Palliative care: evaluation instruments in daily clinical practice

F. Strasser
Oncology and Palliative Medicine, Section Oncology/Haematology, Department Internal Medicine, Cantonal Hospital, St. Gallen, Switzerland

introduction

Palliative care is active total care aiming to improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement (WHO definition 2002) [1]. The ESMO/ASCO task force of the Global Curriculum in Medical Oncology recommended that oncological aspects of palliative care are an integral part of the Global Core Curriculum (e.g. 4.2.3.5.2.2.) [2]. To become an ESMO designated centre of integrated oncology and palliative medicine, advanced care and knowledge in palliative care should be offered [3]. In addition, an expert level academic collaboration should be cultivated across different diseases categories (e.g. including non-oncological palliative care) [4].

Effective palliative care interventions can be administered only in the context of a continual, disciplined, multidimensional assessment of patients and family members. Such assessments need to be used by clinicians when making treatment decisions [5]. In patients with advanced cancer the assessment of relevant psychological domains, but also of physical symptoms as asthenia/fatigue, nutritional problems or pain, is often underestimated [6, 7]. Problems may not be detected due to lack of screening. They may also not be quantified by the patient resulting in a lack of individuals’ symptom distress measurement.

A fair amount of evidence supports the observation that patients and health professionals’ assessment of patients’ symptoms do not match sufficiently [7–9]. Finally, the symptoms and problems may not be judged by its impact on patients’ various domains of function (lack of estimation of the magnitude of the problem).

Physicians’ concern about time constraints arising from dealing with complex syndromes (e.g. anorexia/cachexia, fatigue) or unexpected symptoms (e.g. anxiety, demoralization) may contribute to underestimation.

The aim of this review is to highlight important aspects underlying clinical evaluation and to provide a practical assessment approach for daily practice.

aspects of clinical evaluation

Evaluation includes aspects of structured assessment of target indicators of palliative care as physical, psychological/emotional, social/familial and spiritual/existential issues [1].

four pillars of cancer care

In advanced cancer care it may be important to separate (1) evaluation of tumor size and activity (e.g. response criteria) and (2) specific toxicity of anti-neoplastic treatments (e.g. toxicity criteria) from (3) patients subjective multidimensional experience (e.g. symptoms, such as pain, loss of appetite, dizziness) and (4) objective consequences of advanced cancer (e.g. syndromes, such as opioid use, involuntary weight loss, delirium).

difference of toxicity and symptoms

Various recent reports documented that toxicity evaluation instruments insufficiently overlap with symptom assessment [14, 15]. Professionals’ (physicians, nurses, other) evaluation of patients’ experiences is at risk of underestimation of, so called, silent symptoms (e.g. fatigue, depression) [7] and of psychological/emotional (e.g. anxiety, feeling of abandonment, uncertainty), spiritual/existential (e.g. inability to let go, hurt dignity, darkness of soul) [16] and social aspects (e.g. family distress). Therefore, toxicity assessments should be distinguished from patients’ experience assessments.

difference of symptoms and syndromes

Patients’ symptom experience may often not go parallel with the severity of the associated syndrome. For example changes in opioid use, as a description of the pain syndrome, may often not go parallel with patients’ expression of pain levels and with impaired function caused by the pain syndrome [17, 18].

continuous care—fluctuating priorities and complications

During the trajectory of illness symptoms and syndromes fluctuate, with changing priorities. Several reports document
risk factors of symptom expression and symptom interaction

Symptoms can be produced by a variety of conditions. They can change over time and are ultimately expressed by the patient in his or her own words. The expression of a symptom can be affected by cognitive impairment, emotional distress, the patient’s coping style and history of alcohol abuse (e.g. habitual use, response to a stressful life event or response to fears about the cancer diagnosis) [21, 22].

Symptoms may also present as another symptom than the main underlying symptom. Patients may say fatigue but mainly are depressed, or may say anxiety but mainly suffer from pain or shortness of breath. These observations lead to the novel concept of symptom masquerade [23]. A recent report documents the interaction of high and poor quality sleep, depression and pain amplification [24].

influencing factors of professional–patient communication

The assessment of patients’ needs may be substantially influenced by the physician’s communication style [25]. A good communication experience involves finding a good setting (a quiet place to sit down with the patient) [26], asking the patient for permission to talk and giving the patient the opportunity to choose a convenient time, determining what information will be shared (which influences the outline of the discussion), determining the patient’s level of knowledge about his or her cancer, identifying the patients’ emotions, attaching the emotion to an event in the past, present or future and acknowledging and normalizing the emotion, and finally try to help the patient to find a way to express this emotion in an individual way [27].

