CURRENT CHALLENGES IN THE DELIVERY OF END OF LIFE CARE IN NEURODEGENERATIVE CONDITIONS

A systematic review

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Indices

Abstract

Background

Quality palliative care can benefit individuals living with a wide range of conditions such as dementia, Motor Neuron Disease (MND) and Chronic obstructive pulmonary disease (COPD), yet there is significant evidence that those with terminal conditions other than cancer are less likely to be offered palliative care services. This results in unplanned treatment at the end of life which may be futile and not cost effective and leads to poor patient and family experiences. There is a need for more multi-disciplinary and client centred approaches that contribute to quality end of life care. Understanding the challenges that influence the delivery of end of life care can support professionals to develop effective responses to those challenges.

Methods

A search was completed using the databases PubMed, Cochrane Library (Wiley) and Sabidi to identify articles published between 2017 to 2023. Search engines were also used; PLOS One, Google, Google Scholar and available Nursing, Psychology and Occupational therapy journals, supplemented by reference tracking.

Results

Each study was analysed using the Cochrane data collection form and the Hawker et al. checklist criteria. The main qualitative findings were grouped into the perspective of the patient and caregiver and include lack of communication between healthcare teams and families and lack of understanding of resources such as ACP or hospice services. The healthcare professional perspectives included challenges around initiating timing of discussions; perception of patients or families preparedness to discuss the modification or cessation of treatment and lack of training of specialised care.

Conclusion

Some of the key challenges identified have the potential to be overcome by focusing on education and training of healthcare professionals. Further research is required to look at more condition specific training needs so that educational resources can be developed, which include communication and spiritual aspects of end of life care, to help health professionals provide individualised support and improve the quality of care for individuals with neurodegenerative conditions.

Keywords: end of life care; palliative care; neurodegenerative disease; neurological condition.

Introduction

Advances in medical practices have prolonged life and reduced much of the physical pain associated with dying (1) from around the time of the initial discovery of antibiotics in 1907 (2), only the beginning of many milestones in medical advancement. Despite this rather incredulous progression, the prolongation of life is, at times, at the expense of the quality of life. Sometimes, preservation of life is no longer the goal (3). It is safe to say of the palliative care professional that there is a strive to improve the quality and length of our patients' lives; nonetheless, death remains the inevitable end of that journey (4). In these cases, palliative care has been shown to benefit people with many conditions and has been hailed as a proactive solution to minimise disability and transform the last years of life into a person centred, meaningful existence (5). However, there is significant evidence that those who have terminal conditions other than cancer are less likely to be offered or have access to palliative care services (6). This can result in unplanned aggressive treatment at the end of life and can be associated with inappropriate treatment, and poor patient and family experience (7) which may be futile and not cost effective (4).

Literature regarding staff perspectives provides a concerning insight into the challenges faced in the end of life or palliative care environment. Hospice carers and medical staff are regularly confronted by change and pressure to provide sincere end-of-life care, which has been noted to cause physical and psychological exhaustion (8,9,10). A study with occupational therapists revealed that 73% respondents considered that their education had not prepared them to deal with clients' spiritual needs at the end of life, and 64% wanted further training in spiritual care (11). A literature review carried out among Intensive care unit (ICU) staff found a lack of knowledge among healthcare professionals about how to conduct challenging conversations about death with patients and families (12). In the context of dementia, Robertson et al found that medical providers may feel ill-equipped or under prepared to have discussions around advanced care planning (ACP) for end of life scenarios and that conducting ACP is outside their scope of practice (13). Furthermore, research identified that members of the multidisciplinary team of patients with neurodegenerative diseases may experience feelings of depression, anxiety and burnout as a result of prolonged involvement with patients and families coping with continual loss (10,14).

Due to the complexity of the physical symptoms in neurological diseases such as Huntington disease (HD), Motor Neuron Disease, Creutzfeldt Jackob Dementia (CJD), Amyotrophic Lateral Sclerosis (ALS), and Multiple Sclerosis (MS), access to and input from specialist clinicians with palliative care expertise is an important and essential consideration (15,16,17).

Despite recent advancements in neuropalliative care, there remains a need for increased collaboration between neurology and palliative care (16,18,19) which should include a multidisciplinary, multi-dimensional approach to end of life care, not only from the perspective of pain management, pressure care management, equipment prescription, nutrition and to provide opportunity to set goals and participate in palliative rehabilitation (19,20) but to also identify the roles and skill set necessary to recognize, assess, and compassionately address the psychosocial, existential, and spiritual aspects of the patient's dying experience.

