SUPPLEMENTARY FILES

TABLE-1- SEARCH STRATEGY	
Search terms (same search terms used in all databases. When possible exploded subject headings were used, when no subject heading existed terms were used as keyword searches)	
CONTEXT	Palliative* OR “End-of-life” OR Hospice* OR “Terminal care” OR “Bereave” OR “Advanced cancer” OR “Terminally ill” OR “Palliative care”
POPULATION	Psychosis OR Schizophrenia OR Schizophrenic OR “Psychotic disorder” OR “Schizoaffective disorder” OR “Delusional disorder” OR “Bipolar disorder” OR “bipolar affective disorder” OR “Depress*” OR “Major depress*” OR “Major depressive disorder” OR “Depressive disorder” OR “Mani*” or “Mania” OR ‘Intellectual disabilit*’ OR ‘mental retard*’ OR ‘Mental deficienc*’ OR ‘Personality disorder’ OR ‘Psych* disorder’ OR ‘Serious mental disorder*’ OR ‘Psych*’ OR ‘Serious mental illness*’
METHODS	Qualitative OR ethnography OR “mixed methods”
EMBASE	
1) Context	353687
2) Population	3427832
3) Methods	414312
1 AND 2 AND 3	4670
After applying limits (Humans and English language)	4420
MEDLINE	
1) Context	150237
2) Population	3281793
3) Methods	324462
1 AND 2 AND 3	4807
After applying limits (Humans and English language)	4468
CINAHL	
1) Context	101663
2) Population	1204246
3) Methods	214680
1 AND 2 AND 3 with limits (humans and English language)	3674
PsychINFO	
1) Context	28025
2) Population	2150379
3) Methods	230742
1 AND 2 AND 3	1250
After applying limits (Humans and English language)	1182

Figure 1: PRISMA Flowchart

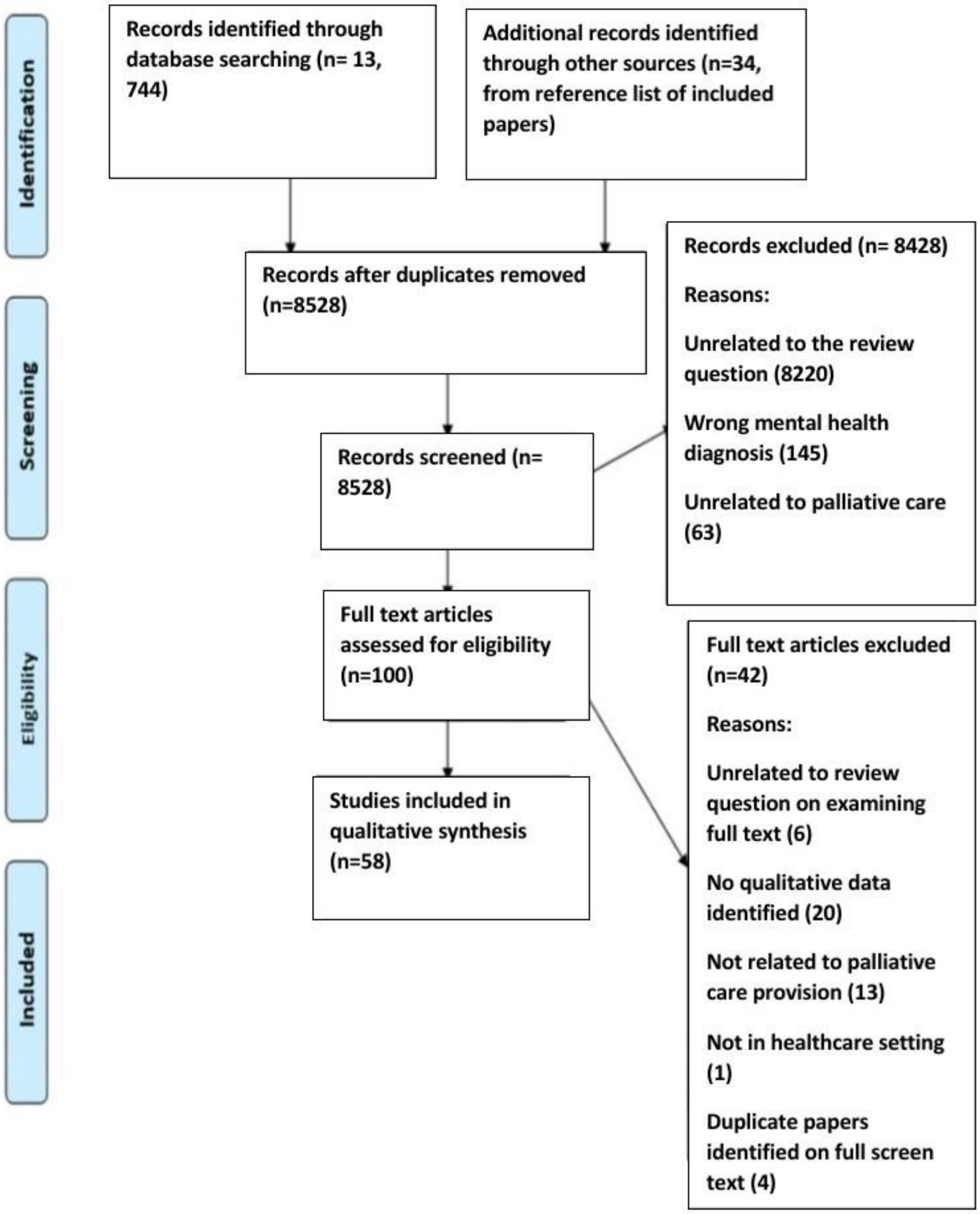

TABLE 2- TABLE OF INCLUDED STUDIES							
First author, date, country and quality assessment	**Title**	**Aim**	**Participant population and sample size**	**Study Setting or context e.g., home (community)/MH or acute hospital/hospice**	**Mental Health or Learning Disability diagnoses included**	**Methods**	**Limitations**
Baird 2021 U.S.A S1/S2 (Consensus= S1)	A qualitative study: health professionals' perceptions toward psychiatric palliative care for people with serious mental illness[31]	To explore the feasibility of PPC as a supportive care model for people with serious mental illness	Psychologists, psychiatrists, ethicists, researchers, administrators and counsellors/social workers based in the USA (n= 12) and Europe (n= 3) Sample size- 15	Palliative and mental health settings	Serious mental illness defined by the author as "persons aged 18 or older who currently or at any time in the past year have had a diagnosable mental, behavioural, or emotional disorder (excluding developmental and substance use disorders) of sufficient duration to meet diagnostic criteria specified within Diagnostic and Statistical Manual of Mental	Fifteen health-care professionals' in the USA and Europe participated in semi-structured phone interviews regarding PPC for people with SMI. The Qualitative Analysis Guide of Leuven (QUAGOL) was used to conduct thematic analysis of the data	Those who are the targets of interventions are not included in the conceptualization of what will ultimately affect their lives. Another limitation is that the QUAGOL is a paper and pencil time intensive system.

					Disorders (DSM-V) that has resulted in serious functional impairment, which substantially interferes with or limits one or more major life activities”		
Baker 2005 U.S.A S2	Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population[63]	To explore the need that exists for health care providers to address the end-of-life needs of people who suffer from SPMI and who are facing a terminal illness.	Health care professionals who work with persons with SPMI Sample size- Not addressed	Services providing care to persons diagnosed with an SPMI	Serious and Persistent mental illness undefined by the author	Review of the literature available on the topic of care provision to a person with an SPMI and terminal illness	Lack of papers included
Bekkema et al 2015 The Netherlands S3/S4 (Consensus= S3)	‘From activating towards caring’: shifts in care approaches at the end-of-life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians[65]	To gain more insight into the following research questions: do relatives, ID care staff and ID physicians perceive a shift in their care approach and attitudes when the death of a person with ID is imminent? And if so, what shifts in care approaches and attitudes do they perceive? And what	Professionals and relatives close to recently deceased patient with ID Sample size-45 participants	Intellectual disability care services organizations including community homes and houses in a residential complex	Intellectual Disability undefined by the authors	Individual in-depth semi- structured interviews were conducted with participants at the place of preference of interviewees. Data were analysed inductively, using elements of thematic analysis	The study was conducted retrospectively, so the experiences of the interviewees may have been subject to a recall bias.

		values underlie these shifts					
Bekkema et al 2016 The Netherlands S3/S4 (Consensus =S3)	Perspectives of people with mild intellectual disabilities on care relationships at the end-of-life: A group interview study[94]	To explore the relevant dimensions of the care relationship in end-of-life care from the perspectives of people with mild ID.	Individuals with mild ID who were able to decide about participation and give informed consent, and not receiving end-of-life care. Sample size- 33 participants	ID care services, and a theatre company.	Intellectual disability undefined by author	Group interviews were conducted with participants. Data were analysed inductively, using thematic analysis	A limitation of this study is that all except one participant were not receiving end-of-life care. As such, their views may differ from people who are receiving end-of life care. Another limitation is that we only included people with a mild ID
Bekkema et al 2014 The Netherlands S3/S4 (Consensus =S3)	Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study[95]	To explore the challenges caregivers and relatives face and the qualities they consider as important for respecting autonomy and to reflect on the extent to which the results correspond with a relational concept of autonomy as described in care ethics	Caregivers and relatives of recently deceased people with ID (several professional caregivers and trained volunteers as well as relatives) Sample size- 47 participants	Any setting providing end-of-life care to persons with intellectual disability	Intellectual disability undefined by the author	Individual in-depth semi-structured interviews were held at the place of preference of the interviewee, Data were analysed inductively, in the sense that the content of the transcribed interviews was given priority in identifying key themes	The study was performed retrospectively, which is a limitation as the experiences of the interviewees at the actual time that end-of-life care took place remain unknown. Another limitation is that the experiences of the people with ID

							themselves could not be studied
Brown et al 2003 England S3	'Please don't let it happen on my Shift!' Supporting Staff who are Caring for People with Learning Disabilities who are Dying[43]	To document how the service learned of the person's illness, how they mobilised services and made decisions, how agencies worked together and what support staff needed in the person's last months and weeks. This study also considers the way staff, as individuals and as teams, made sense of their experiences and evaluated the input of other professionals	Twenty-one individual case studies were included from twelve service. Interviews were conducted with care staff, service managers, health care/learning disability professionals, service users, family members, local community representatives and external representative. Sample size- 83	Community-based services	Learning disabilities undefined by the author	Interviews with the participants, data was mapped to show various results	
Cithambaram et al 2020 Ireland S3/S4 (Consensus =S3)	Disclosure and plan of care at end-of-life: Perspectives of people with intellectual disabilities and families in Ireland[92]	The study aimed to illustrate the accounts of people with intellectual disabilities and families regarding the need for information and decision-making at the end of life.	People with mild and moderate intellectual disabilities, and family members of people with severe and profound intellectual disabilities Sample size- 19	An intellectual disability service which provides care for people with Intellectual disability in both residential and community setting	Intellectual disability undefined by authors	Semi structured interviews, face to face, using an interview guide	Study was only carried out with people with a mild and moderate level of intellectual disability and did not include the voices of people with severe and profound intellectual disabilities. The opinions of the

							participants may not have reflected the actual experiences of having a life-limiting illness. o, the study was carried out in a specific location with a small sample, and therefore, the results may not be generalisable to a wide extent.
Coffey et al 2021 U.K S4/S5 (Consensus= S4)	End-of-life care for people with severe mental illness: mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study)[40]	To synthesise material from case studies relating to the organisation, provision and receipt of care for people with SMI who have an end-of-life (EoL) diagnosis.	42 papers reporting 51 case studies were identified and were reported in this study Sample size- 42 papers	Hospitals, hospices and other institutional settings (such as care homes, prisons and hostels), and care provided in the home and via outreach to people who may also be homeless	Severe mental illness defined by the author as "SMI was defined as including those with, but not limited to, schizophrenia, schizophrenia spectrum and other psychotic disorders, schizotypal and delusional disorders, bipolar affective disorder,	All case studies which were gathered after searching databases using a search strategy, were available in full-text form, were read and re-read, uploaded to NVivo, inductively coded by one reviewer and checked by a second, and then synthesised into five themes	Most papers were from high-income countries, and thus limiting transferability

					bipolar and related disorders, major depressive disorder and disorders of adult personality and behaviour” PTSD and anorexia were also included		
Donald et al 2019 Canada S2	A scoping review of palliative care for persons with severe persistent mental illness[33]	To determine the extent, range, and nature of research activity about people with SPMI requiring palliative care, and to identify gaps and opportunities for future research	The profession of the first author was identified: physician (MD; 21), nursing (11), social work (five), and other or unknown (nine). Sample size- 46 articles	Facilities where psychiatric or palliative care is provided to individuals	Severe persistent mental illnesses (SPMIs) defined by the author as "those that are prolonged and recurrent, impair activities of daily living, and require long-term treatment"	Scoping review with the following phases 1) identifying the research question; (2) identifying relevant studies; (3) determining study selection;(4) charting the data; and 5) collating, summarizing, and reporting the results.	Not addressed
Evenblij et al 2016 The Netherlands S2/S3 (Consensus =S2)	Palliative care in mental health facilities from the perspective of nurses: a mixed methods study[96]	The aim of this study was to explore nurses' experiences with and identify barriers to providing palliative care to psychiatric patients in Dutch	Nurses with experience concerning palliative care provision. Sample size- 9	Dutch mental health facilities	Chronic psychiatric disorders- undefined by author	Face-to-face interviews at the participant’s workplace, the participant’s home or via telephone. The interviews consisted of open-	The use of a union list to recruit respondents might have caused sampling bias. Second, the survey relied on

		mental health facilities.				ended questions and were guided by a semi-structured interview guide. Interviews were analysed using thematic coding	the self-reporting of respondents about the care they had provided. Respondents may have wished to portray themselves in a certain way. Potential recall biases in the survey. Finally, the survey response rate was relatively low.
Fahey-McCarthy et al 2009 Ireland S3/S4 (Consensus =S3)	Developing an Education Intervention for Staff Supporting Persons with an Intellectual Disability and Advanced Dementia[72]	To understand staff experiences in supporting persons with ID and advanced dementia.	Staff in ID settings and specialist palliative care services Sample size- 57 participants in the first phase, 16 participants in the second phase	Intellectual disability and Palliative care services in metropolitan Dublin	Intellectual disability with dementia undefined by the authors	Focus group interviews conducted in 14 groups followed by information collected from 16 participants who completed a pilot educational intervention. Computer-assisted qualitative data analysis software (QAQDAS) NVivo 7 was used. *Phase One qualitative analysis:* Codes were generated	Not addressed

						from the data and systematically applied throughout the analysis. *Phase Two qualitative analysis:* Further coding involved grouping the nodes and making linkages.	
Flynn et al 2009 England S1/S2 (Consensus =S1)	The palliative care experiences of adults with learning disabilities/intellectual disability: The implications for ethical decision making[30]	To present some of the ethical challenges facing services supporting adults with learning disabilities/intellectual disability with life-limiting conditions and arises from a qualitative investigation of the preparation for, and responses to their deaths	Health and social care Professionals and relatives Sample size- 21 case studies	Intellectual disability Services	Intellectual disability undefined by the author	ICommenntary on case studies	Not addressed
Foo et al 2021 Australia S4	Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews[82]	To explore the experiences of specialist palliative care staff in talking with people with intellectual disability about their dying and death, and factors that influence these conversations	Palliative care staff from health services across Australia were interviewed. Participants were employed in multidisciplinary specialist palliative care teams and had provided palliative	Multidisciplinary specialist palliative care services	Intellectual disability undefined by the author	Participants could elect either phone or in-person interviews. Inductive thematic analysis was conducted on data from a larger qualitative semi-structured	The study's findings may be influenced by the self-selecting nature of participation, and interpretation of these results warrants a

			care to dying persons with intellectual disability. Sample size- 20			interview study which sought to understand the experience of multidisciplinary specialist palliative care teams.	degree of caution. The study's qualitative nature reflects participants' personal experience and may not be generalisable to equivalent groups
Forrester - Jones, et al 2017 U.K S3	People with intellectual disabilities at the end of their lives: The case for specialist care?[59]	To explore the organizational context of a specialist palliative and end-of-life care home (i.e., to our knowledge the only one in the UK) to see how it related to the quality of life of people with intellectual disabilities who were approaching the end of their lives and to identify the care costs	The home manager (HM) of the nursing staff and 14 of the 40 staff Sample size-15	A specialist, high dependency registered nursing home for older people with intellectual disabilities with multiple needs including dementia and terminal illnesses	Intellectual disability- undefined by author	1.For the focus groups, open-ended questions were developed from previous literature to explore staff roles and experiences of working 2. Informal participant observation was carried out. Focus group interviews were transcribed verbatim and analysed using a six-step thematic analysis process	The study was too small for the results to be generalizable. Data concerning individuals with intellectual disabilities were collected via staff interviews, and this invariably poses questions around data reliability.
Geppert et al 2011 U.S.A	To Treat or Not to Treat: Psychosis, Palliative Care, and	To demonstrate the ethics involved in end-of-life decision making	Bioethics experts- psychosomatic professionals	Hospital- in a setting associated with palliative care	Schizophrenia undefined by author	Commentary on a case study	Not addressed

