

Patient perceptions and knowledge of Parkinson's disease and treatment (KnowPD)

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ARTICLE INFO

Article history:

Received 21 April 2019

Received in revised form 28 September 2019

Accepted 25 November 2019

Available online 16 January 2020

Keywords:

Parkinson's disease

Patient education

Questionnaire design

Health education

ABSTRACT

Background: As the 2nd most common neurodegenerative disorder, Parkinson's disease (PD) affects over 1 million Americans. Treatment is complex and may include pharmacotherapy, rehabilitative measures, and surgical intervention. A comprehensive understanding of the patient's perceptions about PD is a vital step towards improving health literacy and clinical outcomes.

Methods: KnowPD is a web-based survey with Likert responses for a cross-sectional, nonrandomized study to assess patients' knowledge of PD symptoms, medications, deep brain stimulation (DBS), rehabilitation, and other factors relevant to disease management.

Results: Of the 98 subjects surveyed, 90% agreed they had sufficient knowledge of PD. However, in this cohort, 82% incorrectly believed levodopa stops working as the disease progresses, 77% erroneously thought DBS improves balance and reduces falls, and, < 50% could answer specific questions regarding the dosing of levodopa despite over 75% reporting managing their own medications. A majority of patients (84%) believed it was possible to live well with PD, correlating with their self-reported knowledge of the disease. Finally, patients selected electronic video (13.7%) and reading (20.0%) material, yearly symposia (20.0%), and lunch lectures (28.4%) as their preferred method of information delivery.

Conclusion: Misconceptions are prevalent among PD patients, and these appear to be unrelated to gender, provider type, or education level. Identification and characterization of this knowledge gap is vital towards allocating patient education resources, and the findings described herein will form the basis for effective educational interventions.

1. Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disorder worldwide and affects one million Americans [1,2]. Since its description in *An Essay on the Shaking Palsy* published in 1817 [3], PD epidemiology, possible etiologies and risk factors, diagnostic criteria, motor and non-motor symptoms, pharmacological and surgical therapeutics and the role of ancillary services have all been extensively explored in the literature. The diagnostic criteria [4,5] underscore the complexity of PD both in terms of the diverse symptomatology patients experience and the myriad of pharmacological and surgical treatment options available. The former encompass up to four motor symptoms and common non-motor symptoms such as sleep disturbances, dysautonomia, hyposmia, and psychiatric dysfunction [5]. Pharmacological treatment options are numerous including 5 main classes (levodopa, dopamine agonists, monoamine oxygenase

inhibitors, catechol-*o*-methyltransferase inhibitors, and amantadine) for motor symptoms alone, each with differing adverse effect and benefit profiles. Surgical options are rapidly expanding with three deep brain stimulation (DBS) devices, all of which offer unique design features, and other options being explored such as high frequency ultrasound. As such, managing PD patients has become incredibly complex leaving patients vulnerable to misinformation and naiveté with regards to many aspects of the disease and its treatment.

The current literature offers a paucity of insight into the prevalence and extent of knowledge gaps that might exist in PD patients and their families. Although questionnaires do have a long history of utility in PD (dating back to the 1990's with the advent of the Parkinson's Disease Questionnaire-39 (PDQ-39) [6]) studies have not specifically assessed patient knowledge of PD. Educational interventions aimed at improving health literacy have shown significant impact on patient health measures and quality of life in diverse chronic illnesses such as asthma [7], heart disease [8], diabetes [9], and Alzheimer's disease [10]. In fact, in a prior study of patients with PD, patient education sessions correlated with improved quality of life and reduced caregiver burden [11]. Revealing those existing knowledge

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gaps is vital in determining how best to improve patient involvement in their disease management, which in turn may lead to improved health outcomes and quality of life.

2. Methods

2.1. Recruitment and participants

Over 12 months, convenience sampling was used to recruit 98 participants from movement disorder clinics and a local Parkinson's disease support group; of note, the majority of the patients (82) received treatment in the Movement Disorders Clinic at UT Southwestern Medical Center (Dallas, TX). Subjects at least 18 years of age, English-speaking, previously diagnosed with idiopathic PD, and having sufficient cognitive ability to independently complete a survey were recruited in person and via email. Prisoners, Non-English speakers, and patients who resided over 150 miles from Dallas, TX were excluded. The patients' medication state was not queried and therefore not controlled for in this study. Patient characteristics are summarized in Table 1.

A survey was generated using commercial software (RedCap®) and administered via electronic tablet or e-mail. The 69-point questionnaire utilized Likert response options (Supplementary information) to explore patient knowledge of PD medications, DBS, motor versus non-motor symptoms, perceived role of ancillary support services, and patient perspectives of disease management. Instructions provided to patients stipulated that answers to the questions be made without caregiver input. No personal health or identifiable information was collected. Data was stored electronically in a password-protected system.

