with a busy clinician's schedule. Further, elderly patients and the seriously ill are often not in a condition to tolerate lengthy interviews. In addition, inclusion of the family members and community in the process makes it even more expansive. It is also not a one-time-only assessment. In quality continuing care, a comprehensive assessment is updated continuously through the entire course of care.

The consequence is that assessment must screen for problems using questions designed to be highly sensitive for anything of concern in a general domain so that the full range of domains can be assessed within practical time constraints. If screening questions identify a problem area, more specific questions are used to probe further. Other areas are left unprobed. The traditional history-taking approach uses this method, although it has not been formalized into a validated assessment instrument.

Broad screening and unfolding approaches to assessment

In palliative care, instruments are being developed and validated to capture this process for the comprehensive assessment. Validation studies are not yet fully rigorous for the most part, but progress is underway. One instrument, the Palliative Care Outcomes Scale (POS) is a brief hospice inventory designed to allow a comprehensive assessment at the time of intake into a hospice program [1].

Two other instruments are designed to use an unfolding approach; each instrument has been constructed with some level of validation. The Needs at the End of Life Screening Tool (NEST) starts with screening questions and moves to more specific evaluation questions and then measurement scales; it is available and aspects are also still under development (Appendix) [2]. The Resident Assessment Instrument has a similar construction and is specifically designed for residents of long-term-care institutions. It has a palliative care version, RAI-PC, and also needs further development [3].

Domains

To use a validated approach to screening, evaluation, and measurement, it is necessary to first have an overarching framework that identifies and defines the domains that are to be included in a comprehensive assessment [3]. In palliative care, several groups have provided research that defines these domains and they have extensive similarities, providing some external validation for the list of domains, but also some differences [3–8].

In geriatrics, the domains have some overlap with palliative care as well. The list includes cognitive function; affective disorders; visual impairment; hearing impairment; dental health; functional status; nutritional status; gait and balance impairment; social support; environment; caregiver burden; and quality of life. In addition, spirituality has had some attention. However, there has been less research into the list of domains that should be included.

The World Health Organization (WHO) recently published a new definition of palliative care and emphasized prevention and relief of suffering by means of early identification and treatment of pain and other problems (physical, psychosocial, and spiritual; http://www.who.int/cancer/palliative/definition/en/). This new definition differs from its earlier version by recognizing the necessity of applying principles of palliative care as early as possible in the course of any chronic, ultimately fatal, disease.

In this article, the authors stayed in parallel with the domains of the WHO definition but added new domains when necessary. In what follows, some validated scales for each domain and areas within them are described. Because of their number, they are not all provided here. For a comprehensive compilation in geriatrics, the reader is referred to a text such as Rubenstein et al's [9] *Geriatric Assessment Technology: The State of the Art*. Most of these scales are best used as measurement instruments in outcomes evaluation studies, but many can also be used for clinical evaluation and for following clinical progress. The domains treated are listed in Box 1.

Instruments for in-depth/research assessment by domain

Once an instrument such as POS, NEST (see Appendix), or RAI-PC has been used to screen for problem areas, the next step is evaluation. If the instrument is

Box 1. Domains treated

Competency and communication

- Vision and hearing
- Cognitive function

Functional status
Physical

- Nutrition
- Mobility

Symptoms and distress

- Pain
- Shortness of breath
- Fatigue
- Confusion/delirium

Psychological (depression, anxiety)
Social and environmental

- Sociodemographics
- Support system
- Financial burden
- Caregiver needs/burden

Spiritual

- Spirituality and religiousness
- Purpose and settledness (personal acceptance)

Care services

- Health literacy
- Goals of care
- Therapeutic relationship/information preferences
- Perceived quality of care

Subjective experience

- Quality of life

an unfolding instrument, the next level of that instrument can be used. Alternatively, other instruments that are specific for the domain or areas within the domain can be used.

Competency and communication

Sensory function (vision and hearing)
Definition. This domain refers to hearing and vision function.

Purpose/importance. Hearing and vision impairment are prevalent in the elderly. Hearing impairment is one of the most common medical conditions reported by older persons, affecting approximately one third of those 65 years of age or older. About 5% of adults 65 years of age or older have vision impairment (greater than 20/40). This would continue to increase up to 20% among those 75 years and older [10]. Sensory deficits impact the communication capacity of the person, resulting in poor health, function, isolation, and quality of life. Because of the significant impact on communication and quality of life, sensory assessment should be part of the assessment of the elderly not only in clinical settings but also as a research area.

Instruments and characteristics. Hearing: Screening tools include both self-report and performance-based measures [11,12]. A hand-held audiometer gives the most accurate measurement. It has a sensitivity of 94% and specificity of 72% [13]. A validated whispered voice test is also available [14]. The Hearing Handicap Inventory for the Elderly can evaluate the impact of hearing impairment on the social and emotional well-being of elderly patients.

Vision: Performance based methods include Jaeger Pocket card and Snallen wall-mounted chat. Validated self-report instruments, including the Activities of Daily Vision Scale, the VF-14, and the National Eye Institute Visual Function Questionnaire, can be used to assess functional impact of visual impairment especially in a research setting [15–17].

Cognitive function
Definition. Cognitive function includes attention, memory, language, visuospatial skills, and executive capacity.

Purpose/ importance. Prevalence of chronic dementing illnesses and other types of acute (delirium) or chronic cognitive impairment increases with age. Inability to diagnose a dementing illness may lead to prolonged suffering as well as unnecessary morbidity and excessive health care use.

Areas of inclusion/instruments and characteristics. Brief instruments measuring cognitive function will improve the detection and management of dementing illnesses in the elderly. The Mini Mental Status Examination (MMSE) is the most extensively used cognitive screening instrument [18]. The instrument tests

multiple domains of cognitive function, including orientation, registration, attention and calculation, short recall, language, and visual-spatial function. It has been validated in different settings and takes 5 to 10 minutes to apply [19]. However, the MMSE does not seem to be sensitive enough to detect executive control function problems and is affected by the age and education level of patients [20,21]. Several shorter screens have also been validated, such as the Time and Change [22] and the Mini-Cog [23] tests. When available, combining the MMSE test scores with proxy information on a patient's functional status, or adding a quick, performance-based cognitive test, such as the clock drawing test or the Time and Change test, may satisfy some of these concerns [24,25]. The Mini-Cog test combines three-item recall and clock drawing; the Time and Change test combines clock recognition and counting change. The clock-drawing component of both tests is less affected by education and cultural differences and measures executive function [21,23].

Many other screening tests are available and widely used in the research setting. These include the Mental Status Questionnaire [26], the Short Portable Mental Status Questionnaire [27], the Short Blessed Memory-Orientation-Concentration Test [28], and the Geriatric Mental Status Schedule [29].

Recommendations for clinical use. The authors recommend a brief screening instrument, such as the Mini-Cog test, followed by a more in-depth cognitive assessment test if it is abnormal.

Functional status

Definition. Functional status can be described as the ability to perform self-care, self- maintenance, physical activities, and fulfill social roles.