In recent years with increased interest and investment in research around neurodegenerative conditions with initiatives such as European Platform for Neurodegenerative Diseases (EPND) (21) launched in 2021, there is emerging evidence available to examine the end of life outcomes for this client group.

Evidence demonstrates there is a need for more client centred approaches that contribute to a good death by continuing to develop compassionate, individually tailored, and effective responses to the mounting vulnerability and increasingly difficult physical, psychosocial, and spiritual challenges facing persons living with neurological conditions at the end of life (22).

Hypothesis

Understanding and knowing challenges that influence the delivery of quality end of life care in neurodegenerative conditions can help health professionals provide focused individualised support and improve quality of life for this population.

Objective

The aim of this study is to synthesize evidence from previous studies in order to provide an up to date comprehensive data set of the current challenges that have been identified as barriers to positive outcomes for those at the end of life, including families and professionals.

Methodology

Design: A systematic review of the research literature was carried out to identify relevant studies addressing the review objective. A review protocol was developed and followed, based on the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement (23) and guided by the Cochrane Effective practice and organisation of care (EPOC) (24) and The Cochrane risk of bias assessment tool (25) was also considered for each of the selected studies.

Search strategy: Established based on the PICOS (26) criteria, which is a structure to define the study population, the intervention performed, the comparison group and the results and the scope of application, the search criteria is presented in Table 1.

Table 1

Population	Intervention	Comparison	Outcome
Diagnosed neurodegenerative disease Long term neurological condition The above receiving or who have received end of life care who are deceased Their families and or informal caregivers	Palliative care Spiritual care (a component of palliative care) Advanced care directive and or advanced care planning Training and or education	Usual care No training or education	Quality of life Symptom reduction Care giver burden Healthcare provider outcomes Cost effectiveness

Inclusion criteria

- Concerns people with neurological or neurodegenerative disease and/or their relatives and/or their professional caregivers.
- Describes the use of tools or interventions (interventions may or may not be supported by a specific tool e.g., manual or checklist) for:

- Identification and/or discussion of the approaching end of life and/or related palliative care needs, and/or
- Management of physical, psychological, social or spiritual palliative care needs and symptoms.

- Concerns empirical qualitative and qualitative research on the effects of the tools and interventions with respect to:

- The quality of care provided to people with neurodegenerative diseases at end of life.
- Usability and cost effectiveness of the intervention

Exclusion criteria

- Publications focusing on palliative care in cancer, mental health and palliative care in children with a neurodegenerative condition;
- Existent reviews of the literature (although the review reference lists were studied to identify relevant references);
- Studies which assessed the effectiveness of measures used to evaluate the quality of end of life care.

Search criteria

A comprehensive search was completed using the databases PubMed, Cochrane Library (Wiley) and Sabidi as demonstrated in Table 2. Search engines were also used; PLOS One, Google, Google Scholar and available Nursing, Psychology and Occupational therapy journals. Reference tracking was completed on existing systematic reviews on similar topics to have a wider scope in the field of health. Mendeley was used to manage references.
Years of publication – due to the objective being to review current evidence articles from the last 6 years will be searched 2017 – 2023.

Keywords: end of life care; palliative care; neurodegenerative disease; neurological condition.

Table 2

Search	Query	Results
PubMed	(end of life palliative neurodegenerative) NOT (cancer) Filters: Free full text. Year 2017 - 2023	54
	(end of life palliative neurodegenerative) NOT (cancer) Filters: Free full text, Clinical Trial, year 2017 - 2023	1
	((palliative care) AND (end of life)) OR (neurodegenerative)) AND (neurological)) AND (qualitative) Filters: Free full text, Clinical Trial, Randomized Controlled Trial. Year 2017 - 2023	4
Sabidi	End of life care; neurodegenerative; palliative Use of “expand” function. Year 2017 - 2023	216 581

Cochrane Library	Palliative care; neurodegenerative. Year 2017 - 2023	16
PLOS One	End of life AND neurodegenerative disease NOT cancer; palliative care. Year 2017 - 2023	4

A first review was carried out in which duplicate studies were eliminated in the different databases, those articles with irrelevant information at first sight were eliminated. Articles that examined the efficacy of specific end of life measurement scales or aimed to validate scales were not included. Other articles were excluded as they did not meet the quality criteria. Articles found through the references of included articles were also screened.