S2	Ethics at the End-of-Life: A Case Analysis[60]	in a patient with a chronic mental illness.	Sample size- Not applicable	and mental health			
Irwin et al 2014 U.S.A S2	Cancer Care for Individuals With Schizophrenia[64]	To summarize known disparities in cancer prevention, diagnosis, treatment, and end-of-life (EOL)care among individuals with schizophrenia, and to discuss challenges in caring for these patients, highlighting points of intervention, and suggest research priorities.	Data based on studies from patients, and professionals caring for persons with schizophrenia and cancer Sample size- 9	Services providing care to individuals with schizophrenia and cancer	Schizophrenia undefined by the author	Review summarising relevant literature on providing care for someone with schizophrenia and cancer	Not addressed
Li et al 2008 U. K S2/S3 (Consensus =S2)	End-of-life care: Nurses' experiences in caring for dying patients with profound learning disabilities - A descriptive case study[61]	To identify areas of expertise and deficits in the specific knowledge and practical skills of nurses in the care of dying patients with profound learning disabilities in one NHS Primary Care Trust in the UK	Qualified nurses with a first level registration in mental handicap Sample size- 5	Residential homes in one primary care trust in the South of England	Intellectual disability undefined by the author	Semi structured interviews with five disability nurses. Data were read separately by 2 authors until an agreed definition of themes emerged which were based on observations of respondents' noticing along patients' disease trajectory	Small sample size, in one Trust leading to limited scope
Loge et al 2013 Norway	Depressed patients with incurable cancer: Which depressive	To explore which depression symptoms are experienced by	Norwegian (n = 20) and Austrian (n = 10) patients with an	Palliative care settings	Depression undefined by the author	By the phenomenographic method, patients'	The present findings must be regarded as

S3	symptoms do they experience?[44]	patients with incurable cancer and limited life expectancy, and treated with antidepressants for clinically recognized depression	incurable cancer, 1 year life expectancy, and a recent history of a depressive disorder experienced were included Sample size= 30			symptom experiences were extracted and sorted by headings, first individually and then across patients. The patients subsequently rated 24 symptoms numerically including the DSM-IV depression criteria	hypotheses for future work. The sample was pragmatically recruited, and the diagnosis of a depressive disorder was determined by clinicians on a clinical basis
Madrigal 2010 U.S.A S2/S3 (Consensus =S2)	Hospice professionals report about end- of-life care for persons of schizophrenia[47]	To explore the availability and quality of end-of-life care for a person with schizophrenia	Providers were selected from end-of-life service agencies in Southern California. Sample size- 10 service providers	End-of-life service agencies	Schizophrenia defined by the author as "a cluster of essential signs and symptoms (both positive and negative). To diagnose the condition, these symptoms must be present for up to six months."	A semi structured questionnaire for in-person interviews with end-of-life service providers.	Not addressed
McGinley et al 2017 U.S.A S2/S3 (Consensus	Emergency medical services providers' perspective of end-of-life decision making for people with intellectual disabilities[85]	The aim of this study was to understand the decision-making processes that occur when EMS teams are called to the home of someone with an	Emergency Medical Service (EMS) providers Sample size- Survey participants (n = 239)	EMS providers reported calls to residential settings for people with intellectual disabilities	Intellectual disability undefined by the authors	After an initial survey, participants were invited to an interview. Interviews were conducted in	Laws dictating EMS care and medical orders are created on the state level; therefore, these findings may not

=S2)		intellectual disability who is imminently dying from a terminal illness rather than an acute event	Interview participants (n= 48)			person or by phone utilizing a demographic questionnaire and a semi-structured interview guide either individually or in small groups	be generalizable to other states and countries with different laws governing end-of-life decision making and EMS care. Using the CDA framework may impose some barriers to data analysis. EMS providers who self-selected into this study provide only one perspective about how medical orders inform decision making at the end of life; this study did not include the perspective of people with intellectual disabilities or their caregivers
McGrath et al 2006 Australia S3	Ethico-legal issues in relation to end-of-life care and institutional mental health[87]	To explore important ethico-legal issues at the interface of palliative care and institutional mental health.	Participants involved in providing care to patients in an institutional mental health setting. The participants were	Mental health institution in Queensland, Australia	Serious mental illness undefined by the author	Interviews conducted at interview rooms at the institution, The interviews were recorded verbatim	Small sample size is a potential limitation

			involved in nursing, care coordination, education and advocacy roles at the institution Sample size- 8			and transferred to a computer program to be analysed thematically	
McKenzie et al 2017 New Zealand S3/S4 (Consensus =S3)	"I'm still here": Exploring what matters to people with intellectual disability during advance care planning[93]	To identify, from the perspective of people with intellectual disabilities and life limiting conditions, the factors that strengthened and inhibited their Advance Care Planning.	A formal diagnosis of intellectual disability; a formal diagnosis of a life-limiting condition; awareness that their condition was life-limiting; involvement in (or completion of) a process of advance care planning; the capability to participate in an interview situation. Sample size- 4	Intellectual disability services	Intellectual disability undefined by the authors	Semi structured interview by topic guide undertaken in person with each primary participant (and elected support people if wanted). Separate interviews were carried out with the person's family/whanau (in person or by phone), and disability service staff (in person), where permission was given by the person to do so, Interviews were transcribed verbatim and thematic analysis was carried out to identify emerging themes	Small number of primary participants and the limited data set resulting from this. The study made no attempt to be representative of the intellectual disability population and focused solely on those with life-limiting conditions

McKibben et al 2020 U.K. S4	Determining the informational needs of family caregivers of people with intellectual disability who require palliative care: A qualitative study[79]	To determine the informational needs of family caregivers of people with intellectual disabilities who require palliative care	Family caregivers (n = 10) participated in individual interviews. HSC professionals' (n = 28) perceptions of informational needs were explored within focus groups (n = 6). Sample size- 38	Five Health and Social Care (HSC) Trusts and two Hospices in one region of the United Kingdom	Intellectual disability undefined by authors	A purposive sample of 10 family caregivers, who had been, or were involved in the care of an adult with intellectual disability who required palliative care, and 28 HSC Professionals were recruited to semi-structured interviews. Data were recorded and transcribed verbatim. NVIVO was used for data management. Thematic analysis for both focus groups and interviews involved the widely used Braun and Clarke framework	A small sample of family caregivers (n = 10) There was more intellectual disability than palliative care professionals recruited
McLaughlin et al 2014 Northern Ireland S4	Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study[50]	This study aimed to develop a best practice model to guide and promote partnership practice between specialist palliative care and intellectual disability services.	Health and social care professionals, working in intellectual disability and palliative care services Sample size- Phase one (66), Phase 2 (30)	Intellectual disability services, care homes and palliative care services in primary and secondary care	Intellectual disability undefined by the authors	Participants who completed a questionnaire (phase 1) were invited to Semi structured interviews. Qualitative data was then analysed	Not addressed

						using a computer program and by 2 members of the research team to come up with themes	
McNamara et al 2020 Australia S3/S4 (Consensus =S3)	Creating person-centred support for people with intellectual disabilities at the end-of-life: An Australian qualitative study of unmet needs and strategies[74]	To document the range of needs adults with an intellectual disability experience during the last months of their lives and identify challenges in meeting these needs and aims to identify strategies that may help alleviate unmet needs	Experienced health professionals and paid carers Sample size- 26	Both disability services and palliative care/end-of-life services; organizations with different funding arrangements (e.g., State and Federal governments, fee for service, donations and combinations of these arrangements); different accommodation settings (private homes, high and low care residential disability facilities, residential aged care facilities); and a variety of disciplinary,	Intellectual disabilities, undefined by the authors	Face-to-face, semi-structured individual interviews. An additional three interviews were conducted by telephone. Two group interviews with three participants in each group were conducted due to difficulties in scheduling individual interviews.	Relatively small sample size. Some of the participants felt they lacked specific or extensive experience in caring for people with intellectual disabilities at the end of life. It was not possible to include people with intellectual disabilities approaching the end of life, or their family, in the study.

				educational and work backgrounds.			
McNamara et al 2018 Australia S4	Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need[48]	To address the paucity of research by documenting possible need, experiences of health care service use and factors affecting palliative care use for people with schizophrenia who have advanced life limiting illness.	Experienced health professionals who were caring for, or had experience of caring for, people with schizophrenia Sample size- 16	Palliative care, mental health, community services residential homes and community-based supported accommodation, including psychiatric hostels	Schizophrenia undefined by the authors	Semi structured interviews guided by topic guides through in- depth interviews, qualitative data was collected. Simple descriptive analyses were used for the demographic and personal data. All other data were de-identified and interview audiotapes were transcribed. Transcripts were analysed using a thematic qualitative approach with broad themes identified from readings of the transcripts	The sample size for this study was small. Schizophrenia prevalence is relatively low and therefore specialist palliative care workers may not be familiar with caring for patients with schizophrenia. Likewise, mental health workers may not have had a high level of experience with people with schizophrenia at the end of life. Persons with schizophrenia not included in study.
Morgan 2016 U.S.A S3	“No Right Place to Die”: Nursing Attitudes and Needs in Caring for People with Serious Mental Illness at End-of-Life[35]	To explore both hospice/ palliative care nurses’ and psychiatric/mental health nurses’ attitudes and needs	Nurses (psychiatric/mental health nurses and hospice/palliative care nurses) local specialty professional	Psychiatric hospitals, palliative care settings/ hospices	Serious mental illness undefined by the author	Interviews were conducted with participants until saturation of topics occurred. Following this	The themes presented are representative of people who volunteered to participate in the

		toward people with SMI at the end- of-life	groups, other nurses who cared for the population of people with SMI at end-of-life were recruited Sample size- 20			thematic analysis of qualitative data was done to identify topics	study and not of the general population of nurses caring for people with SMI at the end-of-life. The study also took place in the north-eastern part of the United States and therefore is not representative of the whole country or of other nations. The volunteers may have been people who were specifically interested in this topic and therefore more concerned about the issue than those who did not volunteer.
Morton-Nance et al 2012 England S3/S4 (Consensus =S3)	End-of-life care for people with a learning disability[57]	To explore the experiences of learning disability and district nurses caring for people with a learning disability at the end of their lives	Three community learning disability nurses and three district nurses, all from the same locality who had experience of providing care for people with a	Two specialist healthcare settings: community learning disability service and district nursing service	Intellectual Disability undefined by the author	Informal meeting consisting of eight open ended questions. The data from this was analysed for emerging themes and patterns using Collaizzi's seven-	Small sample size. The study also represents the findings of healthcare professionals in one locality. All healthcare

			learning disability at the end of life Sample size- 6			stage process of thematic analysis	professionals were female and covered only two specialist areas. Practice in other areas may vary and therefore findings may not be generalisable. Overall, transferability of findings from qualitative studies is limited.
Ng et al 2014 Australia S3	How Do Palliative Medicine Specialists Conceptualize Depression? Findings from a Qualitative In-Depth Interview Study[37]	To explore and characterize how palliative medicine specialists conceptualize depression.	Palliative medicine specialists (i.e., consultants/attending physicians in palliative medicine) practicing in Australia Sample size- 9	Palliative medicine services	Depression undefined by the author	Individual semi-structured, in-depth interviews were conducted to explore their conceptualizations of depression. Nine participants were interviewed to reach data saturation. Interview transcripts were analysed for themes.	The first author's status as a psychiatrist might have inadvertently influenced interviews; for example, participants might have refrained from criticizing psychiatric concepts
Ng et al 2014 Australia S2	Palliative medicine specialists' causal explanations for depression in the palliative care setting:	To investigate and describe the causal explanations of depression in the palliative care setting, from the perspective	Palliative medicine specialists practising in Australia Sample size- 9	Palliative medicine services	Depression undefined by the author	Individual semi-structured, in-depth interviews were conducted to explore their explanatory	The first author's status as a psychiatrist might have inadvertently

	a qualitative in-depth interview study[45]	of palliative medicine specialists.				models of depression, including a focus on causal explanations. Nine participants were interviewed to reach data saturation. Interview transcripts were analysed for themes.	influenced interviews
Ng et al 2015 Australia S3/S4 (Consensus= S3)	Treatment approaches of palliative medicine specialists for depression in the palliative care setting: Findings from a qualitative, in-depth interview study[46]	To investigate and characterise the treatment approaches of palliative medicine specialists for depression.	Palliative medicine specialists practising in Australia Sample size- 9	Palliative medicine services	Depression undefined by the author	Semi structured, in-depth interviews were conducted to explore explanatory models of depression from palliative medicine specialists, including a focus on treatment. Verbatim interview transcripts were analysed for themes	Limitations on the transferability of the present findings are recognised, given the influence of local medical education and practices on the treatment approach of individuals.
Read et al 2012 UK S2/S3 (Consensus =S2)	Critical reflections on end-of-life care for people with intellectual disabilities: a single case study approach[69]	To present a case study of the end-of life care that was provided to one young woman with an ID in a hospice context	Staff at a hospice Sample size- Not applicable	Hospice that houses beds, an active day hospice service, a community team that provides a 24/7 advice and	Intellectual disability defined by the authors as "‘having a reduced ability to understand	Interviews with professionals regarding case study	Not addressed

				support line staffed by nurses and an education unit that provides specialist palliative care courses at levels two and three in conjunction with a local university.	new or complex information or to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood and with a lasting effect on development'		
Relyea et al 2018 Canada S4	On the Margins of Death: A Scoping Review on Palliative Care and Schizophrenia[81]	To enhance understanding of hospice and palliative care for patients with schizophrenia	Articles were excluded if their main focus was the perspective of caregivers and families of people with schizophrenia or schizoaffective disorder. Sample size- 32	Hospitals, inpatient psychiatric settings, nursing homes, hospice/ other organizations where palliative care provision takes place	Schizophrenia defined by the authors as, "Schizophrenia is a serious chronic mental illness, which can affect how a person thinks, feels, and behaves"	The scoping review method of synthesizing and analyzing a wide range of relevant literature was used. Computerized search of the literature was conducted. A manual search of the references in the selected articles was conducted. All of the resulting articles underwent a review process	Not addressed

						using the same inclusion and exclusion criteria.	
Ryan et al 2010 Ireland S3/S4 (Consensus =S3)	An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities[49]	To describe the provision of palliative care to people with intellectual disabilities in one Health Service Executive Area in Ireland and to conduct a corporate assessment of the population's palliative care needs.	Intellectual disability staff and specialist palliative care staff Sample size- 91	Intellectual disability organizations and a specialist palliative care service	Intellectual disability undefined by the author	Interviews conducted in 12 focus groups, data was recorded, transcribed, anonymised and analysed to identify themes.	The survey population was a convenience sample and was accessed indirectly via service managers. This may have limited generalizability, although the high response rate acts as a mitigating factor. It should be noted that no doctors working in the intellectual disability services responded to the questionnaire, although they were represented in the focus group discussions.
Ryan et al 2011 Ireland S4	Communication contexts about illness, death and dying for people with intellectual disabilities	To explore how staff managed communication about death and dying with people with intellectual disabilities	Staff of ID organizations and a specialist Palliative care unit Sample size- 91	Intellectual disability Organizations and palliative care unit	Intellectual disability defined by the authors as "an impairment of intelligence and	Interviews conducted of staff members in 16 focus groups, these were transcribed, anonymized and	Not addressed.

	and life-limiting illness[76]	in a Health Service Executive area in Ireland.			social functioning"	analysed for data and themes.	
Ryan et al 2011 Ireland S3/S4 (Consensus =S3)	End-of-Life Care for People with Intellectual Disabilities: Paid Carer Perspectives[68]	This qualitative study formed part of a project which aimed to describe the provision of palliative care to people with intellectual disabilities in one Health Service Executive Area in Ireland and to conduct a corporate assessment of the population’s palliative care needs	Intellectual disability staff from the following disciplines: nursing, medicine, social work, psychology, physiotherapy, occupational therapy, complementary therapies, pastoral care, social care staff, management, and household staff. Sample size- 64	Intellectual disability services- community group homes, campus style residential centres, psychiatric hospital, specialist dementia unit, activation centre, sheltered work centre, and intensive placements with special requirements for challenging behaviour, profound or multiple disabilities	Intellectual disabilities undefined by the authors	Focus group interviews using a topic guide and conducted at the participant's place of work, recorded, transcribed, anonymised and analysed to identify themes.	Not addressed.
Ryan, K et al 2011 Ireland S3	Exploring the experiences of people with intellectual disabilities when service users die[88]	To describe the provision of palliative care to people with intellectual disabilities in one Health Service Executive (HSE) area in Ireland and to	Staff working as nurses, doctors, social workers, psychologists, physiotherapists, occupational therapists,	Community group homes, residential centres, psychiatric hospitals, a specialist	Intellectual disability undefined by the authors	Interviews conducted in 16 focus groups, data was anonymized and analysed	Not addressed.

