

OPCARE9. Signs and symptoms of approaching death

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Objective

OPCARE9 is an EU-project with the aim to optimize the care of cancer patients in last days of life. Work package 1's topic is "Signs and symptoms of approaching death".

Crucial questions are:

Which signs and symptoms are considered to identify that somebody is in the last days of life?

How accurate are these signs and symptoms to predict that someone is having only a few more days/ hours to live?

Two cycles of Delphi questionnaire were used to identify and collate a list of signs and symptoms associated with approaching death.

In the first cycle 257 (241 professionals and 16 volunteers) from nine OPCARE9 countries, experienced in care of dying patients, were asked to list signs and symptoms associated with dying. Findings were analyzed by hermeneutic approach.

In the second cycle OPCARE9 experts rated the initial signs and symptoms in terms of importance of identification that somebody is in his/ her last days/ hours of life.

Results

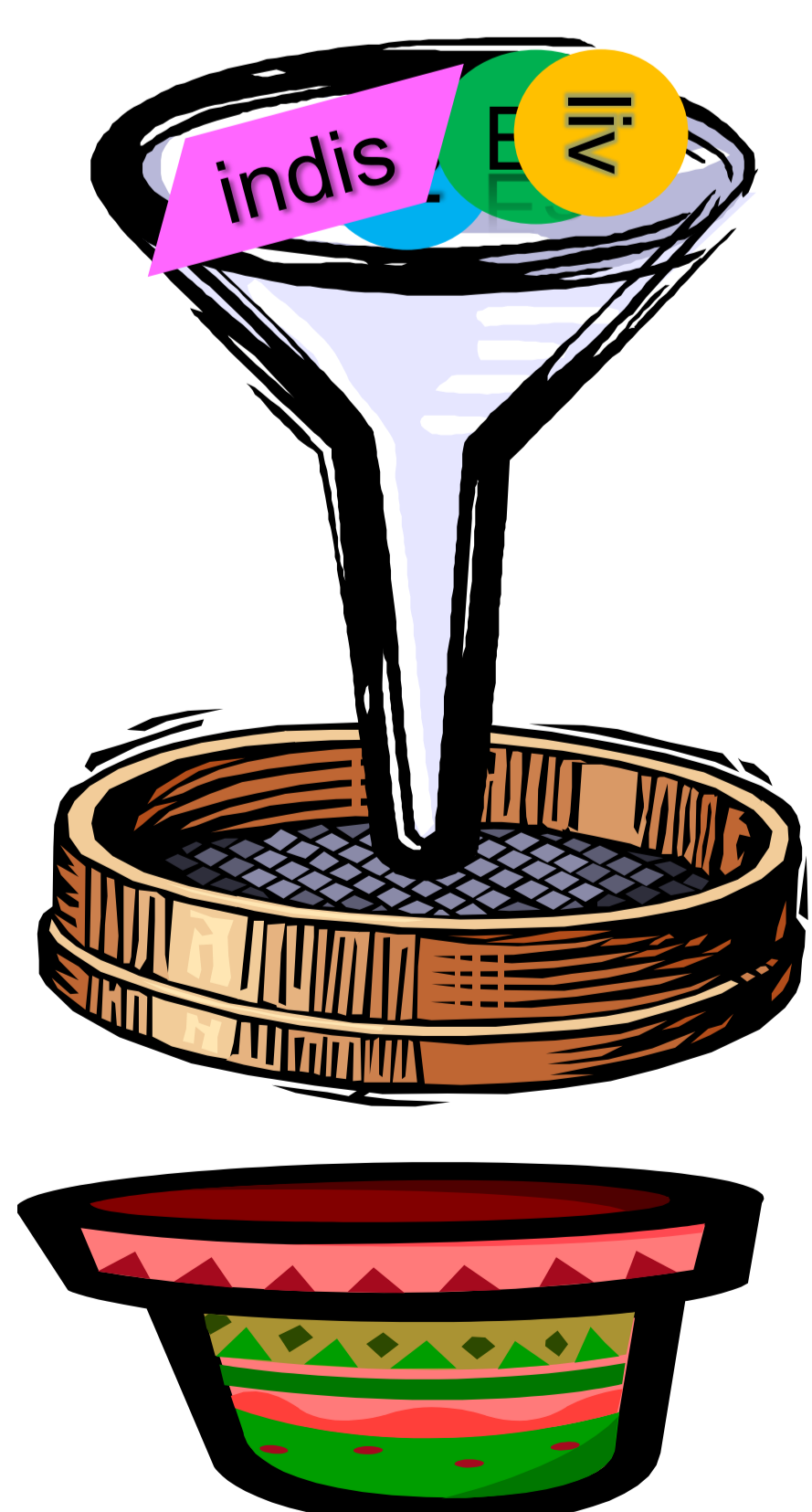
In the first cycle 194 signs and symptoms were identified. Some of them seem to have the same meaning, but the wording varies. Outcomes also showed big differences between professionals and volunteers. Volunteers emphasize social/psychological withdrawal, professionals signs and symptoms involving breathing.

