REVIEW ARTICLE

Experiences of advance care planning in Parkinson's disease and atypical parkinsonian disorders: a mixed methods systematic review

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Abstract

Background and purpose: Advance care planning allows people to plan for their future care needs and can include medical, psychological and social aspects. However, little is known on the use, experience of and attitudes towards advance care planning in patients with parkinsonian disorders, their family carers and healthcare professionals.

Methods: A systematic search of online databases was conducted in April 2019 using a narrative synthesis approach with thematic analysis and tabulation to synthesize the findings.

Results: In all, 507 articles were identified and 27 were included. There were five overarching themes: (i) what is involved in advance care planning discussions, (ii) when and how advance care planning discussions are initiated, (iii) barriers to advance care planning, (iv) the role of healthcare professionals and (v) the role of the family carer. This evidence was used to highlight eight effective components to support optimal advance care planning in parkinsonian disorders: advance care planning discussions should be individualized in content, timing and approach; patients should be invited to discuss advance care planning early and regularly; palliative care services should be introduced early; a skilled professional should deliver advance care planning; support to family carers should be offered in the advance care planning process; healthcare professionals should be educated on parkinsonian disorders and palliative care; advance care planning should be clearly documented and shared with relevant services; and healthcare professionals should be enabled to conduct effective advance care planning.

Conclusions: These components can inform best practice in advance care planning in patients with parkinsonian disorders.

Introduction

The worldwide prevalence of Parkinson's disease (PD) is estimated to double, from 6.9 to 14.2 million, by 2040, predominantly through the increase in life expectancy [1]. Atypical parkinsonian disorders are estimated to affect 5%–10% of these patients, who characteristically experience poor levodopa benefit and a worse prognosis [2]. Patients can later enter the palliative phase, defined by ineffective dopaminergic therapy, unsuitability for surgery and the presence of advanced comorbidity, e.g. dementia [3]. Planning for this can be achieved with advance care planning (ACP), a process that 'enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate' [4].

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Despite studies exploring ACP in neurodegenerative conditions [5–7], international working groups concluded that there is a lack of research in ACP [8,9]. However, ACP should be considered in PD and atypical parkinsonian disorders, as these progressive conditions lead to increasing disability due to physical and neurobehavioural symptoms with advancing disease, although disease progression is variable [9]. In addition, a significant proportion of these patients develop dementia and may loose capacity to make decisions regarding end-of-life care [10].

Although UK and American guidelines state that patients should have opportunities to discuss ACP, it is unclear when that should occur, with whom and what should be covered [11,12]. This leads to variation in what is meant by ACP and how it is delivered [13]. Furthermore, little is known regarding how patients with PD or atypical parkinsonian disorders, their families or healthcare professionals (HCPs) experience ACP and their thoughts towards it [14,15]. Therefore, the aim of this systematic review was to explore the experiences of ACP for people with PD or atypical parkinsonian disorders, their family carers and HCPs.

METHODS

Design

A systematic review of qualitative and quantitative studies was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines [16]. A protocol was registered on PROSPERO (CRD42019132686). Ethics committee approval was not required.

Inclusion and exclusion criteria

Included papers explored the use, experiences and attitudes towards ACP in PD and/or atypical parkinsonian disorders (progressive supranuclear palsy, multiple system atrophy and corticobasal degeneration). Atypical parkinsonian disorders were included because it was anticipated that the results would apply more broadly to disorders associated with parkinsonism, although treatment and prognosis can be different. Studies involving participants who developed dementia after being diagnosed with PD or atypical parkinsonian disorders were also included. There was no limit on date of study or country where studies originated.

Review articles, commentaries and conference proceedings were excluded. Also, studies where dementia with Lewy bodies was the primary diagnosis were excluded as, although there is overlap, our focus was on parkinsonism as the presenting complaint.

Search strategy

A systematic literature search of MEDLINE, Embase, PsycINFO, AMED and EBSCO CINAHL was performed on 3 April 2019. Search and index terms were generated from an initial scope of the literature and expert opinion. Synonyms and abbreviations were added where appropriate. Appendix A shows an example search strategy. The references of relevant articles were checked, and forward and backward citation tracking identified further relevant articles. Existing literature reviews on this topic were checked ensuring that relevant articles were identified in our search.

Selection procedure

DN and LH initially screened all articles by title and abstract, and then read the full text for all relevant articles. Articles were included or excluded based on the above criteria. DN and LH did this independently and subsequently reviewed each other's work to increase validity and reliability of the selection procedure [17]. Disagreements were arbitrated by a third reviewer (ND).

Quality appraisal and TIDieR checklist

DN and LH used the Critical Appraisal Skills Programme (CASP) checklists, depending on whether studies were qualitative [18] or quantitative (CASP case–control study [19] and CASP cohort study checklists [20]) to independently perform quality appraisal of all included papers [21]. Disagreements were resolved through discussion and if necessary with a third reviewer (ND). No articles were excluded based on their quality assessment but were used to develop the discussion.

DN and LH independently analysed all included studies for adherence to the TIDieR checklist (Table 1). The TIDieR checklist encourages authors to describe interventions in enough detail for replication [22].

Data extraction and synthesis

A data extraction tool was used for included articles, including aims; research design; study population; participant demographics; details of ACP; sample, recruitment, main findings, conclusions, quality appraisal and limitations. DN and LH independently completed data extraction for all included articles, which was checked by the rest of the research team (ND, ELS, AS, KW).

Table 1 Components of the TIDieR checklist [22]

Item number	Item
1	Describe the intervention
2	Why is the intervention developed?
3	What materials and procedures are used in the intervention?
4	Who will provide the intervention?
5	How will it be delivered?
6	Where will it occur?
7	When and how many times was the intervention delivered?
8	Describe how the intervention will be tailored for a certain group
9	Describe if the intervention was modified or changed during the study
10	Assess intervention adherence and the extent to which it was delivered to plan

A narrative synthesis was performed due to the predominantly qualitative nature of the studies, using tabulation and thematic analysis to organize and categorize findings [17]. DN and LH independently coded all included studies to devise an initial coding frame. They met to discuss this and disagreements before agreeing a refined coding frame to apply to the remaining studies. Disagreements were discussed with a third reviewer (ND). Finally, the coding was discussed through a series of meetings with the entire team (DN, LH, ND, ELS, AS, KW), who agreed the themes and organization to present the data [17]. Meta-analysis was not conducted as the studies were heterogeneous, using different questions and outcomes (Fig. 1).