		conduct a corporate assessment of the population's palliative care needs.	complementary therapists, pastoral care workers, social care staff, management, and household staff Sample size- 91	dementia unit, activation centre, sheltered work centres, intensive placements with special requirements for challenging behaviour, profound or multiple disability, general hospitals and hospices			
Sweers et al 2013 Belgium S3/S4 (consensus= S3)	End-of-Life (Care) Perspectives and Expectations of Patients with Schizophrenia[80]	To gain better insight into the perspectives and expectations of patients with schizophrenia about EOL (care).	Male and female schizophrenic patients in remission were recruited. To determine remission, eight systematic operational criteria of PANSS items were used for which patients must attained a score ≤3 Sample size-16	Two Belgian psychiatric hospitals specialized in psychotic disorders	Schizophrenia undefined by the authors	Interviews conducted with the participants d at the hospital or at the interviewees' home. Data collection and analysis were inspired by the grounded theory approach. The transcripts with the extracted codes were then imported into NVivo9, a qualitative data management and analysis program (NVivo, 2010). Similar codes are	The general limitations of qualitative research, Sample size was small and patients were mainly non-acute outpatients from only two treatment settings. Not accounted for cognitive functioning and symptoms. At the time of the interviews none of the patients was confronted with a potentially terminal medical

						grouped into concepts and categories which are the basis for the creation of a theory or theoretical insights	condition, so we were only able to capture their perspective on an event in the future
Todd 2013 UK S3/S4 (Consensus =S3)	'Being there': the experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities[58]	To develop an understanding of how staff interpreted and responded to the death of a person with intellectual disability and the values that shaped their accounts of these	Staff from five intellectual disability residential services in England and Wales Sample size- 22	Five intellectual disability residential services from England and Wales where a resident had died	Intellectual disability undefined by the authors	Semi structured interviews in the residential care setting	Lack of empirical evidence leads to inability to answer questions such as: -The extent to which the desire to support people at the end of their lives is translated into actual opportunities to provide a good quality of care at the end of life - The extent to which preferred place of care approximates actual place of care. -Whether the deaths of people with intellectual disability in care settings could be considered

							‘good’ or ‘bad’ deaths
Tuffrey-Wijne et al 2008 UK S3	Communication difficulties and intellectual disability in end-of-life care[70]	To address the issues of- failure by carers and professionals to communicate in a way that can be understood; and carers’ reluctance to disclose the truth for fear that the person will become upset or unable to cope.	Staff from Palliative care and Intellectual disability services Sample size- not applicable	Palliative care services and intellectual disability services	Intellectual disability defined by the authors as "‘a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development’	Interviews with the participants, qualitative data transcribed onto paper	Not addressed
Tuffrey-Wijne et al 2013 England S3/S4 (Consensus =S3)	Developing Guidelines for Disclosure or Non-Disclosure of Bad News Around Life-Limiting Illness and Death to People with Intellectual Disabilities[90]	The aim of this study was to develop guidelines for decisions about (non-)disclosure of bad news around life-limiting illness and death to people with intellectual disabilities, by	Participants were 21 people with mild/moderate intellectual disabilities, 28 family carers, 26 specialist intellectual disabilities professionals from health or social care	NHS Hospitals, Primary care trusts, independent disability organizations and online focus groups	Intellectual disability undefined by the author	Semi structured interviews either in person or on call/ online and either in focus groups/ one on one. Data from these were analysed using content analysis, following	Study relied on retrospective accounts. There is both memory and reporting bias in this. The study is further limited by significant sampling bias.

		examining stakeholders' preferences (and reasons) around disclosure and non-disclosure	services, 34 general health professionals including nurses, physicians and allied health professionals specialized in cancer or palliative care Sample size- 109			Grounded Theory procedures	Only those participants who were willing to reflect on breaking bad news could be recruited, leading to a likely over-representation of participants who were in favour of openness. Participants with intellectual disabilities were unrepresentative, as they had to have sufficient cognitive and communication ability to cope with the demands of a focus group.
Tuffrey-Wijne et al 2007 England S3/S4 (Consensus =S3)	Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London[75]	To identify the issues affecting the delivery of services by specialist palliative care professionals to people with ID in London	Specialist palliative care professionals Sample size- 32	Hospices and hospital palliative care teams from the Greater London area representing suburban as well as inner city communities	Intellectual disability undefined by the authors	Semi structured interviews with topic guide, data was transcribed and analysed using computer software and team members to code for themes	Not addressed.
Tuffrey-Wijne, I	A new model for breaking bad news to	To develop a model for breaking bad news	General health and Intellectual disability	National Health Service hospitals,	Intellectual disabilities	(I) focus group meetings, on-line	The collected data consisted of

2013 England S3/S4 (Consensus =S3)	people with intellectual disabilities[88]	that meets the needs of people with intellectual disabilities (IDs).	professionals: experience of supporting an adult patient/client with IDs who had a life-limiting illness (prognosis of one year or less). Adults with IDs: capacity to consent to taking part in the study and some verbal ability (able to understand and speak short, simple sentences). Family carers: at least monthly contact with a relative with Intellectual disabilities. Sample size- 109	Primary Care Trusts, independent organisations and on-line forums across England	undefined by the author	focus groups and one-to-one interviews; (II) structured feedback from participants and other stakeholders. Data analysis took place throughout the data collection period, using thematic content analysis. An initial coding framework was developed based on the step-by-step models for breaking bad news and on themes that had emerged in the literature	verbal recollections of past events and participants' opinions. Real-life situations may be different. The participant recruitment process included self-selection, which meant that there was a bias towards participants who were willing and able to engage with the issue of breaking bad news. Participants with more severe or profound IDs, who did not communicate in words and/or were unable to give informed consent, were excluded from the study, and therefore their preferences and opinions could not be gauged directly.

Tuffrey-Wijne, I 2002 U.K S2	The palliative care needs of people with intellectual disabilities: a case study[42]	The aim of the study was to explore critically the needs of people who have intellectual disabilities and a terminal illness.	The client, his home manager, two carers, the general practitioner (GP), district nurse and a hospital staff nurse. Sample size- 7	Residential care settings	Intellectual disability defined by the author as 'a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development'	Face-to-face semi-structured interviews with the client and professionals involved in his care. Data was collected and analysed for emerging themes	Not addressed
Tuffrey-Wijne, I 2003 U.K S2	The palliative care needs of people with intellectual disabilities: a literature review[71]	To identify palliative care needs of persons with intellectual disability	Papers with data from persons with intellectual disability, their carers, relatives, palliative care professionals Sample size- Not applicable	Intellectual disability services, residential services, palliative care services	Intellectual disabilities have been defined as "significantly subaverage intellectual functioning; existing concurrently with related limitations in two or more of the following	Review of literature by searching databases	Not addressed

					applicable adaptive skill areas: communication, self-care, home living, social skills, use of community resources, functional academic skills, health and safety, leisure and work; manifested before the age of 18"		
Voss et al 2017 The Netherlands S4	Advance Care Planning in Palliative Care for People with Intellectual Disabilities: A Systematic Review[83]	To gain more insight into what is known about the use and effects of ACP in palliative care for people with ID.	Intellectual disability professionals, carers, persons with intellectual disability, relatives Sample size- Not applicable	Intellectual disability services, residential facilities, hospices	Intellectual disability (ID) defined by the authors as a disability characterized by significant limitations both in functioning and in adaptive behaviour, which covers many everyday social and practical skills. The disability develops before the age of 18	Systematically conducted review following PRISMA guidelines	Lack of research leading to challenges in answering the research questions. The review is that only included articles found in PubMed, PsycINFO, Embase, and CINAHL which could have led to deletion of more relevant articles

					years and is often expressed using the IQ scale"		not included in these databases
Voss et al 2019 The Netherlands S3/S4 (Consensus= S3)	Advance care planning in the palliative phase of people with intellectual disabilities: analysis of medical files and interviews[86]	To explore how advanced care planning takes place in cases of people with intellectual disabilities (ID)	Care professionals and relatives of the people with ID whose files had been studied. Sample size- 63	Six organisations in the Netherlands caring for people with mild to severe ID living in group homes with 24-h care or in residential settings	Intellectual disability undefined by the author	Medical files were analysed, and interviews were held in six care organisations for people with mild to severe ID. The data concerned people with ID in the palliative phase and who had died after an identifiable period of illness. Additional pre-structured telephone interviews were conducted with their relatives (n = 30) and professionals (n = 33). Data was transcribed and analysed.	Reports by care-staff were not examined. Study was retrospective. Possible selection bias
Voss et al 2020 The Netherlands	What is important for advance care planning in the palliative phase of people with	To explore what is important for ACP in the palliative phase of	People with intellectual disabilities (n = 5), relatives (n = 7) and	Five intellectual disability residential care	Intellectual disability undefined by the authors	Interviews lead by topic guide. The data were analysed inductively, using	Study participants (n = 20) were recruited via

S3/S4 (Consensus =S3)	intellectual disabilities? A multi-perspective interview study[84]	people with intellectual disabilities	professional caregivers (n = 8) Sample size- 20	organizations in the Netherlands.		principles of thematic analysis. After slight adjustments in formulations of themes and subthemes and their interpretations, consensus was reached with all authors about the themes. In the next step, the themes were reviewed in relation to the entire data set and refined in a discussion	intellectual disability care organizations. As a result, the findings may not apply to individuals with milder disabilities who receive care outside the intellectual disability care sector. Moreover, all the participants with moderate intellectual disabilities lived in one residential care organization and were familiar with the second author, who is involved in their care as a specialized intellectual disability physician. This could possibly lead to a selection bias
Vrijmoeth et al 2016	Physicians' identification of the need for palliative	To explore how the need for palliative	Intellectual disability physicians and physicians in training	Intellectual disability services	Intellectual disabilities	Interview guide consisting of a semi-structured	The results may reflect the experiences of

The Netherlands S3	care in people with intellectual disabilities[41]	care is recognized in people with ID	Sample size-10		undefined by author	part. Interviews were transcribed verbatim, read, and reread for familiarization with the data. Data analysis was performed	ID-physicians interested in palliative care, rather than the average physician working with people with ID, since it used a sample of ID-physicians who completed a retrospective survey about the care provided to a patient with ID with a non-sudden death. Furthermore, the results are limited to the perspectives of ID-physicians, as it did not include other people involved in the provision of palliative care for people with ID
Wagemans et al 2017 The Netherlands S3/S4 (Consensus	Do-Not-Attempt-Resuscitation orders for people with intellectual disabilities: dilemmas and uncertainties for ID physicians and trainees. The	To clarify the problems and pitfalls of non-emergency DNAR decision-making for people with IDs, from the perspective of ID physicians.	Intellectual disability physician and trainees Sample size- 40	Participants recruited through Dutch Association for ID Physicians and Dutch vocational training	Intellectual disability undefined by the authors	Semi-structured individual interviews, focus group interviews and an expert meeting. Data was recorded digitally and transcribed	Study only interviewed ID physicians and not other medical specialists or general practitioners. Furthermore,

=S3)	importance of the deliberation process[73]			programme for ID physician		verbatim. All interviews were analysed following the procedures of Grounded Theory	only physicians interested in the subject participated. People with IDs and paid care staff were not involved. The study was limited to the Netherlands and the way health care for people with IDs is organised in the Netherlands
Wagemans et al 2012 The Netherlands S3/S4 (Consensus =S3)	End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives[91]	To clarify the process of end-of-life decision-making for people with intellectual disabilities from the perspective of patient representatives	Patient representatives after deaths of patients with ID Sample size- 16	Residential facilities for people with ID	Intellectual disabilities defined by the authors as "characterised by significant limitations both in intellectual functioning and in adaptive behaviour, originating before the age of 18 years"	Semi structured interviews from an interview guide. The interviews were analysed following the procedures of Grounded Theory	Not addressed
Wagemans et al 2013 The Netherlands	The factors affecting end-of-life decision-making by physicians of patients with intellectual disabilities	To investigate the process of end-of-life decision-making regarding people with intellectual disabilities	Intellectual disability physicians Sample size- 12	Intellectual disability Facilities in the community or	Intellectual disability undefined by the authors	Interviews conducted following an interview guide. All interviews were	As the patients had died during a period of one year preceding the interviews, it

S3/S4 (Consensus =S3)	in the Netherlands: a qualitative study[66]	(ID) in the Netherlands, from the perspective of physicians		part of a larger campus		recorded on a digital voice recorder and transcribed verbatim. The interviews were analysed following the procedures of Grounded Theory	may have been difficult for the physicians to recall the detailed considerations leading to a decision
Wagemans, et al 2015 The Netherlands S3/S4 (Consensus =S3)	End-of-Life Decision-Making for People with Intellectual Disability from the Perspective of Nurses[67]	To investigate the process of end-of-life decision-making regarding people with intellectual disabilities (ID) in the Netherlands, from the perspective of nurses	Intellectual disability nurses working in chronic care interviewed after the deaths of patients with ID Sample size- 9	Residential facilities- small residential facilities in the community of facilities in a large campus	Intellectual disability undefined by the authors	Interviews from interview guide. Data was collected and transcribed. The interviews were analyzed following the procedures of Grounded Theory	Study only interviewed a limited number of nurses working in Dutch ID residential care situations. The study only examined those processes of end-of-life decision-making in which relatives were involved. We assume that nurses will have a different, and probably stronger position in situations when relatives are not involved.
Wark et al 2017 Australia	Challenges in providing end-of-life care for people with	To gain the direct input of support staff in both rural and city	Paid disability support staff who provided end-of-life	Disability support organizations, two metropolitan	Intellectual disability,	Semi- structured interviews conducted in focus	Comparisons to other areas would need to be

S4	intellectual disability: Health services access[51]	locations who have assisted individuals with intellectual disability during their end of life.	care to an individual with intellectual disability Sample size- 35	and four rural in Queensland, Australia	undefined by the authors	groups of four to twelve participants	carefully considered with respect to any difference in legislative frameworks. The decision to seek greater representation from rural areas resulted in an overall bias towards non-metropolitan respondents.
Wiese et al 2012 Australia S3	End-of-Life Care and Dying: Issues Raised by Staff Supporting Older People with Intellectual Disability in Community Living Services[62]	to explore the current status of end-of-life care and dying of people with intellectual disability based on the experiences of staff in community living services.	Staff of community group homes Sample size- 33	Three agencies in Australia that provide community group home accommodation to clients.	Intellectual disability undefined by the authors	Focus group interviews, Audio recordings were transferred as data files to a password-protected computer. Each audio recording was transcribed verbatim. Analysis done based on grounded theory	The perspective gained was from staff only, although many of the issues they raised pertained to other partners involved in end-of-life care, including the dying client, other clients, fellow staff, the family, external health services and the coroner. The degree to which these issues are true from the

							perspective of these other partners is an avenue for further research. While the study was able to report on how many people had knowledge about dying in their professional role, death in their personal lives was not appraised, and its influence upon end-of-life care was unknown. Additionally, the present research, being qualitative, recognizes the subjectivity of participants' individual experience and therefore does not propose that the findings are generalizable
Williams et al 2003 England	A qualitative study of clinical nurse specialists' views on depression in	To determine how specialist palliative care nurses, working both in the	Palliative care nurse specialists who had completed a six-week specialist `care of the	A large hospital and a community palliative care	Depression undefined by the author	Semi-structured interviews were carried out. All transcripts were	Not addressed

S3/S4 (consensus= S3)	palliative care patients[36]	community and within a hospital, perceive, assess and manage depression in their patients	dying' course and six had obtained nursing degrees Sample size- 17	team in central England.		analysed. After this phase was complete, each coding category was read and conceptually organized to identify the major emergent themes.	
Wilson et al 2020 U.K S4	End-of-life care and place of death in adults with serious mental illness: A systematic review and narrative synthesis[56]	To assess the empirical evidence describing end-of-life care and place of death for people with serious mental illness.	Papers with data from adults (18+years) with a diagnosis of serious mental illness, who had died or were in the last year of life; reported either health care access/utilisation in the last year of life or place of death Sample size- 23 studies	Any service involved in providing palliative care to persons with SMI	Serious mental illness undefined by the author	A systematic review of original, peer-reviewed research, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Data were analysed using a narrative synthesis approach.	The heterogeneity and diversity of the included studies. The range of diagnoses included
Woods et al 2019 Canada S3	Palliative Care for People with Severe Persistent Mental Illness: A Review of the Literature[32]	To identify what the literature says about palliative care for people with pre-existing severe persistent mental health illness	Studies looking at people with SPMI, families, mental health care, palliative care, family medicine, and social services all involved in the provision of optimum palliative care to persons with SPMI	Any service involved in providing palliative care to persons with SPMI	Severe persistent mental illness defined by the author as people aged 18 years and older who suffer from a prolonged or recurrent	Searches were conducted in online databases based on a search strategy. A data abstraction form provided a consistent framework for data collection. Papers	The limited number of empirical studies may reduce the generalizability of the results. The literature may not represent the experiences of

			Sample size- 68 studies		mental illness, are impaired in activities of daily living, and require long-term treatment.	that met inclusion criteria were reviewed by all authors. The empirical papers were critically appraised and included in discussion under the appropriate theme.	people who have SPMI. It may overrepresent a population with very difficult problems. Actual care may be ahead of the literature.

