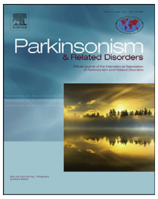
Parkinsonism and Related Disorders xxx (2017) 1–8

Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis



Review article

Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research

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ARTICLE INFO

Article history:
Received 21 April 2016
Received in revised form
1 December 2016
Accepted 10 January 2017

Keywords:
Palliative care
Parkinson's disease
Clinical research

ABSTRACT

Introduction: Palliative care is an approach to caring for patients and families affected by serious illnesses that focuses on the relief of suffering through the management of medical symptoms, psychosocial issues, advance care planning and spiritual wellbeing. Over the past decade there has been an emerging clinical and research interest in the application of palliative care approaches to Parkinson's disease (PD) and outpatient palliative care services are now offered by several movement disorders centers.

Methods: An International Working Group Meeting on PD and Palliative Care supported by the Parkinson's Disease Foundation was held in October 2015 to review the current state of the evidence and to make recommendations for clinical research and practice.

Results: Topics included: 1) Defining palliative care for PD; 2) Lessons from palliative care for heart failure and other chronic illnesses; 3) Patient and caregiver Needs; 4) Needs assessment tools; 5) Intervention strategies; 6) Predicting prognosis and hospice referrals; 7) Choice of appropriate outcome measures; 8) Implementation, dissemination and education research; and 9) Need for research collaborations. We provide an overview of these discussions, summarize current evidence and practices, highlight gaps in our knowledge and make recommendations for future research.

Conclusions: Palliative Care for PD is a rapidly growing area which holds great promise for improving outcomes for PD patients and their caregivers. While clinical research in this area can build from lessons learned in other diseases, there is a need for observational, methodological and interventional research to address the unique needs of PD patients and caregivers.

1. Introduction

Growing evidence suggests current standards of care do not adequately meet many important aspects of care for Parkinson's disease (PD) patients and their caregivers including: 1) Underrecognition and treatment of non-motor symptoms such as pain, depression and fatigue [1,2]; 2) High rates of nursing home placement, hospitalization in the last year of life and in-hospital deaths [3,4]; 3) Caregivers being under-prepared for their role [5]; and 4) High levels of burden, depression and increased mortality among

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http://dx.doi.org/10.1016/j.parkreldis.2017.01.008

Please cite this article in press as: B.M. Kluger, et al., Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research, Parkinsonism and Related Disorders (2017), http://dx.doi.org/10.1016/j.parkreldis.2017.01.008

PD caregivers [6,7]. Palliative care focuses on the relief of suffering for patients and families affected by serious illness through the assessment and treatment of physical, psychosocial and spiritual issues [8]. While traditionally associated with cancer, palliative approaches have been successfully applied to several chronic progressive illnesses including heart failure and pulmonary disease [9,10]. Several recent reviews propose palliative care approaches for PD [11,12], and a small but growing cadre of centers worldwide now offer interdisciplinary outpatient palliative care for PD.

Currently there are scant data and no randomized clinical trials to guide clinicians or researchers in this emerging field. While there have been several opinion pieces and reviews, there are no statements reflecting the opinions and discussions of an international working group. This is a notable gap as there is likely to be significant variability in this new field in terms of which services are offered to whom, what outcomes are followed and how to prioritize research questions.

2. Methods

In recognition of these needs, the Parkinson's Disease Foundation sponsored an International Working Group meeting October 3–4, 2015 in Aurora, Colorado consisting of an expert panel of clinicians and researchers from PD and Palliative Medicine as well as patients and caregivers. This manuscript presents a summary of the major talks and related discussions including: 1) Defining Palliative Care for PD; 2) Lessons from Palliative Care for Cancer and Heart Failure; 3) Patient Needs; 4) Predicting Prognosis and Hospice Referrals; 5) Caregiver Needs; 6) Needs Assessment Tools and Strategies; 7) Clinical Research Outcome Measures; 8) Intervention Strategies; and 9) Implementation, Dissemination and Education Research. Research priorities for each domain are discussed at the end of each section.