Selected studies were reviewed by the author using the Hawker et al. checklist criteria for quality appraisal "Appraising the evidence reviewing disparate data systematically" which examines nine key research quality areas on a scale of 1-4. (27).

The following articles, as presented in Table 3. were selected for systematic review. They will be referred to as Study 1, Study 2. Etc.

Table 3

Author	Title	Journal	Year	Quality
1. Gao W, Wilson R, Hepgul N, Yi D, Evans C, Bajwah S, Crosby V, Wilcock A, Lindsay F, Byrne A, Young C, Groves K, Smith C, Burman R, Chaudhuri KR, Silber E, Higginson IJ; OPTCARE Neuro Trial Investigators. (28)	Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions: A Randomized Clinical Trial	JAMA	2020	32
2. Armstrong. Slande Alliance, Taylor,A. Corsentino, P. Galvin,J.E. (29)	End-of-life experiences in dementia with Lewy bodies: Qualitative interviews with former care givers	PLOS One	2019	34

3. Holyoke, P. Stephenson, B. (30)	Organisation level principles and practices to support spiritual care at the end of life: a qualitative study.	BMC Palliative Care	2017	34
4. Evans,C. Bone, A,E. Yi, D. Goa, W. Morgan, M. Taherzadeh, S. Maddocks, M. Wright ,J. Lindsay, F. Bruni, C. Harding, R. Sleeman, K.E. Gomes, B. Higginson, I ,J. (31)	Community based short term integrated palliative and supportive care reduces symptom distress for older people with chronic non cancer conditions compared with usual care: A randomised controlled single blind mixed method trial.	International Journal of Nursing Studies	2021	36
5. Walter,H. Seeber, Antje, A. Willems, D,L. de Visser, M. (32)	The role of palliative care in chronic progressive neurological diseases – A survey among neurologists in the Netherlands.	Frontiers in Neurology	2019	36
6. Harrison, M,B. Morrissey, D,L. Dalrymple, A,W. D'Abreu, A. Daly, F,N. (33)	Primary palliative care in Huntington disease	Movement Disorders clinical practice	2023	36

Variables

The main outcome variable is related to psychological, emotional, and spiritual factors in relation to quality of care and patients' and caregivers' experiences.

The secondary variable is related to communication and ethical considerations of healthcare professionals

Data extraction and management:

Each study included in the systematic review was analysed manually by the author using the standardised Cochrane data collection form (34). This method allowed for a detailed and thorough analysis of the data. Data was also extracted around themes that emerged from the research question. The Risk of bias analysis of each article was completed based on the Cochrane risk of bias assessment form (25). We analysed the risk of bias of each article including the following variables: selection bias, study design, confounders, study blind, data collection methods, losses and dropouts; integrity of the intervention and analysis.

Results

The objective of this study was to gather evidence from previous studies in order to provide an example of the current challenges that have been identified as barriers to positive outcomes for those with neurodegenerative conditions at the end of their lives, including families and professionals. Six studies were selected for review from the UK, The Netherlands, USA and Canada and included the following conditions – Amyotrophic Lateral Sclerosis (ALS) (101 participants). Lewy Body Dementia (30 participants), Multiple Sclerosis, Motor Neuron Disease, Idiopathic Parkinsons disease Multiple Systems atrophy, Progressive supranuclear palsy (579 participants in total) as well as additional studies with non-specified non cancer conditions including Huntington's disease and High Grade Glioma (HGG). The key results are demonstrated in Table 4. According to the variables psychological, emotional, and spiritual factors in relation to quality of care - patients' and caregivers' experiences; and communication and ethical considerations of healthcare professionals.

Table 4.

Key results **The challenges in delivering end of life care**	
Patient and caregiver perspectives of psychological, emotional and spiritual factors in relation to quality of care.	**Professional perspectives of communication and ethical considerations**
Lack of communication between healthcare teams and families	When and how to initiate timing of discussions
Lack of understanding of available resources such as advanced care planning or utilising hospice services	Healthcare professionals' perception that patients or families "weren't ready to discuss" the modification or cessation of treatment
	Lack of training in specialised end of life care

Some of the identified challenges are more complex and difficult to modify such as predicting timing of death and withdrawal of treatment without advanced care plans in place however, some of the key challenges do have the potential to be overcome with education and training as well as a shift in the cultural paradigm regarding death and dying. This shift can take many years and involves a widespread change in attitudes and behaviours. The results of each of the six studies are as follows;

