

Annex 3: Summary of included articles and ethical aspects in End-of-life care for persons with SPMI

number	Authors/year	Article type	Aims/description	Ethical aspects and themes
1	Trachsel 2018	opinion	The ethical importance of assessing end-of-life care preferences in patients with severe and persistent mental illness	Risk of over-treatment DMC is present Do not express a wish for MAID more often More research into palliative care approach
2	Stoll et al 2021	Ethical argumentation	The way perceived burdensomeness influences the wish for hastened death in persons with SPMI	Importance of DMC – Autonomy contingent to perceive burdensomeness. Risk of stigma and paternalism. Need to ‘competent supported DM’ Access to MAID Loss of dignity Physician trained to prevent suicide Training and research needed Palliative approach as beneficial Development of guidelines
3	Hodel et al 2019	Original research	Survey regarding attitudes toward assisted suicide request in the context of SPMI in Swiss psychiatrists	Autonomy versus care (prevention of suicide) Responsibility towards vulnerable persons (non-abandonment) Need for guidelines regarding DMC More research needed towards a palliative care approach and sedation
4	Trachsel et al 2019	Original research	Survey regarding the acceptability of palliative care approaches for patients with SPMI in Swiss psychiatrists	Risk of association between palliative care and loss of hope Balancing cure and care A palliative approach does not exclude recovery More research needed (as a conceptual framework)
5	Butler et al 2018	Retrospective study	Study regarding access to specialist palliative care for persons with SPMI	Access to specialist care is 3.5 times lower, needs and expectations are the same

				<p>siloiing of care and bad coordination of it</p> <p>perceptions in healthcare workers regarding DMC</p> <p>stigma</p> <p>responsibility in offering continuity of care (society)</p> <p>more research</p> <p>nurse has an important role as facilitator and liaison</p>
6	Carlsson et al 2017	Critical review	Ethical and methodological issues in quantitative studies involving persons with SPMI	<p>Access to being involved in qualitative research is hindered by</p> <p>assumptions regarding vulnerability (protectionism)</p> <p>Need to consult ethics commission</p> <p>Upholding the principles declaration Helsinki</p> <p>Importance of a balanced Informed Consent</p> <p>Involving patients in research</p> <p>More research could mean less stigma</p>
7	Decorte et al 2020	Opinion/case report	Sketching a palliative care model for persons with SPMI: 'Oyster care'	<p>Unfair treatment of a vulnerable group</p> <p>Need of a palliative approach, causing less harm – doing good</p> <p>Dynamics regarding autonomy and coercion</p> <p>Dynamics regarding MAID</p> <p>Need for more research and societal responsibility</p> <p>Role of care professionals as 'substitute family members'</p>
8	Dierickx et al 2017	Retrospective study	Analysis of officially reported cases of euthanasia for persons with psychiatric disorders or dementia in Belgium	<p>Assessment of DMC</p> <p>Vulnerability</p> <p>Importance of accessibility of MAID</p> <p>Need for quality guidelines</p>
9	Trachsel et al 2016	opinion	Definition, scope, benefits and risks regarding palliative psychiatry for persons with SPMI	<p>A palliative approach can alleviate suffering and improve QOL</p> <p>Debate regarding futility necessary</p> <p>A palliative approach is not opposite to recovery</p> <p>Negative connotations with EOL</p> <p>Controversy regarding palliative sedation and positioning toward MAID</p> <p>Impaired DMC as a barrier</p> <p>More research needed</p>

10	Baruth et al 2021	Systematic review	End-of-life care in schizophrenia	Positioning of a palliative approach DMC/autonomy: role of pathology in decision-making? Refusal of life sustaining treatment Need for ethical analysis in DM process Coercion and the role of the guardian/surrogate decision-maker Negative behavior and communication-problems limit access to care Stigma Importance of ACP Role of ethics commission and ethical expert Importance of early detection and training to limit disparity Virtues: being compassionate, having patience
11	Roberts et al 2004	Ethical analysis	Ethical use of long-acting medications in treatment of SPMI	Autonomy: DMC and doubt about 'authentic choice' Role of coercion: how to do no harm, do good and be just?
12	Deodohar 2016	Retrospective study	Current trends and future directions in end-of-life care and psychiatry in India	Principles of a 'good death': dignity, privacy and spiritual support Four principles of biomedical ethics are essential in EOL care Need for ACP Futility debate Psychiatrist as ethical expert Chances for palliative psychiatry Access to palliative care is limited
13	Levitt et al 2020	opinion	Reflections regarding the concept of futility in psychiatry	Do no harm: prevention of therapeutic stubbornness Doing justice to autonomy: give patients a voice, against 'beneficent paternalism' Beneficence: improving QOL Importance of staging in palliative psychiatry Futility does not equal terminal or loss of hope. There is room for recovery Need of safe places to dialogue

