

# 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, end-points 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 (PRC) 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).

| Edmonton Symptom Assessment System:<br>(revised version) (ESAS-R) |   |   |   |   |   |   |   |   |   |   |    |                                    |
|---|---|---|---|---|---|---|---|---|---|---|----|------------------------------------|
| Please circle the number that best describes how you feel NOW:    |   |   |   |   |   |   |   |   |   |   |    |                                    |
| No Pain   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Pain                |
| No Tiredness<br>(Tiredness = lack of energy)                      | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Tiredness           |
| No Drowsiness<br>(Drowsiness = feeling sleepy)                    | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Drowsiness          |
| No Nausea   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Nausea              |
| No Lack of Appetite   | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Lack of Appetite    |
| No Shortness of Breath  | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Shortness of Breath |
| No Depression<br>(Depression = feeling sad)                       | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Depression          |
| No Anxiety<br>(Anxiety = feeling nervous)                         | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Anxiety             |
| Best Wellbeing<br>(Wellbeing = how you feel overall)              | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible Wellbeing           |
| No _____<br>Other Problem (for example constipation)              | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Worst Possible _____               |
| Patient's Name _____  |   |   |   |   |   |   |   |   |   |   |    |                                    |
| Date _____ Time _____   |   |   |   |   |   |   |   |   |   |   |    |                                    |
| Completed by (check one):   |   |   |   |   |   |   |   |   |   |   |    |                                    |
| <input type="checkbox"/> Patient                                  |   |   |   |   |   |   |   |   |   |   |    |                                    |
| <input type="checkbox"/> Family caregiver                         |   |   |   |   |   |   |   |   |   |   |    |                                    |
| <input type="checkbox"/> Health care professional caregiver       |   |   |   |   |   |   |   |   |   |   |    |                                    |
| <input type="checkbox"/> Caregiver-assisted                       |   |   |   |   |   |   |   |   |   |   |    |                                    |

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 further measures.

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.

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