Study 1 – Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions: A Randomized Clinical Trial

Randomised clinical trial of the effect of Short term Integrated Palliative care (SIPC). Sample size – 350 patients with long term neurological condition (LTNC) and 229 informal caregivers. The most common diagnosed conditions in this study were Multiple Sclerosis (n=148) and Idiopathic Parkinsons disease (n=140) The other conditions included Motor Neuron Disease, Multiple systems atrophy and Progressive super nuclear palsy. SIPC (intervention n=176) and

standard care (control, n=174). Primary outcome - Palliative care symptoms were measured using the Palliative care outcome scale for neurological conditions. The secondary outcomes were health related quality of life, caregiver burden and cost.

Results – There was no significant difference found in the primary outcomes; Minimal statistical difference in cost benefit of the SPIC group was identified; SIPC was considered by patients and care givers, to build resilience, attend to function and deficits and enable caregivers.

Main challenges identified – The authors report that although best efforts were made to standardise SIPC, differences were noted across the research sites. Varying disease course and progression of LTNC makes it difficult to select appropriate outcome measures as these are an important factor in how the intervention effects are interpreted.

Study 2 – End-of-life experiences in dementia with Lewy bodies: Qualitative interviews with former care givers

Semi structured interview process among caregivers and family members of individuals with a diagnosis of Lewy Body Dementia, who had passed away within the last 5 years. Sample size – 30 participants. Participants were recruited via the Lewy Body Dementia associated and consenting participants took part in a 30 minute telephone interview. The semi structured interview consisted of 11 questions based on end of life experiences of the participant or his or her loved one. Emerging themes were identified and significant quotes included.

Results – The key themes which were identified from the qualitative research included poor management of expectations, end-of-life trajectories and hospitalisation, advance care planning, lack of family understanding, hospice, views regarding right-to-die, medications at the end of life, approaching end of life, the death experience, and activities that enhanced end of life.

Main challenges identified – Participants reported that they did not know what to expect from the disease duration and difficulty predicting timing of death was a frequently expressed challenge, nor were some participants aware that LBD is a terminal diagnosis. The need for support or confirmation from the healthcare professionals in the case of lack of understanding between family members would have been beneficial in some reported cases, family members also reported a lack of knowledge of hospice services and the benefits it could offer. The lack of communication between the healthcare providers and the families was also reported as a common challenge.

Study 3. Organisation level principles and practices to support spiritual care at the end of life: a qualitative study.

Interviews were completed with bereaved family members and care providers across 4 hospice sites in North America to determine what principles support high quality spiritual care at the end of life. Sample size – 46 Participants were recruited to complete a semi structured interview focusing on the perceptions of support received or expected support received in the hospice environment with regards to spiritual care. Unfortunately, this study did not determine the conditions of those who were bereaved so the spiritual principles identified may or may not be applicable to spiritual care in neurodegenerative conditions.

Results – The nine Principal themes which supported high quality spiritual care were;

1. The spiritual is not merely a part or element of care, but rather a descriptor of the kind, nature and quality of all care. 2. Quality spiritual care is guided and directed by the dying person and the family. 3. Hospice palliative care is fundamentally a vocation, and the work is inherently spiritual. 4. Quality spiritual care requires care providers to allow spiritual questions and issues to emerge. 5. Quality spiritual care entails the act of 'witnessing.' 6. Quality spiritual care considers place as sacred. Principles that enable the spiritual care practices of care providers 7. Quality spiritual care includes rituals and times dedicated to marking transitions and processing experiences. 8. Quality spiritual care involves creating and sustaining relationships beyond those typical between co-workers. 9. Quality spiritual care emphasizes the role of volunteers, whose presence and work reinforces and ensures that hospice palliative care is grounded as vocational and spiritual. These principles provide a framework for the improvement of spiritual care within end of life care.

Main challenges identified - The meaning of spiritual can be subjective resulting in varying perspectives of what quality spiritual care is and how it is interpreted. This research was carried out within specific spiritual and religious foundations and the principles may not translate into other care settings.

<u>Study 4. Community based short term integrated palliative and supportive care reduces symptom distress for older people with chronic non cancer conditions compared with usual care: A randomised controlled single blind mixed method trial.</u>

A randomised single blind trial was completed to examine the clinical outcomes of short term integrated palliative care for patients with non-cancer conditions. Sample Size – 50 participants and 26 caregivers were selected for the trial and randomised. Information from the intervention n = 24(patients) n=10(caregivers) and Control n=24 (patients) n = 16 (caregivers) were gathered using the Integrated Palliative care outcome scale (IPOS) which measured five key symptoms. Secondary outcomes were measured using the IPOS, The Barthel activities of daily living index and Zarit carer Burden interview.

