Supplementary

Appendix 1: conceptual framework and working definitions of (treatment) decisions regarding end-of-life care in and outside the medical context (14)

Medical assistance in dying (MAID)
Active termination of life
Euthanasia
The act of a clinician intentionally ending the life of an individual by administering life ending/lethal drugs, upon the individual's explicit request
Physician-assisted suicide (PAS)
The act of a clinician intentionally helping the individual to hasten death by providing or prescribing the individual with lethal medication, that the individual self-administers
Active ending of life without explicit patient request
The act of administering drugs with the explicit intention of hastening death, in the absence of the individual's request (non-voluntary) or against the individual's will (involuntary)
(Forgoing) Curative and/or life-sustaining treatment
Starting or continuing curative or life-extending treatment
Refusal of treatment
The cessation or failure to provide curative or life-extending treatment because the patient refuses
Non-treatment decision
The withholding or withdrawing of treatment, knowing that this may or will hasten the patient's death:
1) Withholding treatment
The physician allows the individual to die by withholding life-prolonging treatment when believing that this serves the individual's best interest and/or because the individual competently refused life-prolonging treatment
2) Withdrawing treatment
The physician allows the individual to die by withdrawing life-prolonging treatment when believing that this serves the individual's best interest and/or because the individual competently refused the continuation of the life-prolonging treatment
3) By allowing the individual to voluntarily stop eating and drinking and hence the refusal of all food and liquids, including those taken through a feeding tube
Pain and symptom control
Palliative care
Specialized medical care for individuals suffering from a serious illness. This type of care is focused on the alleviation of suffering due to, e.g., symptoms or the distress surrounding illness, aiming to improve quality of life for both the patient and the family, based on the needs of the patient, not on the patient's prognosis.
Palliative sedation
The most far-reaching form of intensified pain and symptom alleviation at the end of life is intermittent or continuous deep sedation until death: the act of using medications intended to induce a state of decreased awareness or actual unconsciousness to relieve the burden of otherwise intractable suffering.
Palliative psychiatry (PP)
An approach that improves the quality of life of patients and their families in facing the problems associated with life-threatening severe and persistent mental illness (SPMI), e.g., refractory anorexia nervosa, through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual needs. PP focuses on harm reduction and on avoidance of burdensome psychiatric interventions with questionable impact.

A palliative care approach (PCA): living with severe and persistent mental illness
A model of care, e.g., Oyster Care, designed for persons experiencing severe and persistent mental illness, based on elements of palliative philosophy. This approach may be appropriate if other, recovery-oriented treatment options have no (lasting) effect on the person's quality of life. Based on the futility of other treatment options with often serious side effects, a different approach in which quality of life, symptom control, therapeutic presence, and a thorough holistic and creative approach are key. A palliative care approach can be a stage within a continuum of care with different phases, within which upscaling and downscaling can occur.
Dying without the assistance of physicians
Suicide
The individual intentionally hastens her death
Assisted suicide
A non-physician helps the individual to hasten her death
Discussing end-of-life and treatment options
Advance care planning
A process in which a person engages in conversations beforehand about their expectations and wishes regarding serious illness, the final stage of life, and death, and also documents these matters in their patient file
Coping with loss and imminent death
Bereavement care
Services offered pre and post loss, aimed at preparing relatives for their loved one's imminent death, and/or to support them in coping with it afterwards

Appendix 2: demographics

Caregivers, managers and experts (n=44)

Gender	Male: 18	Female: 26	X:0	
Age group (in years)	20–30: 8	31–40: 7	41–50: 16	50+: 13
Background	Nurse: 20	Physician: 6	Therapist: 4	Other: 14*

*, personal assistant/ethicist/pastor/experience-worker/social worker.

Care users (n=17)

Gender	Male: 5	Female: 12	X: 0	
Age group (in years)	20–30: 2	31–40: 3	41–50: 7	50+: 5
Primary diagnosis	Psychosis: 9	Drug-abuse: 3	Mood disorder: 3	Bipolar disorder: 2

Next of kin (n=12)

Gender	Male: 3	Female: 9	X: 0		
Age group (in years)	20–30: 0	31–40: 1	41–50: 4	51–60: 2	60+: 5
Kinship	Sibling: 5	Partner: 1	Parent: 4	Child: 2	

Appendix 3: interview guide caregivers, managers and experts

- Demographic data
- What is your relationship to the target group of persons experiencing severe and persistent mental illness?
- How do you encounter end-of-life care in this target group? What experiences do you have with this topic? (with regard to advance care planning, palliative care, euthanasia, suicide and bereavement care)
- Can you provide examples of good practices and facilitators?
- Can you give examples of barriers encountered?
- What are the needs and expectations of care users in this situation?
- What are important ethical issues in this and how do you deal with them?
- What are important existential aspects and how do you deal with them?
- Are you familiar with the palliative care approach for this target group? If so, what are the advantages and disadvantages of this approach?
- What are sources of strength and meaningfulness; and sources of meaninglessness for you and the caregivers?
- Do you have any additions of your own regarding end-of-life care for persons experiencing severe and persistent mental illness?

Appendix 4: interview guide care users and next-of-kin

- Demographic data
- Can you briefly outline the course that was taken in mental healthcare?
- What does good care mean to you?
- What barriers do you encounter in care?
- Do you ever think about end of life and the care you would want then?
- What does good end-of-life care mean to you?
- What are your sources of strength and what do you sometimes worry about?
- Are there no issues you would like to add?

Appendix 5: inclusion criteria

For all target groups, an effort was made to achieve a representative distribution in terms of characteristics such as age, gender, education, condition, relationship, etc.

Care providers:

- Any gender or religious background;
- Involved in the care of persons with severe and persistent mental illness (SPMI)
- Of legal age;
- Understand and speak Dutch;
- Willingly agree to participate in the study and are willing to sign the consent form.

Close contacts:

- Any gender or religious background;
- Are family members or are closely involved with a person experiencing SPMI
- Of legal age;
- Understand and speak Dutch;
- Willingly agree to participate in the study and are willing to sign the consent form.

Persons in management, policy, or expert roles:

- Any gender or religious background;
- Hold a management position, policy role, or specific expert role in an organization providing care for persons experiencing SPMI;

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- Of legal age;
- Understand and speak Dutch;
- Willingly agree to participate in the study and are willing to sign the consent form.

Care users experiencing SPMI:

- Have had a hospitalization duration of two years or more and have a diagnosis according to the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) (30) and experience severe impairments in daily life (1);
- Of legal age;
- Understand and speak Dutch;
- Willingly agree to participate in the study and are willing to sign the consent form;
- Capable of providing an account of their experiences;
- If a legal representative has been appointed for the individual, the representative is also asked to sign the consent form;
- The treating physician and caregivers have no objections to participation in the study;
- Not in an acute crisis situation (e.g., suicide, grief, etc.);
- If desired, the person may be accompanied by a confidant (relative or caregiver) during the interview.

References

30. Diagnostic and Statistical Manual of Mental Disorders: Dsm-5 (Fifth edition, text revision). American Psychological Association (APA); 2013.