2.2. Data analysis

Survey responses were tabulated and numerically encoded in Excel (Microsoft) and exported to SAS (SAS Institute) and Matlab (Mathworks) for analysis. Missing data were not imputed as >98% of all non-followup questions had fewer than 4 blank responses. To investigate the relationship between the distributions of responses to various questions, one-way analysis of variance (ANOVA) was used to assess the existence of linear associations, and the Mann-Whitney *U* test was used where no underlying assumption of the relationship was imposed; *p*-values < 0.05 are considered statistically significant.

3. Results

3.1. Patient perceptions of Parkinson's disease

To determine the landscape of participant understanding of Parkinson's disease, we queried responses to the statement "I am knowledgeable about

PD." An overwhelming majority (88 of 98 participants) responded in the affirmative, either agreeing or strongly agreeing with the statement (Fig. 1A). In contrast, only 3% reported lacking knowledge about the disease. We subsequently explored whether this level of perceived knowledge in our participant population could be explained by demographic variables that might influence, for example, patient exposure to educational resources, comprehension thereof, or as yet undefined experiences. There was no statistically significant relationship between the distributions of perceived knowledge of PD within gender or provider type ($p > 0.05$, Mann-Whitney *U* test; Fig. 1B–C). This suggests that having specialized providers managing the care of PD is not necessarily associated with higher levels of patient understanding of the disease. Similarly, there was no significant linear association between participant education level and knowledge of PD (one-way ANOVA, $p < 0.05$; Fig. 1D). Thus, we currently lack an explanation for the preponderance of participants that judged their knowledge of PD as substantial. As discussed below, such insight might reveal convenient paths of intervention in correcting widely held patient misconceptions about PD.

3.2. Patient misconceptions

Does patients' confidence in their understanding of the disease that afflicts them belie incorrect notions, beliefs, or myths? We used responses to survey questions regarding PD medications, DBS, and symptomatology to directly ascertain the degree and pervasiveness of patient misconceptions regarding PD. Analyses were constrained to patients who reported being knowledgeable about the disease ($n = 88$). Dopaminergics, like levodopa-carbidopa, represent the most effective agents in the pharmaceutical arsenal to treat PD, and so it was revelatory that only 71% of participants who presumed to be knowledgeable about the disease could identify it from its trade name, Sinemet (Fig. 2A). Even fewer participants could answer specific questions regarding the dosing of the medication (45–50%) and the decline in its efficacy with advancing disease (20%), despite over 75% of patients reporting managing their own medications (Fig. 2A).

Deep brain stimulation is a neurosurgical procedure employed for symptom control in PD patients who have failed or cannot tolerate pharmacotherapy. Participants were surveyed about key characteristics of this treatment modality, with questions primarily directed at the symptoms it does and does not address. All participants had at least 1 incorrect response (for example, not recognizing rigidity, dyskinesia, or tremor as symptoms targeted by DBS), with 55.7% having 5 or more and 31.8% having at least 8 incorrect answers (Fig. 2B). When constrained to patients who have had DBS ($n = 10$), 3 participants answered all but 1 question correctly, 7 had 5 or fewer incorrect answers, and only 1 patient answered 8 or more questions incorrectly. Of note, none of the patients perceived DBS to be a cure for PD. These results reinforce the finding that misconceptions with regard to PD treatment are indeed prevalent albeit somewhat improved with personal experience with DBS.

When queried about their own experience regarding the nature of the symptoms associated with PD, 65 patients agreed to the statement "I am familiar with the non-motor symptoms of PD." All 65 (100%) had 4 or more incorrect responses (failing to identify, for example, constipation as a non-motor symptom of PD) and 16.9% answered at least 7 questions wrongly (Fig. 1C).

3.3. Patient education and outlook

Although the precise factors responsible for the high self-reported knowledge of PD among study participants or the prevalence of misconceptions held among many of them currently elude identification, prior work has demonstrated the efficacy of education sessions in improving various patient health measures [11]. This suggests that learning experiences tailored to PD patients that complement the knowledge shared by clinical practitioners and gained through their own struggles with the disease

Table 1
Cohort characteristics.

	No. of patients	Fraction
Level of education		
No formal education	1	0.01
High school or less	6	0.06
Few years of college	26	0.27
College graduate	37	0.38
Post-graduate education	28	0.29
Gender		
Male	39	0.40
Female	59	0.60
Current provider		
Movement disorders specialist	82	0.84
Other	16	0.16
Deep brain stimulation		
Yes	10	0.10
No	88	0.90

Summary of demographic variables analyzed further in this work.

