

What are patient perspectives in atypical and idiopathic Parkinson's Disease of the benefits and timing of advance care planning and palliative care input?

30/07/21

Review Methods

Search Strategy: A systematic search was conducted across a wide-ranging set of databases: Ovid MEDLINE(R) ALL, Ovid Embase, EBSCO CINAHL, Ovid PsycINFO, and Cochrane Library.

The preliminary search strategy was developed on Ovid Medline using both text words and Medical Subject Headings (MeSH). The search strategy was modified to capture indexing systems of the other databases. The search was restricted to English language only and from January 2010 to June 15, 2021

(Search strategies available upon request).

To identify additional papers, the following two websites were searched: Parkinson's Foundation and Parkinson's UK. Furthermore, electronic tables of content for the last two years were scanned for the following journals:

- BMJ Supportive & Palliative care
- Journal of Parkinson's Disease,
- Parkinsonism & Related Disorders
- Palliative Medicine

Reference lists of systematic reviews were checked for any relevant studies. The searches generated 102 citations after removing duplicates and irrelevant records. Figure 1 represents the flow of information through the different phases of the review.

Inclusion: Patients diagnosed with idiopathic or atypical PD. Qualitative studies reporting patients perspective on palliative care input and ACP in patients with PD.

Exclusion: Studies set in anon-Organization for Economic Cooperation and Development (OECD) countries; Case series studies consisting of less than 25 patients; non-English language studies.

Study selection/Quality Assessment/Data

Extraction: Study selection was based upon review of the abstract by two independent reviewers. The full text was then assessed independently using a pre-designed eligibility form according to inclusion criteria.

Any discrepancies between the two reviewers were resolved by consensus or by recourse to a third reviewer.

Context

Parkinson's Disease (PD) is a progressive neurological condition affecting 145,000 people living in the UK. The disease trajectory is both unpredictable and highly variable with a recent review of patients dying with a diagnosis of idiopathic PD in Cardiff, (personal communication) showed the time from diagnosis to death ranged from 2-23 years. The review also showed that fewer than 5% of patients had any documented advanced care planning (ACP) and only 8.5% had been referred to a palliative care service prior to being in their last days of life in hospital. This rapid review aims to examine the evidence on patient perception of these issues.

The review findings will be used to identify patients perspectives on the benefit and timing of advanced care planning (ACP) and palliative care team involvement and subsequently a Cardiff and Vale University Health Board development project enhancing palliative care in advanced Parkinson's Disease.

Key Findings

Out of 106 abstracts identified for screening, 15 full papers were retrieved. Six studies are included in the review which met our eligibility criteria. The study designs varied. Two studies consisted of face-to-face semi-structured interviews, one (Fox 2017) exploring perceptions about/understanding of palliative care in relation to PD and another (Shaw 2017) exploring patient engagement and wishes around ACP. Another study used a mixture of telephone interviews along with some video calls (Lum 2019), describing patient and care partner perspectives on advance care plans to inform a patient and care partner-centered framework for clinical care. A study using in-depth individual interviews and 4 focus groups (Boersma 2016) examined patient perspectives on their perceived needs and care preferences. A study consisting of a 39-item survey which assesses overall Health-related quality of life (HRQOL) (Kluger 2018) looked at patients' preference, knowledge and use of ACP. A study consisting of structured face to face interviews (Krietz 2018) explored patient perspectives on receiving information about palliative care and ACP. Additionally, a study of a postal questionnaire survey followed by a qualitative inquiry with semi structured interviews (Churm 2021) assessed the awareness and perception of benefits of ACP in patients with PD.

For ACP, a consistent finding across studies was the uncertainty and lack of structured information on the meaning of ACP and practical content. One study (Lum 2019) found that this unmet need led to a wide variation of personal definitions of ACP between patients which affected their perception of benefit. Most studies reported patients felt ACP would be beneficial at least in advanced disease and that they wished discussions to be facilitated by a physician. Regarding perception of best timing for ACP, there was a lack of agreement between studies on the timing of intervention. Individual study conclusions varied between most patients wishing ACP in advanced disease only (Fox 2016) to most patients wishing to address this before or at diagnosis (Kluger 2018). Another found patients felt ACP was for the future (Churm 2021) but had already engaged in some of the more practical aspects. Again, a need for greater information giving was a persistent theme and felt to affect perceptions of timing, with need for information about potential PD linked cognitive decline highlighted (Shaw 2017).