Results

Description of studies

Figure 1 displays the result of the searches. An additional two publications were identified through forward and backward citation tracking [5,23]. They were published after the date of our electronic search and included after screening for relevance. A total of 27 studies were included, of which 15 were qualitative [5–7,23–34] and 12 were quantitative [14,15,35–44].

Appendix B summarizes the characteristics of the included studies. Nine studies addressed ACP from the perspective of the patient only, five from the carer only, five from the HCPs, six from both patients and carers, but only two studies covered the patients, carers and HCPs. Six studies included participants with dementia. Four studies focused on atypical parkinsonian disorders. Three studies did not include people with PD with Hoehn and Yahr score 1, indicating mild unilateral disease without balance impairment [45]. With the exception of one study each in Australia and Singapore, all of the included studies occurred in North America or Europe.

Quality appraisal

Appendix B shows the quality appraisal of the included studies, demonstrating how many of the CASP checklist criteria were met. Overall, quality varied. Many provided insufficient proof that sample sizes were adequate or whether they used a sample size calculator. For example, a survey of 125 HCPs had a response rate of 15% and only 58% of those fully completed the survey [15]. This is below the 60% response rate expected by journals, depending on format, population and survey distribution [46].

Few studies fully described details and content of ACP interventions and none covered all items of the TIDieR checklist [47]. Fourteen studies described when ACP occurred, but only five of these discussed how they modified or tailored ACP, e.g. for dementia patients [31].

Synthesis of results

Findings were grouped into five themes:

1) What is involved in ACP discussions?
2) When and how are ACP discussions initiated?
3) Barriers to ACP
4) The role of the professional
5) The role of the family carer

What is involved in ACP discussions?

What is discussed?

Advance care planning discussions involved a range of topics and terms (Appendix C), including advance directives [14,26,38], advanced decisions [30] and living wills (the individual writes wishes for end-of-life care in the event that they become unable to communicate decisions) [14,38,40], medical orders (standardized forms that address major healthcare decisions), e.g. on cardiopulmonary resuscitation (CPR) [14,15,29,40,42], ventilation [15,40], intensive care unit [15], nutrition/artificial feeding [6,14,15,40], symptom control [7,14,15,37], hydration [37], preferred place of death [14,15,37], respite [7,24,34] and power of attorney/healthcare proxy [14,38].

Adherence to ACP

Such ACP documentation has been shown to influence end-of-life decisions, e.g. leading to more people

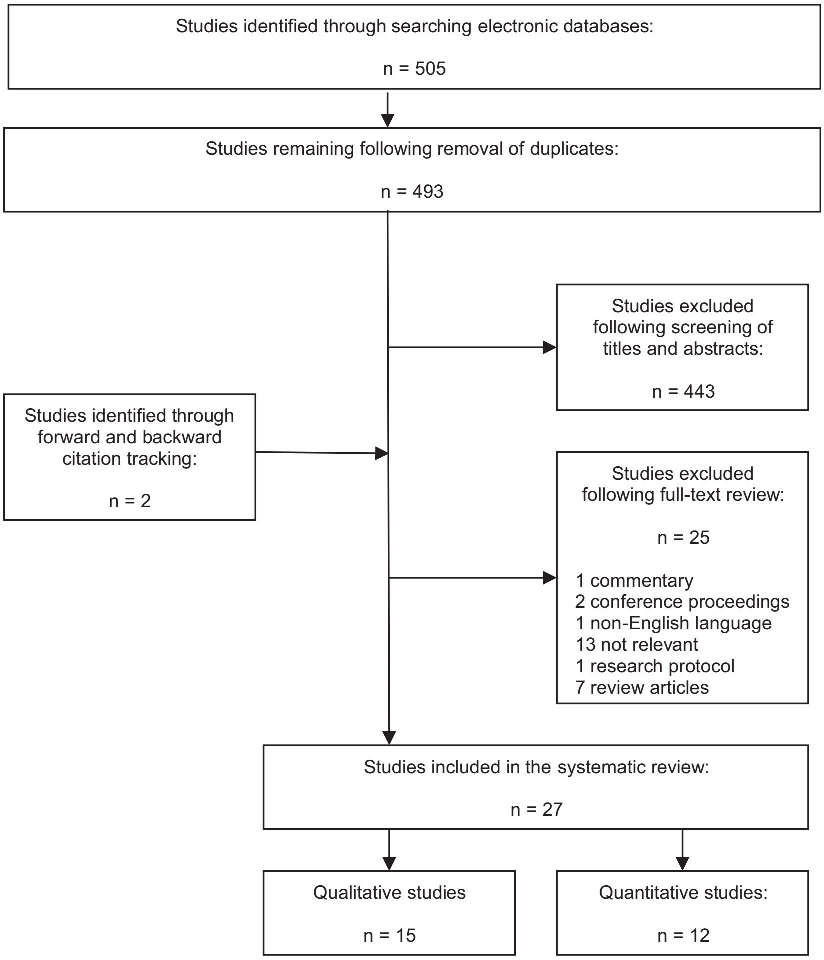

Figure 1 Result of the searches.

with PD to forgo life-sustaining treatment in favour of comfort measures, increasing the likelihood of dying at a hospice or home [14,40,44]. One study analysing routinely collected data found those with a physician order for life-sustaining treatment, which addresses resuscitation status and preferences for artificial nutrition and medical care, were half as likely to die in an inpatient facility compared to those without [44]. However, the proportion of people utilizing such documentation differed between studies. For example, in three US studies, rates varied between 14.6% and 53% [38,40,44]. This highlights variation within the same country, due to differences in population characteristics (e.g. ethnicity or socio-economic status), study setting (e.g. home and hospitals) and state-specific guidelines related to life-sustaining treatment orders and their legal standing, and other variables not examined.