Common obstacles to a good palliative care assessment are the use of elements, which skew or terminate communication (e.g. false and early reassurances that affect the patient’s willingness to talk openly about serious issues; overloading the patient with information; focusing on physical issues while avoiding psychosocial, existential and spiritual concerns) [28]. A mismatch of physicians’ perception of patients’ decision-making preferences and patients’ decision-making preferences may not result in optimal encounters [29].

patient evaluation instruments

Assessments done to determine a patient’s palliative-care needs generally involve:

1. screening instruments to measure and document main cancer-related symptoms;
2. screening tools to assess risk factors for altered symptom expression; cognitive impairment; psychosocial and existential distress; gastrointestinal dysfunction (e.g. constipation); social, family, and lifestyle disruptions; stability of the care network; preparation for end-of-life; existential distress; and
3. discussions to determine the patients’ understanding of his or her disease and prognosis as basis for decision-making.

These three elements reflect a basic screening and advanced diagnosis battery used to improve palliative cancer care. If necessary, more comprehensive, specialized assessments focus on specific cancer syndromes (e.g. pain, cachexia, delirium), organ function, treatment side-effects and the dynamics of the cancer within the context of the individual patient.

setting and levels of instruments

The clinical setting and external priorities may fundamentally influence the application of patient evaluation instruments.

In busy out-patient clinics focused on anti-neoplastic treatment delivery it may be appropriate to screen for the main symptoms by a simple instrument. Therefore, for daily clinical practice, simple assessment instruments are needed that do not require for those who are administering them to have specialized skills and such instruments should be used routinely without disrupting clinical practice [30].

A clinical service focusing on palliative care aspects of oncology will apply wider screening and also advanced diagnosis batteries. And, finally, in specialized clinics (such as interdisciplinary palliative pain or nutrition and fatigue clinics) or in-patient units in depth comprehensive assessment can be applied [31].

screening for patient’s self-report of symptoms

Patients can be asked to report their symptoms daily using a questionnaire that enables them to document the occurrence and severity of the main common cancer-related symptoms (Table 1) on a visual analogue or categorical scale.

A commonly used instrument is the Edmonton Symptom Assessment Scale with 10 symptoms, having a scale of 0 to 10, with 10 being the worst manifestation of the symptom [32, 33]. The patient may complete the scale before the examination or respond to the questionnaire verbally during the examination. Based on this assessment, advanced assessments can be used, most often needed before a treatment plan can be formulated. Many other instruments may be used, as recently reviewed [34]. The widely used EORTC-QLQ-C30 questionnaire was recently adapted for and evaluated in patients in the palliative care context and may be used also for symptom assessment in clinical practice [35].

Several studies assessed whether the provision of health-related quality of life (HRQL) data to oncologists, using touchpad symptom assessment devices [36, 37], by using prompt sheets [38], or summaries of HRQL [30], improve communication between the oncologist and patient and symptom control. The provision of a summary of HRQL (EORTC-QLQ-C30) to patients and oncologist in a randomized crossover trial resulted in more frequent discussion of HRQL-issues and detection of unexpected psychosocial topics and symptoms [6]. However, whether the longitudinal use of such instruments improves patients’ quality of life, symptom control and communication is a matter of actual clinical trials.
**basic assessment of important syndromes**

Clinicians often use several instruments to evaluate patients' palliative care needs and presence or likelihood of symptom interaction (Table 2).

**cognitive impairment**

When the patient is merely asked 'How have you been doing?' cognitive impairment can easily be underestimated. Also the question 'Can you tell me who you are and where you are?' may not detect cognitive dysfunction. Cognitive impairment may go undiagnosed, either because the patient knowingly or unknowingly compensates for the deficits it imposes or because it is misdiagnosed as depression [39].

**psychosocial and existential distress**

To screen for emotional distress (psychosocial or existential), a verbal statement to prompt the patient to express his feelings can be made by an interviewer. For example he may say 'I wish this situation was less difficult for you' or 'I am sorry to see how much you and your family are going through'. Some clinicians might be tempted to avoid such questions because they fear entering into a difficult-to-handle situation with an

<table>
<thead>
<tr>
<th>Table 1. Advanced assessment of common symptoms of patients with advanced cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Symptom</strong></td>
</tr>
<tr>
<td>Fatigue</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Pain</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Drowsiness</td>
</tr>
<tr>
<td>Nausea</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Loss of appetite</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
</tr>
<tr>
<td>Insomnia</td>
</tr>
<tr>
<td>Sense of well being</td>
</tr>
</tbody>
</table>

ADL, activities of daily living; IADL, instrumental activities of daily living.