Regarding palliative care input a consistent theme across the studies was that palliative care input would be beneficial but the need for this was often unmet and more information regarding it is needed. This led to patients having a variable understanding of what palliative care as a term means affecting the perception of both benefit and best timing. Patients felt the multidisciplinary approach used would fill gaps in current services, and felt it had a beneficial role to play in facilitating ACP. With regards to timing patients saw benefit at all stages of disease but were most receptive and saw greatest benefit in advanced illness.

A. Reliability of evidence

The studies generally had well described participant groups, data collection methods and analysis frameworks. Appropriate qualitative methodology was used throughout. For some studies the information relevant to the questions was part of a much larger study with the analysis mainly focused on other parts of the study which limits reliability (Klietz 2018, Kluger 2018). Though most of the studies had good sample sizes (Boersma 2016, Klietz 2018, Kluger 2018, Lum 2019), some were small (Fox 2016) or linked to a very specific patient group e.g., Shaw 2017 – all from a “Patients as Educators” program, Churm 2021 – patients with idiopathic PD only, or Klietz 2018 – all patients were over the age of 65 with longstanding disease.

B. Consistency of evidence

There was significant heterogeneity in the overall aims of the studies included with many only focusing on part of the question for this review. However, there was significant consistency in themes across different studies, especially an unmet need for information giving regarding ACP, a wish for more physician involvement to facilitate ACP discussions, and a perception that palliative care input would be beneficial and help meet currently unmet need.

C. Relevance of evidence

The majority of these studies were from a non-UK setting – US, Germany and Ireland. This may limit relevance to UK practice to some degree given a range of practice in PD care provision. However, consistency across the studies and with the UK studies means that the findings are likely to be relevant to UK practice.

Glossary:

ACP (Advanced Care Planning)

EOLC (End-of-Life-Care)

HRQOL (Health-Related Quality of Life)

PC (Palliative Care)

PD (Parkinson's Disease)

PwPD (Patients with Parkinson's Disease)

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Evidence Implications:

Clinical:

Healthcare professionals caring for patients with PD should be aware that patients wish to receive information about palliative care and ACP to help inform their decisions. This information should include definitions of both terms to help patients understand the benefits over their disease course. They should be prepared to explore whether these are discussions a patient wishes to have from diagnosis and routinely following this. Access to relevant information in varied formats would support this process and take account of the possibility of cognitive decline making discussions and decision making more challenging in advanced disease. Professionals should be able to facilitate discussions regarding ACP and palliative care with their patients.

The holistic MDT approach of specialist palliative care practice resonated with patients in the included studies as a means of identifying and addressing their unmet needs, and considered by the majority as particularly relevant in advanced illness.

Policy:

The evidence shows significant unmet need for information regarding ACP and palliative care for patients with PD and their preference for this information to be discussed with a healthcare professional. Therefore, a policy implication would be a need for teams currently caring for patients with PD to be trained in facilitating discussions around ACP and palliative care referral. Consequently, there should be structured information available in multiple formats to explain the meaning of and practicalities of both ACP and specialist palliative care.

These studies also show patients feel they have an unmet need for holistic palliative care input especially in advanced disease. Therefore, more research is recommended into how best to integrate services to meet palliative care needs into current PD care.

Flow Diagram:

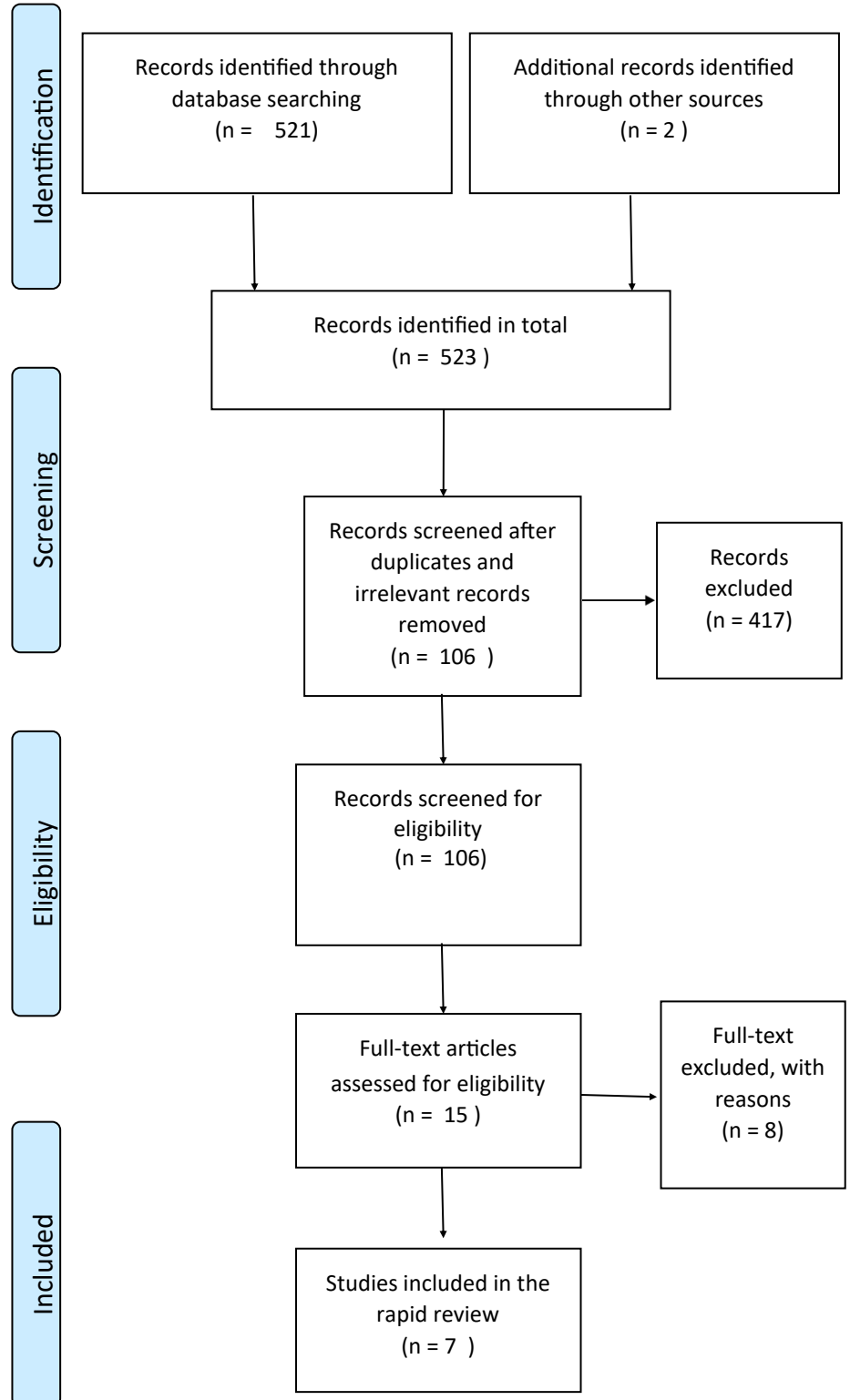


Table 1: Characteristics of Included Studies

Boersama et al. 2016	Study Setting & Design – An academic tertiary care centre, a Veterans Affairs Medical Centre, an inner-city clinic, and community support groups in Canada and USA. In-depth individual interviews and 4 focus groups.
Study Objective	To better understand Parkinson's disease patients' perspectives on their perceived needs and care preferences.
Participants	A total of 30 patients with varying stages of PD including dementia patients able to meaningfully answer questions.
Interventions/ Comparators/ Methods	Patient perspectives on their perceived needs of palliative care and care preferences were explored using in depth individual interviews and four focus groups (4-7 patients).
Proposed Outcomes	Identification of unmet palliative care needs and preferences for addressing these needs.
Summary of the Study Results	<p>Patients were receptive to outpatient palliative care even early in the disease but more receptive if this is discussed in terms of multidisciplinary services provided rather than simply described by the term 'palliative care'. The following themes emerged:</p> <ul style="list-style-type: none"> • challenges of living with motor and nonmotor symptoms • loss, grief, and identity • worries about the future • spiritual well-being • gaps in care • impressions of physicians • responses to palliative care
Appraisal Summary	Usefully generalizable, with good sample size and conclusions backed up by findings.
Churm et al. 2021	Study Setting & Design – North Tyneside General Hospital, North-East of England. Questionnaire followed by structured interviews.
Study Objective	To determine the extent people with PD were aware of ACP and currently engaged in planning for the future; and to explore the views of people with PD and relatives concerning planning for the future and their understanding of the issues involved and associated with ACP in PD.
Participants	Patients diagnosed with idiopathic PD, able to consent to participation, not hospital inpatients or approaching the end of their life. A total of 196 participants fitted the inclusion criteria.
Interventions/ Comparators/ Methods	A postal questionnaire was sent out to all the eligible participants followed by a qualitative inquiry with semi-structured interviews to understand patients and relative's knowledge of ACP and planning for the future.
Proposed Outcomes	Wishes regarding timing of ACP and information provision giving and future discussions around ACP.
Summary of the Study Results	<p>3 main findings:</p> <ul style="list-style-type: none"> • the awareness of ACP was low among people with PD and their relatives. • Patients are interested in ACP but all feel it is something to address in the future • the suggestion that practical future planning (e.g. making a will) is seen as different to health care planning
Appraisal Summary	Good qualitative method with large sample size and clear description of sampling. However, generalisability is limited by the exclusion criteria and homogenous patient group.