However, ACP discussions and resulting decisions were not always adhered to. In some cases feeding tubes and breathing support were used when patients had opted for comfort care only [39]; and CPR was reported to have been performed on a patient with a 'do not attempt resuscitation' order [37]. Poor documentation was a reason given for not adhering to ACP decisions, and a lack of awareness of patients' wishes [40].

In a survey at a Regional Parkinson Centre in North America, 60/64 (95%) carers of patients with advanced PD reported that they had made a living will that was also shared with proxies [40]. Forty-seven per cent reported that the patient wanted CPR, 16% and 20% reported that they wanted a ventilator and feeding tube, respectively, and 42% did not know the patient's preferences for one or more treatments. Only 38% had shared this information with physicians. However, those who had shared advance directives with physicians were significantly more likely to choose hospice care than CPR and feeding tubes, compared to those who had not shared this information. Whilst rates of advance directives in this study were higher than in other studies, the results suggest that many patients, at least in advanced stages of PD, have prepared such documentation, but often do not share it with their physicians. This may at least partly explain lack of adherence.

In summary:

- Advance care planning discussions included a range of topics, but coverage was inconsistent and there was a lack of standardization on what should be included.
- Advance care planning resulted in greater patient choice in determining end-of-life preferences, yet these decisions were not always adhered to or shared with physicians.

When and how are ACP discussions initiated?

When are ACP discussions initiated?

Timing of ACP discussions was covered in 16 studies (qualitative and quantitative). Studies varied in their approach to delivering information and the amount given. In early disease stages, patients often did not want this information due to fear, denial, hope of a cure, wanting to live a normal life or to focus on symptom control [5,6,23,25,26,35,40,43]. On the other hand, some patients and family carers wanted to know about prognosis and the disease trajectory early. In a large survey of patients with PD in Oregon, approximately half wanted to discuss advance care documents early, although some patients wanted to discuss life expectancy, end-of-life care planning and end-of-life care options (e.g. hospice) when their disease worsened. A small number felt these issues should never be discussed [35]. Carers were often prepared for ACP discussion earlier than patients [32]. Important factors influencing attitudes towards ACP discussions included patient understanding and personal definition of ACP, information on the prognosis and choices available, level of education and desire to direct their own care, as well as care partners taking an active role [23,35].

Healthcare professionals from a range of disciplines involved in caring for patients with PD believed that ACP should be discussed early [5,28,31], as the risk of developing dementia and cognitive issues increases with time [31,39]. However, it was suggested that neurologists do not discuss ACP at diagnosis as the focus at that point is to optimize medical treatment [5]. In a qualitative study of 30 HCPs (doctors, nurses and therapists), HCPs highlighted that it is better for patients and families to be clear from the outset that the disease is incurable but they were divided when to initiate further discussions. Opinions ranged from at diagnosis to advanced disease, highlighted by a number of triggers indicating decreasing effectiveness of treatment. Others suggested an individualized approach, responding sensitively to cues from the patients to initiate the conversation [31].

It can be difficult, however, to gauge when patients are ready for these discussions due to the above individual patient factors, and as some patients and carers may be ambivalent themselves [32,33]. In addition, due to the high variability in disease progression some patients will never develop certain symptoms, e.g. dysphagia, and ACP discussions at diagnosis or early in the disease course would therefore be inappropriate [6]. This uncertainty often meant that discussions occurred in response to a crisis, e.g. hospital admission [31,34,36], at the start of cognitive decline or the terminal phase [15,28]. The need for discussion therefore depends on the individual and disease characteristics including diagnosis, symptom progression, age, values, personality, attitude, disease state and care needs [6,27,32].

A diagnosis of atypical parkinsonian disorder was more often reported as a trigger to discuss ACP [6,38]. These patients experience rapidly progressive symptoms compared to people with PD, and have been reported to be more informed about prognosis and ACP [6].

Who should initiate ACP conversations?

The views on the responsibility of initiating conversations varied amongst papers [5,15,23,25,26,31,33,35, 37,41,43]. Overall, people with parkinsonian disorders felt it was often left to them to initiate such discussions, e.g. in one study of 26 people with PD in Northern Ireland [25] and a survey of 267 patients with PD in Oregon [54]. However, approximately half of these felt these issues should be raised by the neurologist [35]. HCPs believed that in certain circumstances it was appropriate for patients to lead such conversations, e.g. if they were clear on what they wanted to discuss [26]. However, overall HCPs felt that HCPs should initiate ACP conversations [5,15].

How should ACP be initiated?

Advance care planning includes multiple steps which typically include discussion of personal views and values, documentation of preferences for future care in an advance directive, identification of a surrogate decision-maker and translation of preferences into medical care plans. There was variability in how these ACP discussions were initiated and conducted between studies, but overall it was concluded that family carers should be present [35] and physicians should initiate assessments of readiness for ACP discussions at least annually, advocating for a palliative care approach with team-based and whole-person care tailored to the individual [23,32]. The most common situation when ACP was discussed was during a crisis, e.g. a hospital admission, and challenges and situations presented by patients were often used as opportunities to initiate ACP. For example, a patient in one study said:

> I decided to give up driving. Every time [sic] I went out I would be driving along the street and I would hit the kerb.

The authors reported this was a cue to discuss fitness to drive, which could lead to a discussion about advancing symptoms [26]. However, HCPs also felt these issues should be raised when discussing increasingly reduced quality of life or development of unresponsive symptoms [31].

In summary:

- People with parkinsonian disorders often felt it was left to them to initiate ACP but would prefer the HCP to initiate the discussion.
- There was variability in views when the ACP should be initiated as it depends on several patient and disease-related factors, patient readiness, as well as HCP willingness to discuss the topic. This often resulted in discussions first taking place in response to a crisis, e.g. hospital admission.
- Whilst the majority of patients do not want to have discussions at the time of diagnosis, a proportion of patients would like to have discussions early.
- Advance care planning should be team-based and person-centred with family input.

Barriers to advance care planning

Multiple barriers to ACP were highlighted in the literature that led to a perception of unmet need.

Lack of information, education and experience

A lack of information on parkinsonian disorders, palliative care and ACP was consistently identified as a barrier by patients, family carers and HCPs. In addition, patients and carers often did not know how to initiate ACP discussions [29].