<table>
<thead>
<tr>
<th>Table 2. Instruments for screening for syndromes of patients with advanced cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Condition or syndrome</strong></td>
</tr>
<tr>
<td>Cognitive impairment</td>
</tr>
<tr>
<td>Altered symptom expression</td>
</tr>
<tr>
<td>Psychological and existential distress</td>
</tr>
<tr>
<td>Gastrointestinal dysfunction</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Social, family and lifestyle adjustments</td>
</tr>
<tr>
<td>Unstable–insufficient care network</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Distressing end-of-life preparation</td>
</tr>
</tbody>
</table>

MMSQ, Mini Mental Status Questionnaire; CAGE, Cut-down, Annoyed, Guilty, Eye opener.
emotional patient. However, skillful screening for emotional distress can stimulate patient-to-care-team interactions [28, 41].

gastrointestinal dysfunction—constipation
Constipation is a syndrome rather than a symptom. It can occur without symptoms or eventually worsen and cause symptoms such as abdominal pain, bloating, nausea, vomiting, delirium or urinary retention. For assessment we should ask patients daily about the frequency, size of stool parts, overall volume, consistency, and quality of bowel movements and excretions. An interdisciplinary approach is essential and the nursing staff should confirm information provided by the patient [42]. To quantify the stool content of the bowels a flat radiography of the abdomen should be performed. This information can guide the administration of oral and rectal laxative treatment and is useful also in the diagnosis of partial bowel obstruction [43].

nutritional status
Assessment of nutritional status is often underemphasized. A few simple questions can serve to alert the clinician to a possible problem, including questions about weight loss over time or the presence and severity of anorexia. In addition, it should be routine practice to assess the volume of oral intake by asking the patient to recount the meals consumed within the previous 1–3 days. In addition, loss of muscle and fat tissue should be assessed by estimating the degree of loss (none, minimal, moderate or severe) [44].

social, family and lifestyle disruptions
To determine areas of stress for the patient and for others involved, a brief history of the patients’ social background, including information about his or her profession, family relations, work environment, primary caregiver and living arrangements, is required. The questions should be simple. The responses from the patient and family members might indicate the need for referral to psychosocial oncology and social services. Questions about spiritual beliefs and perceived needs for referral to psychosocial oncology and social services. Questions about spiritual beliefs and perceived meaning of life can be made using the template FICA (Faith and belief, Importance, Community, Address in care) [45]. The answers are useful in assessing the need for referral to a chaplain for spiritual counseling.

unstable—insufficient care network
For a rapid assessment of the professional network involved, a few questions should explore which service is involved in care, how much time is available, and how is the communication? It should be emphasized to what extent bridge services, hospice services, and respite care opportunities are available [3].

In addition, the clinicians should be alert to detecting various degrees of dysfunctional family structures and insufficient family resources [46]. Practical questions address the following: How do you communicate in the family? How are decisions made? Who is present how much time per day in which function?

distressing end-of-life preparation
A brief assessment of the patients’ preparation for the end-of-life process and death can be integrated in the daily practice. Often patients are thankful to discuss practically these issues, and already have begun or completed a patients’ will. The preferred place of death should be asked.

It may often be helpful to address the needs of patients and family members to ‘finish business’, including financial and legal aspects, but also issues of saying ‘good bye’, ‘thank you’, ‘I love you’ or ‘I forgive you’ [47]. It may be a matter of increasing dignity of patients to actively support patients’ steps to complete their legacy. Such communication may be difficult, but by using the structure of the double way, ‘prepare for the worst, hope for the best’ [48], such interactions may often be very satisfactory.

specialized comprehensive assessment
Several in-depth assessments are routinely used, examples include pain, delirium, anorexia/cachexia or fatigue assessments [17, 22, 34, 39, 42, 44].

patients’ knowledge of the disease and prognosis
An assessment of the patients’ understanding of his or her disease can be made by asking a few simple questions following the skills of good communication skills [27]. The patient can be prompted to discuss the cancer in his or her own words.

conclusions
Delivery of efficient palliative care for advanced cancer patients is driven by continuous, systematic, multidimensional assessments ideally performed by an interdisciplinary team. Screening assessments include main symptoms, factors influencing symptom expression and main syndromes associated with symptoms. Skillful communication enables useful assessments.

references