Purpose/ importance. Functional status is an essential part of assessment in geriatric and palliative care. It summarizes the overall impact of health conditions in the context of a person's environment and social support network [30]. Self-perceived or observed difficulties define functional decline. Assessment of functional status is also an important outcome measure to monitor response to treatment and provide prognostic information to plan future care.

Instruments and characteristics. Instruments to assess functional status are most commonly thought of as covering basic activities of self-care (basic activities of daily living or ADL), higher level activities necessary to live independently in the community (instrumental activities of daily living or IADL), or highest-level activities (advanced activities of daily living or AADL).

The Katz Index [31] assesses the need for assistance in bathing, eating, dressing, transfer, toileting, and continence. The Barthel Index and Lawton Physical Self-Maintenance Scale also assess these areas and add walking, grooming, and stair climbing [32,33]. IADL are important tasks and are necessary to be independent in the community. These include shopping for groceries, driving or using public transportation, using the telephone, meal preparation,

housework, medication taking, and handling finances. Advanced activities of daily living include societal, family, and community roles, and participation in occupational and recreational activities. Scales should measure performance rather than capacity (ie, Do you eat without help? versus Can you eat without help?). They should also be detailed enough to differentiate between those who are completely dependent and those who can function with help [34]. A summary scale combining a limited number of ADL/IADL items has been shown to capture 93% variation of complete scales in a recent study of a Medicare population [35]. ADL/IADL scales have been extensively used in clinical practice and in geriatric research for several decades.

In addition, functional assessment tools based on performance, such as the Karnofsky Performance Scale [36] and the Eastern Cooperative Oncology Group Performance Status Scale, are validated and widely used tools in cancer care [37]. The Karnofsky Performance Scale has been evaluated in a geriatric outpatient setting and correlates well with ADL and IADL scales [38,39]. These scales provide limited information compared with ADL/IADL scales. Other more recently developed tools are available. These instruments include the Rapid Disability Rating Scale (RDRS), the Health Assessment Questionnaire (HAQ), and the Functional Independence Measure (FIM). The RDRS-2 uses a four point scale and includes eight items on activities of daily living, three on mental capacity, and one each on dietary changes, continence, medications, and confinement to bed. The HAQ is a widely used instrument with strong reliability and validity. The HAQ is a good descriptive instrument but may be less appropriate as a tool for measuring clinical change in outcome studies. The HAQ or the RSDS is recommended for brevity [40]. The FIM instrument assesses physical and cognitive disability regarding burden of care. It has been used to monitor a patient's progress. It is a rating scale applicable to different age groups and diagnoses and is used by clinicians and nonclinicians. It is well validated, but its use is limited in clinical practice except in a rehabilitation setting, and should be considered for research purposes.

Recommendations for clinical use. The authors recommend the use of ADL/IADL scales in a clinical setting for their ease of use, brevity, and substantial contributions to elderly patient assessment and care plan. They have established a common language between medical care and research communities during the past 20 years.

Physical function

Mobility

Definition. The ability to get around.

Purpose/ importance. Mobility is an important component of physical function. Balance and gait are different aspects of mobility. Impairment of this function is

associated with increased risk of falling and injuries and suggests increased need for help.

Instruments and characteristics. Although performance measures are beyond the scope of this article, because of its importance a simple performance-based mobility assessment is provided.

The Sickness Impact Profile (SIP) mobility subscale [41] is a community-based definition of mobility. This subscale focuses on a patient's ability to move around inside a residence, such as ability to get from a bed to the bathroom; moving outside the residence; the frequency of leaving the residence; and the ability to use transportation. The SIP mobility scores are only moderately correlated with performance measures, such as gait speed, meaning that they measure different things, and are used mainly for research purposes.

The Timed Get Up and Go test involves observation of the patient getting up from a seated position, walking 3 meters, turning around, returning to the chair, and sitting down. A score longer than 20 seconds should prompt more in-depth evaluation. It is a simple and reliable measure of mobility and may be useful for following functional decline over a period of time [42].

Recommendations for clinical use. The authors recommend a single question asking if a fall incident has occurred in the past 3 months and if there is a fear of falling. If the answer is affirmative, it is followed by a timed Get Up and Go test.

Nutrition

Definition. There is no uniformly accepted definition of malnutrition among the elderly. Abnormal weight loss (eg, greater than 10 pounds/6 months), body mass index (eg, greater than 27 or less than 22), and abnormal biomarker or micronutrient levels have been suggested as ways to define malnutrition.

Purpose/ importance. The risk of developing one or more nutritional disorders increases as a function of age, mainly due to increased prevalence of disease and disability. Even though obesity is the most common nutritional disorder among elderly living in the community, undernutrition is especially common among in frail elderly long-term care residents, those in acute care settings, and patients with terminal illnesses.

Instruments and characteristics. Assessment instruments include a history of five or more reported or documented weight loss episodes over a 6-month period, self-report screening tools, anthropometric measurements, biochemical markers, or combinations of these.

For healthy elderly persons, the Nutrition Screening Initiative is a 10-item, self-administered checklist that was developed within the context of the United States National Screening initiative. A score of 6 or higher suggests high risk for malnutrition and is followed by a two-step evaluation by health care professionals [43]. This instrument appears to be overinclusive with poor specificity [44].

In frail elderly, the Mini Nutritional Assessment Instrument (MNA) has been tested and validated in different settings. The instrument is composed of dietary and global assessment questions, anthropometric measurement, and optional biological markers. It classifies the individual as well nourished, at risk of malnutrition, or malnourished in less than 15 minutes. The short version of the MNA (MNA-S), which takes 3 minutes to complete, has been validated in community-dwelling elderly [45].

Symptoms and distress

Definition. Symptoms are defined as "subjective physical and psychological phenomenon that arise from pathological states or disorder" [46].

Purpose/ importance. Patients experience diseases through the symptoms and distress they produce. Symptoms present not only diagnostic clues but also therapeutic challenges. Understanding and managing disturbing symptoms successfully at any stage of the disease process, particularly at the advanced and incurable stages, will mitigate disease effect and improve quality of life.

Instruments and characteristics. Symptoms are multidimensional in nature; they have physical, emotional, functional, and spiritual components. Psychosocial and cultural factors affect how patients perceive symptoms. There are instruments available to measure prevalence, characteristics, and distress of common physical symptoms, but absence of validated instruments (particularly those that target elderly patients) for common symptoms is still the major methodological barrier to improving symptom assessment and management.

Some instruments measure multiple symptoms; others target individual symptoms. The Memorial Symptom Assessment Scale (MSAS) is one of the best known [47]. A 10-item brief subscale of this instrument, the MSAS Global Distress Index, is an easy-to-interpret, stand-alone measure of symptom distress. The MSAS has been used in cancer and AIDS patients. Other available scales include the Rotterdam Symptom Checklist [48], a 34-item psychological and physical distress measure for adult cancer patients, and Edmonton Symptom Assessment System (ESAS) [49], which consists of nine 100-mm visual analog scales for pain, activity, nausea, depression, anxiety, drowsiness, appetite, shortness of breath, and sensation of well-being. The ESAS was developed for terminally ill patients in a palliative care setting. Scores were obtained twice a day, providing a graphic representation.