TABLE 3: DATA MAPPING TO RESEARCH QUESTIONS AND IDENTIFICATION OF THEMES									
First author, date, country, title and quality assessment outcome	**What works for receiving appropriate combinations of MH and palliative care?**		**What doesn't work?**		**Care challenges**		**Opportunities for improvement in care**		**Themes**
	1st order data	**2nd order data**	**1st order data**	**2nd order data**	**1st order data**	**2nd order data**	**1st order data**	**2nd order data**	
Baker **2005** **U.S.A** **Palliative and End-of-Life Care in the Serious and Persistently Mentally Ill Population**[63] **(S2)**		"When caring for the dying patient with SPMI, educating the health care team about the psychiatric diagnosis, symptoms, and treatment will allay the team's concerns and misconceptions and lead to better patient care. Knowledge and understanding are key to providing compassionate care" "Developing a trusting and therapeutic						"Being able to anticipate the patient's pain and properly and aggressively treat it is crucial for effective end-of-life care. If a patient needs to be hospitalized, a psychiatric/medical unit would be ideal in which both illnesses of the patient can be effectively addressed" "Educating the nursing home's staff about mental illness and helping them to understand the source of uncooperative behaviors and to	Increased training needs Joint collaboration Increasing support for the homeless population with SPMI

		relationship with the homeless and incarcerated seriously mentally ill population is most important in providing end-of-life care. Greater individual and societal commitment and more proactive and forceful measures are needed to provide care to this population”						recognize limits in treating the long-standing psychiatric disorder”	
Bekkema et al, 2014 **The Netherlands** **Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative**		“There was more potential for involving people with mild ID in communication about the illness” “Communication was not only about sharing information but was also a		“Important decisions at the end-of-life, such as whether or not to start life-prolonging treatment or whether to move to another home, were often taken		“For relatives and caregivers, this raised the difficult question of how to communicate to the person with ID about the situation, estimate what he/she would want to know and how much information		“It was especially difficult for social workers to respond adequately, as they lacked nursing skills and basic knowledge of end-of-life care. For some it was the first time they had a client who was dying.”	Questions around disclosure Training and knowledge No autonomy Respecting decisions

multiple-case study[95] (S3/S4, consensus=S3)		means to help the person feel familiar with his illness.” “They therefore wanted to act on their care needs in the best possible way. This required basic knowledge and skills in end-of-life care that enabled caregivers to recognise a care need, to interpret symptoms like pain, rest-lessness and fatigue, and to know what type of care should be offered”		in multidisciplinary meetings together with relatives. There was no sign from the interviews that the person with ID was present at these meetings. Decisions were based on what were thought to be the wishes of the person with ID or what seemed to be best for that person.”		he/she was able to handle. The interviewees thought that the person with ID had the right to be informed. However, in the case of very ill people with severe ID in particular, what they understood about the situation was largely unknown, making it very difficult to ascertain their need for information” “People with mild ID were better able to express their wishes. Although this made communication easier, their wishes could conflict with the wishes of others”			Knowledge on symptoms

						“The struggle her relatives and caregivers had with the dilemma between respect for her own wishes and the moral obligation to provide good care and therefore intervene to reduce her fear symptoms.”			
Bekkema et al, 2015 **The Netherlands** **‘From activating towards caring’: shifts in care approaches at the end-of-life of people with intellectual disabilities; a qualitative**	‘There are no ‘musts’ anymore. It's more about letting go…’ ‘The doctor said that that was not going to happen, he gave me the confirmation that they would relieve his suffering. That was what I needed to hear. I wanted	“In the last stage in life, even regular care, such as showering or eating, was sometimes burdensome and new solutions needed to be found, such as reducing time taken showering, washing in a bath chair and offering			“But the identification of pain is largely done by the care staff and the family. I think in Joe’s case it was his sister who first said to me he’s in pain now. And over time everyone agreed that he was in pain.”	“In particular it was often a challenge to identify pain, anxiety and other signals of distress in people with severe ID. Often these symptoms only became visible through small changes in behaviour or signals such as grimaces or stretching the neck. These	“It felt like we (the relatives and care staff) were really one family, all care was finished, and we were there for each other”	“Openness to cooperation and sharing’ the care was an important value to accompany the intensified presence of two ‘families’”	Shifting care Challenges identifying pain Collaboration with relatives

study of the perspectives of relatives, care-staff and physicians[65] (S3/S4, consensus=S3)	to be able to look at myself in the mirror and tell myself that I did not do anything very burdensome to him at the end of his life.’	favourite foods in a liquid form.” “Physicians usually discussed medical information with relatives and mentors and tried to come to shared decisions with them.”				changes were not easily recognized. This meant that physicians now relied heavily on information from people closely involved with the person, mostly relatives and care staff”			
Bekkema et al, 2016 **The Netherlands** **Perspectives of people with mild intellectual disabilities on care relationships at the end-of-life: A group interview study[94] (S3/S4, consensus=S3)**	“I think the people who know her, her family and friends, the ones who were always around her, looked after her and sympathised with her, they should be able to see from her behaviour what her wishes are.” “You want the person to stay cheerful [...]	“Participants indicated that ascertaining the incurably ill person’s personal care wishes and preferences is very important. Care professionals and relatives should find out what the person’s practical care wishes are...” “According to the participants,			“Somebody should be there. Someone who can help her. [...] I don’t know if they have 24/7 care where she lives. That would be good. Good help.”	“Participants emphasised that when a person is incurably ill, (s)he needs care professionals or relatives to be there for practical help and doctors for medical help.”	“…(about the person’s wishes regarding medical treatment) It could be that you can’t speak anymore at the end, but if you have it on paper, then your doctor would know and then they wouldn’t make a wrong	“The discussions about wishes also seemed to express a deep desire that the person with ID should be in control. Participants stressed that wishes should not only be ascertained but also be recorded.”	Respecting wishes Keeping a record of wishes Autonomy Increased support

	Maybe you can talk to her about her wishes. Maybe she wants to meet her favourite pop singer. [...]. I find these things very important. That she is not only sad, but also has some joy” “It is important to do what was agreed. Else the care staff will fill in things for her, and not stick to the agreements they made. [...] What the person wants is the most important thing.”	the most important aspect of dealing with wishes in the care relationship was that people should make sure that the person with ID is in control, that their wishes take priority and are actually honoured”					decision afterwards” “Saycomforting words. That she doesn’t need to be afraid. [...]. Tell her that it will be all right. That we are thinking about her.” “Take somebody outside if the weather is nice, and go for a walk. Try to make them think of other things, distract them.” “If you’re about to die, then it may help to hear about other		

							people's experiences, or near-death-experiences of other people"		
Brown et al, 2003 **England** **'Please don't let it Happen on my Shift!' Supporting Staff who are Caring for People with Learning Disabilities who are Dying**[43] **(S3)**	'They were terrified of his going into a hospice... [because his] communication was so subtle, it was all about eye movements and lip movements and everything, and they just thought, we would rather he didn't have to move and he could stay with people who knew him'	"Daniel communicated using facial expression and eye movements and the staff managed his pain relief on the basis of their understanding of his signals, for example they came to see his 'lemon juice face' as a possible sign of pain."	"Patients are highly likely to be left to guess for themselves that they are dying and the emotional isolation that these produces can only be guessed at in the absence of the patient's own stories"	"These sudden shifts in acknowledgement were more likely to have happened where a planned approach had not been taken or where there had been no consensus about the merits of openness"	"…she'd done all that before regardless of the difficulties she had with her learning disability and that changed the way that she was being treated because they just saw her as someone that was always like that anyway."	"This problem of diagnostic overshadowing, where symptoms are understood by health care professionals as part of the learning disability rather than part of the person's illness, was also highlighted in the account" "Barry was admitted to a hospice on a respite-care basis, and although he staff at the hospice were keen to remain involved in his care, they felt		"…there was no agreed format for making decisions. There was confusion about who should be involved and especially about the role of relatives. Nor were decisions made against a background of clear principles about consent or best interests."	Diagnostic overshadowing Communicating better Location of care Capacity and consent

						that he should be able to go home with an outreach palliative care service”			
Cithambaram et al, 2020 **Ireland** **Disclosure and plan of care at end-of-life: Perspectives of people with intellectual disabilities and families in Ireland**[92] **(S3/S4, consensus=S3)**	“People like us should know what is happening to us be-cause ... we have choices to make like...where to die, how to die, how to be buried. Yah...the person who is dying should know everything and people should let them make choices. Listen to them and we should do whatever they ask” “Communication is very essential and there are	“The communication flow between families and professionals is essential at the end-of-life, and this communication should be concerned with disease conditions, prognosis and future possible care choices for their loved ones”			Mm... I would say certainly not because it is difficult for them to understand and even if they understand it will be very hard for them to take. I prefer not to tell them anything.	“One family member disagreed with the wishes of people with intellectual disabilities to be informed about their clinical situation as the family member assumed that it would be difficult for those with intellectual disabilities to understand what was happening and, even if they understood, it would be hard for them to manage the situation. “	“Also, they have to make us write down our wishes in a paper or tell the nurses, doctors and parents what are our wishes. This will clear all confusions, and everybody will be in the same line of care” “I think it is a very good idea to have everything on the clinical file. It will give a clear direction to	” Ultimately, it can be seen how a document consisting of a person's wishes, preferences and needs would be an excellent resource for healthcare providers to utilise in order to give appropriate care. This document would eliminate any confusion among professionals…”	Disclosure Collaboration with relatives Good planning

	different ways, some people say total communication, and some say no. I think communication is crucial, especially with family members”						the professionals about what to do at the time of emergencies and everybody knows what to do and what is expected of them. This information will be very helpful for the professional to provide good care at the end-of-life” “The nurses and doctors should make people realise they are dying. They definitely need a lot of support… support and care and		

							helps to make a plan.”		
Coffey et al, 2022 **U.K** **End-of-life care for people with severe mental illness: mixed methods systematic review and thematic synthesis of published case studies (the MENLOC study)[40] (S4/S5, consensus = S4)**				“A consistent picture of delayed or late diagnosis and diagnostic overshadowing appears in case studies. Complex and enduring mental health problems may contribute to these issues.... Denial, or a lack of insight, is a possible complicating factor. It is not unknown for persons diagnosed		“Decisional capacity of individuals to consent to treatment and/or to refuse treatments are reported and implicate professional dilemmas of determining the value of attempting curative treatments versus palliation”		“Case studies reveal issues in the provision of care for treatment teams, such as how to handle psychiatric presentations” “Challenges reported include mental health staff being emotionally unprepared for caring for people who are terminally ill.	Diagnostic overshadowing Questions around capacity Increased training of palliative care and psychiatric staff

				with other serious conditions to deny the gravity of their situation, and for people with pre-existing mental health conditions it appears that this is no different.”					
Donald et al, 2019 **Canada** **A scoping review of palliative care for persons with severe persistent mental illness**[33] **(S2)**		“Many authors recommended joint endeavours between palliative care and mental health, whether that was collaborating in treatment teams or providing cross-training and sharing resources”		“Late diagnosis is emblematic of difficulties accessing and being properly assessed by the health-care system, both in general and specialist care settings” “This concentration of resources		“People with SPMI at the end of the life are part of a highly complex population. Studies showing early mortality reveal that those with SPMI are approaching end-of-life early, and late presentation often results in high needs and a short timeline for care”		“Psychiatric symptoms lend their own complexity to palliative care, such as delusions, psychosis, denial of illness (both psychiatric and physical), and social withdrawal or apathy, all of which can hinder or obstruct participation in care” “Analyses of palliative care use and related	Late presentation Understanding psychiatric presentations- lack of training Joint collaboration

				results in limited access to settings with capacity to care for complexity, such as for a person with SPMI who is experiencing active psychiatric symptoms and cannot be cared for on a general medical unit despite the potentially high need for medical care”		“Palliative care clinicians were more likely to report discomfort with care-seeking, care-rejecting, or aggressive behaviours”		indicators show that those with SPMIs are not receiving the same palliative care services as their counterparts without an SPMI” “Lack of training in palliative care or mental health care, particularly for those outside of mental health or palliative specialties, is a recurrent issue in the literature that inhibits access to palliative care for those with SPMIs”	
Evenblij et al, 2016 **The Netherlands** **Palliative care in mental health facilities from the perspective of nurses: a**	“Although, communication about the end of life can bedifficult and takes more effort, time and experience,nurses stated that fruitful conversations about end-of-				“…a woman who had been giving very subtle signs of pain...turned out to have very advanced breast cancer...We hadn’t picked up on the signs coming from this	“Psychiatric conditions were reported to have a negative impact on adequate and timely physical care in the palliative phase. Nurses reported that psychiatric patients might perceive and			Challenges due to psychiatric conditions- Late presentation Open communication

mixed-methods study[96] (S2/S3, consensus=S2)	lifeissues are possible.”				lady...or not enough. But that was very much to do with the fact that we considered the complaints of pain from a psychiatric point of view rather than as genuine complaints about pain.” “I think that it’s even more difficult to ensure a decent end- of life for psychiatric patients because it’s so much more difficult to make contact at the mental level” “But even so, I think however mentally incompetent someone is,	express pain differently.” “Nurses did report that psychiatric disorders can add an extra dimension as psychiatric patients might react more extremely and might be less effective in dealing with bad news.”			

					however low their IQ, you should always start a discussion with that person”				
Fahey-McCarthy et al, 2009 **Ireland** **Developing an Education Intervention for Staff Supporting Persons with an Intellectual Disability and Advanced Dementia[72] (S3/S4, consensus= S3**	“...oh yes, that would be done after death, we would make the arrangements. ..but, here, if somebody is dying, we make the arrangements already...but no, not in my country, we don’t do this until we confirm that they are dead.” “...no, no, we have to adapt...these are your ideas, and this is your culture...we came here				“...well, it might sound very basic, but knowledge of intellectual disabilities to start with would be most helpful.” “...but we also come into difficulties in trying to determine...like that when we did the pain scale and we were trying to pick up on those signals at that stage...are they in pain...are they distressed...you know it is very difficult to tell, I	“Such a lack of knowledge of the needs of persons with ID by staff in general acute medical settings has previously been identified as leading to diagnostic overshadowing and unexpected and unexplained deaths” “Pain recognition and pain management were also required skills, yet many reported lacking the needed theoretical and practical knowledge”	“But we know that occasionally some people will need something more [i.e., specialist palliative care expertise]and we know where to go to look for it—so that rather than looking within an isolated little pocket, we will deliver everything in our service and we won’t look outwards.”	Participants in the study acknowledged that they would benefit from improved skills in caring for the dying person and his or her family, and expressed the desire to be able to easily approach specialist palliative care when they needed support”	Increase staff training on intellectual disability and palliative care Diagnostic overshadowing Culturally competent caring Pain assessment

	and we have to adapt and by adapting we are learning and by learning we grow in our understanding.”				suppose even in the general population.”				
Foo et al, 2021 **Australia** **Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews**[82] **(S4)**	“I've also done bereavement training...[and] some I used to see in my private counselling...had intellectual disability as well...that skilled me up a bit to try and reframe things... [talking about dying and death] comes with experience and skill.” “...we would visit her on a regular basis just to build up that				Not with [a person with] an intellectual disability...it's out of the room, talking to family or the carers employed to care for them. But in the general community, [talking about dying and death with the dying person] is a very big part of my role” “We'll often either encourage the [hospital team caring for the dying person]		“I probably don't feel that well-educated about intellectual disabilities to know the best way to communicate those things...my biggest [knowledge] gap [is] in knowing how to respond or how to share that information with them.” “It's my own inadequacy, lack of experience,		Questions around disclosure Increased training around communication Build strong rapport

	rapport so when she did get sick and have to come in [and have these conversations] ...She was happy to come in because she knew us.”				or we will do the end-of life conversations. .. if somebody had an intellectual disability where they were non-verbal...we would still include them in the conversation.” “...there are different levels of disability...there was one in particular who we were able to discuss [his dying] with him...With the others it was really more supporting family members or carers because...even if you...talked to [the dying person] I don’t		lack of interaction, which probably holds me back.” “It was much more challenging with this person with intellectual disability because it’s just really hard to know... how to”		

					think they would have comprehended” “It’s hard to know – particularly if they don’t speak...what they’re understanding...how much they’re comprehending and if it’s a one-way conversation” “I didn’t know that she had the intellectual capacity to take it on and that it could cause more harm.... People with longstanding intellectual disability...[have] been protected from having discussions				

					about death and dying...all their lives”				
Forrester-Jones et al, 2017 **U.K** **People with intellectual disabilities at the end of their lives: The case for specialist care?[59]** **(S3)**	“That clinical aspect of the home is what makes us quite unique and makes the difference between what we do and what the [nursing] home down the road does... we’re a lot smaller we have a lot more specialised care because of the type of clientele that we take on...so I think it’s very different to an elderly care nursing home.” “It’s more homely than	“Staff unanimously reported that LH provided a person-centred approach, incorporating dignity, knowing people well, and compassion/empathy, especially when residents lacked communication skills”	‘There definitely needs to be more places like this. You can’t put somebody with Down [syndrome] and dementia on a hospital ward where the nurses go and see them maybe for 3 seconds every 2 hours, you know.... They need to have one to one when they’re really poorly. So,	Quality of life then was key to care provision even where death was a “possibility” rather than a “certainty			...to be there for them all the time, give them the choice, the respect, the dignity, if they want to do something. Help them achieve it rather than, you know “you can’t do that” “...we are here to make sure that their last days are their best and while they’re with us we make them as comfortable and as happy as we	“Rather, staff aimed to ensure that residents received the best quality of life possible right up until “the last days.” In some cases, the care was seen as compensating for an individual’s previous negative experiences”	Place for end-of-life care Consent and choice

	the very large care homes that you get, which do become quite institutionalised.:		I don’t feel hospitals are the place for them.’				can...they come with such bad histories, don’t they? It’s like... at least while they’re with us we can try and make up for what they’ve been through”		
Geppert et al, 2011 **U.S.A** **To Treat or Not to Treat: Psychosis, Palliative Care, and Ethics at the End-of-Life: A Case Analysis**[60] **(S2)**		“The ideal of patient centred care suggests a continuum encompassing multiple settings and care-givers. For example, someone in the final stages of life may live and die most comfortably in a hospice setting but have been best served in a mental health				Patients assessed to have decision-making capacity are authorized to make all available choices regarding their own medical care. Persons with decisional capacity can understand the nature of their illness; weigh the risks, benefits and alternatives of proposed			Questions around capacity Multidisciplinary care

		setting only days prior.” “Psychosomatic medicine psychiatrists can serve to bridge the gaps between multiple settings and staff.”				treatments; and express a choice, all with some recognizable logic. When individuals lack these abilities, others make decisions for them”			
Irwin et al 2014 **U.S.A** **Cancer Care for Individuals with Schizophrenia [64] (S2)**		“Early psychiatric consultation and communication with the patient’s outpatient mental health team are key strategies to optimize cancer outcomes and enable oncologists to focus on the delivery of quality cancer care”						“Individuals with severe mental illness are generally interested in EOL care discussions and are able to articulate their preferences.” “In addition, oncologists and psychiatrists, when available, have the responsibility to continue to educate patients to maximize the patient’s ability to provide con-sent"	Collaboration Involve patients in decision making