Results - Quality of life increased from baseline for 12 weeks with the intervention compared to control, and cost of care decreased; a reduction in symptom distress on the five key symptoms in the intervention group was noted as well as decreased costs. The trial demonstrated that community-based specialist palliative care integrated with community nursing and primary care was clinically effective at reducing symptom distress for older people with chronic noncancer conditions and frailty. Short term integrated palliative care is effective and cost effective to reduce symptom concerns for older people with multi morbidity living at home.

Main challenges identified – Low sample size and not culturally reflective in that most participants were white British people. The authors also reported that they failed to assess the carer burden as a secondary outcome.

Study 5. The role of palliative care in chronic progressive neurological diseases – A survey among neurologists in the Netherlands.

A national survey was completed among Neurologists and their role in palliative care in progressive neurological conditions, in the Netherlands. An online survey of 57 questions was performed including questions on education and training. Sample size - 125 Neurologists and residents participated, these neurology professionals mainly worked with Parkinson's disease, Multiple Sclerosis and High Grade Glioma (HGG).

Results – More than half of the participants felt they needed more education and training on how to commence discussions around end of life and treatment restrictions.

Main challenges – Timing of these discussions in important because often physical and cognitive decline had already become apparent before these discussions occurred. It is important to be mindful that an individual may be losing their ability to make informed choices or give consent around advanced care planning.

Study 6. Primary palliative care in Huntington disease

This pilot project collected data on the impact of communication skills training among members of the multi-disciplinary team members of an existing Huntington's disease clinic. The communication skills training was based on evidence-based strategies from VitalTalk (29) on delivering serious news, responding to emotion, defining goals, and mapping a care plan. Sample size - eight of the nine participants completed the pre/post self-evaluation survey where their understanding of palliative care and their readiness to engage in advance care planning discussions before and after their participation in the communication skills training was rated.

Results - Despite reporting above an average understanding of palliative care prior to the intervention the participants demonstrated marked improvements; more likely to initiate conversations around care planning (25% increase) and being more prepared to have serious or difficult discussions (38% increase). The authors report that successful implementation of primary palliative care requires communication skills training for clinicians, education and psychosocial support for patients and care partners, and modification of clinic operations.

Main challenges identified – The training and evidence gathered was specifically among the Huntington's disease population in one clinic. Conducting further research across more clinics and including other neurological conditions using this training framework may be beneficial.

Conclusion

Several challenges to the delivery of high quality care have been identified throughout this review (see table 4. of key results). My study has shown a lack of support provided with regards to the spiritual aspects associated with end of life care and demonstrates gaps in healthcare provider training which both provide challenges for the overall delivery and experience of quality end of life care. The study by Holyoke et al. (30) found that even when establishments have a specific commitment to providing spiritual care at the end of life, the challenges in providing individualised care remain. Spiritual care has an essential role in the end of life treatment and current literature offers few insights to support clinicians in navigating this often-challenging aspect of patient care. Additional research is needed to understand how to address spiritual and religious needs (36).

More than half of the neurologists interviewed in the study by Walter at al. (32) reported that they needed to improve their skills in performing discussions in end of life planning and treatment restrictions, on the other hand the study by Harrison et al.(33) carried out among primary palliative care teams working with patients with Huntington's disease demonstrated positive results after staff received communication training, more team members felt well prepared to discuss serious news (12.5% to 50%) and manage difficult conversations (25% to 62.5%) which demonstrates that a focus on education and training for healthcare professionals may provide a significant improvement in future research outcomes. Further research into specific training and its efficacy is warranted.