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Table 1: Characteristics of Included Studies

Fox et al. 2016	Study Setting & Design – Three Movement Disorder Clinics in Cork, the Republic of Ireland. Qualitative semi-structured interviews.
Study Objective	To explore the palliative care and related issues most affecting people with Parkinson's disease and their families and to examine perceptions about/understanding of palliative care.
Participants	Parkinson's Disease participants from early to advanced stages of illness. A total of 31 people participated in 25 interviews: 19 PwPD (Patients with Parkinson's Disease) and 12 carers.
Interventions/ Comparators/ Methods	In-depth interviews with 13 individual patients, 6 individual carers and 6 patient and carer dyads interviewed together exploring issues relating to palliative care needs and potential barriers or facilitators to accessing or receiving this care. Perception and perceived benefits of palliative care and Advance Care Planning (ACP) were also explored.
Proposed Outcomes	To understand the participants' perceptions of palliative care needs and identify potential barriers to or facilitators of accessing or receiving this care.
Summary of the Study Results	<p>Key issues faced:</p> <ul style="list-style-type: none"> • Patient burden • Carer burden • Information and support needs • Crisis at diagnosis • Crisis at advancing illness • Experience of healthcare services • Experience and perceptions of palliative care. <p>Some patients with early PD do not want to address ACP. People in advanced stages however, are more open. Best timing for ACP depends on the individual, especially age, personality, and stage of disease. Most people felt they would benefit from palliative care, especially those at advanced stages.</p>
Appraisal Summary	All stages of PD included therefore generalizable but sample size small.

Klietz et al. 2018	Study Setting & Design – Movement disorder outpatient clinic, neurological wards, local PD patient support groups, and outpatient neurologists in the region of Hannover, Germany. A structured interview approach.
Study Objective	The aim of this study was to investigate the current status of palliative care implementation and quality of life in a local cohort of advanced PD patients in order to frame and improve future care.
Participants	A total of 76 patients with idiopathic PD over 65 years of age and who had the condition at least 5 years, causing loss of autonomy defined as severe restrictions in activities of daily living measured by the Barthel index.
Interventions/ Comparators/ Methods	The need for and frequency of palliative care use and ACP was explored using a structured interview.
Proposed Outcomes	Patients' perspectives on the benefit of receiving information about palliative care and ACP.
Summary of the Study Results	72% expressed an unmet need for information about palliative care and ACP especially regarding EOLC. However, only 2.6% had palliative care input. There is an unmet need for palliative care and that palliative care input and encouragement of ACP discussions would be beneficial in advanced PD.
Appraisal Summary	Good sample size but generalisability limited due to restrictive inclusion criteria.

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Table 1: Characteristics of Included Studies

Kluger et al. 2018	Study Setting & Design - Colorado Hospital and Denver Veterans Affairs Medical Center Colorado and Denver, USA. A cross-sectional observational study with a qualitative survey.
Study Objective	To compare palliative needs of PD and cancer patients and assess PD patients' preferences for ACP
Participants	Age over 45, diagnosed with PD by movement disorder trained neurologist.
Interventions/ Comparators/ Methods	Palliative care needs of PD patients in relation to HRQOL. The best timing for discussing ACP, compared with patients with cancer diagnosis. 90 patients with PD filled in the Lyon Advanced Care Planning Survey.
Proposed Outcomes	Understanding the timing to introduce end-of-life decisions, and who on a treatment team is best suited to bring up ACP.
Summary of the Study Results	<p>PD and cancer patients' preferences, knowledge, and use of advance care planning.</p> <ul style="list-style-type: none"> Higher proportion of PD patients reported completing medical power of attorney paperwork (76% vs. 53%; P = 0.018) Reporting a preference for completion of this paperwork before or at the time of diagnosis (92% vs. 78%; P = 0.048). Majority of patients reported a preference for discussing these issues with a physician (either primary care physician, oncologist, or neurologist). 80% felt EOL decisions should be brought up prior to diagnosis, 12% at diagnosis. Only 2% to wait until the patient is dying.
Appraisal Summary	This is part of a larger study which makes data collection and analysis harder to review as the part of the study regarding ACP was not analysed in the discussion. Despite some mentioned limitations of a single centre, single point in time review, this information is still reliable and useful.