Pain

Multiple pain instruments have been developed, but available data on the use in elderly patients is limited. Available instruments are either one dimensional or multidimensional. One-dimensional instruments are easy-to-administer single items that relate to pain intensity, require minimal training and time, and produce reasonably reliable results [50–54]. Multidimensional pain instruments assess pain in different domains (eg, intensity, location, and affect) and provide more

stable assessment of pain, but they may not be feasible for busy clinical practices [55–57]. The McGill Pain Questionnaire is one of the well-studied, manageable, valid, and responsive instruments to consider, especially for intervention studies [40]. Most of these instruments can be used for elderly patients with mild to moderate cognitive impairment [58]. For patients with more advanced dementia, the Hurley Discomfort Scale may be used to assess discomfort, but it requires skill and experience [59].

Dyspnea

A simple scoring of dyspnea can be accomplished by the verbal categorical scales (none/mild/moderate/severe), numeric rating scales (0 = no dyspnea and 4 = severe dyspnea with dressing or cannot leave the house) [60], and linear visual analog scales. Validated instruments such as the University of California, San Diego Shortness of Breath Questionnaire, a 24-item self-administered instrument that measures dyspnea during different activities of daily living [61], and the European Organization for Research and Treatment of Cancer Quality of Life Core Questionnaire [62], together with its Lung Module, may be a useful validated tool, especially for research settings [63].

Fatigue

Because of its subjectivity and lack of consensus, measurement of fatigue is a challenge, especially in elderly and chronically ill patients [64]. A simple verbal numeric scale is the most efficient assessment instrument in a clinical setting. In a research setting, other validated instruments are available. These include the Visual Analog Scale of Fatigue [65], the Fatigue Severity Scale [66], the Fatigue Questionnaire [67], the Fatigue Symptom Inventory [68], and the Multidimensional Fatigue Symptom Inventory, an 83-item instrument that measures global, somatic, affective, cognitive, and behavioral symptoms of fatigue [69].

Confusion/delirium

Confusion and impaired awareness of the surrounding world and reality is a common symptom among elderly at the end of life. Simple questions targeting orientation to place, person, and time provide quick warning of the presence of confusion. Delirium, an acute confusional state, is a fluctuating impairment in attention and consciousness. Several assessment instruments can facilitate the diagnosis of delirium. Delirium causes increased morbidity, prolonged hospital stays, nursing home placement, and increased mortality. The Confusion Assessment Method helps the clinician make reliable diagnoses in different settings and can be used for clinical and research purposes [70]. Although this instrument is highly sensitive and brief, it does not give information on severity. Other available instruments include the Memorial Delirium Assessment Scale [71] and the Delirium Rating Scale [72,73], both of which provide severity assessment.

Psychological function (depression, anxiety)
Definition. Mainly refers to mood function.

Purpose/ importance. Depressive illness and anxiety are the most common type of affective disorders resulting in significant suffering among older individuals.

Instruments and characteristics. Many short screening instruments have been developed for depression. Some of these tools include the Geriatric Depression Scale (GDS) [73], the Center for Epidemiological Studies-Depression Scale [74], the Hamilton Rating Scale [75], Zung Self-Rating Scale for Depression [76], Homogenous Scale of Depression [77], and Hopkins Symptom Checklist [78]. The Hospital Anxiety and Depression Scale is a 14-item instrument that measures anxiety and depression in medical settings. It is not specifically designed for older adults. Respondents can score 0 to 21 points on each of the subscales on anxiety and depression. According to Zigmond and Snaith [79], 0 to 7 points on a subscale represent a noncase, 8 to 10 points represent a doubtful or possible case, and 11 to 21 points represent a definite case of anxiety or depression. Most of these scales have been used in research studies and a few are extensively used in geriatric practice (eg, GDS).

Recommendations for clinical use. The authors recommend a single question, such as Do you often feel sad or depressed?, which is usually oversensitive, as a first step to screen depression. This is followed by a more detailed screening instrument, such as the GDS (5-, 15-, or 30-item version) in a busy clinical practice. Screen-positive patients require detailed physician assessment for diagnosis.

Social and environmental

Sociodemographics

A simple questionnaire that compiles demographic questions, including age, sex, race, marital status, family structure, living environment, and religious preference, will help to draw the general picture of a patient.

Social function and support system
Definition. A complex, multidimensional concept of social contacts, relationships, social roles, resources, and activities.

Purpose/importance. Social functioning affects health and vice versa. Patients with a low quantity and quality of social relationships are at increased risk for mortality. Social factors are associated with recovery from illness and maximum physical functioning, and during emotional and physical stress, a good social network/support may make the difference between staying in the community and going to a nursing home. Care plans usually affect patients' and families' well-being and require appropriate attention.

Areas of inclusion/instruments and characteristics. Less agreement has been reached about which dimensions of the social domain should be included in a clinical assessment and which instruments to use, compared with other areas of assessment, such as physical and cognitive functioning. Although there are many research instruments to measure social support networks, well-being, and interactions [80,81], they are not widely accepted or readily interpreted clinical measurement tools for screening and comprehensive assessment.

Social networks. The Lubben Social Network Scale (10-item) is highly correlated with independent social worker judgments as to whether social isolation was ruled out, possible, or confirmed [82]. If the number of questions feasible to include in the assessment is limited, the following three questions can differentiate those who are isolated from all others: (1) Is there any one special person you could call or contact if you needed help? (if yes, identify); (2) In general, other than your children, how many relatives do you feel close to and have contact with at least once a month? (number); (3) In general, how many friends do you feel close to and have contact with at least once a month? (number) [82].

Social support. It seems the most crucial aspects of social support may be the number of sources of support and the amount of various types of support available (emotional, instrumental, and informational). Berkman [83] has assessed social support by asking the following four questions: (1) When you need help, can you count on anyone for house cleaning, groceries, or a ride? (2) Could you use more help with daily tasks (receive sufficient support)? (3) Can you count on anyone for emotional support (talking over problems or helping you make decisions)? (4) Could you use more emotional help (receiving sufficient support)? The Modified Provisions of Social Relations Scale breaks down support from different sources [84]. The following questions can be used as a brief screening of social support: (1) In the past 2 weeks, how often would you say someone let you know they care about you? (2) In the past 2 weeks, how often has someone provided you with help like giving you a ride somewhere, helping in the house, or assistance with some other kind of activity?

Subjective well-being and satisfaction. The Life Satisfaction Index-A [85] is widely used. A shorter version, with three of the original six dimensions (total of seven questions, agree/disagree) is promising [86].

Social resources. Available resources could be assessed by asking straightforward questions on income, assets, housing, transportation, and insurance.

Financial burden

Definition. This area refers to the financial difficulties that many patients and families face as a result of illness and illness care.

Importance. Studies have repeatedly demonstrated that illness and its care causes significant financial loss to patients and families. In one large study, the SUPPORT study, 40% of families with patients near the end of life dropped below the poverty line [87]. Financial concerns can exacerbate the problems of illness, and clinicians should routinely inquire about this area and if necessary, provide the services of a social worker to ensure the patient's and family's have access to relevant benefits that could alleviate the situation.