The study by Evans et al (31) identified that ACP is an important aspect of palliative care but other studies identify that there is a lack of awareness about these directives which limits their integration into care environments (10-14). Although this research question focused on the challenges in end of life care, the studies by Walter et al . (32) and Evans et al. (31) provided

recommendations regarding advanced care planning, and reported positive cost benefit of end of life care intervention when compared with no intervention. Advanced care planning is supported by The Huntington's disease association (37), National Health Service UK(38), The Parkinsons disease association (39) and the multiple sclerosis society (40). Due to the cognitive and communication difficulties associated with progressive neurological conditions it is recommended that these discussions are started well in advance (36,37,38,39,40). Literature on optimal timing of discussions around advanced care planning is scarce however many benefits have been identified such as allowing the person to have more control over what happens to them; Improving the quality of the end of life care; Reducing the chance that someone receives treatment they do not want; More likely to die in their preferred place of death and reducing anxiety and depression in family and friends after the person dies (41). Although we may be aware of the benefits of early ACP, barriers may remain in the initiation and integration of new care pathways across all healthcare areas. Harrison et al (33) provide a useful guide to ACP as demonstrated in Table 5.

Table 5

Personal Goals/Priorities	Medical Care	Resources
• Personal sources of support	• Symptom management	• Financial resources: POA, disability, insurance, estate planning
• Occupational and recreational goals	• Care planning education	• Counselling, pastoral care
• Engagement with family and community	• Advance directives, health care POA	• In-home and respite care
• Preferences for long-term care	• Options for long-term in-home or facility care	• Community resources, benefit programs

Further research into the integration of advanced care planning and its economic benefit , may provide evidence for the ongoing development and funding of advanced care planning

pathways and warrant modification of local policy to include these pathways for anyone with risk of, or a diagnosis of a neurodegenerative condition.

Discussion

The goal of this systematic review was to examine the current challenges which affect the quality of care delivered to those with neurodegenerative conditions receiving end of life care. By examining the specific challenges, more tailored solutions to these challenges can be found, as supported by Harrison et al (33) which demonstrated positive outcomes following communication training with staff working in a Huntington's disease clinic. Further research and education development can contribute to the overcoming of the challenges faced by staff, improve staff knowledge, confidence, job satisfaction and ultimately improve the quality of life of the dying. The evidence demonstrated in this systematic review could contribute to the further development of education or training programs for healthcare professionals who are interested in increasing their skills in this area. While the findings are valuable, it is important to also note the limitations of the study, which included data collection and search terms – more condition specific data could have been collected should each condition have been searched individually however, due to time restrictions and skill limitation, the terms "neurodegenerative" and "neurological condition" were used instead. That being said, the author found that there was not an abundance of primary research articles available in this field of research. Many articles were also only available through a subscription service, which were costly. A wide search scope was used with a view to gathering international data, this was achieved as articles from the UK, US and Canada and the Netherlands were reviewed however, there are some negative aspects in that it was time consuming and made it challenging for the author to maintain a clear focus on the objective. To mitigate these shortcomings in the future it will be necessary to refine the search focus and narrow the scope, while practicing effective project management and utilising more advanced search techniques In order to make the research findings more robust and impactful.

The challenges for future research include a high rate of death or drop out in this population; Cultural spiritual and religious considerations, which limit a broader applicable framework of delivering end of life care; Inconsistencies in intervention teams, for example access to all members of the multi-disciplinary palliative care team depending on patient location and the healthcare policies in that location. In addition, the symptoms and progression of neurodegenerative conditions have varying aspects and may be difficult to capture condition specific needs at the end of life. More localised and condition specific research needs to occur on an ongoing basis and the data reviewed continuously, with training and education programs

adapted to the needs of those specific populations and strive to achieve better outcomes for people who are approaching or can expect to approach the end of their lives due to a neurodegenerative condition. The World Health Organisation (WHO)(42) also support this, stating in Palliative Care for older people; Better Practices, that high-quality research is urgently needed on palliative care in general, and especially in palliative care for older people, and such research needs to include information on the cost–effectiveness of treatment and services.

Overall, providing end-of-life care for patients with neurodegenerative conditions requires a unified collaborative approach involving national policy makers, healthcare professionals and patients and caregivers to ensure that the best possible care pathways are established and provided, which are aligned with individual values and goals, and that professionals working in that area have the resources and feel confident to consistently provide high quality end of life care.