14	Lopez-Castroman 2017	Opinion	Reflections regarding the practice of psychiatric euthanasia	MAID in psychiatry as controversial theme Importance of assessing DMC Palliative psychiatry as alternative
15	Forrster et al 2006	Qualitative study	Ethico-legal issues in relation to end-of-life care and institutional mental health in Queensland, Australia	Perceived caregiver dilemma: providing death with dignity versus risk of legal pursuit Autonomy/DMC related issue: ACP not possible because authentic informed consent is not possible Need for good education in care professionals so to better understand EOL legal issues Some care professionals perceive not providing reanimation as 'death making'
16	Lindblad et al 2019	opinion	Reflections regarding the idea of a palliative care approach in psychiatry	A separate definition might lead to more stigma Palliative care has a connotation with the terminal phase What is the relation between a palliative care approach and MAID? Need for more research and practice-based examples
17	Verhofstadt et al 2020	survey	Belgian psychiatrists' attitudes towards, and readiness to engage in euthanasia assessment procedures with adults with psychiatric disorders	Psychiatrists may have moral reasons not to participate in the euthanasia assessment procedure Reference to the general ethical debate regarding euthanasia in this context Questions regarding the accessibility of MAID for the target group More research needed regarding values, norms and religious aspects in euthanasia and psychiatric suffering
18	Harman 2017	Retrospective study	Psychiatric and palliative care in the Intensive care unit	DMC is complex in the SPMI target group. This affects ACP Surrogate decision-makers and guardians have an important role (if they can be found) Palliative care needs to compensate for a lack of ACP, DMC and social network
19	Ebenau et al 2020	Qualitative study	Experiences of healthcare professionals, volunteers and experts-by-experience, of	Stigma Virtue: building a relationship of trust

			Palliative care for persons with substance use disorder and multiple problems in the Netherlands	<p>Siloing in care, bad coordination, limited resources and late detection</p> <p>Need of consultation, training and creativity</p> <p>Autonomy/DMC: patients sometimes refuse life-saving treatment</p> <p>Dilemma: Access to pain medication in persons know for substance-abuse?</p> <p>Virtue: responsibility (especially incases with limited social network)</p> <p>Virtues: alert, active, taking time, respect, non-judgmental, non-hierarchical</p> <p>Access to care: homelessness</p>
20	Ebenau et al 2018	methodological	A study protocol regarding palliative care for persons with a substance use disorder and multiple problems	<p>Homelessness and limited social network</p> <p>Strong autonomy regarding EOLD decisions, but limited communication</p> <p>Methodological: time to decide, IC, anonymity, experts by experience consulted, tailored interviews (time-management)</p>
21	Torres-Gonzalez et al 2014	review	Unmet needs in the management of schizophrenia	<p>Stigma</p> <p>Importance of respecting autonomy</p> <p>Justice: relation between unmet needs and suicide/lower life expectancy</p>
22	Shalev et al 2017	editorial	End-of-life care in patients with severe mental illness	<p>Limited access to palliative care as ethical dilemma</p> <p>Access is limited by: siloing, limited resources (care models now are expensive and offer limited QOL), stigma and perceptions of DMC, lack of expertise and training</p> <p>Opportunities lie in the use of technology, a multidisciplinary approach, palliative approach and community-based models</p>
23	Kirby 2019	Original research	Two models to balance competing interests and obligations in mental healthcare practice and policy	<p>Value-based deliberative tool</p> <p>Using moral relational space (power free) in therapeutic engagement</p>