Li et al, 2008 **U.K** **End-of-life care: nurses' experiences in caring for dying patients with profound learning disabilities—a descriptive case study**[61] **(S2/S3, consensus=S2)**	'You get to know certain ways about them, certain sounds and movements'	"Respondents reported that knowing the intimate habits and behaviour of patients with profound learning disabilities enabled them to make a contrast between what their patients were like before and after the onset of illness." "The analysis of data showed perception of good working relationship between general practitioners (GP), hospice palliative care team and learning disability nurses in the residential care homes."			'This is where she is the happiest and unless there was an emergency ... this is where she would die'	"...judgement it would have been better if their patients died in their residential homes. However, they also took into consideration the nature of the illness in view of preference and also the view of patients' relatives and friends."		"The respondent's statement 'we had an inkling...we knew that there was something there but we weren't quite sure' shows evidence of their uncertainty"	Understanding behavioural changes Place for end-of-life care Uncertainty about symptoms Collaboration

Loge et al, 2013 **Norway** **Depressed patients with incurable cancer: Which depressive symptoms do they experience?**[44] **(S3)**		“The somatic symptoms fatigue and loss of weight or appetite were prominent but often indistinguishable from manifestations of the progressing cancer. Despair, anxiety, and social withdrawal emerged as alternative symptom criteria”	“I kept my distance from friends. When neighbours asked me home to tea, I said no. I used detours in order not to talk to the neighbours. I avoided people.”	“The patients withdrew from others and isolated themselves. Characteristically they did not answer the telephone. They did not initiate contact, did not issue invitations or visit others. Participation in conversations was reduced, and they talked less”	“I couldn’t stand it anymore, and I was crying all the time. I was not anxious, but despaired. Why me? Why do I have to go through this?”	“In sum, the findings point to a need for a broader understanding of “recurrent thoughts of death or suicidal ideation” in patients with incurable cancer”	“One can say that everything is black. There’s nothing at all. It’s black” “I haven’t lost my will to live, but the joy in living”	“Anxiety was experienced commonly and described as a strong feeling. The salient and invariant theme was the fear of death. Fear of the progressing disease accompanied by suffering or the loss of roles was also described.” “The two main symptoms of the DSM-IV for MDD; “depressed mood” and “diminished interest and pleasure in activities” (anhedonia), were major and dominating symptoms in the interviews.”	Looking at appropriate symptom criteria Social isolation
Madrigal, 2010 **U.S.A** **Hospice professionals**					“Yes, due to increased symptoms, makes it difficult to work with them [people	"They felt people with mental disorders do present different challenges than		"Staff trainings and in-services were reported as very minimal. One of the 10 directors stated that weekly trainings are	Increase staff training Challenges due to symptoms

report about end- of-life care for persons of schizophrenia [47] **(S2/S3, consensus=S2)**					with mental disorders.]”	people without mental disorders "		conducted by the program director, who is a psychologist. All 10 directors stated that the staff had the greatest knowledge about depression, anxiety, and dementia but very little to none of the staff had training in schizophrenia”	
McGinley et al, 2017 **U.S.A** **Emergency medical services providers' perspective of end-of-life decision making for people with intellectual disabilities**[85] **(S2/S3, consensus=S2)**	“There’s nothing different from a developmentally disabled person versus (another) person.”				‘The way the system is going now, they want more person-centred decisions, which is perfectly fine. But I still think that they’re guided by family, their social care workers, their case managers, or social workers. Well, they have to				Equity of care Making decisions for themselves Questions around capacity

					explain it to them. This is what you want, are you sure this is what you want... They may be influenced by other factors’ ‘I guess the question for me is always: these are people that don’t necessarily have the capacity to understand what choices are or make their own choices. So, is it the staff that are making the decisions about it? Is it the family? Does it really represent what the person would want?’				

McGrath et al, 2006 **Australia** **Ethico-legal issues in relation to end-of-life care and institutional mental health**[87] **(S3)**	"It is humanistic . . . Our focus is connecting with the person, connecting with the person and forgetting the illness, reconnecting with the person and we are trying very hard to do that and it is not easy." "We working in mental health are supposed to be holistic practitioners."				"You really have to do this [CPR] knowing that the law says you have got to do it as well." "You can't officially let die with dignity . . .you have got to give the whole "resus" ......even though the doctors to their credit will learn to say "do not make resuscitative" "He wasn't really able to . . . he understood he was dying . . . but he wasn't able to	"The findings from this project documented the perception that in this mental health institution there is no choice for either staff or consumer. Rather, the necessity is to engage in resuscitation practices as a legal imperative no matter what the circumstances." "The reason behind the need for CPR is seen to originate from the difficulties associated with obtaining a legally valid consent"			Holistic care Lack of autonomy DNR Questions around consent

					process it or understand it on that level of his wishes…” “But if people are saying, well you know, “My God if I’ve got to resuscitate this man what for?”				
McKenzie et al, 2017 **New Zealand** **“I’m still here”: Exploring what matters to people with intellectual disability during advance care planning[93] (S3/S4, consensus=S3)**	“As hard as it might be, get the discussion going, get something put in place” “We have to do it in little bits and pieces. [Primary participant] understands but we can’t have a whole conversation about it [in one go]. You can only go at the person’s	“They described feeling more relaxed and prepared for the future following the completion of the planning process, and no longer felt that delaying the start had served them well.” “…approach needed to be sensitive and start gently so that the			“He can’t read or write, so we had to do visuals and we had to be really really straight up and not muck around, but be careful not to put words into his mouth.” “I make the final decision, “cause I’m an adult, and I’m responsible” “I absolutely love the fact	“…make sure that they understood all information that was presented to them. Although they did not necessarily recognize that this required someone to specifically adapt information for them, they recognized that they needed some support to make sense of information so		“All agreed that their past experiences and knowledge gave them a level of confidence in talking about death and dying that many of their col-leagues might not have. All felt that they would not have been able to take on the planning role in the absence of this training and/or experience” “Collaborating with these	Early planning Importance of staff training Adapt the process Clear information to make decisions Autonomy

	pace and with what they want to talk about. It's about giving the information but not needing them to bring it up." "[We need to make sure] they've got as much information as they need, and we're asking the questions for them .... so that they can make some choices."	primary participants were comfortable and could take part in a meaningful way" "They looked for signs (such as being unsettled, acting out with behaviour or asking to stop)" "The primary participants all said that they wanted their support team and family/whanau to "talk straight" with them."			that [primary participant] is so involved in it when it's so important – it's all her wishes, her thoughts"	that they could make decisions" "A key concern for primary participants was that they were able to make their own choices and be in control of the decisions being made. All had strong opinions. In three instances, these opinions were directly sought and understood by those around them"		additional people helped to address knowledge gaps (medical detail, family/whanau values, cultural practices, future disability service options) within the team, aided the identification of possible future requirements and the re-sources that might be available to meet these…''	
McKibben et al, 2020 **U.K.** **Determining the informational needs of**	"When you're in the middle of somebody who has an illness, and they're going down rapidly, you're dealing with every	"Family caregivers also acknowledged the importance of information about respite and psychosocial support, and		"There was an apparent presence of diagnostic overshadowing, when professionals interpreted changes in		"Perceptions were that discussion around death was a barrier to information sharing and how this influenced	"Nobody wants to think about those sort of things … at the end of the day you need to make them		Increased training and information for relatives

family caregivers of people with intellectual disability who require palliative care: A qualitative study[79] (S4)	moment very quickly … so I wasn't thinking up questions at the time." "I was given the suction machine, with no training not showed how to switch it on, not shown how to use it, nothing. I was given an oxygen bottle, no training … I wasn't even given any manual handling training." "… when he first got the diagnosis and we went to that training course [on Dementia and Learning Disability] … it just prepared	how to avail these supports, but these were not cited as frequently as information need surrounding the disease, finances, or practical support" "Joint working fostered consistent communication which promoted more effective provision of information and support" "Cross agency communication and partnerships were identified as ways of addressing information needs"		behaviour or symptoms to the person's disability instead of an illness which may require further investigation and treatment"		advance care planning, and complications with consent where there were capacity issues"	decisions early on, so people have their choices and wishes known early on."		Joint collaboration Avoid diagnostic overshadowing Questions around capacity Early communication

	us so much and let us understand what he was going through and why” “I think we don’t know when to refer and to who, there’s Macmillan … Hospice … district nursing … there’s no real guidance on who we should be linking in with, when and where, and why”								
McLaughlin et al, 2014 **Nothern Ireland** **Developing a best practice model for partnership practice between**	“…yes, it was a hospital, but it had been his home all of this life.” “They could see in action palliative care at its best and it had a good outcome for	“One important outcome was the person being able to die in their place of care, with continuity of care by familiar people”			“When our clients are well at the best of times, they present lots of challenges about access to services and about co-operation and stuff ...”	“Marginalised life reflected how services may not have been tailored for people with intellectual disabilities or their needs were often not understood”	“I felt quite scared because I wasn’t clear of my role and the whole process was disjointed, un-co-ordinated ... what would	“A number of service improvement areas were highlighted such as more co-ordinated care, with better communication” “Learning needs in palliative care	Not tailored for people with ID Lack of equity Better co-ordination and partnership

specialist palliative care and intellectual disability services: A mixed methods study[50] (S4)	the organisation because the staff worked to their finest level – the patient got to die in their place of care, the family were content.” “I think I would be happier now that we have good established links and I think it was the recognition of my own inabilities and the limitations of my practice in relation to this group.”	“Increasing confidence in working with intellectual disability. This was linked to the feelings of fear, which specialist palliative care services had in this area of practice, and which could be addressed through joint working”			“I think ... it is about equity – in that this is a population who is very vulnerable – and it is about ... the valuing of human beings and it’s about humanity” ““I think it’s difficult because we are slightly ‘siloed’ and slightly ostracised from the health service in palliative care services or in learning disability and that bruises us a little bit and makes us nervous to becoming too involved”	“People with intellectual disabilities had the right to an equitable service at the end of their life. This included widening access to hospice care” “These revolved around the ‘medical’ versus ‘social’ model of care, time, lack of access and limited referrals to specialist palliative care services. Other challenges were around mistrust between people, at a human level, coming together to collaborate”	be helpful is a lead person to co-ordinate palliative care services and if all the relevant professionals were then invited to a case discussion and there was a clear plan and pathway.” “I think there needs to be a greater appreciation of patients with learning difficulties in primary care” “I would identify it as an area we do need, as a team,	services. This included ‘understanding learning disability’, knowing where and how to access local intellectual disability services and issues around communication and assessment:” “Increasing confidence in working with death and dying. This described the difficulties that intellectual disability services experienced in caring for someone who was dying and how they could be empowered by the support of palliative care services” “Learning needs in intellectual disability services. In particular, this is knowing about pain and symptom management,	between specialities Familiar place for end-of-life care More education- of staff on intellectual disability and palliative care, matters of death

							more education, in assessment, communication, ethical issues.” “There was a number of staff found it very difficult ... some of the staff had never seen anybody die, so it was that whole gentle, teaching on what happens as somebody is approaching death, when somebody actually dies”	conditions in end-of-life care, bereavement care and caring for people with cultural differences.”	
McNamara et al, 2017 **Australia**	“Our residents are reviewed by the GP…. That is then communicated with a multi-	“Participants spoke about how open communication leads to clearer decision		If there is not an effective understanding...it may lead to	“There are shared challenges around decision making and	“The issue of information processing and communication (e.g., understanding	“There’s a lot of issues I think around how well-equipped	“The introduction of palliative care must be done sensitively, and palliative care teams must also	Information processing and communication challenges

Palliative care for people with schizophrenia: a qualitative study of an under-serviced group in need[48] **(S4)**	disciplinary team and in particular our palliative care link team which we have formulated and this is to inform everyone, make sure everyone's on the same page" "they actually had their dedicated mental health worker as part of that team, so they work collaboratively with the community palliative care service, and their kind of health worker, maybe their GP and family, so again you've got this really nice	making, careful care plans and appropriate advance care planning." "All of the participants noted that caring for people at the end-of-life requires a team approach."		decisions being made that are inappropriate...a person may be judged on their behaviour at a particular point in time which could lead to a range of consequences around whether a service is provided or not."	the ability to weigh up complex information, provide informed consent to different sorts of treatments...they may have challenges with self-care...and little insight about their needs to live safely at home" "Additionally, family, informal carers and even staff in psychiatric group homes or nursing homes may not recognise the declining health of the person" We're seeing some dying in hospital	of the problem, decision-making, communication) was identified as a particular concern. People with schizophrenia as well as a progressive life limiting illness are often challenged as their physical illness progresses" "However, many of the participants noted that hospital-based and care staff are under-resourced and are often not aware of the needs of people with schizophrenia as their physical health fails."	health professionals generally are to work with people with a range of mental health issues in a community setting and often health teams are not necessarily the best equipped."	be prepared as they may not have the required skills" "Many patients with chronic schizophrenia take Clozapine, a pharmacologically complex drug which, when combined with other treatments and medications, can lead to unwanted and possibly dangerous side-effects. It was reported that staff unfamiliar with patients with schizophrenia experiencing physical decline at the end-of-life may not recognise the signs indicating the patient is in distress"	Advanced planning Multidisciplinary approach Staff training

	partnership model.” “There really does need to be a shared understanding about who’s doing what and why...so that does bring up a whole range of practical issues just in terms of gaining access, documentation, all of that sort of thing, so that needs to be an open transparent shared care situation”				because no-one else knows where to put them. A hospice might see schizophrenia and think “hmm a bit hard to manage in the hospice environment” ...have to be in a hospital where they potentially might need a guard...if they come from the (name) Mental Health Hospital...they’re prison sentences there, so they’re dying in custody”				
McNamara et al, 2020 **Australia** **Creating person-**	“People with an intellectual disability that live in a residential house are often there	“If they live in a well-supported accommodation setting with experienced nursing staff, accessible			“The most important thing is about control...over the decisions in your life. They are	“Additional problems reported by participants included health professionals’ inability to	“A number reported working with families, or with other staff to help	“The ability to experience a good death is reliant on the knowledge, capacity and receptivity of the	Familiar place for end-of-life care Ethics and capacity

centred support for people with intellectual disabilities at the end-of-life: An Australian qualitative study of unmet needs and strategies[74] (S3/S4, consensus=S3)	for a range of quite complex issues and we've had to deal with sickness and grief and loss and moving away from their family...while some people certainly would see that house as their home...some people would also still see their family home as their home..."	palliative care and good end-of-of policies and plans, that person is more likely to have a peaceful death and be supported to die in familiar surroundings." "As one social worker said, 'it takes a team to look after someone who's dying'. People with intellectual disabilities at the end-of-life need to be surrounded by people who know them well"			almost...wiped off the slate once you walk into a hospital with an intellectual disability. There is no ability it seems within that particular service system to understand the need of an individual with an intellectual disability to take control over any decisions, from how much medication they take to what sort of ward they're put into." "People need to look beyond the label and actually see what the person's needs are..."	determine whether a person with an intellectual ability was competent and, at times, their refusal to include the person in end-of-life decision-making"	educate them, but found little resources and limited time impeded their efforts." Communication is a big thing, particularly with residents who are non-verbal and like (name), he started doing things like playing with my clothes or wanting a hug...I knew straight away something wasn't quite right"	workforce in that setting." "People with disabilities have differing levels of awareness and ability to communicate, but as their health deteriorates and they become seriously ill, communication problems come to the forefront."	Increase staffing and resources Training on communication Collaboration