References

1. San Filippo, David Ph.D., "Historical Perspectives on Attitudes concerning Death and Dying" (2006). Faculty Publications. 29. https://digitalcommons.nl.edu/faculty_publications/29
2. Williams KJ. "The introduction of 'chemotherapy' using arsphenamine - the first magic bullet". 2009 Aug. *Journal of the Royal Society of Medicine*. 102 (8): 343–8. doi:10.1258/jrsm.2009.09k036. PMC 2726818. PMID 19679737
3. I.R Byock. Conceptual models and the outcomes of caring. 1999 Feb. The Journal of Pain and symptom management. VOLUME 17(2):83-92. AVAILBLE FROM: https://doi.org/10.1016/S0885-3924(98)00139-0
4. Lakasing E. Death's worsening taboo: is hampering the provision of high quality palliative care. Br J Gen Pract. 2014 May;64(622):243. doi: 10.3399/bjgp14X679769.
5. World Health Organisation. Palliative care for older people – Better practices. [Internet] 2011. (Accessed on 1 February 2023). Available from: https://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf
6. Hawley P. Barriers to Access to Palliative Care. Palliat Care. 2017 Feb 20;10:1178224216688887. (Accessed on 12 February 2023). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5398324/
7. Teno, J. M., Gozalo, P. L., Bynum, J. P., leland, N. E., Miller, S. C., Morden, N. E., Scupp, T., Goodman, D. C. & Mor, V. 2013. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. JAMA, 309, 470-7.
8. Keidel, G. C. (2002). Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice & Palliative Care, 19(3),* 200–205. https://doi.org/10.1177/104990910201900312
9. Bharmal A, Morgan T, Kuhn I*, et al.* Palliative and end-of-life care and junior doctors: a systematic review and narrative synthesis. *BMJ Supportive & Palliative Care* 2022;12:e862-e868. Available from: https://spcare.bmj.com/content/12/e6/e862
10. Moody, C. D. Exploring the Impact and Lived Experiences of Hospice Staff Working in End-of-Life Care: An Interpretative Phenomenological Analysis (IPA). 2022. *OMEGA - Journal of Death and Dying*, *0*(0). https://doi.org/10.1177/00302228221085467
11. Rose A. Spirituality and Palliative Care: The Attitudes of Occupational Therapists. *British Journal of Occupational Therapy*. 1999;62(7):307-312. doi:10.1177/030802269906200707
12. Ivany E, Aitken L. Challenges and facilitators in providing effective end of life care in intensive care units. Nurs Stand. 2019 May 24;34(6):44-50. doi:

10.7748/ns.2019.e11248. PMID: 31468932. Available from: https://pubmed.ncbi.nlm.nih.gov/31468932/

13. Robinson L, Dickinson C, Rousseau N, Beyer F, Clark A, Hughes J, Howel D, Exley C. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. Age Ageing. 2012 Mar;41(2):263-9. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3280677/
14. Nair K, Lee M, Hobson E*, et al.* End-of-life care of people with long-term neurological conditions. *Practical Neurology* 2022;22:385-391 https://pn.bmj.com/content/22/5/385
15. Brennan,F. Matthew D. Gardiner, MD. Narasimhan, M. Chapter 3 - The neuropalliative multidisciplinary team—Members and their roles. Handbook of Clinical Neurology, Elsevier. 2022. 190(33-59)
16. Tarolli CG, Chesire AM, Biglan KM. Palliative Care in Huntington Disease: Personal Reflections and a Review of the Literature. Tremor Other Hyperkinet Mov (N Y). 2017 Apr 11;7:454. doi: 10.7916/D88057C7.
17. De Vries K, Cousins E, Harrison Dening K. Palliative care in Creutzfeldt-Jakob disease: looking back, thinking ahead. BMJ Support Palliat Care. 2021 Jan 22:bmjspcare-2020-002799. doi: 10.1136/bmjspcare-2020-002799.
18. Oliver, D.J., Borasio, G.D., Caraceni, A., de Visser, M., Grisold, W., Lorenzl, S., Veronese, S. and Voltz, R. 2016. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. Eur J Neurol, 23: 30-38. https://doi.org/10.1111/ene.12889
19. Rehabilitative Palliative care. [internet] (accessed on 2 February 2023) Available from: https://www.hospiceuk.org/innovation-hub/clinical-care-support/rehabilitative-palliative-care
20. Chochinov, H.M. (2006), Dying, Dignity, and New Horizons in Palliative End-of-Life Care. CA: A Cancer Journal for Clinicians, 56: 84-103. https://doi.org/10.3322/canjclin.56.2.84
21. The European Platform of Neurodegenerative diseases. [internet] (accessed 12 February 2023). Available from: https://epnd.org/
22. Rehabilitative Palliative care. [internet] (Accessed on 2 February 2023) Available from: https://www.hospiceuk.org/innovation-hub/clinical-care-support/rehabilitative-palliative-care
23. PRISMA checklist. [internet] (Accessed on 22 March 2023). Available from: https://www.equator-network.org/reporting-guidelines/prisma/
24. Cochrane Effective practice and organisation of care, [internet] (Accessed on 12 March 2023). Available from: https://epoc.cochrane.org/resources/epoc-resources-review-authors