Patients and family carers

Many patients and family carers felt they were not given enough information on disease progression and prognosis, and wanted this earlier [6,25,29,30,32,33]. Some patients reported not knowing that PD is incurable, whilst others delayed thinking about the future in the hope that a cure might be developed [23,31,32].

> Interviewer: So has he talked to you about how the condition will progress in the future? Has the doctor explained…? Participant: No. As far as he is concerned he doesn't have an appointment with me for another 6 months. (PD patient P211) [6]

A lack of knowledge and stigma was associated with the term 'palliative care' [5,25,27,29–32,34]. Many were unfamiliar with palliative care or associated it with cancer, unaware that specialist palliative care services can provide support for them.

> … I don't know about them [palliative care], but they are for cancer patients I know that, but whether they apply to [PD], I suppose they probably do. I don't know. (Carer 5) [32]

However, once informed about palliative care and the services provided, most were receptive to it [5,23,29–32].

Professionals

A lack of knowledge of disease progression and/or palliative care approaches was reported amongst non-specialist HCPs [5,15,25,27,28,31]. HCPs involved in the care of patients with PD reported a deficit in palliative care skills and recognized a need for further training and education on palliative care [5,15,27,31]. Some saw palliative care as terminal care, defining it as 'care in the last few hours' [31]. One study reported that a lack of education about palliative needs of people with PD led to few being referred to palliative care services [27]. Conversely, and as a consequence, palliative care services were less experienced in supporting and managing those with PD or atypical parkinsonism, perpetuating a negative view of the usefulness of palliative care in this condition. An integrated approach was seen as beneficial, with access at any time to the acute and general palliative care in non-specialist settings and also access to specialist palliative care when needed [31].

A randomized controlled trial comparing a palliative care approach to standard PD care found integrating palliative care with traditional PD care better facilitated ACP conversations. This included systematic and routine inclusion of ACP in visits with clear and open conversations, including the care partner and involvement of trained interdisciplinary team members who facilitated ACP conversations. In contrast, participants in the standard PD care arm of the randomized controlled trial felt ACP was poorly integrated into their care, and, if an ACP conversation occurred, it was common for it to be a one-time conversation, often with lawyers and without medical input [23].

Practical barriers

Key barriers to the provision of effective ACP identified by HCPs were lack of sufficient funding, time and resources in healthcare services for patients [5,27,28,31]. A lack of sufficient clinic time for specialists and availability of other staff, in particular psychologists, social workers and allied health professionals [27,31], led to high workloads and a lack of time with patients and unavailability of multidisciplinary input [27].

Inequity in specialist and palliative care resources was also a barrier, as found in an Irish study of 30 HCPs [31]. It found that areas with a lack of PD nurse specialists, compounded by poor transport in rural areas, resulted in limited access to services.

Communication difficulties due to symptomatic progression

Progression of symptoms brought about challenges surrounding communication, speech, cognitive dysfunction, apathy and depression. These symptoms all impacted on the ability of patients to make and communicate decisions, including ACP [5,23,29,30].

It was also suggested that cognitive impairment not fulfilling diagnostic criteria for a diagnosis of dementia can sometimes impact on the ability to make decisions even in early disease, and on the validity of those decisions. This is because the decisions 'may not be congruent with their values prior to developing executive dysfunction' [43].

In summary:

- Barriers to ACP discussions in patients and carers included lack of knowledge about progression of parkinsonian disorders and about palliative care.
- Barriers to ACP discussions in HCPs included deficit in skills, knowledge, lack of resources and time to undertake ACP discussions.
- Features of advanced disease can limit the ability to have ACP discussions.

Role of the professional

Collaboration and shared responsibility

Neurologists were mostly not involved in ACP, but many HCPs believed that physicians should initiate the process [29]. It was generally recognized that multidisciplinary working was important, but a lack of collaboration and integration between services and disciplines hindered ACP, leading to inadequate symptom management and care opportunities for carers [25]. Availability and fragmentation of palliative service delivery resulted in difficulties deciding how and when these services should be delivered [34,31]. This is an important gap as non-palliative HCPs felt they were sometimes unable to support patients once they were too unwell or disabled to attend clinics.[7]

Multidisciplinary team

Ten studies found ACP discussions were facilitated by multidisciplinary teams (MDTs), including occupational therapists, physiotherapists, social workers, nurses, speech and language therapists, psychologists, dietitians and chaplaincy [5,7,23,24,27,28,30,32–34]. These provided support and education for ACP discussions that led to clear plans and access to resources, such as support in writing advance directives and access to the wider MDT [23]. When an MDT approach was not used there was a focus primarily on medication with little emphasis on psychological support [7,32,34].

Specialist and general palliative care

Many HCPs believed that people with PD should have access to both general palliative care (within PD services) at any time and specialized palliative care, when needed [31].

In summary:

- Multidisciplinary team access to and collaboration with palliative care services were facilitators to delivering effective ACP, leading to clear plans and appropriate access to specialist palliative care services.
- Both general and specialist palliative care approaches should be available, depending on need at the time.

Role of family carers

Family carers reported a variable experience of ACP, particularly those who had undergone a role reversal, finding it difficult to make decisions about their relative's care [30,32]. However, most accepted their responsibilities and acknowledged they would have to take more control over their care as the disease progressed.

> As a care partner, I don't think you can opt out. If I'm going to be responsible for doing it, I've got to know what I'm supposed to do. (Care partner) [23]

Some carers expressed a desire for more support and guidance on ACP from HCPs for themselves [24,25,30,32,34]. [27,28,34] and social workers were key to addressing these needs [28,29].

The burden felt by carers was reported by several studies, and it was felt that this often went unrecognized [5,24,25,27,28,30,32,34]. Whilst carers were seen as facilitators in ACP, particularly when they played an active role, some HCPs commented that emotionally burdened carers could instead be a barrier [5,23], particularly when the wishes of people with PD differed from those of the carer or there was a lack of discussion of wishes between the carer and person with PD previously.

In summary:

- Carers were a key facilitator to ACP but could also be a barrier if emotionally burdened.

