

10 relevant issues in palliative care for people with ID

based on reconstructed stories according to family and staff

Nienke Bekkema Anke de Veer Cees Hertogh Anneke Francke

Research aim

- Gaining insight into the issues that are relevant for clients, family and staff in palliative care for people with ID
- Providing recommendations for professional education, health care practice and health care policy

1. I can't put my finger on it: picking up signals

- it is important to take signals about changes in the clients' behaviour seriously
- staff and family suspicions about pain or other symptoms can be made concrete by using (observatory) measurement instruments

2. Transition to another care strategy

- switching to a more caring strategy can be difficult for staff who are used to stimulate independence
- extra responsiveness in the palliative phase is needed to notice changes in the needs of the client

3. Learning and cooperating in palliative phase

- staff is in need of more base-line knowledge on palliative care and consciousness about the limits of their knowledge and skills
- more cooperation with experts of other organisations is necessary, e.g. GPs, home care, specialized volunteers and palliative care networks

4. Right to information and right to feel safe

- clients have different information needs
- differences in understanding and fear among all parties (client, family and staff) can hamper communication about illness and death
- agreement among family&staff on what to communicate is important

5. End of life decisions: who is in control?

- not all clients are involved in end-of-life decisions, such as life-prolonging treatment and palliative sedation
- deciding *for* clients is very difficult for family and staff ("*am I doing the right thing?*")
- *self-deciding* clients can create doubts among caregivers, when they question the client's competence to make decisions

6. Care for other residents

- other residents are important sources of support for dying clients
- staff needs to address other residents' feelings of loss and acknowledge their wishes in paying their last respect

7. Dying at home: the best place?

- dying at home (which is safe and familiar) is preferred
- obstacles for dying at home are: incompetence among staff, lack of staff, insufficiently equipped housing
- alternatives are: intensive unit of the same organisation, hospice, a relatives house

8. Fading boundaries between staff and family

- intense emotions among staff, as well as deeply involved family-members can hamper cooperation and can lead to fading boundaries between staff and family
- organisations need to address the position of staff in relation to family and need to support staff in emotional times

9. Supporting the family

- it is unclear to staff what tasks "supporting the family" exactly entails
- family members feel especially supported by staff who are competent in supporting the client and have a warm and caring attitude

10. Communication with the hospital

Obstacles in communicating with the hospital are:

- differences in health care policies (care/cure)
- lack of staff in the hospital who are competent in supporting ID clients
- lack of transfer protocol

Methods

Twelve stories of recently deceased clients with ID were reconstructed. **Client characteristics:**

Sex	Men: 6, women: 6
Severity of intellectual disability	Mild: 4 Mild/moderate: 1 Moderate: 3 Severe/profound: 4
Average age	53 years
Place of death	Own home: 6 Intensive care unit of organisation: 2 Hospital: 3 Hospice: 1

Data collection

- Interviews with 47 staff and family members
- 2 expert meetings with staff, teachers and policy experts