					“We need to support them through advocating for what the person’s communicated they want. Often when that’s missing the person doesn’t get the approach they really want, or we don’t know, and it’s a human rights violation almost just to not know...”				
Morgan, 2016 **U.S.A** **“No Right Place to Die”: Nursing Attitudes and Needs in Caring for People with Serious Mental Illness**					“They’re really scared . . . when it comes to someone who has mental illness, ‘specially schizophrenia, they’re really, kinda . . . they don’t want to handle them. I	“Almost all of the nurses in both groups discussed the effect of stigma on the delivery of care to this patient population. The lack of understanding about mental illness and fear	I don’t know so much about my bipolar patients. A lot of times . . . I feel like those people you can’t take care of by yourself. Like, you	“Fears about the potential effect of SMI symptoms with a new patient”	Stigma Lack of knowledge about bipolar disorder Lack of knowledge around communication

at End-of-Life[35] (S3)					think they're afraid" "With the person who's hostile and paranoid . . . and who not only has their mental illness to deal with but now they have a physical illness so now they're feeling things that are real and yet often unable to describe, unable to um, verbalize." "She would not do what people (staff) wanted her to do, and so people disliked her, and get really disappointed when she could not follow through. That	of providing end-of-life care" "Another common issue was concern that the symptoms of SMI would interfere with the nurse's ability to provide good care to the patient" "Another psychiatric nurse described the difficulty patients have trusting staff and following through with instructions and a plan of care" "One of the palliative care nurses described how difficult it can be to have realistic conversations about the	have to have the entire team with you, helping you, giving you relief from taking care of them…. It's probably their splitting and their personality as far as you know. . . what they say they want, but what they actually do . . . or, um, their unpredictability" "I was nervous before I met her…And I was afraid that she would not be comforted by me or		Difficult to follow instructions Staff training

					was part of her illness . . . and that would get people mad…” “When we have discussions regarding goals of care, um, she has a very flat affect and she’s not very expressive and she’s also kinda, paranoid and afraid of people, doesn’t really trust medical people, uhm and so when we try to talk about goals of care, she really essentially doesn’t want to talk about it at all”	patients’ wishes at end-of-life”	feel safe with me ...” . . I think there is also a need to educate people in dealing with pain management and that number one, just because narcotics are prescribed, you’re not going to make everyone an addict ...” “I think psych nurses need to have a good background in medical nursing . . . continue to keep up their skills in physical		

							assessment and medical issues”		
Morton-Nance et al, 2012 **England** **End-of-life care for people with a learning disability[57] (S3/S4, consensus= S3)**	‘A good experience is when the family are prepared. The carers were good and accepting of what was happening and the patient seemed to be prepared for it’ ‘I think as well... giving them choices... empowering them somehow to have the right to say what it is they want to say and contribute to decisions about treatment’	The majority expressed favourable thoughts when palliative care involved person-centredness, good planning, preparation, outreaching and sharing of information with other healthcare professionals” “The importance of patient choice was identified, ultimately affecting dignity in death” “Building therapeutic relationships with patients is important.	‘Where there isn’t somebody familiar around... in my experience the person with a learning disability just ends up in hospital... which then creates all sorts of other problems’ “In the community it comes down to staff [carers] within the care homes... some of	“They recognised that there were limited choices offered to this patient group and acknowledged unsatisfactory outcomes when a patient was placed in an unfamiliar environment” “Participants stated that their experience of care delivery was dependent on the attitude of other healthcare	‘In some respects, I suppose the problem is... that how can you get that concept of death across or should you... or should you... no actually... that may be cruel’ ‘They say that everybody has the right to know their diagnosis, but within learning disability they tend to, well, the carers all know the diagnosis, but the person with a learning disability usually	“Participants expressed withholding information with good intentions to be able to help, advise and protect patients” “Reflecting on negative experiences concerning end-of-life, participants recognised that inequalities in palliative care remained for people with a learning disability” Difficulties in communication between healthcare professionals were thought to	‘... better joint working practices... actually linking in with the appropriate people and being able to access these services’ ‘I wouldn’t know where to begin. it is very hard to say to somebody you may not survive this... but someone with a learning disability, I mean how would you couch it?’	“Participants also recognised the importance and need for collaborative working and sharing of expertise across disciplines” “Inexperience and lack of understanding, skills and training on the part of some carers significantly affected quality of care at the end-of-life” “Participants expressed feelings of discomfort when breaking bad news and discussing issues surrounding death and dying directly with the person	Questions around disclosure Early preparedness Autonomy Familiar environment for end-of-life care Inequalities in care Collaborative working Staff training- on intellectual disability and matters of death

	‘We try to anticipate and fulfil all their [patients’] needs. Certainly, the team I work in would all go the extra mile if we know what the person wants... helping to facilitate the planning for the death as well... and the funeral... and the aftercare’	Participants spoke about planning and taking control in the working environment, and valuing people involved in providing care. working proactively was observed and internalised as the norm”	them will put in extra time... others are... “well, I am off duty now”	professionals and carers.”	doesn’t... if they don’t know, then it’s not going to hurt them’ ‘From today’s standards... it is a bit hit and miss for them’ ‘Communication between the different people and professionals involved... that is generally very fragmented’	affect the quality of palliative care. Participants raised concerns about a failure to share important information appropriately, making it difficult to meet patients’ basic needs		with a learning disability”	
Ng et al, 2014 **Australia** **How Do Palliative Medicine Specialists Conceptualize Depression? Findings from a Qualitative In-Depth**	‘‘I think that the issues that people deal with at the end of their lives, the emotions they experience and so on, don’t necessarily fit easily into those boxes. It will always be the case that		‘It’s a tricky thing. It’s somewhat person-dependent, in terms of the clinician. guess, because it doesn’t have a physical or you can’t		‘‘There is that classical process of understandable depression. Where of course a person who has advanced cancer and who’s losing their strength and all those sorts of things, of course they	“As a concept, depression was considered difficult to understand, especially when contrasted with the more tangible nature of physical illness. Depression was also considered to be a gray area, with the	‘‘I will often talk to people about the fact that if you had a broken leg, I wouldn’t just ignore your broken leg, I’d try to do something about it. If you’re		Equal importance to mental health symptoms Causative explanations for depression Can be overlooked Stigma

Interview Study[37](S3)	there’s the sort of spectrum of disorders and distress and causation, and we have to pick our way through that.’’		do a test actually looking for biological abnormalities, to some extent, it remains a, you know, gray area, I suppose.’’ “People who are depressed are possibly more generally withdrawn and I guess for that reason, possibly, it may be overlooked.”		would feel depressed. Wouldn’t you feel depressed if that was the situation? But, you know, it’s not clinical depression, it’s just understandable sadness.’’ “You know, what as I think about depression more and more is that when people get de novo depression in the palliative care setting, most of the time it’s a cancer-related syndrome, so it’s a bit like anorexia, cachexia, fatigue, those sorts of syndromes that are often associated	absence of somatic diagnostic markers and the subjective nature of discerning what constitutes depression being factors that make depression imprecise” “Participants commented on the different meanings of the word ‘‘depression”	getting angina. I’ll do something about it. So if you’re feeling really low and very down and very depressed, because your brain chemicals aren’t right, I don’t want to ignore that anymore than I did other parts of your body.’’		

					physically with those things, and the mood is physically associated with that.’’ “I think depression largely in our society is something that people see as a mark of and a stigma, and often people will defend against admitting depression.”				
Ng et al, 2014 **Australia** **Palliative medicine specialists’ causal explanations for depression in the palliative care setting: a qualitative in-depth**	“Obviously, you know, seriously depressing life situations can cause people to become depressed.” “…there’s such pressure on people to maintain hope and be positive, that	Receiving bad news such as disease progression and transitioning into palliative care were considered to be triggers that accounted for increased incidence of depression at those times in the illness	“…the patients that come to mind (as more vulnerable to depression) are often the patients who are more isolated, so patients who live	The devaluing by society of those who are old, ill, debilitated and dying was also considered to contribute to depression in terminally ill patients	“I think it’s hard to pin down to one cause, or even say what the contribution is…there’s possibly a bias from other members of the team to look for psycho-socio-spiritual issues in terms of causing the				Difficult to conceptualize depression in palliative care Understanding context Social isolation can increase risk

interview study[45] (S2)	it almost denies them the opportunity to think about the negatives, and by not acknowledging that, I think that generates a lot of anxiety and fear and uncertainty, which again might be interpreted as depression.”	trajectory. Another subtheme was that inability to accept illness and dying leads to depression.” “Participants articulated multiple causal explanations for depression, and how individual explanations were understood in relation with one another”	on their own…people who are estranged from families…it seems to be more of a problem for those people who are socially isolated and alone.”		patient’s mental distress and depressive symptoms, rather than thinking there’s a disease that requires physical treatment…I don’t think it’s one or the other.” “I think it’s part of a biopsychosocial response…with people who have got cancer, it’s because of illness. Others see it as a major challenge to their personal integrity as a person, and there is a lot of stress, physically, psychologicall				

					y, emotionally, spiritually on the body, and I guess depression comes about as an abnormal delay in response to everything that’s happened.”				
Ng et al, 2015 **Australia** **Treatment approaches of palliative medicine specialists for depression in the palliative care setting: Findings from a qualitative, in-depth interview study[46] (S3/S4, consensus= S3)**	“I think you can’t address emotional things in isolation…it goes without saying that we rigorously address the obtrusive physical symptoms, and are obliged then to follow up their emotional pain and their spiritual pain…I think holistic care means that				“…it’s that business of just…how much of it is depression and how much of it is an appropriate reaction to a horrible situation. And often, I guess, we treat it as depression because if we can make them a bit better, it’s a good thing.”		“…the complexity of their lives is a unique and individual thing…if you recognise that and approach it as that, and then take each person on their own merits…rather than trying to categorise them…in some people you		Equal importance to mental health symptoms Individualize care More training and collaboration Different causal explanations

	we look at the whole person…to see if we can relieve their distress in other parts of who they are, and that may mean then that we need to address a depressed state.” “There is obviously…a difference in the way in which various disciplines respond to depression,…I suspect that the social workers from their perspective more look at the way in which people interact and their environment, and the nurses look at						might use some antidepressants, but in all of them, you need to look at the context in which they are approaching the end of their life, and their experiences and what’s shaped them the way that they are.” “…we would do better if I think we knew that particularly for a group of patients who we felt that we were struggling with, that we could actually ask for some		

	how they can actually provide support and care, and to prevent bad things from happening to people, and medical staff are probably in more of that diagnostic doing-stuff mode…One of the benefits of having a team, is that each of those three aspects can actually be brought to bear on the patient, hopefully constructively.”						more help, so if we could actually have a psychiatrist, for example, who could go out and do a home visit on some of these patients and look at some better strategies, or even to say to us, yeah…I do agree with you, I think this person is depressed, or no, I don’t. That second opinion is really quite powerful.”		
Read et al, 2012 **UK**		"Shortly before she died, she described the hospice to her bereavement				“The professionals involved may not know whether the		“The Mental Capacity Act (2005) establishes the statutory framework for	Good environment for end-of-life care

Critical reflections on end-of-life care for people with intellectual disabilities: a single case study approach[69] (S2/S3, consensus= S2)		counsellor as what she thought heaven might be like- 'quiet and peaceful'—and said that she hoped to meet her (deceased) father there." "Written documentary evidence of a patient's wishes can enable appropriate supportive action, ensuring that all associated health professionals are fully informed of the patient's choices."				patient simply does not want to talk, does not understand the concept and finality of death, or lacks the verbal repertoire to engage in such conversations. Professionals need to provide open invitations for patients with an ID to talk about death using clear and simple language and visual stimuli, such as booklets"		care planning when the capacity to make decisions is lost (either temporarily or permanently), best interest discussion groups…. may actively support the decision-making process and make it more transparent." "This perceived sense of vulnerability among both patients and staff emerged from the focus group discussion, particularly in relation to a lack of knowledge and skills"	Capacity and ethics Early planning Disclosure Communication barriers Improve staff training
Relyea et al 2018 **Canada**		"It is imperative that individuals with schizophrenia are provided with holistic person-		"Health-care providers described difficulties communicating with these		"...health-care providers often overlook medical symptoms and attribute these to the mental		"Dying individuals with schizophrenia were unlikely to be referred to palliative end-of-life care and received	Less access to end of life care Diagnostic overshadowing

On the Margins of Death: A Scoping Review on Palliative Care and Schizophrenia [81] **S4**		centered care. Research has demonstrated that hospice can be facilitated in any type of setting that the individual considers their home, such as a group home, assisted living facility, shelter, or long-term care home” “Collaboration between palliative care teams, community partners, and community mental health settings providing staff with educational opportunities to develop competency in caring for patients at the end of life is reported as the		patients due to the lack of training and experience working with this patient population, which is detrimental to providing quality end-of-life care”		illness...When this occurs, patients were less likely to be referred to the necessary specialized medical treatment.” “Individuals with schizophrenia were reportedly interested in discussions regarding end-of-life care and have the ability to communicate their preferences.[17] However, more often health-care providers associate a diagnosis of schizophrenia with the incapacity to make decisions as a result of their incompetence and emotional fragility,		significantly less acute care, home care, and pain management at the end of life in comparison to end-of-life patients without schizophreni..Explanations for these discrepancies in care were accredited to the high prevalence of homelessness, incarceration, health-care provider bias, and under treatment of physical illness within the population of people living with schizophrenia.”	Questions around decision making capacity and ability to understand and pastake in end-of-life conversations Familiar location for end of life care Collaboration among different teams Increased training for staff providing care to this population

		best way to serve complex individuals who suffer from mental illness at the end of life”				consequently disregarding the need to incorporate patients in end-of-life care conversations” “Patients with schizophrenia will more often refuse to engage with medical practitioners and even if they do engage, the diagnosis is often not properly explained”			
Ryan et al, 2010 **Ireland** **An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people**				“Individual units within the intellectual disability organizations did not appear to share their experiences of palliative care provision with each other, and as	‘...You do the best you can within the situation, and you hope that its appropriate to the situation’ “I remember, you know, when I was training it was – I can even see the	“It was often more ‘difficult'. It was felt that people with intellectual disabilities and their carers had special needs in a number of areas, and participants were unsure of their abilities to meet these needs. Due to	‘You’re always very aware of the primary care team, and you’re only giving advice and support, so you don’t want to do anything that upsets people...probably more	“Participants felt that their shortcomings could be overcome, to some degree, by working in partnership. Interestingly, however, it became apparent that a shared desire to cooperate was not sufficient to	Increase staff training Collaboration

with intellectual disabilities[49].(S3/S4, consensus= S3)				a result there was little organization-wide learning gained from isolated interactions. ”	section in the book – it was like, maybe two pages.... ‘‘Care of the Dying Patient’’...two pages...and ‘‘Preparing the Body’’. I’m like, ‘‘Oh my God! Is this what I’ve to do?’’ But that was it. There was no such thing...I don’t remember the buzz-word of ‘‘palliative care’’ at the time...’	their lack of knowledge and experience” “There was agreement among ID staff that their training to date had not adequately prepared them for the role of caring for service users towards the end-of-life.”	so with learning disabilities... you don’t want to upset people’.	guarantee effective collaboration. PC staff felt limited by their perceived lack of skills in the area and admitted that their approach was not as proactive as it would normally be when dealing with a person from the general population”	
Ryan et al, 2011 **Ireland** **Communication contexts about illness, death and dying for people with intellectual disabilities and life-**				“Staff relied on the carers of the person with intellectual disabilities to bridge communication gaps and to remedy their perceived shortcomings. However,	‘You don’t know what they...how they have...computed, interpreted what you have said to them and what effect it’s having on them. And that would	“Participants recognized that many people with intellectual disabilities have communication impairments, and therefore the participants felt that this was one of the most significant difficulties facing this	“But when it comes to speaking about death to them, we’re not familiar with it. We’re familiar with nursing them and everything else, but to sit down	“Importantly, many staff spoke of their lack of knowledge and skills in the area. They did not feel that their training adequately prepared them for these encounters, and they were fearful of causing additional harm to the individual by	Issues around communication Questions around capacity Training on communication

limiting illness[76] (S4)				palliative care staff were commonly over-reliant on carers to meet communication needs.”	have...that would apply to quite a number of situations’	population. Participants considered the issue to be most problematic when communicating with people with severe and profound disabilities, but admitted to anxiety even when communicating with people with mild disabilities’ ‘However, in practice, staff did not appear to have an agreed-upon way of assessing this, and different team members could have quite different opinions about a person’s level of insight.”	and discuss with them, even when they want to talk about it, I even find it hard.” “We did have two incidents where families said, “No, we don’t want them to know.” And the families’ wishes were respected, as opposed to the clients.’	engaging in such conversations in an inappropriate manner” “They were unused to talking about end-of-life issues with service users or their families. They commented that they found it complex and challenging to speak of these issues, and revealed feelings of uncertainty while speaking of their experiences” They also tried to develop a trusting relationship with the family and to explore the possible consequences of collusion with them”	Questions around disclosure

Ryan et al, 2011 **Ireland** **End-of-Life Care for People with Intellectual Disabilities: Paid Carer Perspectives**[68] **(S3/S4, consensus=S3)**			“And then they [the relatives] were coming every week. And they were by the bed….and we were brushed out of the picture completely.”	“There were a number of issues which appeared to consistently heighten the emotional distress of staff caring for service users at the end-of-life. The first was when relationships between family members and staff were strained.”	‘I think a lot of the guilt comes from when we can’t send staff down to support our clients because we’re not allowed to- because the units have to be run and managed and supported due to staff shortages, and sick leave and that.” “I had where the family had made the decision again this person was in care most of their lives and the family had made the decision for no resuscitation and I found that really, really difficult that this	“Staff experienced particularly strong feelings of guilt if they thought that they had failed a service user by failing to get them ‘home’ from hospital or by not being able to remain with them in hospital” “Staff thought that the situation was particularly difficult when service users lacked the capacity to make their own decisions and felt that they operated in a difficult medico-legal environment where legislation did not provide adequate guidance or	“At times he may have been communicating his pain in a way that we weren’t recognising. Because there was a lot of times when he refused to eat and became very withdrawn. When it was all over, I often wondered was that him telling us that he couldn’t, that he was in pain?”	“The multidisciplinary team was regarded as being valuable in the management of complex situations, participants felt that many multidisciplinary teams did not function effectively” “Individual houses and units within the intellectual disability organizations did not appear to share their experiences of palliative care provision with each other, and as a result, there was little organizational wide learning gained from isolated interactions” “…participants’ concerns that they	Familiar place for end-of-life care Collaboration with staff and family Staff training Understaffed Ethics and capacity

					person loved life...”	protection for service users, families or staff.”		were not skilled enough to assess or manage symptoms”	
Ryan et al, 2011 **Ireland** **Exploring the experiences of people with intellectual disabilities when service users die[88] (S3)**	‘I think that maybe that they forget quicker, it’s just that something has happened, and that, you know...Their grief, I think might be a little bit different”	“Palliative care staff had a more varied understanding of the impact of bereavement on people with intellectual disabilities. Most acknowledged that people with intellectual disabilities experience feelings of loss and that it was important to assess needs and provide appropriate supports.”	We’d often hear them refer to things like ‘If she’s sick, is she going to [name of a high support unit where service users are often cared for towards the end-of-life] or is she going to [name of hospital]?’ They automatically, like, associate it with... presumably with death”	“Particular units or hospitals had become synonymous with death”	‘They come up with theories that would frighten you. You’d go ‘‘God!’’ It’s like listening to a child...like a child would come up with things that you wouldn’t think of yourself...’	“Intellectual disability staff commented that service users who experienced the death of a peer often had incomplete understandings of illness and death”	‘...That was strange ‘cos for a family that only came in in the latter years of her life that was very hard...very hard’	“The relatives of the dying service user had an influential role in allowing service users to be involved in the dying and death of their peer.”	Place of care Unable to understand concept of death Collaboration with relatives Different expression of symptoms