Comparison between Parkinson's disease and atypical parkinsonian disorders

Four studies focused on atypical parkinsonian disorders [6,7,37,38]. One addressed ACP from the perspective of patients, carers and HCPs [7], two from the perspective of patients and carers [6,38] and one exclusively covered patients with multiple system atrophy [37]. Similar challenges were found in atypical parkinsonian disorders as in PD, including the perception of unmet need and a lack of standardization in the approach to ACP.

However, in a qualitative study including 29 people with a range of neurological conditions (dementia, PD, Huntington's disease, progressive supranuclear palsy, motor neurone disease, multiple sclerosis), those with progressive supranuclear palsy were better informed about the prognosis of their condition and about possible decisions, e.g. on percutaneous endoscopic gastrostomy feeding, compared to people with PD [6]. It was felt that this may be due to the less predictable and longer disease trajectory in PD, where giving information on complications they may never develop may be distressing [6].

DISCUSSION

To the best of our knowledge, this is the first systematic review exploring ACP in PD and atypical parkinsonian disorders. ACP was found to cover a range of topics and patients with ACP interventions were less likely to opt for life-sustaining treatments. Also, collaboration and MDT input were facilitators by ensuring holistic care whilst barriers included a lack of knowledge among patients, carers and HCPs.

A common theme was that people with PD or atypical parkinsonian disorders and their carers felt they were not fully informed about the progression of their condition and palliative care. Many expressed a wish to know more about treatment options at the later stages. However, some appeared not to want any information at all. The latter group presents the greatest challenge to ACP. It is important to respect individuals' wishes, but a basic understanding about symptom progression and palliative care should be encouraged, with opportunities to revisit the topic over time. They should also be aware of why it is important to plan in advance and be provided with adequate information about future options, e.g. CPR.

Our review also highlights components of ACP that remain unclear, e.g. who should initiate discussions and when. In terms of timing, studies interviewing HCPs found it difficult to identify the right time but favoured earlier discussions before people progressed to a stage where they lacked capacity. This aligns with current best practice on how to achieve ACP [48]. However, this is at odds with what is observed in clinical practice and what was found on reviewing the literature: although some individuals want to know early, others were internally conflicted due to factors such as denial, hope of a cure, wanting to live a normal life or to focus on symptoms. Heterogeneity and differences in progression rates are also factors that make the decision of when and which patients to discuss the future with challenging. It was found that 'the right time' depends on patient factors such as their values, goals and care needs, as well as HCP characteristics, such as their willingness to discuss the topic.

Our findings are relevant for other progressive neurological conditions such as motor neurone disease and dementia [49,50]. For example, in dementia there are examples of good practice in ACP but few clear resources available [50]. It is known what decisions and conversations need to happen, but it is unclear how they should happen [51]. In 2011, the European Association of Palliative Care's white paper outlined the first definition of palliative care in dementia [52]. It provides HCPs with a template for supporting ACP in dementia and includes recommendations similar to what was found in the literature in PD and atypical parkinsonian disorders. However, it does not describe how ACP should be implemented.

This study has several limitations. Many studies did not include components of the TIDieR checklist, making it difficult to draw definitive conclusions around individual elements of ACP. Also, the generalizability of the findings is limited by several factors:

- There are a small number of papers ($n = 27$), with varied stakeholders and a combination of PD and/or atypical parkinsonism studies.
- Several papers were produced by similar authors, e.g. four studies from Northern Ireland involved similar authors.

Table 2 Effective components to support ACP in parkinsonian disorders

As there is no clear time when ACP discussions should occur, they need to be individualized and tailored in timing, content and approach. In ACP discussions the HCPs should take into account: patients' different disease stage and characteristics, age and disease duration, fears and expectations, backgrounds, social circumstances, values and wishes. Some people with PD, atypical parkinsonian disorders and their carers may want to discuss ACP at diagnosis and others later at different stages as the condition progresses.
Some people felt they were not fully informed regarding prognosis and progression. To improve this, HCPs should invite patients to discuss planning ahead early and regularly, as willingness to discuss future plans fluctuates, e.g. when symptoms change. They should provide information to patients and carers early so they can make informed decisions about their future. Regular meetings would avoid overloading them and allow more difficult topics to be introduced. This would result in more meaningful ACP discussions.
Palliative care involvement facilitated ACP and should therefore be introduced early.
Collaboration between specialties and disciplines was also found to facilitate ACP. Members of the MDT should be utilized (including social workers where applicable) to ensure holistic care and that all aspects of ACP are considered, not just medical interventions. Flexibility is required when defining roles so the right professional delivers support depending on their skill set.
Some carers felt they lacked support in the ACP process; thus, they should also be offered support; carers and patients have separate and individual needs, which should be addressed. This would help to alleviate their burden, positively impacting on them and those they care for.
Non-specialists should be educated on PD and atypical parkinsonian disorders. Specialists should be educated on aspects of general palliative care as both reported a knowledge and skills gap in these respective areas. Topics should encourage prognosis, different aspects of symptom management and advanced communication skills. This will enable confidence in discussing and managing symptoms, proactive referrals to specialist palliative care services when needed and collaborative working.
Poor documentation was identified as a reason why some ACP decisions were not adhered to. Thus, documentation should be clear and easily accessible and importantly also shared to allow adherence to ACP decisions and help future discussions.
Practical barriers, particularly a lack of time, were highlighted as a barrier to ACP discussions. Policy makers should consider how HCPs are supported in good ACP. For example, ensuring staff have protected time for such discussions, readily available access to specialist palliative care services and free courses on ACP that can be used towards professional development.

ACP, advance care planning; HCPs, healthcare professionals; MDT multidisciplinary team; PD, Parkinson's disease.

- Studies used small sample sizes with heterogeneous populations.

There are also limitations of the wider ACP literature that should be noted. For example, experts disagree on the definition of ACP and there are differences in legislation between countries and states. It is therefore difficult to assess its impact in different populations, settings and contexts [53].

However, our search was rigorous and according to published guidelines [17]. Two independent reviewers were involved in the selection procedure, data extraction, quality assessment, analysis and writing of results. There were also high-quality qualitative studies providing valuable insights into the experiences of ACP in PD and atypical parkinsonian disorders. Finally, a broad MDT was involved in the interpretation of results.

