Symptom assessment in palliative medicine

The Edmonton Symptom Assessment System (ESAS) is the most widely used instrument for assessing symptoms in palliative medicine. A new, revised version, ESAS-r, has recently been developed, and it is recommended that this be introduced in Norway.

The alleviation of distressing symptoms plays a key part in palliative care. Symptoms are subjective, and studies have shown that systematic assessment is an important prerequisite for optimal symptom relief (1). The Edmonton Symptom Assessment System (ESAS) is a tool that was developed to allow repeated measurement of symptom intensity with a minimum of patient burden (2). It is now one of the most widely used forms for self-reporting of symptoms in palliative medicine (3). In Norway the ESAS is recommended as the standard assessment tool for patients receiving palliative care (4), and it must be used in order to enable DRG reimbursement for this care.

The original version of the ESAS form covers seven of the most common symptoms of advanced cancer: pain, fatigue, nausea, depression, anxiety, loss of appetite and shortness of breath. In addition, general well-being is assessed, and the form has an open category where the patient can specify a particular symptom (2, 3). Symptom intensity is indicated on an 11-point numerical rating scale. When the form was first translated and used in Norway at the Palliative Medicine Unit, Trondheim Regional Hospital (now St Olavs Hospital) in 1999, the open category was omitted, while dryness of the mouth and pain on movement were added to the form. This version, known as the Trondheim Palliative Assessment Tool (T-PAT), became widely used in Norway, and is the one that up to now has been recommended and included in the national palliative care programme (4).

The four regional centres of excellence in palliative care gradually discovered a series of local adaptations of the ESAS. In 2010 it was therefore agreed that a survey should be conducted to find out which Norwegian versions were in use, and what the differences were. ESAS forms were collected from hospital departments, palliative care units and palliative care networks in all the Norwegian health care regions. A total of 40 different versions of the form were systematically reviewed for differences in content, wording, endpoints and scale format. The review revealed major variations in heading, introduction, time frame, symptoms included, sequence and wording, anchoring adjectives on the numerical rating scales, and actual format of the response scales.

Revised version

Despite the extensive use of the ESAS, studies have shown that patients can have problems with the form – they misunderstand both the terminology and the numerical values (5). The tool has also not been sufficiently validated, and there are many different versions in use (3). A Norwegian qualitative study has revealed a number of sources of error in patients’ understanding of both the symptoms and the response categories (6). The study also showed that completed forms are often not used by the caregivers.

A revised version of the ESAS – the ESAS-revised (ESAS-r) – was developed recently (7). This version was developed in close collaboration with the user group. It has explanations for a number of the symptoms and a better layout. A Canadian study has shown that patients prefer the new version (7). The ESAS-r is now being used in an international prospective symptom assessment study coordinated by the European Palliative Care Research Centre (EPCRC) in Trondheim (8). In this connection, the ESAS-r has been translated into a number of languages, including Norwegian (fig. 1), while validated versions are already in use in Switzerland and Spain.

The Norwegian translation was made in accordance with international procedures, with back-to-back translation carried out by four independent translators (9) and has been tested on patients. Pilot testing was performed at the Section for Palliative Care, Oslo University Hospital, Ullevål, where seven cancer patients completed the form and were interviewed about the way the questions were phrased, the choice of words, unclear points etc. in accordance with the standard interview guide for translation procedures (10).

Figure 1 The revised version of the ESAS form
Assessment and conclusion
The order and phrasing of the questions, the wording of the end-points and the scale format influence how people answer a questionnaire, which in turn affects the reliability (stability) and validity of the tool (11). The results of studies using different versions of the ESAS cannot be directly compared. The fact that obvious errors were found in a number of the Norwegian versions is also a cause for concern, and one wonders how these forms can have functioned in practice. It is therefore important to have one common version of the form, both for research purposes and for ordinary clinical use.

Some of the problems in the «old» version of the ESAS have been resolved in ESAS-r. Several studies have shown that patients have had problems in understanding the concept «well-being» (5). In the ESAS-r form, this question is placed at the end to make it clear that it is of a general nature and to reduce the risk of misinterpretation (7). None of the patients interviewed in the Norwegian pilot study had any problem understanding this question (6). The time frame is emphasised as being «now» – in line with recommendations that unclear time frames should be avoided. On the other hand, the ESAS-r form also has formulations that may cause problems, for example the question on appetite (7). The questions regarding dry mouth and pain on movement have been taken out. It will still be important to go through the completed form with the patient to make sure how the contents have been understood (5–7), and as an opening for discussing symptoms and distress. A score above a certain threshold (normally 3) should lead to more detailed assessment and conclusion.

The ESAS is a constructive and useful tool for everyday clinical use, and there is an evident need for a common Norwegian version. The ESAS-r is an improved version that has been developed in close dialogue with the patient group in question. We recommend that it be introduced as the standard general assessment tool in palliative care in Norway.

Irmelin Bergh
Regional Centre of Excellence in Palliative Care, South-Eastern Norway Regional Health Authority, Oslo University Hospital and Institute of Psychology University of Oslo

Nina Aass
Regional Centre of Excellence for Palliative Care, South-Eastern Norway Regional Health Authority, Oslo University Hospital and Institute of Clinical Medicine University of Oslo

Dagny Faksvåg Haugen
Regional Centre of Excellence for Palliative Care, Western Norway, Haukeland University Hospital and European Palliative Care Research Centre, Faculty of Medicine, Norwegian University of Science and Technology

Stein Kaasa
Clinic of Oncology, St. Olavs Hospital, Trondheim University Hospital and European Palliative Care Research Centre, Faculty of Medicine, Norwegian University of Science and Technology

Marianne Jensen Hjermstad
Regional Centre of Excellence for Palliative Care, South-Eastern Norway Regional Health Authority Oslo University Hospital and European Palliative Care Research Centre, Faculty of Medicine, Norwegian University of Science and Technology

Irmelin Bergh (born 1973) Research fellow at the Institute of Psychology, University of Oslo. She is a nurse and has worked at the Radium Hospital, in the Norwegian Cancer Society, and as charge nurse at Clinic of Oncology, Oslo University Hospital. She was employed at the Centre of Excellence until recently. She has a master’s degree in psychology, and her master’s thesis was a qualitative study of patients’ perception of the ESAS (Edmonton Symptom Assessment System) form.

Conflicts of interest: None declared

Nina Aass (born 1955) Head of the Section for Palliative Care, Department of Oncology, Oslo University Hospital and Professor of Palliative Medicine at the University of Oslo.

Conflicts of interest: None declared

Dagny Faksvåg Haugen (born 1957) PhD, specialist in Oncology and Radiotherapy with further education in Palliative Medicine. She is Section Head and Lead Consultant at the Regional Centre of Excellence for Palliative Care, Western Norway, Haukeland University Hospital, and Senior Advisor at the European Palliative Care Research Centre, Norwegian University of Science and Technology.

Conflicts of interest: None declared

Stein Kaasa (born 1953) Head of Clinic, Clinic of Oncology, St Olavs Hospital, and professor of Palliative Medicine at the Norwegian University of Science and Technology.

Conflicts of interest: The author is adviser to and has received fees for lectures from Nycomed, Grunenthal Italy, Cephalon, and Archimedes.

Marianne Jensen Hjermstad (born 1962) Nurse, PhD and researcher at the Regional Centre of Excellence for Palliative Care, South-Eastern Norway Regional Health Authority, Oslo University Hospital, and Associate Professor at the European Palliative Care Research Centre, Norwegian University of Science and Technology.

Conflicts of interest: None declared

References