Instruments. There are no instruments specifically designed for clinical use that assess financial burden. However, a simple question is usually sufficient. The item in NEST, provided in Appendix, can be used. If need is detected with this question, further questions for evaluation are also provided as part of NEST.

Caregiver needs and burden

Definition. Caregiver needs and burden refers to the psychological, physical, and financial burden associated with caregiving.

Purpose/importance. One in every four adult Americans provides care for a relative or a friend who is chronically ill, disabled, or frail. Among caregivers of terminally ill patients, most (96%) are family members, one third are age 65 years or older, and one third have poor health [88]. Caregivers are at risk for depression, physical illness, and death [89]. Caregiver burden independently predicts use of medical services and nursing home placement of elderly patients [90]. Interventions that target stressed caregivers may extend care at home and delay nursing home placement [91].

Instruments and characteristics. Available instruments include the Screen for Caregiver Burden [92], a 25-item self-administered questionnaire that measures burden in spouses of Alzheimer's disease (AD) patients. It is sensitive to changes over time and has a clinical application. The Caregiving Hassles Scale [93], a 42-item self-administered instrument, focuses on daily irritations associated with daily care of AD patients.

The revised Burden Interview [94], composed of 22 items, assesses the degree to which caregivers perceive their responsibilities as having an adverse effect on their health, personal and social life, finances, and emotional well-being. This measure, then, provides a direct assessment of the caregiver's perception of how their involvement with the patient has had an impact on the caregiver's own life. Prior studies have demonstrated good reliability and validity of this instrument. Japanese and Spanish versions have also been validated and used in various populations with disability, including palliative care patients and their caregivers [95,96]. Four-item screening and 12-item short versions produce similar results to the full version [97] and may be appropriate for clinical use.

Home environment

A room-by-room assessment of potential environmental hazards can be done by a trained nurse or physical/occupational therapist using a standard checklist derived from preexisting environmental assessment instruments [98,99].

Spiritual

Spirituality and religiousness

Definition. Spirituality is that which gives meaning to one's life and draws one to transcend oneself. Spirituality is a broader concept than religion, although that is one expression of spirituality [100].

Purpose/importance. For many elderly persons, spirituality is an important component of quality of life. For clinicians, it is another way to assess a patient's suffering. The essential component of spiritual assessment is to determine the meaning of the illness to the patient. If not addressed, feelings of guilt, unworthiness, hopelessness, and abandonment could trigger a crisis.

Instruments and characteristics. Many reliable and validated instruments have been developed [39]. The Meaning in Life Scale is an excellent, easily administered scale used to assess patients' views on their life's worth. It was tested in a broad group of patients, including terminally ill patients [101]. The Death Transcendence Scale looks at how people transcend death and can be used by health care professionals to guide patients through their last days [102]. The Herth Hope Index is an excellent scale used to assess the patient's hopefulness. This scale has not been used specifically in the dying population [103]. The Spiritual Well-Being Scale is a 20-item self-administered scale designed to measure spiritual well-being in religious and existential senses [104].

Purpose and settledness (personal acceptance)

Definition. Purpose and settledness are two distinguishable areas that research has identified as important to patients who are facing the last months of life.

Importance. In this context purpose refers to a sense of purpose appropriate to the end of life, and it usually entails having a sense for the kind of work that needs to be done before departing this world. People often want to settle personal issues, finish a piece of work, attain spiritual readiness for death, show their loved ones how to die, or leave a particular story or personal legacy. When embraced, these types of "work of dying," bring a special sense of purpose that often helps the patient and the family.

Settledness relates to purpose in that it may be the end result of accomplishing the "work of dying". It may also relate to a slightly different area, namely, reaching an acceptance of and readiness for death. Patients and families often aspire to reach a sense of peace before the patient's death.

Embracing purpose and settledness with respect to the dying process may be important for bereaved family members also in that they may have less unfinished business to cope with in their bereavement and they may draw strength from the accomplishments of purpose-related activities and achieving settledness before the patient's death.

Instruments. Instruments are underdeveloped for these areas because of their recent definition. However, single questions for each—each with their own scale—are a part of the NEST instrument, and should the first responses indicate relevance, evaluation questions are also included as part of NEST (see Appendix).

Care and services

Health literacy

Assessment of literacy is important to establish and maintain effective communication with patients. There are available instruments to measure health literacy in the adult population. Health literacy can be assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM), a validated and individually administered 66-item health word recognition test [105,106]. REALM scores are highly correlated with general literacy test scores such as those obtained with the Test of Functional Health Literacy in Adults [107].

Goals of care

Definition. Goals of care refers to the purpose for which health care is sought or provided.

Importance. Without attention to the goals of care it is all too easy to intervene in ways that are not consistent with the patient's wishes and therefore run contrary to fundamental aspects of medical ethics. Situations that end in strife and may be categorized as futile or may become embroiled in legal battles often start with disparate goals among the concerned parties.

Goals of medical care tend to fall into two categories: to cure or to provide care or palliation for a condition. The two categories are not mutually exclusive. One is usually better for the presence of the other, and their relative balance can change imperceptibly over the course of the life cycle and over the course of an illness. Palliative care concerns itself with the latter category and accepts that there are many specific goals within its scope. Goals could include getting home from the hospital, perhaps to be able to die in one's own home, extending life until a loved one arrives, or managing distressing symptoms as well as possible.

Instruments. Sparse work has been done to develop valid assessment instruments for goals of care. Some advance care planning instruments that have been designed and evaluated for validity include goal statements [108]. The NEST instrument (see Appendix) has an item that asks if the patient feels that the goals of his or her care are consistent with their wishes. In the relative absence of well-researched instruments, clinicians should use straightforward questions in their own language to engage this question with patients, pointing out by way of introduction that the goals of medicine are many and that it is important to be sure that the patient and clinical team are aiming for the same outcomes.

Therapeutic relationship/information preferences

There are no developed tools for information preferences. Two open-ended questions and one follow-up question may help to identify patients' wishes: (1) What is your understanding of your disease? (2) How much do you want to know about your disease? and (3) If I have important information to share about your medical condition, with whom would you want me to share it?

Perceived quality of care

Outcomes assessment is essential to improve the quality of end-of-life care. Instruments should be selected based on the purpose of the measurement (clinical assessment, quality improvement, or research or accountability-comparison of quality of care between institutions or providers for public and payers), and stage of care (early, advance, or near the end). Many assessment tools reviewed earlier can be used as assessment and outcome measures. Additionally, general satisfaction instruments, such as the Patient Satisfaction Questionnaire (PSQ-III), are available. The PSQ-III is a 50-item instrument to tap global satisfaction with medical care as well as six aspects of care, including technical quality, interpersonal manner, communication, financial aspects of care, time spent with the doctor, and accessibility of care (http://www.rand.org/health/surveys/ware.html). The questionnaire takes 9 to 12 minutes to complete. The PSQ-18 is a short-form version that retains many characteristics of its full-length counterpart, the PSQ-III. The PSQ subscales show acceptable internal consistency reliability. Furthermore, corresponding PSQ-18 and PSQ-III subscales are substantially correlated with one another. The PSQ-18 may be appropriate for use in situations where the need for brevity precludes administration of the full-length PSQ-III. The PSQ-18 takes approximately 3 to 4 minutes to complete [109].

