



Marie Curie Research Grants Scheme

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The palliative care needs of people with motor neurone disease (MND) and their informal care givers

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Abstract

Background

Motor neurone disease (MND) or Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease which has a sudden onset, rapid progression and brings with it the potential for complex and disabling symptoms and care needs. It is currently without cure, with the average time between diagnosis and death being two to three years. The progression of symptoms and subsequent onset of disability are likely to occur over weeks and months rather than years. A need for palliative care arises early in the disease trajectory. Historically, however, whilst a palliative care approach has been routinely adopted for care of patients with primary brain tumours and brain metastases, it has been less recognised as an approach relevant for patients with MND or other neurodegenerative disorders.² This picture is now changing and the rapid progressive nature of MND, the need for anticipatory planning, regular re-evaluation of symptoms and the central role of carers are being seen as highly relevant to the specialism of palliative care.² With this comes recognition that palliative care should be initiated early in the disease process rather than waiting until near the end of life, with the involvement of palliative care specialists to help with advanced planning and symptom control.

Given the emphasis on the importance of palliative care for people with MND, it is vital to understand the palliative care needs of patients and their carers in order that services can be configured to reflect these needs. There is currently an identified gap in synthesised knowledge in this area. The methodologies associated with qualitative research enable individuals' perceptions and experiences about their illness and their care needs to be established. Systematic reviews of qualitative research enable an existing body of qualitative research to be brought together to develop new insights and identify research gaps. The approach is particularly relevant to a palliative care population, as synthesising qualitative research allows maximum value to be gained from primary studies that have overcome problems in accessing and researching vulnerable groups

Aim

The aim of the research is to explore the palliative care needs of adult patients and their informal carers living with MND, or bereaved carers of people with MND through a systematic review of qualitative research.

Methods

Searches

Searches will be developed with the help of an information specialist and will be run in relevant electronic databases, including Medline, Cinahl, PsycInfo, Social Science Citation Index, using terms for MND, ALS, palliative care, using a qualitative research filter.

Data extraction and quality appraisal: Relevant data will be extracted from included papers (aim, type and number of participants, methodology used, methods of data collection, analysis, and results). Data extraction will be undertaken by one reviewer and checked by a second reviewer. Papers will be appraised for quality using an established checklist by two reviewers, with disagreements resolved by consensus. There will be no *a priori* quality threshold for excluding papers; assessment will be undertaken to ensure transparency in the process.

Synthesis: An interpretive approach to synthesis will be used called meta-ethnography used successfully in qualitative reviews of palliative care. Meta-ethnography is an approach to research synthesis which uses iterative processes to understand similarities and differences between studies to determine how findings connect and interact.¹¹ This consists of four iterative stages including: reading each paper's findings; line-by-line coding of data (participant accounts and authors' interpretations) in each paper; comparison and grouping of the codes into broad areas of similarity through reciprocal translation analysis to generate a reduced set of codes (translations); examination and comparison of the translations to identify the 'lines of argument' emerging from the review.

Reporting: the review will be reported in accordance with the 'Enhancing transparency of the reporting the synthesis of qualitative research' (ENTREQ) statement.

Proposed findings

Preliminary searches in Cinahl identified over 100 papers of which more than 30 appeared relevant to the review, indicating there is a significant pool of papers available to be synthesised.

The review will identify the palliative care needs of patients who have MND and their carers, as a result of bringing together existing qualitative research in this area in a systematic way.