24	West et al 2020	Scoping review	Exploring the end-of-life needs of Homeless Persons and Barriers to appropriate care	<p>Dilemma: autonomy versus care</p> <p>Paternalism with regard to ACP</p> <p>Virtues: respect, dignity, responsibility</p> <p>Access to palliative care limited by: -stigma and discrimination</p> <p>-Noncompliance and disturbing behavior</p> <p>-Drug seeking behavior</p> <p>-limited social network</p> <p>-siloing in care and insufficient specialization towards the target group</p> <p>Good practices: enhancing ACP, avoiding 'paternalistic' hospital setting (connotation of coercion), providing care where the patient actually lives</p>
25	Strand et al 2020	opinion	Reflection on and clinical implications of a palliative care approach in psychiatry	<p>A palliative care approach can contribute to the non-maleficence and beneficence principles</p> <p>Questions regarding staging</p> <p>Importance of shared decision-making and patient centeredness</p> <p>Negative connotation with EOL</p> <p>Relation with regard to recovery</p> <p>Importance of an ethical/value-based care approach</p>
26	Etgen 2020	Retrospective study	Care series of introducing palliative care consultation in psychiatry	Possible alternative for the existing limited access to palliative care consultation
27	Grassi et al 2020	Narrative review	Problems and solutions regarding cancer and severe mental illness	<p>Limited access to care, social isolation</p> <p>Stigma (prejudice about patients being unmanageable)</p> <p>attitudes and virtues: dignity, hope, respect, non-abandonment</p> <p>Problems related to DMC and surrogate decision-makers</p>
28	Lemon et al 2016	Survey/pilot study	Trust and the dilemmas of suicide risk assessment in non-	<p>Key value: trust (towards the client, tools and colleagues)</p> <p>Important role of training and professionalism</p>

			government mental health services in Australia	
29	Terpstra et al 2014	Case report	Palliative care for terminally ill individuals with schizophrenia	<p>Access to care palliative care is limited due to lack of insurance, different experience of pain in persons with SPMI, safety-issues, smoking</p> <p>Difficulties regarding DMC and communication</p> <p>Need of better collaboration and sharing of experiences between care professionals</p> <p>Role of care professionals as 'substitute family members'</p> <p>Importance of death with dignity</p>
30	Terpstra et al 2012	opinion	Hospice and palliative care for terminally ill individuals with serious and persistent mental illness	<p>Barriers to care are manyfold, f.i. Anxiety in care professionals to bring up the topic of EOL and stigma</p> <p>Central role of DMC</p> <p>Good practice: cross training among care professionals in mental healthcare and palliative care</p> <p>Attitudes: compassion, person-centeredness</p>
31	Irwin et al 2014	review	Cancer care for individuals with schizophrenia	<p>Central role of DMC</p> <p>Prejudice regarding vulnerability</p> <p>Stigma</p> <p>Disparities (insurance, self-stigma, exclusion from research, communication-issues, homelessness)</p> <p>Virtues: responsibility, trust</p> <p>Importance of clarity in guidelines and the division of tasks in EOL-care</p>
32	Guidry-Grimes 2019	Case report	A case report regarding a very ill, homeless and psychiatrically complex person, told from the perspective of an ethics counselor	The clients fall between the 'mazes of the net' in every aspect: socially, legally, imparities regarding access to quality care

				<p>Autonomy/DMC related dilemma's: absence of surrogate decision-maker or family, refusal of life sustaining treatment, risk of paternalism</p> <p>Ethical advisor as an ambassador between several institutions and as someone with a unique point of view. Can give support in cases of moral distress</p> <p>Risk of being 'given up': cure versus care debate + limits to care?</p> <p>No ACP</p> <p>Stigma by care professionals (different attitude towards elderly patients)</p> <p>Siloing</p> <p>Wrong use of 'comfort care' (giving up on patient)</p> <p>Core Values and attitudes: humility, creativity, trust, responsibility</p> <p>Importance of a multidisciplinary approach to care</p>
33	Roberts et al 2015	Survey/pilot	Attunement and alignment of persons with schizophrenia and their preferred alternative decision-makers regarding treatment and research decisions	<p>Individuals generally make decisions according to their values (autonomy, justice, non-maleficence and beneficence)</p> <p>Central role of assessing DMC and the role of the guardian</p> <p>Decisions of guardians and patients are mostly aligned</p>
34	Nisavic et al 2019	Case report	A 27 year-old woman with opioid use disorder and suicidal ideation	<p>Dilemma: how to assess care and pain medication is someone with drug seeking behavior?</p> <p>Values: trust, do no harm</p>
35	Donald et al 2019	Scoping review	Palliative care needs for persons with SPMI	<p>The voice of the client is rarely heard, due to a lack of research and perceptions about autonomy and DMC</p> <p>Siloing of care and lack of specialization results in limited access</p> <p>Advantages of a palliative care approach and cross-training</p> <p>The importance of care professionals as advocates</p>

