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Role of shared decision-making and early palliative care in progressive long-term neurological conditions

Mithila Vijay[1,2], Krishnan Padmakumari Sivaraman Nair[1,2,3]^

[1]Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK; [2]The University of Sheffield, Sheffield, UK; [3]Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

Correspondence to: Professor Krishnan Padmakumari Sivaraman Nair, MBBS, MD, DM, FRCP. Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK; Honorary Professor, The University of Sheffield, Sheffield, UK; Consultant Neurologist, Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust, Glossop Road, Sheffield S10 2 JF, UK. Email: siva.nair@nhs.net.

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A progressive long-term neurological condition (PLTNC) is a progressive illness of the nervous system that impacts a person and their family for the rest of their life. The trajectory of PLTNCs can differ greatly. Patients with amyotrophic lateral sclerosis (ALS) typically have a life expectancy of two to four years after diagnosis, whereas those with conditions such as multiple sclerosis (MS), and Parkinson's disease (PD) may live for decades with significant ongoing symptoms and disabilities. The clinicians managing PLTNCs often need to select from different treatment options. The approaches towards making the treatment choices include: (I) the clinician recommending a treatment they believe aligns with the patient's values, in order to support the patient's decision-making; (II) the clinician choosing the treatment they consider best and giving the patient the option to either silently agree or object—this is known as "informed non-dissent" (III) the clinician and patient working together to decide on a treatment through a collaborative process known as shared decision-making (SDM) (1-3).

SDM is a collaborative process where healthcare providers, patients, friends, and families engage in discussions that incorporate their values, preferences, and goals of the patient alongside clinical evidence. SDM includes empowering the patients and families to understand the trajectory of the PLTNC, treatment options, and potential outcomes. The patients then collaborate with the clinicians to make informed choices that align with their goals and values. SDM supports patient autonomy and self-determination without entirely removing clinician input. It creates a collaborative relationship in which the clinician contributes medical expertise, while the patient offers insight into their own body and personal values (1-3). SDM ensures that patients receive care tailored to their individual needs, leading to higher satisfaction and improved psychological well-being. In many cases, treatments may have uncertain benefits and unpredictable risks, making it ethically appropriate to support patient autonomy in making decisions based on their own values (1-3).

At the initial stages of PLTNCs, neurologists often concentrate on diagnosis and disease-specific treatments. However, individuals with these conditions still face many needs that are not being adequately addressed (4). Usually, the neurology teams managing PLTNCs seek palliative care (PC) support only when the patient approaches end-of-life. Early PC involves initiation of PC early during the disease trajectory of PLTNC. The goal of early PC is to give patients, their families, and caregivers a stronger sense of control while improving their overall quality of life, throughout the course of the PLTNC. Advantages of early PC in PLTNC include better focus on management of symptoms such as refractory pain, advance care planning

^ ORCID: 0000-0002-4004-2315.

(ACP), addressing psychosocial and spiritual needs, and support for the family and carers, right from the time of diagnosis. Early PC enhance quality of life and alleviate symptoms such as pain, breathing difficulties, bowel problems, and sleep disturbances. Brief PC interventions have been shown to reduce symptoms and lessen the burden on caregivers in PLNTCs (5,6).

Spirituality goes beyond religious beliefs and includes broader ideas such as meaning, hope, peace, creativity, and resolving unfinished matters, regardless of a person's faith. Since spirituality and religion are part of a person's cultural identity, they help to understand how cultural values, traditions, and social background influence patients' and their families medical decisions According to the National Consensus Project for Quality Palliative Care, addressing spiritual, religious, and existential needs is one of the eight key elements of quality PC (7-9). Early discussions about spiritual aspects will help patients and family to accept and cope with the PLTNC.

The nature of PLTNCs means patients may eventually lose their ability to make and/or convey their own treatment decisions. ACP is a process that helps individuals to document their wishes and preferences for future medical care. The patient could choose a representative to make decisions on their behalf if they lose the ability to make decisions for themselves (10). The treating team, patient and family should use SDM to formulate the advanced care plan. The treating team, patients and family need to discuss the diagnosis, prognosis, and plan for interventions (or advance directives to refuse) such as gastrostomy, ventilatory support, and hospitalisation. The ACP made following the principles of SDM, allows patients to make choices about their treatment and end-of-life care while they are still able. Sometimes, patients may not wish to engage in these discussions. Clinicians should gently assess whether the patient is prepared to engage in these conversations.

Patients with PLNC face barriers to access SDM and PC. The specialist PC services are unable to keep up with the growing demand from patients with PLTNC and Neurology teams may lack training in communication skills required to discuss withholding and/or withdrawal of life sustaining treatments and end of life care (11). Neurology service providers need training to use SDM for ACP in PLTNC (12). They should be able to recognize the need for and should have access to specialized palliative input not only during the end-of-life phase but also throughout the course of the PLTNC.

We propose an integrated care approach for individuals with PLTNCs, led primarily by the neurology team using SDM for symptom management, advanced care planning, spiritual support, and assistance for family and friends. The neurology teams need to have access to specialists in PC for opinion and brief interventions as and when required.

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Footnote

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