3. Results

3.1. Defining Palliative care for PD

Faculty, patients and caregivers all endorsed a broad conception of palliative care as an approach to the care of PD patients and their families which seeks to relieve suffering through the management of medical symptoms, psychosocial issues, spiritual wellbeing and advance care planning [12]. This approach is not limited to end-of-life care [13]. Patients and caregivers identified palliative care needs for early (e.g. emotional support at diagnosis), middle (e.g. discussing goals of care, nonmotor symptom management) and late-stage PD (e.g. hospice) and stressed that the time of diagnosis is particularly challenging and is a time where increased support and resources are needed. Patients proposed a “three-legged stool” model to provide palliative care including: 1) Community organizations ranging in size from local support groups to international advocacy foundations; 2) Primary care physicians, geriatricians and neurologists; and 3) Specialist palliative care including team-based outpatient clinics, home palliative care and hospice. In this model each leg has its own role and strengths.

Further research is needed to define what approaches are most appropriate for specific patient and caregiver needs. Faculty agree that palliative care is best seen as an approach to care with specialist palliative care services (e.g. interdisciplinary clinics, hospice) being only one aspect of this. It is not feasible for all PD patients to get all of their palliative care needs met in these clinics and PCP/neurologist education as well as utilization of community resources (e.g. support groups, online education) are needed to cover the full spectrum of patient and caregiver needs.

The timing of referral and role of specialist palliative care for PD is challenging to define. Palliative care is commonly associated with end-of-life care and palliative resources are certainly needed during this time [14]. However research suggests that even in cancer, earlier palliative care may improve patient quality of life and even survival [15]. Although reimbursement for hospice care is tied to prognosis in many payment systems (e.g. Medicare), outpatient palliative care referrals are reimbursed regardless of prognosis as standard clinic visits and a more useful conceptual model for referral may be based around needs rather than prognosis, stage or specific events. A prospective study of ambulatory palliative care for PD enrolled patients with uncontrolled symptoms, neurobehavioral symptoms limiting treatment, cognitive impairment or caregiver distress [16]. For the represented PD palliative care clinics, referrals are made as limited consults for specific issues, for co-management or to assume ongoing care. As discussed below, validated needs assessment tools are needed to aid clinicians in making appropriate referrals and to define inclusion for research trials.

The term “palliative care” was discussed as potentially problematic for patients and clinicians who may have strong preconceptions about palliative care. Several clinicians described patients not interested in “palliative care” but excited to come to a team-based clinic providing intensive symptom management and psychosocial support. As a result, most clinics have changed their names to “Supportive Care,” “Next Step Clinic” or “Complex Symptom Management” to reduce confusion and increase acceptance by healthcare providers, patients and families. Some felt that misconceptions about palliative care need to be directly tackled rather than hidden under another name.

3.2. Lessons from palliative care for cancer and heart failure

Most palliative care services have arisen in conjunction with oncology. Although evidence supports an early integrated care service delivery model [15,17–19] this is implemented variably, often influenced by the funding system. In the UK and Australia, an integrated service, where cancer patients access palliative care services according to need rather than prognosis and in conjunction with ongoing cancer-directed treatment, is becoming the standard of care. In the US, the largest health care system, the Veterans Health Administration, also provides concurrent cancer and palliative care [20]. US hospital-based palliative care consultation has grown significantly, while outpatient palliative care has grown more slowly due in part to low financial incentives [21,22]. Thus the traditional view of palliative care being inconsistent with disease-directed treatment continues despite i) the evidence in support of early integrated care, and ii) being an outmoded concept for much of oncology where successive cancer treatments can modify the disease trajectory to be one more akin to a chronic disease.

Heart failure (HF) was one of the first non-cancer conditions to recognize the significant symptom burden and concerns of patients and caregivers as palliative care issues [23–27]. Despite palliative care recommendations in national guidelines and policy [28,29], implementation of this approach is patchy [30]. Barriers to implementation are well described and relevant to PD including:

1. Disease trajectory. The pattern of deteriorations and restorations, and the fact that cardiac treatments remain appropriate until very late stage disease, make it difficult to predict patients who are in the last few months of life. When palliative services are predicated upon estimated prognosis rather than patient-identified concerns or needs, the result is that conversations about advance care planning do not occur for fear of “not being at that stage yet” (despite lack of clarity about when “that stage” starts).

Please cite this article in press as: B.M. Kluger, et al., Palliative care and Parkinson's disease: Meeting summary and recommendations for clinical research, Parkinsonism and Related Disorders (2017), http://dx.doi.org/10.1016/j.parkreldis.2017.01.008