				Importance of training in care professionals to do EOL conversations
36	Le Melle et al 2005	Case report	Heart transplant in a young man with schizophrenia	Stigma and discrimination based on diagnosis of SPMI Access to care limited/denied Wrong use of 'comfort care' (giving up on patient) Importance of the healthcare team and social network Important value: trust Dilemma: DMC in ACP Role of ethics commission in resolving the case
37	Weimand et al	Descriptive study	A Qualitative/phenomenographic study regarding life sharing experiences of relatives of persons with severe mental illness	Key values and attitudes: trust, love, compassion, responsibility Ethical dilemma: autonomy versus coercion when confronted with suicidality and aggression
38	Gloecker et al 2021	Pilot survey	Nurse's view on palliative care for those diagnosed with SPMI in Switzerland	Little support for coercion, in favor of QOL Autonomy as central value – sometimes dilemmas arise with regard to optimal care/beneficence Palliative care approach as an ethical alternative: cure (harm) versus care
39	Coulter et al 2021	opinion	Evaluating ineffective treatments: a proposed model for discussing futility in psychiatric illness	Futility in psychiatry is an ethical problem, balancing autonomy, beneficence and non-maleficence Palliative psychiatry as valid alternative Decisions should be made with regard to quality of life, rather than based on than DMC
40	Stoll et al 2021	Survey	Attitudes among Swiss psychiatrists with regard to compulsory interventions in SPMI and EOL situations	Dilemma: autonomy versus paternalism Beneficence and benefice as crucial to the psychiatrist's role Importance of ethics support DMC as important dilemma legislation

41	Knippenberg et al 2020	Qualitative study	Patient semi-structured interviews with regard to severe mental illness and palliative care	<p>Little research has been done</p> <p>Difficulties: communication, insight, medication, negative experiences with care professionals</p> <p>Importance of ethical standards in research</p> <p>Access to care limited: patients are reluctant to discuss EOL topics</p> <p>Important role of trusted care professionals</p>
42	Scolan et al 2013	Case study	Ethical dilemma of the therapeutic decisions in the care for a patient with severe anorexia nervosa	<p>Refusal of life sustaining treatment</p> <p>Balancing autonomy, non-maleficence and beneficence</p> <p>Crucial role of DMC</p> <p>legislation</p>
43	Lopez et al 2009	Case report	Medical futility in psychiatry: palliative care and hospice care as a last resort in the treatment of refractory anorexia nervosa	<p>Need for ethics support in difficult cases</p> <p>Palliative care is a good alternative in some situations with regard to QOL</p> <p>DMC as a central dilemma</p> <p>legislation</p>
44	Taylor et al 2018	Case report	A clinical ethics case report on a case of refractory schizophrenia, attempted suicide and withdrawal of life support	<p>Plead to take seriously the mental suffering and the wish for ACP</p> <p>Role of ethics commission in supporting healthcare workers in difficult EOL cases</p>
45	Moonen et al 2015	Qualitative study	Experiences of psychiatric nurses in Flanders (Belgium) in dealing with existential suffering of patients with SPMI	<p>Important values: autonomy, trust</p> <p>Risk of paternalistic approach</p> <p>Need for more research</p> <p>Importance of the development of a palliative care approach</p> <p>Context of euthanasia and the ethical debate regarding it</p>
46	Elie et al 2017	Survey	A comparative cross-sectional study regarding EOL care preferences in patients with SPMI and chronic medical conditions	<p>Importance of palliative psychiatry with focus on QOL</p> <p>Assessment of Autonomy and DMC in the context of treatment refusal</p> <p>More research needed on ethical themes in this target group</p> <p>Persons with SPMI have no negative attitude towards MAID</p>

47	Den Boer et al 2019	Systematic review	A systematic review in palliative care tools and interventions for persons with severe mental illness	Very little research regarding the target group Conversations about EOL with persons with SPMI are possible should be encouraged Access to somatic care is limited due to siloing of care and difficulties in communication
48	MCGorry et al 2012	opinion	Commentary on 'palliative models of care for later stages of mental disorder: maximizing recovery, maintaining hope and building morale	Importance of a staging model that has room for upward and downward movement Negative connotations with regard to the concept 'palliative care' Siloing of care
49	Berk et al 2012	Literature review	Palliative models of care for later stages of mental disorder	Importance of a staging model in SPMI Palliative care approach as beneficial to QOL Risk of doing harm (over-treatment) Stigma towards persons with SPMI
50	Woods et al 2008	Systematic review	Palliative care for persons with SPMI	Very little research available DMC as central theme Key values and attitudes: respect, truthfulness, dignity, hope, non-abandonment, compassion, power ACP not self-evident Access to care restricted Lack of social network, role of substitute decision-makers Treatment refusal