25. Cochrane Risk of Bias Tool. [internet] (downloaded on 12 March 2023). Available from: https://www.bmj.com/content/bmj/366/bmj.l4898.full.pdf
26. PICOS - Cochrane Training. Chapter 3: Defining the criteria for including studies and how they will be grouped for the synthesis. [internet] (Accessed on 23 March 2023). Available from: https://training.cochrane.org/handbook/current/chapter-03
27. Hawker S, Payne S, Kerr C, Hardey M, Powell J. Appraising the evidence: reviewing disparate data systematically. Qual Health Res. 2002;12(9):1284–99.
28. Gao W, Wilson R, Hepgul N, Yi D, Evans C, Bajwah S, Crosby V, Wilcock A, Lindsay F, Byrne A, Young C, Groves K, Smith C, Burman R, Chaudhuri KR, Silber E, Higginson IJ; OPTCARE Neuro Trial Investigators. Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions: A Randomized Clinical Trial. JAMA 2020 Aug. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7455856/
29. Armstrong. Slande Alliance, Taylor,A. Corsentino, P. Galvin,J.E. End-of-life experiences in dementia with Lewy bodies: Qualitative interviews with former care givers. PLOS One. 2019 May. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0217039
30. Holyoke, P and Stephenson, B. Organisation level principles and practices to support spiritual care at the end of life: a qualitative study. BMC Palliative Care. 2017. Available from: https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-017-0197-9
31. Evans,C. Bone,A,E. Yi,D. Goa,W. Morgan,M. Taherzadeh,S. Maddocks,M. Wright,J. Lindsay,F. Bruni,C. Harding, R. Sleeman, K.E. Gomes,B. Higginson,I,J. Community based short term integrated palliative and supportive care reduces symptom distress for older people with chronic non cancer conditions compared with usual care: A randomised controlled single blind mixed method trial. International Journal of Nursing Studies. 2021 May. Available from: https://www.sciencedirect.com/science/article/pii/S0020748921001231?via%3Dihub
32. Walter, H. Seeber, A. Willems, D,L. de Visser, M. The role of palliative care in chronic progressive neurological diseases – A survey among neurologists in the Netherlands. Frontiers in Neurology. 2019 Jan. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6340288/
33. Harrison, M,B. Morrissey, D,L. Dalrymple, A,W. D'Abreu, A. Daly, F,N. Primary palliative care in Huntington disease. Movement Disorders clinical practice. 2023 Jan. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9847290/
34. Cochrane Data Collection form. (Downloaded on 2 January 2023) Available from:https://training.cochrane.org/sites/training.cochrane.org/files/public/uploads/reso

urces/downloadable_resources/English/Collecting%20data%20-%20form%20for%20RCTs%20only.doc

35. 29. VitalTalk . VitalTalk Quick Guides [Internet]. c2019. [Cited on 2023 March 08] Available from https://www.vitaltalk.org/resources/quick-guides/
36. Gordon, BS. Keogh, M. Davidson, Z. Griffiths, S. Sharma, V. Marin, D. Mayer, AS. Dangayach. NS. Addressing spirituality during critical illness: A review of current literature. Journal of Critical Care (2018) 45:76-81. Available from: https://doi.org/10.1016/j.jcrc.2018.01.015
37. Huntington's disease association [internet] (Accessed 5 March 2023). Available from: https://www.hda.org.uk/information-and-support/getting-help/end-of-life/
38. NHS. End of life care. [internet] (cited on 12 March 2023) Available from: https://www.nhs.uk/conditions/end-of-life-care/
39. Parkinsons Disease Assosciation- Preparing for end of life. [internet] (cited on 4 March 2023) Available from: https://www.parkinsons.org.uk/information-and-support/preparing-end-life
40. Multiple Sclerosis Society – Support for planning end of life care. [internet] Available from: https://www.mssociety.org.uk/care-and-support/support-for-carers/planning-end-of-life-care
41. Marie curie - https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/advance-care-planning#benefits
42. World health organisation – Palliative Care in older People. Downloaded from: https://www.who.int/news-room/palliative-care

Appendix

Cochrane data collection form

Prisma Checklist

Hawker et al checklist

Cochrane risk of bias assessment