Sweers et al, 2013 **Belgium** **End-of-Life (Care) Perspectives and Expectations of Patients with Schizophrenia [80] (S3/S4, consensus= S3)**	‘It is good to have a relationship with someone who has the expertise, to get support from someone whose is specialized in that field, a professional who already had the same experience with other patients. Psychological this it is better for a patient. Patients will feel safer because they know it is an expert. These persons also have a better understanding of the situation, are good listeners, can give advice and comfort	“Good palliative and psychiatric care requires, besides personally involved caregivers who are able to be empathic listeners, also effective pain relief, comfort and medical care as well as an expertise in psychiatric diseases and palliative care.”	‘I do not have many friends but I have some and that is really important. In fact, relationships will keep me stable. Psychosis is losing your mind because you have become unstable and friends and medication keep me more stable.’ ‘No, I do not want to die alone. Looking into another person’s	A restricted social environment or even social isolation is one of the most important consequences for schizophrenic patients			‘For each patient to be able to choose his own way of death, with dignity. I want people to let me do my thing, to let me do it my own way, without complaining. I want to decide when my time has come. That they let me spend the rest of my time like I want it with the people I choose. You have to let people make their own decisions, especially when it concerns		Good knowledge on palliative and psychiatric management Allow patients to make their own decisions where possible Social interaction

	when necessary”		eye, holding one’s hand all these things are not possible when the other is not physically present when you die. Therefore, it is good to be surrounded by people.’				the end-of-life.’		
Todd, 2013 **UK** **‘Being there’: The Experiences of Staff in Dealing with Matters of Dying and Death in Services for People with Intellectual Disabilities**[58]	A hospital death would have been a bad death. She’d lived in a hospital before. So, it was right for her to die at home! I don’t think it is right that people should go back into an institution to die. That	““When death was expected, hospital deaths were seen as being inappropriate and something to be resisted.” “Not all hospital deaths were seen as completely ‘failed deaths. The key here seemed to be			We kind of said’ Don’t worry, everything will be ok!’ That’s terrible now looking back. But I think it was the right thing to do. I don’t think she’d have coped. Well, I don’t think so anyway. She was someone	“As might be expected, the decision not to inform someone of their dying status was done for reasons of care and emotional protection.” “Dying was seen by staff as involving emotional			Familiar place of death Collaboration among staff Questions around disclosure Challenges around death and dying

(S3/S4, consensus=S3)	would be wrong, wouldn’t it? I would say that this was her home. “But we did work together. We cared for Dylan and they cared for us. I think they (hospital staff) were lost and they needed us.”	the perceptions of staff about the value of the person with the intellectual disability to hospital staff, and to what extent the contribution of intellectual disability staff were valued by them.”			we loved and cared for. So, what was the point in upsetting her?” “You’re too involved with people to be distant. I’m human. I think I thought about leaving a lot since then really. I couldn’t cope with his dying. You’ve got be attached to people here and I don’t think I’d survive again. I felt as if we had no support”	suffering, and staff prevented this by managing a dying individual’s awareness of it” “Death presented a number of challenges to staff that threatened or undermined their caring commitments… ”			
Tuffrey-Wijne, 2013 **England** **A new model for breaking bad news to people with**	‘A fifteen-minute clinical appointment may not be the best way to tell somebody with a learning				‘If it was me, I don’t know if I’d want to be told, really. I think I might be too upset.’ ‘If [my son] was to ask us	“Most participants with IDs thought that people with a poor prognosis should be told, although some	“Breaking bad news was attempted several times and always seemed to go well to	“Whether they experience the news of a poor prognosis as ‘bad news’ depends on their comprehension of the diagnosis and prognosis, as well	Questions around disclosure Adapt the process Capacity and

intellectual disabilities[88] (S3/S4, consensus=S3)	disability. They may need that fed in their own environment with the care staff around, the picture books and you know, other bits around them, to really be able to understand it’				what’s going to happen to me, I think I’d lie for his own good... I can’t see the point in telling the end situation.’ ‘The person comes first. You know, the family are not my patient... but we work very hard to try and support people and to explain it, and they can see that it is alright afterwards’ ‘If I was going to be told bad news, I much rather if a GP or a doctor at the hospital to tell me, instead of hearing it second hand from my mum	voiced reservations” “Family carers were almost unanimous in their desire to be told first if their relative had a poor prognosis, and wished to protect the person with IDs from such news” “Physicians were clearest about their responsibilities around truth disclosure”	those present – until the next episode when it became evident very little had been understood. ” “His understanding is very concrete. My sister was dying of cancer, and every time I had visited her, he would ask, ‘is she dead yet? You told me she was going to die!’ You can’t tell him something is going to happen, and then not tell him when”	as on their concept of time and abstract”	understanding

					or from my dad.'				
Tuffrey-Wijne et al, 2007 **England** **Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London.[75] (S3/S4, consensus=S3)**	"It was felt it would be appropriate for a joint visit between a nurse and the social worker from the outset, whereas in normal circumstances the nurse would go out to make an assessment, and it may or may not be necessary for a social worker to go." "What I would have really liked was if the learning disabilities team had come up here and advised us on this	"Liaising with ID professionals who knew the patient well was particularly helpful around issues of mental capacity and consent, for example, in giving palliative care staff the confidence to administer analgesia without the patient's knowledge or without a full assessment if necessary"			There was just a lot of difficulty around his understanding of his illness... "The difficulty is their level of understanding , and knowing how much you should keep repeating yourself, and how much they're never going to understand anyway." "If people aren't communicating in a normal conventional way, then there's always the danger that you're	"Participants needed to keep repeating information or answering the same questions, which could be time-consuming." "The need to involve family or carers in gaining an understanding of the patient's emotions or symptoms, in some cases relying on them heavily. It could be difficult to know how to communicate and how much the person understood."	"I gave some informal teaching to the staff on end-of-life issues, symptoms they should be looking out for and giving them information on the illness this chap had been diagnosed with so that they had an idea of what was going on and what they should expect"	"Palliative care professionals working in the community were called to residential care settings, not so much to support the patient but to support the care staff, who were highly dedicated but lacked knowledge and confidence"	Increase staff training on end-of-life issues Adapting the process-Communication Collaboration

	specific patient. . . What I wanted was advice on what to do with this lady and her particular issues, and I think a training session on learning disabilities in general, although it would be very helpful, may not have answered my specific questions on her”				missing something.”				
Tuffrey-Wijne et al, 2008 **UK** **Communication difficulties and intellectual disability in end-of-life care[70]**	‘The first thing I would find out is how this person communicates; what their communication systems are, so hopefully there would be carers or relatives that	“Palliative care staff may be aware of different forms of communication, and often recognize the key role of family and carers”	‘They are unable to ask for things that are not actually present and are dependent on others to present them with		‘Communication was basically non-existent, so if we went to talk to him, he would pull the sheet over his head and that was it. I don’t think he ever communicate	“Non-verbal aspects include facial expressions, touch, gestures, interpersonal spacing and posture.”			Non-verbal communication Other forms of communication

(S3)	you could talk to maybe first.’		the real tangible items... [they] can only react to situations as they arise. Such reactive communicative behaviour is often interpreted as challenging (for example, “He spits his food out on purpose”)’.		d; he certainly didn’t communicate with us. His communication had always been very limited.’ ‘I couldn’t communicate with the person because he couldn’t verbalise how he was feeling so you are dependent on the family for what he is feeling, what his symptoms are, what his likes and dislikes are.’				
Tuffrey-Wijne et al, 2013 **England** **Developing Guidelines for Disclosure or Non-Disclosure of**					“If [my son] was to ask us what’s going to happen to me, I think I’d lie. I’d lie for his own good…”	“Most family carers, almost all of whom were parents of people with intellectual disabilities in their 20s and 30s, felt strongly that it	‘I do think ignorance is bliss if you can get away with it’ ‘We label that as “oh, the person	“They felt that bad news would cause the person distress and that if non-disclosure prevented such distress, this was a good thing. Many could not see any	Questions around disclosure

Bad News Around Life-Limiting Illness and Death to People with Intellectual Disabilities[90] (S3/S4, consensus=S3)					‘There’s that bit that’s saying, “oh, you know, they’re an adult and they have a right to know. “But I think your motherly instinct overtakes you and think, “Why give them more misery?” ‘I don’t feel confident as a manager that I’d have the power not to tell somebody’. ‘I think each case must be looked at on an individual basis with the needs of the patient and their level of understanding and comprehensio	was better to protect their son or daughter from the truth” “Professionals working in intellectual disabilities services were overwhelmingly in favour of disclosing bad news to someone with intellectual disabilities” “Doctors and nurses working in hospitals, hospices or palliative care services also felt that the person with intellectual disabilities should be told about their own ill-health and poor prognosis, but only if full disclosure was right for the particular individual.”	is not ready for it or they couldn’t cope,” but actually it is us that can’t cope with its sometimes’. ‘Somebody became acutely ill and was asking me, “Am I going to die?” And I wasn’t able to answer that question, because I didn’t fully understand the prognosis.’ ‘He had very complex needs and a very severe learning disability and there was no way that we	benefit in giving bad news” “The prospect of breaking bad news to someone with intellectual disabilities was overwhelming for many participants, in particular family carers (who are often recipients of the bad news too), but some intellectual disabilities professionals as well.” “An inability to understand the information was an important reason for non-disclosure.”	

					n kept central to the decision-making process…' 'The person comes first. The family are not my patient'. 'As long as they've been supported by somebody, then I think that they have the right to know as an adult, because if it was any of us, we feel like we would'		could have explained it in any way'.		
Tuffrey-Wijne, 2002 **U.K** **The palliative care needs of people with intellectual disabilities: a case study[42] (S2)**	'The GP readily being there and talking us through his condition, and to reassure us... When he'd come back from hospital, the district nurses	'The GP and the carers readily identified the district nurses as the most supportive agency. Their offers of training and general support, as well as the prompt	'When he was going downhill, people maybe saw it as manipulation.'	"They admitted that this had obscured their initial judgement of his symptoms. Similarly, his complaints of pain were not	'His understanding may be limited, it's difficult to say this is the mark where, you know, what's for his own good and where we should be	"While most respondents identified this as an issue of 'non-compliance', the real difficulty was around the important ethical issue of consent to treatment..."	'It polarised him in a way. His loyalty tohis family and his loyalty to the staff.'	People with intellectual disabilities can have close links and loyalties to both the residential home where they live and their own family. This can cause difficulties if there are different	Diagnostic overshadowing Autonomy and ethics Collaboration Disclosure

	have been brilliant... It’s been a good network.’	provision of equipment, were highly appreciated.’		identified as significant at the time, but rather as ‘playing up’	respecting his right of choice.’ ‘They say, when he asks things like ‘am I going to die’, they just sort of reflect it back to him. I thought that was just slightly ducking the issue, I must admit.” “We don’t want to make him feel ‘oh I’m dying’. So, we’ve cheered him up... we just say, “well, things couldn’t be worse. It may get better for good Jim”, and we just console him.’	“Most felt that it should be discussed, and one carer raised the ethical issue of a client’s right to information, but all were concerned what effect such information would have on a client with intellectual disabilities.”		views about important issues.	

Tuffrey-Wijne, 2003 **U.K** **The palliative care needs of people with intellectual disabilities: a literature review[71]** **(S2)**		"There was a clear need to develop greater understanding of the respective roles of specialists in intellectual disabilities and in cancer and palliative care services. Satisfaction with services occurred when there was a good partnership working between the different organizations involved in providing services, and a sharing of knowledge and information"				"Symptoms were just tolerated or expressed atypically as irritability, inactivity, loss of appetite or sleep problems. The author concluded that diagnosis and intervention require knowledge of specific risk factors and atypical presentation of symptoms, close observations by carers and regular routine diagnostic screening" "While some people would cry in pain, others used a specific word, or even a type of laugh. This indicates the value of		"They found that educational needs centred on understanding intellectual disability and its effect on social competence, assessment of pain and interpretation of alternative communication system" "Training needs of intellectual disability carers include knowledge of terminal illness, practical help and advice to enhance their health surveillance role, psychological support to manage their own feelings of fear and anxiety and advice regarding breaking bad news. Palliative care professionals need to develop more effective diagnostic tools for people with	Atypical presentation of symptoms Assessing pain Increase training on symptoms and communication Collaboration

						involving close carers, who know the individual well, in helping interpret possible pain behaviours.”		intellectual disabilities, an understanding of intellectual disability services and skills in communicating with people with intellectual disabilities” “How people with intellectual disabilities experience and communicate their symptoms is a notably under-researched area that needs to be addressed”	
Voss et al, 2017 **The Netherlands** **Advance Care Planning in Palliative Care for People with Intellectual Disabilities: A**		“ACP contributed to effective care for the patient’s illness and conditions, and professionals acted in accordance with the plans that had been discussed. Moreover,				“Physicians preferred to discuss ELDs in a stable and calm situation, when emotions were under control and enough time could be spent on a sensible discussion.34However, this was often not			Advance care planning Communication issues Questions around disclosure

Systematic Review[83] **(S4)**		professionals felt more confident after ACP discussions in their dealings with the patient.”				possible because of a late diagnosis of the illness. Professionals did not always recognize non-verbal symptoms or saw symptoms as part of the disability” “Professionals were not prepared to discuss end-of-life issues with the patient because they believed the patient would not understand and they did not know who had the authority to tell the patient directly”.			Diagnostic overshadowing
Voss et al, 2019 **Advance care planning in the palliative phase of**	“I try to involve them [family] as much as possible so they know how she’s	“In the interviews, professionals acknowledged the importance of relatives’ involvement”			“Getting older …. I don’t know what I should say to her about that. That she is getting	“In the interviews, professionals in 22 of the 30 cases said that it was not possible to			Questions around capacity and disclosure

people with intellectual disabilities: analysis of medical files and interviews[86] (S3/S4, consensus = S3)	doing. And about the deterioration, how it’s progressing and what they [family] think about that.” “I have to say that I’m very satisfied with how it went. We only disagreed when they [professionals] still wanted to arrange the examination – or at any rate wanted to consult a physician – and I didn’t like the sound of it, but we talked about all of this very openly and clearly. I didn’t feel I was being pressured either. And eventually I				older and she will eventually die? I think that would only make her anxious.”	involve the person with ID in ACP because the person did not have the intellectual capacity, could not oversee the situation and/or was too fearful to discuss the matter”			Collaboration with relatives and carers

	thought: they spend so much time with her, they'll be better able than me to estimate whether she can cope with this."								
Voss et al, 2020 **The Netherlands** **What is important for advance care planning in the palliative phase of people with intellectual disabilities? A multi-perspective interview study[84]. (S3/S4, consensus=S3)**	"It is of course essential to act and think in the interest of the client [person with ID] ... that should be a requirement. ... It is important to know who you are talking about, [especially] if people cannot talk about it anymore [themselves]." "For example, there was a client [with ID] who wanted to	"To be able to truly simulate what the person with intellectual disabilities wishes, it is import to set aside own preferences and to model what that person stands for in their life, and adjust care according to their goals and needs." "Additionally, professionals found it important to adapt the ACP process to suit			"And if you can substantiate it very well, then the family understands. Then they see, then they say, 'actually yes, you are telling now what I actually already have seen'. And then you also see that the family is very happy with that afterwards" "It is just hard when it [the need for ACP] is spoken out	"In this way, the person with intellectual disabilities and their relatives could be better prepared and have a better understanding of what can be expected in the future. ACP was also found to be helpful for professionals so that they know how to best support an individual in changing situations"	'Then they [relatives] know what is wrong with me'—Interview 2, participant with intellectual disabilities (2), and 'Otherwise they [relatives] would worry' "If a decision needed to be taken, they would let me know and asked if it was fine. Well, yes, I	"According to participants, it is important that everyone who is involved in the care for persons with intellectual disabilities who need palliative care should work together to inform one another and identify whether things are going well or not" "Participants with intellectual disabilities wanted to be informed about their health situation"	Act in patient's best interest and adapt process Collaboration Start planning early Disclosure-relatives/ patients' opinions

	take her television with her when going to heaven, [that was] very important [for her]. Or her electric wheelchair needed to go with her because how else could she move there?... It was very important for her” “I notice with us, also within the team, it is very discussable. We don’t avoid that subject at all and that is pleasant, because I have worked in a team where it was harder.”	the level of understanding and experiences of the person with intellectual disabilities.” “Professionals explained that honesty and openness within a team of people caring for and about a person with intellectual disabilities contributed to a more positive and calmer ACP process”			loud. stress That everything is just addressed in a timely manner. That not everything needs to be arranged at the last minute, that a lot of things are just fixed, that they really calmly, can be present in the phase of dying” “It is very important to keep discussing the situation continuously. But you [as a professional] should also get a sense of the parents [of people with ID]. Some are really not ready yet to think about the future and		thought they [professionals] will know best how to arrange it. ... We [as a family] just knew, they are caring for T. and for the other residents every day. So,they will know better than us what to do” “If I know what's wrong with me, then I can do something about it.”		

