

Translated research questions National Research Agenda Palliative Care in the Netherlands

Physical dimension

- What is the best way to use corticosteroids as supportive medication in the palliative phase?
- What is the effect and applicability of non-pharmaceutical interventions in treating symptoms, such as delirium, agitation, sleep problems, constipation (e.g. abdominal massage), dry mouth (e.g. rinsing), and pain (e.g. music- or aromatherapy)?
- What factors affect the life expectancy/prognosis of patients with diseases other than cancer, and how can this be predicted more accurately?

Psychological dimension

- How can patients living with an incurable disease for a long time be properly supported? What interventions are available for this purpose and can be (further) developed?
- What coping styles do patients use to deal with an approaching end of life and how effective are these styles?
- To what extent does the fear of death change with changes in the cultural and philosophical landscape? What are the consequences?

Social dimension

- How do patients and relatives experience changing roles during the palliative phase (role as child, sibling, partner, employee, friend, etc.)? How can care and welfare professionals and/or informal caregivers support them in coping with these role changes?
- What are the needs within the social dimension among patients in the palliative phase and their relatives and how can these be addressed?
- How can professionals within the social domain (e.g. social workers) be involved and equipped in the support of people in the palliative phase?

Spiritual dimension

- How does the guideline *Existential & Spiritual Aspects in Palliative Care* function in practice? To what extent do healthcare professionals have sufficient knowledge in this domain to apply the guideline correctly?
- What are promoting and impeding factors for having conversations about the meaning of end-of-life and death? What is needed to make these conversations more prevalent within end-of-life care?
- How can it be ensured that spirituality and meaning in life are given adequate attention in palliative care in interdisciplinary collaboration within a multidisciplinary team? What role can spiritual caregivers play in this?

Identification of the palliative phase

- What are the advantages and disadvantages of identifying the palliative phase for the care process and for patients and relatives?
- What do care and welfare professionals need to identify patients in the palliative phase?
- How can different care and welfare professionals from both community, primary, secondary and tertiary care cooperate to identify patients in the palliative phase?

Advance care planning

- What is the effect of using advance care planning on appropriate care?
- How can advance care planning be systematically implemented for people with an incurable illness or frailty?
- What role can different care and welfare professionals and informal caregivers play in advance care planning?

Shared decision-making

- How can healthcare professionals best discuss different treatment options together with the patient, taking into account both the medical situation and the patient's wishes and needs?
- What interventions or training are effective in improving healthcare professionals' communication skills in shared decision-making?
- How does shared decision-making work for patients with multimorbidity, where multiple healthcare professionals are involved in the care process?

Coordination/ continuity of care and interdisciplinary care

- How can the collaboration between community, primary, secondary and tertiary care be optimized in the palliative phase?
- How can patients and relatives contribute to the coordination and continuity of care and life in the palliative phase?
- What is the effect of care shortages (e.g. staff and beds) and increased workload on the quality of palliative care? And how can increasing staff shortages be anticipated?

End-of-life care, loss and bereavement

- What is the effect of palliative care interventions on grief?
- How can a person facing imminent death maintain their autonomy in the dying phase?
- How can the value(s) of end-of-life, death, suffering and grief be given a more prominent place in our contemporary society?

Cultural aspects

- How can researchers be encouraged to make their palliative care research more inclusive and culturally sensitive?
- What are the experiences of patients and relatives from diverse backgrounds with effective communication about palliative care in different care settings, across diagnostic groups, and with healthcare professionals from diverse backgrounds?
- What intercultural competencies do healthcare professionals need to provide appropriate care? How can these skills be improved to provide more appropriate care?

Ethical and legal aspects

- To what extent can the interests and preferences of relatives play a role in treatment decisions for patients in the palliative phase?
- What moral dilemmas do healthcare professionals in palliative care experience and how can they best deal with them?
- What are the consequences for a patient in the palliative phase of a movement toward supporting more patient autonomy and a greater knowledge position?