

A short-term integrated palliative care intervention for people with long-term neurological conditions: a qualitative study to evaluate impact on perceptions of care

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Background

Palliative care is advocated for people with long-term neurological conditions (LTNCs) to promote quality of life. However, how to deliver is poorly understood. We aimed to evaluate the value and impact of a short-term integrated palliative care intervention for people with LTNCs on perceptions of care.

Methods

Multicentre embedded qualitative study within a definitive trial. The trial intervention comprised integrated person-centred palliative care delivered by multidisciplinary palliative care teams working with neurology services. Qualitative study involved interviews with patients with LTNCs and family carers who received the intervention. Thematic data analysis of interview transcripts was used to explore the impact of the intervention and linkage with key components.

Table 1. Qualitative interview patient characteristics

Variable	Value	Interviewed patients N=26
Age, mean (SD)		63.5 (13.5)
Gender, N(%)	Male	14 (53.8)
	Female	12 (46.2)
Diagnosis, N(%)	Multiple Sclerosis	18 (69.2)
	Idiopathic Parkinson's Disease	6 (23.1)
	Progressive Supranuclear Palsy	2 (7.8)
Years since diagnosis, mean (SD) range		13.7 (10.5) 0-38
Comorbidities, N(5)	No	5 (19.2)
	Yes	21 (80.8)
Patient capacity, N(%)	Consent	24 (92.3)
	Personal consultee assent	2 (7.7)
Baseline IPOS Neuro-S8, mean (SD) range		8.2 (4.1) 2-17
Living status, N(%)	Alone	6 (23.1)
	With spouse/partner and/or children	16 (61.5)
	With friend(s)/with others	4 (15.4)
Ethnicity, N(%)	White	23 (88.5)
	Other ethnic group	3 (11.5)
Employment, N (%)	No	25 (96.2)
	Yes	1 (3.8)

Read the full trial paper here: Gao W, Wilson R, Heggul N, et al. 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 Network Open* 2020; 3(8): e2015061-e

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Results

26 qualitative interviews (patients, n=26 and caregivers n=16) from three trial centres (Brighton, London, Ashford-Surrey) The impact of palliative care centred on three main themes:

(1) Adapting to losses and building resilience

Living with a LTNC was 'always troublesome'. Adapting to losses and building resilience were key strategies to adjust to rising disability and declining function, forming two sub-themes:

- 'Care beyond medicines', psychosocial interventions were valued to support resilience and adaptation and counter feelings of loneliness and isolation, exacerbated by uncertainty about disease progression and outcome, such as loss of function.
- 'Asked about everything' Difficult conversations about 'emotional things' were valued by patients and carers to adapt to progressive condition and nearness of end of life. But, this required trust and rapport. The short-term nature of the intervention limited this.

(2) Optimise function and manage deficits

Optimising function encompassed a duality of:

- 'Little things make a big difference' to reduce distressing physical symptoms such as spasm causing pain; and
- 'Maintaining stability' to support daily work of living with a chronic condition, by 'holding', supporting understanding of the disease trajectory, symptoms, and advise and support as things changed.

(3) Enabling carers to care

Carers valued when asked 'how are you', appreciative of consideration of their needs and reassurance of doing a 'good job'. Too often, carers felt they had to fight for everything and become an expert in the person's care.

"[Parkinson CNS], she's been absolutely brilliant and her sort of enthusiasm, I mean she's been talking to me about giving up work for a long time and kept on saying stop being so stubborn, you know, why can't you just listen or why can't you just you know give up and look after [your wife] full time, have quality of life..... put it aside until we moved, erm where it just suddenly hit me, you know just near the kitchen I thought 'no I can't carry on'. [C01007-M]

Discussion

Patients and carers valued the short-term integrated palliative care intervention by building resilience, attending to function and deficits, and enabling caregivers. What mattered was *to know people are available and willing to try and improve symptom management*. Optimal management required inter-disciplinary working across multi-disciplinary teams, and integrated working with main providers of care to maintain continuity of care.

Vital components included::

- Multi-dimensional assessment of health domains
- Person-centred approach identifying individual priorities
- Multi-disciplinary team working to attend to function and deficits
- Integrated working to support continuity of care
- Integrated working through reciprocal learning between specialities to enhance provision of palliative care approaches