Access to care

A few assessment tools have been developed for general public. The Consumer Assessment of Health Plans (CAHPS) refers to a comprehensive and evolving family of surveys that ask consumers and patients to evaluate the interpersonal aspects of health care. CAHPS surveys are similar to patient

satisfaction surveys but not the same. CAHPS surveys go beyond ratings of providers and health plans by asking patients and consumers to report on their experiences with health care services. For example: Were you given information about your rights? or How often did you wait more than 15 minutes past your appointment time? Though ratings have their own value, reports about care are regarded as more direct, useful, and actionable indicators of quality (http://www.ahrq.gov/qual/cahpfact.htm).

Perception of quality of care and quality of life changes substantially for those with a serious chronic illness and nearing the end of life. As one dies, life takes on new shape—values change and things once ignored become more important. Instruments to measure processes and outcomes nearing the end of life are in early stages of development. An example of a survey has been developed and validated to be used as part of an initial quality audit for measuring quality of end of life perceived by family [110]. Other previously used instruments are also available [40].

Subjective experience

Quality of life

Definition. The term "quality of life" (QOL) refers to a summary aggregation of a broad spectrum of life conditions and circumstances. These include environmental conditions, social surroundings, physical conditions, and personal resources, including mental health and life perspective [111]. QOL in a health context is generally focused on aspects of life quality related to one's health.

Purpose/importance. The goal of supportive/palliative care is to make patients function and feel better. In addition to more objective measures, such as morbidity and survival, systematic measurement of how patients function and feel (quality of life) may be more important outcome measures of treatment success at the end of life. Such measures should help to shape future treatment plans.

Instruments and characteristics. Measures of QOL are subjective and multidimensional. Instruments can target general health status (generic) or focus on a specific condition or treatment (targeted). Generic instruments have broad applicability and allow comparisons across diseases and interventions. Targeted instruments provide greater precision and sensitivity to clinically important changes but cannot easily be used for cross-disease comparison, are often limited to a particular population or intervention, and are rarely able to capture all aspects of health and well-being [111]. Currently, the preferred strategy to overcome these difficulties is to use a combination of generic and targeted instruments.

The European Organization for Research and Treatment of Cancer (EORTC) Study Group on Quality of Life has developed a family of questionnaires to

measure health-related quality of life of cancer patients participating in clinical trials. The EORTC approach includes a core instrument (QLQ-C30) that is supplemented by several disease-specific modules. The core instrument addresses issues relevant to all cancer patients and the modules address issues specific to each type of cancer or tumor location. The diverse membership of the EORTC study group makes the instrument useful for international and national use. It takes an average of 11 to 12 minutes to complete the test. QLQ-C30 is a brief and well-tolerated instrument appropriate for use in clinical trials [62].

The Functional Assessment of Chronic Illness Therapy (FACIT) family of instruments assesses the health-related quality of life of people living with chronic illnesses. The measurement system began as a cancer-specific tool (Functional Assessment of Cancer Therapy, FACT) [112] but has expanded to include other chronic illnesses as well [111]. In addition to the FACT core questionnaire and supplemental subscales, the FACIT measurement system also includes the Functional Assessment of Human Immunodeficiency Virus Infection [113], the Functional Assessment of Multiple Sclerosis [111], and an instrument for use with patients with Parkinson's disease. The FACT consists of a core instrument (FACT-G) that can be supplemented by various subscales [114]. The core instrument addresses domains applicable to patients living with a wide variety of cancers and other chronic illnesses, whereas the "additional concerns" subscales measure issues particular to a specific disease, treatment, or symptom. Subscales are added to the core instrument to create the following measures. The FACIT Multilingual Translation Project aims to ensure that each questionnaire is relevant across cultures and languages without compromising reliability and validity. FACT-G is a 27-item questionnaire that measures four domains of quality of life, including physical, functional, social/family, and emotional well-being. Because FACT-G was developed specifically for use in clinical trials, it appears acceptable to chronically ill patients. As a general instrument, FACT-G provides comparable information across diseases, treatments, and symptoms.

McGill Quality of Life Questionnaire (revised; MQOL) is designed to measure quality of life of people at all stages of a life-threatening illness from diagnosis to death [115]. The instrument takes between 10 and 30 minutes to complete. Because nonphysical domains are important to the overall quality of life of dying patients, physical and nonphysical (eg, existential well-being) domains have been balanced in this instrument. MQOL appears to be acceptable to patients, even those at the end of life.

Medical Outcomes Study, Short Form Health Survey, a 36-item scale, was developed based on the health status measurement of Rand's Health Insurance Experiment [116]. The following domains are measured: physical functioning, role limitations, bodily pain, social functioning, mental health, vitality, and general health perceptions. A short version, the SF-12 survey, has been used for persons with head and neck cancer [117]. In addition, the MOS SF-36 has been employed in persons with symptomatic HIV disease [118].

Appendix

Needs at the End of life Screening Tool [2]

Screening Questions:

The questions below are designed to detect need in an area for evaluation. The scale is provided so that a cut-off score can be used to determine if further evaluation is desirable. For responses that suggest a need for further evaluation, the questions in the next section can be used.

Financial How much of a financial hardships is your illness for you or your family?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

Access to Care How much trouble do you have getting the medical care you need?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

Closeness How often is there someone to confide in?

Anytime I want — Never

0 1 2 3 4 5 6 7 8 9 10

Care-giving needs How much help do you need with things like getting meals or getting to the doctor?

None — A great deal

0 1 2 3 4 5 6 7 8 9 10

Distress How much does this illness seem senseless and meaningless?

A great deal (completely) — Not at all

0 1 2 3 4 5 6 7 8 9 10

Spirituality How much does religious belief or your spiritual life contributes to your sense of purpose?

A great deal (completely) — Not at all

0 1 2 3 4 5 6 7 8 9 10

Settledness How much have you settled your relationship with the people close to you?

Not at all — Completely

0 1 2 3 4 5 6 7 8 9 10

Purpose Since your illness, how much do you live life with a special sense of purpose?

Not at all — Completely

0 1 2 3 4 5 6 7 8 9 10

Physical How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?

Not at all — A great deal

0 1 2 3 4 5 6 7 8 9 10

Mental How often do you feel confused or anxious or depressed?

Constantly (always) — Never

0 1 2 3 4 5 6 7 8 9 10

Patient –Clinician Relationship How much do you feel your doctors and nurses respect you as an individual?

Not at all — Completely

0 1 2 3 4 5 6 7 8 9 10

Information How clear is the information from us about what to expect regarding your illness?

Not at all — Completely

0 1 2 3 4 5 6 7 8 9 10

Goals of Care How much do you feel that the medical care you are getting fits with your goals?

Not at all — Completely

0 1 2 3 4 5 6 7 8 9 10

Area-specific questions

These questions can be used for further evaluation if the screening question detects a need.