Lum et al. 2019	Study Setting & Design – University of Colorado, University of Alberta, and University of California San Francisco. Canada & USA. Telephone or video interviews.
Study Objective	To describe patient and care partner perspectives on ACP to inform a patient- and care partner-centred framework for clinical care.
Participants	Included 60 participants fluent in English, 30 patients aged over 40 meeting UK Brain Bank criteria for a diagnosis of probable PD and 30 care partners. 15 patient – carer dyads and 30 individual patients and carers.
Interventions/ Comparators/ Methods	Palliative care team input compared to standard care. Structured telephone or video interviews with patients and carers interviewed separately.
Proposed Outcomes	Timing and perception of ACP. The impact of palliative care involvement on positive perceptions of ACP in PD.
Summary of the Study Results	<p>Four themes on ACP revealed:</p> <ul style="list-style-type: none"> personal definitions of ACP vary in the context of PD which affects perceptions of best timing patient, relationship, and health care system barriers exist to engaging in ACP care partners play an active role in ACP a palliative care approach positively influences ACP
Appraisal Summary	Large sample size carefully selected to maximise generalizability and thorough method makes this reliable and useful information.

Table 1: Characteristics of Included Studies

Shaw et al. 2017	Study Setting & Design – Medical school's 'Patients as Educators' Program, Sheffield, UK Semi-structured interviews.
Study Objective	To investigate the current ethical issues in relation to recognizing and managing PD from the patients' perspective.
Participants	Twelve patients living with PD, no other inclusion criteria.
Interventions/ Comparators/ Methods	Plans patients had made for future medical treatments managing Parkinson disease. Semi structured interviews consisting of 4 open ended questions.
Proposed Outcomes	Examining whether patients had: <ul style="list-style-type: none"> engaged in ACP if they would want to and whether they felt end of life discussions were adequate
Summary of the Study Results	Four key themes emerged: <ul style="list-style-type: none"> information giving coping identity future medical treatment <p>Some patients had already engaged in ACP though none had considered that cognitive impairment may lead them not to be able to do so in the future. Patients felt the need to be well informed and that end-of-life care discussions could be inadequate. Some had been given information about options for a deep brain stimulator but did not feel ready to discuss this.</p>
Appraisal Summary	All patients being from a patient educator program is a significant constraint that limits generalizability. There is some useful information with regards to the component within the question relating to benefit of ACP.

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Included Studies:

Studies were included that reported patient perspectives in atypical and idiopathic Parkinson's disease of the benefits and timing of advanced care planning and palliative care input.

1. Boersma, I. et al. 2016. Parkinson disease patients' perspectives on palliative care needs: What are they telling us? *Neurology Clinical Practice* 6(3), pp. 209-219.
2. Churm, D. et al. 2021. How Do Patients With Parkinson's Disease Approach Advance Care Planning? A UK-Based Mixed Methods Study. *J Geriatr Psychiatry Neurol*, p. 891988720988917. doi: 10.1177/0891988720988917
3. Fox, S. et al. 2016. Palliative care for Parkinson's disease: Patient and carer's perspectives explored through qualitative interview. *Palliative Medicine* 31(7), pp. 634-641.
4. Kliez, M. et al. 2018. Impaired quality of life and need for palliative care in a German cohort of advanced Parkinson's disease patients. *Frontiers in Neurology* 9(120),
5. Kluger, B. M. et al. 2018. Defining Palliative Care Needs in Parkinson's Disease. *Movement Disorders Clinical Practice* 6(2), pp. 125-131.
6. Lum, H. D. et al. 2019. Framing advance care planning in Parkinson disease: Patient and care partner perspectives. *Neurology* 92(22), pp. E2571-E2579.
7. Shaw, S. T. et al. 2017. Challenges to Ethically Managing Parkinson Disease: An Interview Study of Patient Perspectives. *Journal of Patient Experience* 4(4), pp. 191-196.

Excluded Studies:

A number of studies were excluded due to various reasons including the following:

- No information relating to the benefit and timing of advanced care planning
- Very few study participants with Parkinson's disease
- Poster abstract without full text lacking in data

For a full list of studies excluded at the full text reading stage, please contact PaCERSWCRC@cardiff.ac.uk

Additional materials available upon request:

- Critical appraisal / data extraction forms
- Search strategies

This report should be cited as follows: Palliative Care Evidence Review Service. What are patient perspectives in atypical and idiopathic Parkinson's disease of the benefits and timing of advance care planning and palliative care input? A rapid review: Cardiff: Palliative Care Evidence Review Service (PaCERS); 2021 July.

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