					death. But you can bring it up very openly. And then parents can always say ‘no’”				
Vrijmoeth et al, 2016 **The Netherlands** **Physicians’ identification of the need for palliative care in people with intellectual disabilities[41] (S3)**	“There was an evident physical decline, mainly because of recurrent infections[...] where the effect of antibiotics fails to happen, so that you almost could start treatment after treatment.” “Whereas I completely didn’t recognize it at that stage, my experienced colleague did [...] She had	“The extent in which ID-physicians are able to identify a need for palliative care also depends on experience and knowledge” “How physicians value communication with proxies, such as professional caregivers and relatives, as providers of contextual information is an important care feature that may influence awareness of			“Yes, I think that especially the diagnostic uncertainty makes it difficult whether you should really stop with treatment or not.” “How do you recognize that a patient is in need for palliative care? [...] (IDP) Well, at the moment the course of the illness is not as you expected it to be.” “This woman[...] had an	“Disease of the patient, the stage and prognosis of the disease and the remaining treatment options all affect the process of identification of the need for palliative care. Diagnosis of a life-threatening disease with a poor prognosis and expected death in the near future is likely to induce a sudden awareness of the need for palliative care” “...care for people with ID,	“Those are the people for whom it is difficult to determine whether there are genuine problems, is someone really in pain or does (s)he really suffer. In some people it is evident and in some people it is not.” “yes, that also depends on what someone was able to do before,	“ID-physicians found it more difficult to notice and interpret signals of people with more severe ID. This relates to the inability of people with more severe ID to express themselves in a way that can be understood by the physician.”	Identifying diagnosis and need for treatment Communication challenges Knowledge of physicians Interpreting symptoms

	been a nursing home physician before. Therefore, she had experience in end-of-life care and with patients' death and dying. [...] She recognized something I had never seen before" "Well, if professional caregivers work for a long time with a patient and when they know a patient well, then they are able to assess and manage reactions, and if these are different, they notice that. [...]And that is extremely important."	the need for palliative care"			aversion towards physicians; therefore, professional caregivers were better informed than I was. So, I really needed her professional caregivers to get a view of her situation"	the nature of underlying diagnoses or causes of problems are not always identified, possibly due to the often a specific presentation, physician-patient communicational challenges…." "Other barriers in communication may relate to rigid thought patterns of patients with ID"	whether (s)he was always independent"		

Wagemans et al, 2012 **The Netherlands** **End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives[91]** **(S3/S4, consensus= S3)**	“I thought it, ... it’s what [name of patient] would not have wanted, this resuscitation. It would then be OK for a while and then she’d have to go through it all again. I didn’t want that” “Sister: I think she was very thoughtful in the way she dealt with the family. With the family’s wishes, but also with the family as a family. She knew exactly that someone was the	“One representative said about a sister (a person who never spoke) that she would not have wanted to be resuscitated”	“Death was a topic we never raised with A. We talked about it indirectly, when others ... But not with A himself...... W: He would totally panic. He couldn’t deal with that. M: No, but then he couldn’t really understand what it was”		“But that was the hardest part, I thought, I found that very hard indeed: [name of patient] was someone who was profoundly disabled, to put it in everyday terms. So, he had few hobbies, in fact none. And eating was one of the things he really loved ... And well, this eating was now being taken away from him [by the introduction of a gastric tube]. That’s	“The patient representatives had to decide between various options, such as forgoing treatment (e.g., antibiotics or chemotherapy) or continuing certain treatments (e.g. gastric tube and hospital admission), and felt highly responsible for the outcomes.” “According to the patient representatives, even patients with moderate or mild disabilities were unable to make choices”	I: And how did you feel about that? What was your impression of the doctor at that moment? S2: Reluctant. S1: Yes, distant	“The support failed when there was a conflict of opinion between a doctor and a patient representative, as it emerged that the doctor was in the position to make the decision”	Deciding for someone else Disclosure Collaboration with family

	mother or a brother, and she kept that very much in mind”				what it came down to. And that was really tough for me.”				
Wagemans et al, 2013 **The Netherlands** **The factors affecting end-of-life decision-making by physicians of patients with intellectual disabilities in the Netherlands: a qualitative study[66] (S3/S4, consensus=S3)**	“It’s a process in which everyone involved gradually moves towards a decision. The relatives’ wishes carry a lot of weight” “We made agreements as to what had to be done in case of a recurrent stroke, or a pneumonia, what to do if she refused to eat or to drink. And those agreements did not have to be activated for the next two years.”	“The considerations used for the decisions were developed in a complex and often protracted process, in which participants discussed the direction of the further treatment policy, a policy that could change over time depending on changes in health issues” “The physician felt strongly that this was not in the patient’s best interest and did not comply with the family’s			“No, she was not mentally competent. She might have a mild intellectual disability as regards verbal intelligence, and she had considerable practical skills…development was at a much lower level.” “No, we didn’t consult A about this, as we thought that A did not possess the required level to understand this. This idea of ‘what if...’. A simply wasn’t up to that.”	“Each physician who was interviewed about a patient with moderate or mild ID was convinced that their specific patients had been unable to understand the consequences of a choice and could not comprehend the process of decision-making.”	“We agreed at that time to administer a nasogastric tube, even though I did not agree with that at all. But the relatives were particularly worried about one thing, the familiar story: ‘If they become dehydrated, they get terrible thirst. That’s such a torment.’ However often I told them that this wasn’t true, I think	“According to the physicians, good working relation-ships with relatives and paid care staff were the most important factor to ensure an effective process of decision-making. The ‘working relationship’ with relatives refers to that part of a professional’s relationship with relatives that facilitate contributing d the process of decision-making.”	Capacity and autonomy Collaboration with relatives Early planning

		request, although he found not following their wishes a very difficult thing to do”					I just didn’t get through to them. So, I agreed that a nasogastric tube would be applied if there were signs of dehydration.”		
Wagemans et al, 2015 **The Netherlands** **End-of-Life Decision-Making for People with Intellectual Disability from the Perspective of Nurses.**[67] **(S3/S4, consensus=S3)**	“Well, yes, we had a good working relationship with the doctor in this period, where we were able to say anything, we wanted: what we thought, our feelings about it. And the doctor definitely listened to what we said. Yes, absolutely.” “And the doctor explains the	“End-of-life care was a matter of course for nurses and they acknowledged that ultimately end-of-life decisions should be up to the relatives. Thus, they gave the patient’s relatives enough space to make the end-of-life decisions and in the meantime used their position and knowledge to influence both			“You’re faced with this as a professional, and you want to be open and honest I feel connected to you and I want to share with you. I want to help and sup-port you. And then we’re just sitting there pretending nothing’s wrong. So that makes it difficult” “Well, yes, you do have a kind of	“Nurses and relatives could have different views on the patient’s condition and health decline, with nurses talking about palliative care whereas the relatives were not yet ready for that.” “‘The nurses felt that the patients were not fully capable of making their own end-of-life decisions, such as a decision to			Collaboration between specialities and between relatives

	medical situation. And we usually, if the relatives want us to, add information from the nursing group.... And so together we fill in....you get the complete picture”	the doctor and the relatives”			controlling role there.... you just discuss it with the doctor at that stage. And you gradually come to a conclusion, which the doctor thinks is justified and that we as nurses can agree with. And on the basis of that you discuss it with the relatives”	forgo treatment”			
Wagemans et al, 2017 **The Netherlands** **Do-Not-Attempt-Resuscitation orders for people with intellectual disabilities: dilemmas and uncertainties**	‘…Then it's good to discuss this and see what's to be done in this kind of situation. And that often includes whether to resuscitate or not, that's part of it’	‘The most important considerations for physicians when issuing a DNAR order were longstanding chronic medical conditions like congenital physical defects and epilepsy. Considerations like diminished	Sometimes, at the start of the consultation, relatives say: now I'm the one who has to decide. So that's a reason for me to		‘Of course, he had a very low intellectual level, I'd say severely to profoundly disabled. So that means, and I discussed this with his parents of course, that the chances of successful	“Profound or severe intellectual disability was considered to contribute to a DNAR decision, because of brain damage after resuscitation coming on top of existing brain problems. Physicians also			Reasons for DNR Determining quality of life Decision making role

for ID physicians and trainees. The importance of the deliberation process[73] (S3/S4, consensus= S3)	‘In any case, we said that if she starts to experience real impairments, starts to lose functions, that's when the DNAR policy will be effectuated. As it is, the relatives feel she has a comfortable life, so if anything were to happen, they'd prefer [resuscitation] . And as a doctor you then have to estimate whether that would constitute a meaningful medical intervention.’ ‘The effect was that she ended up at a lower level.’	life expectancy, advanced age and severe decline in health status’” “The whole process of resuscitation and recovery was seen as very burdensome and not suitable for those people who could not go through the whole trajectory into Intensive Care and further treatments. In addition, they expected a diminished quality of life afterwards”	explain again...that it's not their decision, but that we just want their opinion as one of the arguments to consider’		resuscitation are naturally much lower.’ ‘To what extent are they suffering? That's often very difficult to say, especially if someone can't communicate’ ‘‘However, I think there's a sliding scale of quality of life of the clients, but also that of relatives, who maybe so burdened by having a child with ID that they feel like, if something should happen and he should die of it...’	felt that people with profound and severe IDs were more vulnerable and that quality of life was lower for them.” “Quality of life was difficult for ID physicians to use as a reason for issuing DNAR orders, and ID physicians tended to leave the judgement to the relatives”			

Wark et al, 2017 **Australia** **Challenges in providing end-of-life care for people with intellectual disability: Health services access**[51] **(S4)**	"There's also more future planning happening, hopefully, in terms of, like, so we're actually talking about what plans are in place as this person is aging, and so perhaps barriers and gaps could be identified there, and how that's done across services" "Certainly, was available at all times. We could ring him any hour of the night and day." "The hospital were very good to her."	"One focus group in a small rural town discussed how they had pro-actively engaged the palliative care team prior to actually needing this support." "While hospitalization is generally considered a last resort in health care, with serious health concerns it is often a vital component of appropriate support."	"They need to be able to look past the disability, but for many, they don't." "Doctors, when they're looking on screen at a client's history, medical history, and they see their condition, so they only have that definition to work with." "Would a person from the general community be	"Doctors often failed to adequately investigate new health issues and were inclined to instead dismiss emerging physical concerns as instead being the result of the intellectual disability." "Community-based health services were often quick to dismiss new health concerns as resulting from the lifelong intellectual disability."	"We knew that we couldn't actually provide that to our clients…when we went looking for [name], we couldn't find anyone so that's something that other services are probably finding too." "We've had doctors that have refused service. They said they don't have time to take on someone with complex medical issues, meaning an intellectual disability." "…you can't get the	"The term "isolation" was chosen as best reflecting the frustration staff expressed in being aware of the existence of support services, but then being unable to access them consistently or when needed." "One issue highlighted within all the focus group discussions was the lack of funding to support individuals" "Attracting and then retaining suitable staff were also seen as an impediment to the accessing of appropriate health care."	"At [name] Hospital it seems that there were very few staff, if any, that had the specific training around disabilities, intellectual disabilities, and palliative care."	"This lack of training was believed to result in individuals being under supported while in hospital."	No equitable access to care Early planning Lack of training of staff Diagnostic Overshadowing Lack of funding Place for care

			treated the same way? I suspect not, and it gets very hard.”	“Doctors appeared to make judgements about providing medical support for an individual with intellectual disability that would not apply equally to community peers”	balance because there’s not enough funding,” “There’s a high turnover of staff, and continuity of care can be very difficult within that.”				
Wiese et al, 2012 **Australia** **End-of-Life Care and Dying: Issues Raised by Staff Supporting Older People with Intellectual Disability in Living Services**[62] **(S3)**	“...that would honestly pain me to think that he was somewhere new without his familiar surroundings, without the people that he’s worked with for close on ten years.” “I think it is really important for us to all say,	“Unanimously, participants expressed a commitment to providing end-of-life care at the place of client’s choice. Participants felt that end-of-life care should be offered at the place most familiar to the client, and this was interpreted as home.”	..don’t make him an exhibition, somehow or other he cannot lose his identity. He is still Mark, with a personality and a sense of humour and interests.	“Respect for that same client’s individuality”	“It’s not our job obviously to tell, or to convince the father either, but we just think it’s sort of morally wrong. Just because he [Donald] has an intellectual disability doesn’t mean he’s not entitled to know.”	“Despite the difficulty with understanding for some clients, participant opinion on whether clients should be aware of death was unanimous”	“...administering particular medications ...or injections or that we legally [cannot] and have not been trained to do.”	“Participants were clear about medical procedures they were not legally able to provide, including, as articulated by Nicole, the administration of intravenous medication”	Questions around disclosure Familiar place for end-of-life care Collaboration Ethical issues

	let's all learn...we can't do it on our own, but let's all work together. They've [doctors] been very happy to do that." "a really open line of communication...for all the little things, but also that doesn't feel, "I probably should know this but I'm too frightened to say that I don't"	"Preparation was managed in an ongoing way by clear and open communication systems"	He's not somebody just in palliative stages with this need or that need, he's still an individual"		"...they all have different capabilities, but I think they all have a right to know, and I think it would be quite awful to keep something like that from someone..."				

Williams et al 2003 England **A qualitative study of clinical nurse specialists' views on depression in palliative care patients[36](S3/ S4, consensus= S3)**	"We need more help from the psychiatrists ¡/ we think nothing of getting an anaesthetist to see the patients, but ponder for so long over a psychiatrist and when they come . . . they really do help and teach us as well..."		"...we just do not ask about it often enough . . . and when we do, we do not let patients know how common it is ¡/ they often think they are the only ones and that they are not coping . . . You know failing in some way..."	A very experienced nurse specialist who also carried out complementary therapy said early in the interview that she would ask patients during a complementary therapy session, how they were feeling in their mood. When asked what she did if their responses suggested they may be depressed, she said she advised them to contact their GP or mention it at their next hospice out	"...you know when we talk about depression, there is certain stigma . . . I feel depression has a stigma myself..."	" Stigma and the nurses' difficulty of using the word depression were also a recurrent theme. Many of the nurses felt that mental health issues had a stigma within palliative care and that this prevented or inhibited them in some cases from enquiring about a patient's mood"	"I don't remember a single mention of it on the 931 (the English National Board course for specialist palliative care nurses) . . . no come to think of it there was nothing . . . definitely nothing." ". we get so much in service teaching and study days on assessing pain, new drugs for pain, etc., but very little on how to assess for depression..."		Equal importance to mental health symptoms Lack of training Stigma around mental illness Collaborative working

				patient appointment					
Wilson et al 2020 **U.K** **End-of-life care and place of death in adults with serious mental illness: A systematic review and narrative synthesis**[56] **(S4)**				“We found studies that reported associations between serious mental illness and increased likelihood of dying in hospital, decreased like cilities. Care home deaths were more common in patients with serious m lihood, and no		“...patients with schizophrenia were less likely to be registered with specialist palliative care than patients without schizophrenia and were less likely to receive palliative care if they had died from cancer, chronic obstructive pulmonary disease or certain types of organ failure or			Less access to palliative care More information required about ideal place for end-of-life care

				association between serious mental illness and hospital deaths.” “One consistent finding regarding place of death was concerning care homes, which included nursing home and supported care faental illness, for all causes. One potential explanation for this is, for many people with serious mental illness a care home or similar institutional care setting is their usual		neurological disorder”			

				place of care, and may be more likely to be their place of death, than the general population, who may be more likely to reside at home until their death or nearer to the end of life.”					
Woods et al, 2008 **Canada** **Palliative Care for People with Severe Persistent Mental Illness: A Review of the Literature**[32] **(S3)**		“Health care providers may not be experienced with dying or with mental illness. As a result, they may not want to care for someone who has a problem outside their area of expertise”		This response is thought to be multifactorial and related to biological, social, and psychological issues. When these people seek help from health care providers, they may not present in a typical way and a history may be		“Hospital medical wards and hospices often exclude anyone with management or behavioural problems. While a psychiatry unit may be able to offer assistance with SPMI and continuity of care, it may not be able to access palliative pain and symptom expertise”		“Discussions about end-of-life often bypass people with SPMI because there is a presumption of incapacity and a fear that such discussions will be emotionally and cognitively destabilizing” “The authors concluded that while people with SPMI have more difficulty with understanding and reasoning,	Questions around capacity Increase access to treatment Appropriate place for end-of-life care Late presentation Increased training

				difficult to elicit.Comorbid medical conditions may also be complex. Symptoms of medical and mental health illnesses may not be recognized, leading to undertreatment. As a result, people with SPMI may not have access to cure-oriented treatment in a timely manner, and “palliative care may become the treatment from the time of detection and diagnosis.”		“Late or altered presentation may lead to late diagnosis and limit therapeutic options. People with SPMI may fluctuate in their understanding and acceptance of diagnosis”		compared with the general population, tailored educational interventions can improve understanding to a level that falls within the range of informed decision-making capacity.”	