Financial Burden
How much of an economic or financial hardship is the cost of your illness and medical care for you or your family?
How much of a problem have you had getting your health insurance plan to cover your treatment?
Access to Care
How much of a problem have you had getting to see a specialist?
How much of a problem have you had with the choice of doctors, other health professionals, or clinics available to you?
Social Connection (Closeness)
You have the sense of being acknowledged and appreciated.
How often is there someone who shows you love and affection?
How often is there someone to confide in or talk to about your problems?
How often is there someone to share your most private fears and worries?
How often is there someone to talk with about your religious or spiritual feelings?
How often is there someone to have a good time with?
Caregiving Needs
How much help do you need with getting to the doctor or hospital?
How much help do you need with homemaking, such as preparing meals or keeping house?
How much help do you need with nursing care, such as taking medicine or having bandages changed?
How much help do you need with personal care, such as help with bathing or feeding?
In general, how active have you been in the last four weeks?
Psychological Distress
This illness seems senseless and meaningless.
You are distressed by the thought that your life might end.
You feel frightened and anxious
You feel anger or bitterness.
You feel punished.
Have you felt downhearted and blue?
You feel tranquil and serene.
You feel prevented from doing what is necessary...your family or close friends cannot accept... your life may end.
Spirituality/Religiousness
Your relationship with G_d contributes to your sense of well being.
You have a spiritual or religious community that helps in your personal spiritual journey.
Since your illness, you have become more spiritual or religious.
How religious or spiritual do you consider yourself to be?
Prayer or meditation has helped me cope with this illness
During times of illness, my religious or spiritual beliefs have been strengthened
Personal Acceptance (Settledness)
You have settled your personal relationships with the people close to you.
You try to help those around you prepare for the possibility of losing you.
You are ready to pass on your former roles and for others to take them on.
You talk freely about the end of your life.
You feel relieved that life, and all its suffering, will end in the foreseeable future.
Sense of Purpose
You have decided that you will put up a fight against your illness to the end.
Since your illness, you live life with a special sense of purpose.
When you imagine the end of your life, you want to make sure that you have finished an important project.
You feel you can make something good come from this illness.
You are more satisfied with yourself as a person now than you were before your illness.
Patient-Clinician Relationship
Your doctor/nurse respects you as an individual.
You feel that your doctor/nurse will help you through the medical system to get the medical care you need.
You feel that you are able to participate in decisions about your care.
You have complete trust in your doctor/nurse.
You feel that your doctor/nurse listens to what you have to say about your illness or medical treatment.
Your primary doctor tells you bad news in a sensitive and caring manner.
Clinician Communication (Information)
Your doctor/nurse has given you clear information about what to expect regarding your illness and outlook.
Your doctor/nurse has given you a clear explanation of your treatment alternatives
Your doctor/nurse has given you clear information about the risks and side effects of your treatment.

References

[1] Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Qual Health Care 1999;8:219–27.

[2] Emanuel LL, Alpert HR, Emanuel EE. Concise screening questions for clinical assessments of terminal care: the needs near the end-of-life care screening tool. J Palliat Med 2001;4(4): 465–74.

[3] Steel K, Ljunggren G, Topinkova E, et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003;20(3):211–9.

[4] Lynn J. Measuring quality of care at the end of life: a statement of principles. J Am Geriatr Soc 1997;45(4):526–7.

[5] Institute of Medicine. Approaching death: improving care at the end of life. In: Field M, Cassel C, editors. Washington (DC): National Academy Press; 1997. p. 235–58.

[6] Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351(Suppl 2):SII21–9.

[7] Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA 1999; 281(2):163–8.

[8] Ferris F, et al. A model to guide hospice care. Ottawa, Ontario: Canadian Hospice Palliative Care Association; 2002.

[9] Rubenstein LZ, Wieland D, Bernabei R. Geriatric assessment technology: the state of the art. New York: Springer; 1995.

[10] Quillen DA. Common causes of vision loss in elderly patients. Am Fam Physician 1999;60(1):99–108.

[11] Reuben DB, Walsh K, Moore AA. Hearing loss in community-dwelling older persons: national prevalence data and identification using simple questions. J Am Geriatr Soc 1998;46(8):1008–11.

[12] Ventry IM, Weinstein BE. The hearing handicap inventory for the elderly: a new tool. Ear Hear 1982;3(3):128–34.

[13] Lichtenstein MJ, Bess FH, Logan SA. Validation of screening tools for identifying hearing-impaired elderly in primary care. JAMA 1988;259(19):2875–8.

[14] Uhlmann RF, Resse TS, Psaty BM, et al. Validity and reliability of auditory screening tests in demented and non-demented older adults. J Gen Intern Med 1989;4(2):90–6.

[15] Mangione CM, Phillips RS, Seddon JM, et al. Development of the 'Activities of Daily Vision Scale'. A measure of visual functional status. Med Care 1992;30(12):1111–26.

[16] Steinberg EP, Tielsch JM, Schein OD, et al. The VF-14. An index of functional impairment in patients with cataract. Arch Ophthalmol 1994;112(5):630–8.

[17] Mangione CM, Lee PP, Pitts J, et al. Psychometric properties of the National Eye Institute Visual Function Questionnaire (NEI-VFQ). NEI-VFQ Field Test Investigators. Arch Ophthalmol 1998; 116(11):1496–504.

[18] Folstein MF, Folstein SE, McHugh PR. Mini-mental state. A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975;12(3):189–98.

[19] Tombaugh TN, McIntyre NJ. The mini-mental state examination: a comprehensive review. J Am Geriatr Soc 1992;40(9):922–35.

[20] Royall DR, Polk M. Dementias that present with and without posterior cortical features: an important clinical distinction. J Am Geriatr Soc 1998;46(1):98–105.

[21] Nelson A, Fogel BS, Faust D. Bedside cognitive screening instruments. A critical assessment. J Nerv Ment Dis 1986;174(2):73–83.

[22] Froehlich TE, Robison JT, Inouye SK. Screening for dementia in the outpatient setting: the time and change test. J Am Geriatr Soc 1998;46(12):1506–11.

[23] Borson S, Scanlan J, Brush M, et al. The mini-cog: a cognitive 'vital signs' measure for dementia screening in multi-lingual elderly. Int J Geriatr Psychiatry 2000;15(11):1021–7.

[24] Gurland BJ, Wilder DE, Chen J, et al. A flexible system of detection for Alzheimer's disease and related dementias. Aging (Milano) 1995;7(3):165–72.

[25] Royall DR, Cordes JA, Polk M. CLOX: an executive clock drawing task. J Neurol Neurosurg Psychiatry 1998;64(5):588–94.