Based on our findings, effective components of ACP in parkinsonian disorders are shown in Table 2. These components should be considered earlier in atypical parkinsonian disorders, due to a rapid progression of symptoms.

Several recommendations can be made for future research, which should

- explore further how and when ACP in PD and atypical parkinsonian disorders is delivered;
- focus on better describing ACP processes and research methods;
- use larger sample sizes so that results can be generalized.

To conclude, ACP can be used effectively to help people with PD and atypical parkinsonian disorders take control of their future. However, what is covered, how it is initiated and when it should be introduced varies internationally. Evidence suggests that these factors depend on the patient, circumstances, HCP and should be individualized. Proactive discussion by HCPs will help to ensure ACP is completed, shared and adhered to.

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Appendix A

Example search strategy from MEDLINE

Search	No. of hits
1. Exp Advance Care Planning/	
2. (advance* care adj (plan or plans or planning)).tw.	
3. (advance* adj2 (directive* or decision*)).tw.	
4. Living will*.tw.	
5. Right to Die/	
6. right to die.tw.	
7. Patient Advocacy/	
8. ((patient or patients) adj5 (advocate* or advocacy)).tw.	
9. power of attorney.tw.	
10. ((end of life or EOL) adj5 (care or discuss* or decision* or plan or plans or planning or preference*)).tw.	
11. terminal care/ or hospice care/ or resuscitation orders/	
12. (terminal care or hospice or resuscitation orders).tw.	
13. Treatment Refusal/	
14. exp Withholding Treatment/	
15. (treatment adj5 (refus* or withhold* or withdraw*)).tw.	
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15	
17. exp parkinsonian disorders/ or supranuclear palsy, progressive/ or exp system atrophy, multiple/	
18. parkinson*.tw.	
19. (supranuclear adj2 pals* adj2 progressive).tw.	
20. (richardson* adj2 (syndrome or disease)).tw.	
21. (system* adj2 atroph* adj2 multi*).tw.	
22. (shy adj2 drager adj2 syndrom*).tw.	
23. (striatonigral adj2 degenerat*).tw.	
24. (corticobasal adj2 (degeneration or syndrome)).mp.	
25. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24	
26. 16 and 25	

Appendix B

Comparison of demographics and themes explored

Author/year	Country	Method	Sample size and population	Dementia	Severity	Themes/subthemes	Quality ppraisal
Qualitative							
Boersma *et al.*, 2016 [29]*	USA	Semi-structured interviews and focus groups	11 family carers (*interviewed with their relative with PD*) 30 PD	$n = 5$ MoCA: mean 25.1 (SD 4.1); range 14–30	H&Y: I ($n = 2$); I.5 ($n = 1$); II ($n = 13$); II.5 ($n = 6$); III ($n = 3$); IV ($n = 5$) UPDRS III: mean 28.2 (SD 15.4)	ACP: What is discussed (*CPR*) Barriers: Lack of information (*PD; palliative care; ACP; positive palliative care education*); communication (*symptomatic progression*) Carers: Burden	CASP 10/10
Boersma *et al.*, 2017 [30]*	USA	Semi-structured interviews and focus groups	11 family carers 11 PD	$n = ?$ (*not stated but specifically included*) MoCA: mean 25.5 (SD 4.0); range 14–28	H&Y: II ($n = 6$); II.5 ($n = 3$); III ($n = 1$); IV ($n = 1$)	ACP: What is discussed (*advanced decisions*); when is ACP raised (*variation*) Barriers: Lack of information (*PD; palliative care; positive palliative care education*); communication (*symptomatic progression*) Professionals: MDT Carers: Variable experience; lack of support	CASP 10/10
Clarke *et al.*, 2018 [6]	UK (England)	Longitudinal in-depth interviews	*29 family carers and people with neurodegenerative diseases, including:* 3 PD and 3 family carers 3 PSP and 3 family carers	–	–	ACP: What is discussed (*nutrition*); when is ACP raised (*variation*); Special circumstances (*Parkinson-plus*) Barriers: Lack of information (*PD*); PD (*unpredictable nature*)	CASP 7/10
Fox *et al.*, 2016 [31]**	Ireland	Semi-structured interviews	30 HCP	–	–	ACP: Who initiates conversations (*HCP established rapport*); when is ACP raised (*HCP early; crisis*) Barriers: Lack of information (*hope of cure; palliative care; HCP; positive palliative care education*); practical barriers Professionals: Collaboration; palliative care	CASP 9/10

(continued)

Appendix B. *(Continued)*

Author/year	Country	Method	Sample size and population	Dementia	Severity	Themes/subthemes	Quality ppraisal
Fox *et al*., 2017 [32]**	Ireland	Semi-structured interviews	12 family carers 19 PD	–	–	ACP: When is ACP raised (*HCP late*) Barriers: Lack of information (*PD; hope of cure; palliative care; positive palliative care education*) Professionals: MDT; palliative care Carers: Variable experience; lack of support; burden	CASP 9/10
Giles and Miyasaki, 2009 [33]	Canada	Semi-structured interviews	4 family carers 3 PD (though third person too cognitively impaired to be included)	*1 PD with severe dementia, not interviewed*	–	ACP: Who initiates conversations (*power imbalance*); when is ACP raised (*variation*) Barriers: Lack of information (*PD; HCP*) Professionals: MDT	CASP 8/10
Hasson *et al*., 2010 [34]***	UK (NI)	Semi-structured interviews	15 family carers	–	–	ACP: What is discussed (*respite*); when is ACP raised (*crisis*) Barriers: Lack of information (*palliative care*) Professionals: MDT; collaboration Carers: Lack of support; burden	CASP 9/10
Hudson *et al*., 2006 [24]	Australia	Semi-structured interviews	21 family carers 6 HCP 8 PD	–	–	ACP: What is discussed (*respite*) Professionals: MDT; palliative care Carers: Lack of support; burden	CASP 10/10
Lennaerts *et al*., 2019 [5]	Netherlands		39 HCP	–	–	ACP: Who initiates conversations (*HCP should initiate*); when is ACP raised (*variation; HCP early*) Barriers: Lack of information (*palliative care; HCP; positive palliative care education*); communication (*symptomatic progression*); practical barriers Professionals: MDT Carers: Burden	CASP 9/10
Lum *et al*., 2019 [23]	USA		30 family carers 30 PD	MoCA: mean 26 (SD 3.2) *Severe dementia excluded from study*	H&Y: 0 (n = 2); I (n = 10); II (n = 11); III (n = 5); IV (n = 1); V (n = 1)	ACP: Who initiates conversations (*HCP should initiate*); when is ACP raised (*variation*) Barriers: Lack of information (*hope of cure; ACP; positive palliative*	CASP 8/10