Inclusion:

–Agreement (I agree, I strongly agree) that sign/ symptom is important

–Consensus $\geq 80\%$

In the second cycle (36 expert ratings, 30 health professionals, 6 volunteers) 194 signs and symptoms were **reduced to 59**



194 signs and symptoms

Do you agree that this sign/ symptoms is important when identifying or recognizing the last days of life?

- 1 I strongly disagree
- 2 I rather disagree
- 3 I rather agree
- 4 I strongly agree

Signs and symptoms related to last days/ hours of life

The list of signs and symptoms was ranked into 9 categories. Signs and symptoms involve breathing, consciousness – cognition, skin, general deterioration, intake of fluid, food, other, mobility, emotional state, communication and non observations – expressed opinions – other.

Category	Examples
Breathing	Death rattle, changed breathing
Consciousness – cognition	Irreversible deterioration of consciousness, comatose
Skin	Marble-like skin, pale around nose and mouth
General deterioration	Organ failure, rapid degradation of general condition
Intake of fluid, food, other	No fluid or food intake, cannot drink
Mobility	Bedbound
Emotional state	Restlessness
Communication	Apathy towards environment
Non observations – expressed opinions	Intuition of professionals, gut feeling

Again ratings differ between professionals and volunteers and between professions (physicians, nurses, social workers etc.). Health professionals agreed that 51 signs/ symptoms are important when identifying dying, volunteers agreed for 86.

Most important signs and symptoms for volunteers	Most important signs and symptoms for professionals
Death rattles	Death rattles
Changed breathing rhythm	Changed breathing rhythm
Consciousness level deteriorating and slowing	Consciousness level deteriorating and slowing
Changes in breathing	Changes in breathing
Cyanosis	Cyanosis
Irregular breathing	Irregular breathing
Changes in breathing patterns	Marble-like skin
Troubles breathing	Changes in breathing patterns
Intuition of professionals, gut feeling	Troubles breathing
Irreversible deterioration of consciousness	Intuition of professionals, gut feeling

Table 2: Most important signs and symptoms for volunteers and professionals

Discussion

59 signs and symptoms reflect expert opinions from 9 countries with different cultural backgrounds, from a sample of palliative care and other specialized professionals and volunteers involved in care of the dying. The list of signs and symptoms shows the subjective foci of experts when describing that somebody is dying.

Conclusion and next steps

No conclusion can be drawn yet on clinical relevance or predictive accuracy. Further investigation will be undertaken. In a third Delphi cycle each sign/ symptom will be rated by professionals in terms of clinical relevance to predict that someone will die within the next few hours or days. The concrete formulation and sensitivity and specificity of the list of signs and symptoms remains to be established.

References

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