[26] Kahn RL, Goldfarb AI, Pollack M. Brief objective measures for the determination of mental status in the aged. Am J Psychiatry 1960;117:326–8.
[27] Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. J Am Geriatr Soc 1975;23(10):433–41.
[28] Katzman R, Brown T, Fuld P, et al. Validation of a short Orientation-Memory-Concentration Test of cognitive impairment. Am J Psychiatry 1983;140(6):734–9.
[29] Blessed G, Black SE, Butler T, et al. The diagnosis of dementia in the elderly. A comparison of CAMCOG (the cognitive section of CAMDEX), the AGECAT program, DSM-III, the Mini-Mental State Examination and some short rating scales. Br J Psychiatry 1991;159:193–8.
[30] Reuben DB. Principles of geriatric assessment. In: Hazzard WR, editor. Principles of geriatric medicine and gerontology. New York (NY): McGraw-Hill; 2003. p. 99–110.
[31] Katz S, Downs TD, Cash HR. Progress in development of the index of ADL. Gerontologist 1970;10(1):20–30.
[32] Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist 1969;9(3):179–86.
[33] Mahoney FI, Wood OH, Barthel DW. Rehabilitation of chronically ill patients: the influence of complications on the final goal. South Med J 1958;51(5):605–9.
[34] Gill TM, Robison JT, Tinetti ME. Difficulty and dependence: two components of the disability continuum among community-living older persons. Ann Intern Med 1998;128(2):96–101.
[35] Saliba D, Orlando M, Wenger NS, et al. Identifying a short functional disability screen for older persons. J Gerontol A Biol Sci Med Sci 2000;55(12):M750–6.
[36] Karnofsky DA. Determining the extent of the cancer and clinical planning for cure. Cancer 1968;22(4):730–4.
[37] Oken MM, Creech RH, Tormey DC, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. Am J Clin Oncol 1982;5(6):649–55.
[38] Crooks V, Waller S, Smith T, et al. The use of the Karnofsky Performance Scale in determining outcomes and risk in geriatric outpatients. J Gerontol 1991;46(4):M139–44.
[39] Extermann M, Overcash J, Lyman GH, et al. Comorbidity and functional status are independent in older cancer patients. J Clin Oncol 1998;16(4):1582–7.
[40] Center for Gerontology and Health Care Research, Brown University. Toolkit of instruments to measure end-of-life care. Available at: http://www.chcr.brown.edu/pcoc/toolkit.htm. Accessed October 13, 2004.
[41] Froberg DG, Kane RL. Methodology for measuring health-state preferences–II: scaling methods. J Clin Epidemiol 1989;42(5):459–71.
[42] Podsiadlo D, Richardson S. The timed "Up and Go": a test of basic functional mobility for frail elderly persons. J Am Geriatr Soc 1991;39(2):142–8.
[43] The Nutrition Screening Initiative (NSI). Report of Nutrition Screening, 1: toward a common view. Washington (DC): NSI; 1991.
[44] Rush D. Evaluating the nutrition screening initiative. Am J Public Health 1993;83(7):944–5.
[45] Rubenstein LZ, Harker JO, Salva A, et al. Screening for undernutrition in geriatric practice: developing the short-form mini-nutritional assessment (MNA-SF). J Gerontol A Biol Sci Med Sci 2001;56(6):M366–72.
[46] Ingham J, Portenoy RK. The measurement of pain and other symptoms. In: Doyle D, Hanks GWC, MacDonald N, editors. Palliative medicine. Oxford, United Kingdom: Oxford University Press; 1999. p. 203–23.
[47] Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. Eur J Cancer 1994;30A(9):1326–36.
[48] de Haes JC, van Knippenberg FC, Neijt JP. Measuring psychological and physical distress in cancer patients: structure and application of the Rotterdam Symptom Checklist. Br J Cancer 1990;62(6):1034–8.
[49] Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991;7(2):6–9.

[50] Ferrell BA, Ferrell BR, Rivera L. Pain in cognitively impaired nursing home patients. J Pain Symptom Manage 1995;10(8):591–8.
[51] US Department of Health Services, Acute Pain Management Guideline Panel. Acute pain management: post-operative or medical procedures and trauma. No. 92–0032. Clinical Practice Guideline No. 1. Rockville (MD): US Department of Health Services Publication; 1993.
[52] AGS Panel on Chronic Pain in Older Persons. The management of chronic pain in older persons. J Am Geriatr Soc 1998;46(5):635–51.
[53] Herr KA, Mobily PR, Kohout FJ, et al. Evaluation of the Faces Pain Scale for use with the elderly. Clin J Pain 1998;14(1):29–38.
[54] Fishman B, Pasternak S, Wallenstein SL, et al. The Memorial Pain Assessment Card. A valid instrument for the evaluation of cancer pain. Cancer 1987;60(5):1151–8.
[55] Ferrell BA, Stein WM, Beck JC. The Geriatric Pain Measure: validity, reliability and factor analysis. J Am Geriatr Soc 2000;48(12):1669–73.
[56] Melzack R. The McGill Pain Questionnaire: major properties and scoring methods. Pain 1975;1(3):277–99.
[57] Melzack R. The short-form McGill Pain Questionnaire. Pain 1987;30(2):191–7.
[58] Parmelee PA, Smith B, Katz IR. Pain complaints and cognitive status among elderly institution residents. J Am Geriatr Soc 1993;41(5):517–22.
[59] Hurley AC, Volicer BJ, Hanrahan PA, et al. Assessment of discomfort in advanced Alzheimer patients. Res Nurs Health 1992;15(5):369–77.
[60] Brooks S. Task Group on Surveillance for Respiratory Hazards in the Occupational Setting. Surveillance for respiratory hazards. ATS News 1982;8:12–6.
[61] Eakin EG, Resnikoff PM, Prewitt LM, et al. Validation of a new dyspnea measure: the UCSD Shortness of Breath Questionnaire. Chest 1998;113(3):619–24.
[62] Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 1993;85(5):365–76.
[63] Bergman B, Aaronson NK, Ahmedzai S, et al. The EORTC QLQ-LC13: a modular supplement to the EORTC Core Quality of Life Questionnaire (QLQ-C30) for use in lung cancer clinical trials. EORTC Study Group on Quality of Life. Eur J Cancer 1994;30A(5):635–42.
[64] Aaronson LS, Teel CS, Cassmeyer V, et al. Defining and measuring fatigue. Image J Nurs Sch 1999;31(1):45–50.
[65] Lee KA, Hicks G, Nino-Murcia G. Validity and reliability of a scale to assess fatigue. Psychiatry Res 1991;36(3):291–8.
[66] Krupp LB, LaRocca NG, Muir-Nash J, et al. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. Arch Neurol 1989;46(10):1121–3.
[67] Chalder T, Berelowitz G, Pawlikowska T, et al. Development of a fatigue scale. J Psychosom Res 1993;37(2):147–53.
[68] Hann DM, Jacobson PB, Azzarello LM, et al. Measurement of fatigue in cancer patients: development and validation of the Fatigue Symptom Inventory. Qual Life Res 1998;7(4):301–10.
[69] Stein KD, Martin SC, Hann DM, et al. A multidimensional measure of fatigue for use with cancer patients. Cancer Pract 1998;6(3):143–52.
[70] Inouye SK, van Dyck CH, Alessi CA, et al. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. Ann Intern Med 1990;113(12):941–8.
[71] Breitbart W, Rosenfeld B, Roth A, et al. The Memorial Delirium Assessment Scale. J Pain Symptom Manage 1997;13(3):128–37.
[72] Trzepacz PT, Baker RW, Greenhouse J. A symptom rating scale for delirium. Psychiatry Res 1988;23(1):89–97.
[73] Yesavage JA, Brink TL, Rose TL, et al. Development and validation of a geriatric depression screening scale: a preliminary report. J Psychiatr Res 1982;17(1):37–49.
[74] Zich JM, Attkisson CC, Greenfield TK. Screening for depression in primary care clinics: the CES-D and the BDI. Int J Psychiatry Med 1990;20(3):259–77.
[75] Hamilton M. Development of a rating scale for primary depressive illness. Br J Soc Clin Psychol 1967;6(4):278–96.