(continued)

Appendix B. *(Continued)*

Author/year	Country	Method	Sample size and population	Dementia	Severity	Themes/subthemes	Quality ppraisal
						care education; positive palliative approach); communication (*symptomatic progression*); Professionals: MDT Carers: Burden	
McLaughlin *et al.*, 2010 [25]***	UK (Northern Ireland)	Semi-structured interviews	26 family carers	–	–	ACP: Who initiates conversations (*people with PD felt responsible to initiate*); when is ACP raised (*variation*) Barriers: Lack of information (*PD; palliative care; HCP*); PD (*unpredictable nature*) Professionals: Collaboration Carers: Lack of support; burden	CASP 9/10
Shaw and Vivekananda-Schmidt, 2017 [26]	UK (England)	Semi-structured interviews	12 PD	–	–	ACP: What is discussed (*advance directives*); who initiates conversations (*HCP should initiate*); when is ACP raised (*variation*) Barriers: Lack of information (*PD*); PD (*unpredictable nature*)	CASP 9/10
Veronese *et al.*, 2015 [7]	Italy	Semi-structured interviews and focus groups	*21 family carers of people with* neurodegenerative diseases (*unclear how many PD-related*) 11 HCP *22 people with neurodegenerative diseases, including*: 1 MSA 5 PD	–	H&Y: mean 4.5, range 4–5	ACP: What is discussed (*respite; symptom control*) Professionals: MDT; collaboration	CASP 8/10
Waldron *et al.*, 2011 [27]***	UK (Northern Ireland)	Semi-structured interviews and focus groups	13 social workers	–	–	ACP: when is ACP raised *(variation)* Barriers: Lack of information (*palliative care; HCP*); communication (*symptomatic progression*); practical barriers Professionals: MDT Carers: Burden	CASP 9/10
Waldron *et al.*, 2013 [28]***	UK (Northern Ireland)	Semi-structured interviews and focus groups	12 HCP	–	–	ACP: when is ACP raised (*HCP early; HCP late*) Barriers: Lack of information (*HCP*); communication (*symptomatic progression*); practical barriers	CASP 8/10

(continued)

Appendix B. *(Continued)*

Author/year	Country	Method	Sample size and population	Dementia	Severity	Themes/subthemes	Quality ppraisal
						Professionals: MDT; collaboration Carers: Burden	
Quantitative							
Dayal *et al*., 2017 [37]	Canada	Routinely collected data analysis	22 MSA	–	–	ACP: What is discussed (*symptom control; hydration; preferred place of death*); who initiates conversations (*HCP prior to crisis*); adherence (*non-adherence*)	CASP 8/11
Gillard *et al*., 2019 [38]	USA	Survey	49 APD 50 family carers 50 non-family carers (control) 50 PD	MMSE: PD mean 28.51 (SD 1.87); APD mean 27.07 (SD 2.08)	H&Y: PD mean 2.35 (SD 0.88); APD mean 3.17 (SD 0.72)	ACP: What is discussed (*advance directives; power of attorney/healthcare proxy; living wills*); Special circumstances (*Parkinson-plus; dementia*)	CASP 9/12
Goy *et al*., 2007 [14]****	USA	Survey	47 family carers	–	–	ACP: What is discussed (*CPR; nutrition; advance directives; symptom control; preferred place of death; power of attorney/healthcare proxy; living wills*) Professionals: palliative care	CASP 1/11
Goy *et al*., 2008 [39]****	USA	Survey	52 family carers (*for PD and related disorders*) 50 family carers (*for ALS*)	–	–	ACP: when is ACP raised (*HCP early*); adherence (*non-adherence*) Professionals: palliative care	CASP 7/11
Kwak *et al*., 2014 [40]	USA	Survey	64 proxies for advanced PD	*n* = 20	UPDRS: part II (function) mean 21.5 (SD 7.6); part III (motor) mean 31.1 (SD 12.3) Schwab and England ADL Score: mean 53.4 (SD 21.1)	ACP: What is discussed (*CPR; ventilation; nutrition; living wills*); when is ACP raised (*variation*); adherence (*not sharing*)	CASP 10/11
Li *et al*., 2016 [41]	Singapore	Survey	136 PD 60 controls	MMSE: ≥24 *n* = 114; <24 *n* = 22	H&Y: ≤2 *n* = 107; >2 *n* = 29 UPDRS (motor): ≤17 *n* = 72; >17 *n* = 64 Schwab and England ADL Score: >90 *n* = 36; ≤90 *n* = 100	ACP: Who initiates conversations (*HCP established rapport*)	CASP 9/11

(continued)

Appendix B. *(Continued)*

Author/year	Country	Method	Sample size and population	Dementia	Severity	Themes/subthemes	Quality ppraisal
Mahajan *et al.*, 2017 [42]	USA	Case–control	246,625 PD 723,090 without PD	–	–	ACP: What is discussed (*CPR*) Barriers: PD (*unpredictable nature*)	CASP 11/11
Abu-Snineh *et al.*, 2017 [43]	Canada	Mixed methods	50 people with PD	*Participants with cognitive concerns but not dementia included* MMSE: mean 27.76 (SD 1.61) MoCA: mean 24.5 (SD 2.07) MacCAT: mean 14.16 (SD 3.09), range 7–20	UPDRS: mean 20.76 (SD 10.8)	ACP: Who initiates conversations (*HCP prior to crisis*); when is ACP raised (*variation*) communication (*cognitive impairment*)	CASP 7/11
Tuck *et al.*, 2015 [35]*****	USA	Survey	267 PD	–	–	ACP: Who initiates conversations (*HCP should initiate*); when is ACP raised (*variation*) Barriers: Lack of information (*PD*)	CASP 6/11
Tuck *et al.*, 2015 [44]*****	USA	Routinely collected data analysis	373 PD 700 without PD	*Dementia was the most common PD-associated cause of death*	–	ACP: What is discussed (*medical orders influence place of death*) Professionals: palliative care	CASP 9/11
Walker *et al.*, 2014 [36]	UK (England)	Routinely collected data analysis	236 PD	–	–	ACP: when is ACP raised (*crisis*)	CASP 5/11
Walter *et al.*, 2019 [15]	Netherlands	Survey	125 HCP	–	–	ACP: What is discussed (*CPR; ventilation; ICU; artificial nutrition; symptom control; preferred place of death*); who initiates conversations (*HCP should initiate*); Special circumstances (dementia) Barriers: Lack of information (*HCP*)	CASP 7/11

–, not stated; ACP, advance care planning; ADL, activities of daily living; ALS, amyotrophic lateral sclerosis; APD, atypical Parkinson's disease; CASP, Critical Appraisal Skills Programme; CPR, cardiopulmonary resuscitation; HCPs, healthcare professionals; H&Y, Hoehn and Yahr scale; ICU, intensive care unit; MacCAT, MacArthur Competence Assessment Test; MMSE, Mini-Mental State Examination; MoCA, Montreal Cognitive Assessment; MSA, multiple system atrophy; PD, Parkinson's disease; PSP, progressive supranuclear palsy; UPDRS, Unified Parkinson's Disease Rating Scale. * indicates papers with the same or similar authors involved. Studies with the same number of asterisks have the same or similar authors involved.

Appendix C

Description of interventions used in advance care planning

Intervention	Description
Advanced directive	A document outlining a person's provision for healthcare decisions, in the event that in the future they lack capacity to make those decisions
Living will/advanced decision	A type of advance directive outlining wishes about medical treatment, if the person is unable to make decisions regarding medical treatment. They usually instruct medical professionals to withhold or withdraw medical interventions towards the end of life
Lasting power of attorney for health/health proxy	A person designates someone else to make medical decisions on their behalf, if they are unable to make decisions for themselves
Medical orders Standardized forms that address major healthcare decisions. Life-sustaining treatment order	Orders related to life-supporting treatments or procedures, e.g. cardiopulmonary resuscitation, ventilation, artificial feeding

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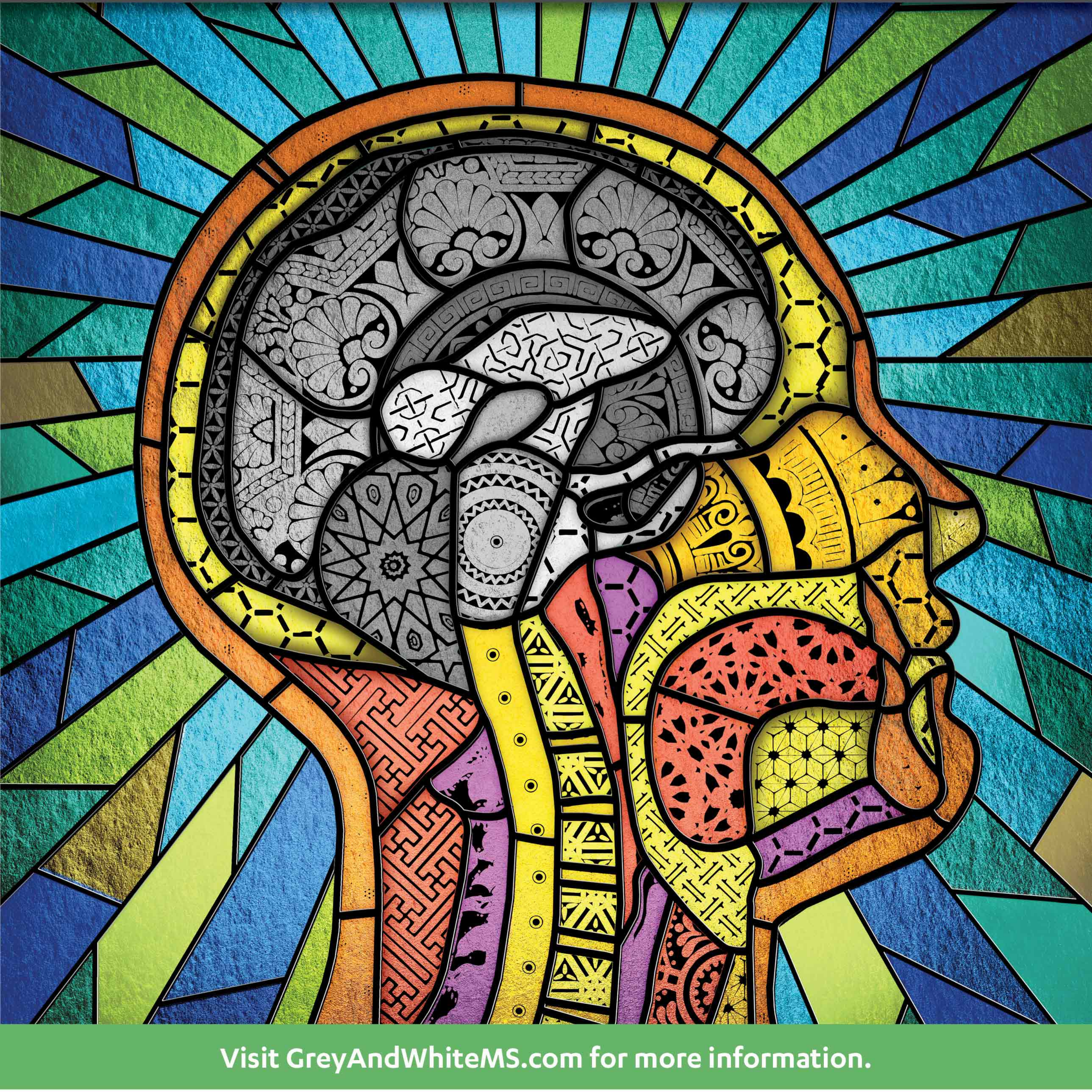

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