[76] Zung WW, Magill M, Moore JT, et al. Recognition and treatment of depression in a family medicine practice. J Clin Psychiatry 1983;44(1):3–6.
[77] Golden RR, Teresi JA, Gurland BJ. Development of indicator scales for the Comprehensive Assessment and Referral Evaluation (CARE) interview schedule. J Gerontol 1984;39(2):138–46.
[78] Derogatis LR, Lipman RS, Rickels K, et al. The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory. Behav Sci 1974;19(1):1–15.
[79] Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67(6):361–70.
[80] Berkman LF. The assessment of social networks and social support in the elderly. J Am Geriatr Soc 1983;31(12):743–9.
[81] Kane RA, Kane RL. Measuring social function in mental health studies: concepts and instruments. Washington (DC): National Institute of Mental Health; 1985.
[82] Kane RA. Geriatric assessment technology: the state of the art. In: Rubenstein LZ, Wieland D, Bernabei R, editors. New York: Springer; 1995. p. 99–100.
[83] Seeman TE, Berkman LF. Structural characteristics of social networks and their relationship with social support in the elderly: who provides support. Soc Sci Med 1988;26(7):737–49.
[84] Turner RJ, Marino F. Social support and social structure: a descriptive epidemiology. J Health Soc Behav 1994;35(3):193–212.
[85] Neugarten BL, Havighurst RJ, Tobin SS. The measurement of life satisfaction. J Gerontol 1961; 16:134–43.
[86] Liang J. Dimensions of the Life Satisfaction Index A: a structural formulation. J Gerontol 1984; 39(5):613–22.
[87] Covinsky KE, Landefeld CS, Teno J, et al. Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? SUPPORT Investigators. Arch Intern Med 1996;156(15):1737–41.
[88] Emanuel EJ, Fairclough DL, Slutsman J, et al. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. N Engl J Med 1999;341(13): 956–63.
[89] Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. JAMA 1999;282(23):2215–9.
[90] Brown LJ, Potter JF, Foster BG. Caregiver burden should be evaluated during geriatric assessment. J Am Geriatr Soc 1990;38(4):455–60.
[91] Mittelman MS, Ferris SH, Shulman E, et al. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. JAMA 1996; 276(21):1725–31.
[92] Vitaliano PP, Young HM, Russo J. Burden: a review of measures used among caregivers of individuals with dementia. Gerontologist 1991;31(1):67–75.
[93] Kinney JM, Stephens MA. Caregiving Hassles Scale: assessing the daily hassles of caring for a family member with dementia. Gerontologist 1989;29(3):328–32.
[94] Zarit SH, Zarit JM, Reever KE. Memory training for severe memory loss: effects on senile dementia patients and their families. Gerontologist 1982;22(4):373–7.
[95] O'Rourke N, Tuokko HA. Psychometric properties of an abridged version of The Zarit Burden Interview within a representative Canadian caregiver sample. Gerontologist 2003;43(1):121–7.
[96] Gort AM, Mazarico S, Balleste J, et al. Use of Zarit scale for assessment of caregiver burden in palliative care. Med Clin (Barc) 2003;121(4):132–3.
[97] Bedard M, Molloy DW, Squire L, et al. The Zarit Burden Interview: a new short version and screening version. Gerontologist 2001;41(5):652–7.
[98] Tideiksaar R. Preventing falls: home hazard checklists to help older patients protect themselves. Geriatrics 1986;41(5):26–8.
[99] US National Safety Council and AARP. Falling, the unexpected trip. A safety program for older adults. US National Safety Council and AARP; 1982.
[100] Center for Gerontology and Health Care Research, Brown University. Toolkit of instruments to measure end-of-life care. Spirituality instrument. Available at: http://www.chcr.brown.edu/pcoc/Spirit.htm. Accessed October 13, 2004.

[101] Warner SC, Williams JI. The Meaning in Life Scale: determining the reliability and validity of a measure. J Chronic Dis 1987;40(6):503–12.
[102] VandeCreek L, Benes S, Nye C. Assessment of pastoral needs among medical outpatients. J Pastoral Care 1993;47(1):44–53.
[103] Herth K. Fostering hope in terminally-ill people. J Adv Nurs 1990;15(11):1250–9.
[104] Paloutzian R, Ellison C. Loneliness, spiritual well-being and quality of life. In: Loneliness: a sourcebook for current therapy. New York: Wiley-Interscience; 1982.
[105] Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. Fam Med 1993;25(6):391–5.
[106] Davis TC, Michielutte R, Askov EN, et al. Practical assessment of adult literacy in health care. Health Educ Behav 1998;25(5):613–24.
[107] Parker RM, Baker DW, Williams MV, et al. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med 1995;10(10):537–41.
[108] Emanuel L. The health care directive: learning how to draft advance care documents. J Am Geriatr Soc 1991;39(12):1221–8.
[109] Marshall G, Hays R. The Patient Satisfaction Questionnaire Short-Form (PSQ-18). Rand Health, P-7865. Santa Monica (CA): The RAND Corporation; 1994.
[110] Teno JM, Clarridge B, Casey V, et al. Validation of toolkit after-death bereaved family member interview. J Pain Symptom Manage 2001;22(3):752–8.
[111] Cella D, Nowinski CJ. Measuring quality of life in chronic illness: the functional assessment of chronic illness therapy measurement system. Arch Phys Med Rehabil 2002;83(12 Suppl 2): S10–7.
[112] Cella DF, Tulsky DS, Gray G, et al. The Functional Assessment of Cancer Therapy Scale: development and validation of the general measure. J Clin Oncol 1993;11(3):570–9.
[113] Peterman AH, Cella D, Mo F, et al. Psychometric validation of the revised Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) quality of life instrument. Qual Life Res 1997;6(6):572–84.
[114] Fairclough DL, Cella DF. Functional Assessment of Cancer Therapy (FACT-G): non-response to individual questions. Qual Life Res 1996;5(3):321–9.
[115] Cohen SR, Mount BM, Bruera E, et al. Validity of the McGill Quality of Life Questionnaire in the palliative care setting: a multi-centre Canadian study demonstrating the importance of the existential domain. Palliat Med 1997;11(1):3–20.
[116] Ware Jr JE. Outcome study foresees greater patient input. QA Rev 1990;2(1):5.
[117] Terrell JE, Nanavati KA, Esclamado RM, et al. Head and neck cancer-specific quality of life: instrument validation. Arch Otolaryngol Head Neck Surg 1997;123(10):1125–32.
[118] Wachtel T, Piette J, Mor V, et al. Quality of life in persons with human immunodeficiency virus infection: measurement by the Medical Outcomes Study instrument. Ann Intern Med 1992; 116(2):129–37.