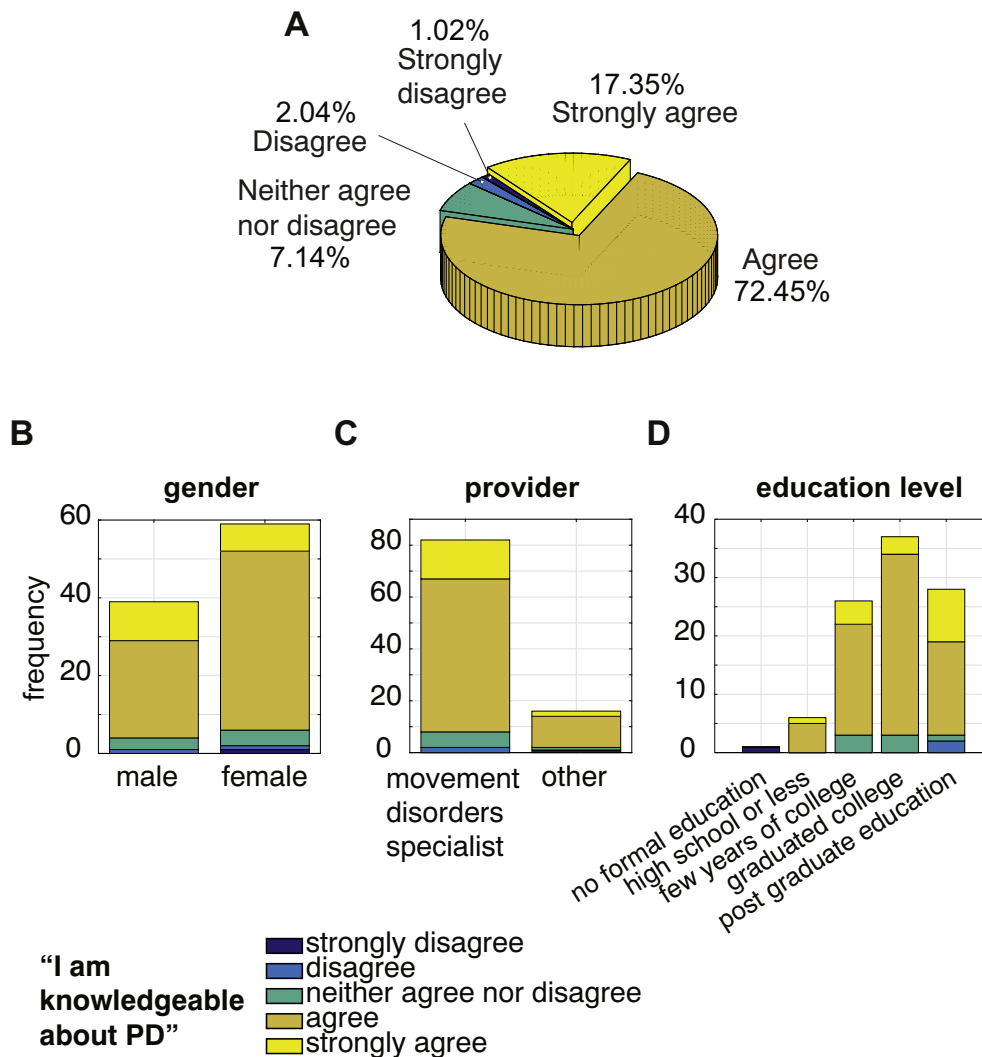


Fig. 1. Landscape of patient self-reported knowledge of PD. (A) Chart showing the distribution of patient responses to the statement “I am knowledgeable about Parkinson disease.” Characterizations by gender (B), provider type (C), and education level (C) further stratified by responses to statement in (A).

may nevertheless address some of these factors. We investigated whether PD patients exhibited preferences with regard to delivery of resources in hopes of designing improved educational interventions. A significant fraction of participants showed a predilection for electronic video and reading material (13.7% and 20.0%, respectively; Fig. 3A), lunch and learns (28.4%), and yearly symposia (20.0%). Importantly, >84% of patients demonstrated willingness to take advantage of these resources if they were offered.

In addition to making available easily disseminated electronic didactic material, another cost-effective intervention might be to offer patients the opportunity to involve nurse practitioners (NP) or physician assistants (PA) in the treatment team. These care providers can often devote more time to patient teaching and more regular assessment of patient understanding, qualities that may have influenced participants' overwhelming agreement to transitioning care to an NP or PA (73.5%; Fig. 3C).

Patients' perceived knowledge of PD may impact decision making regarding therapy, seeking help from other caregivers, and end-of-life planning. When surveyed about their future outlook, the majority of PD patients (84.0%) agreed to the statement “I think it is possible to live well with PD” and their degree of agreement correlated with the level of confidence about being knowledgeable about PD ($p = 8.6 \times 10^{-6}$, one-way ANOVA test; Fig. 3D).

4. Discussion

Patients with PD contend with no shortage of daily challenges due to the intricate nature of their illness: from managing their medications, discerning whether a change they experience is a medication side effect or a new symptom, and making decisions regarding treatment options—in short, adapting to the demands of their disease and its therapy. Patient education is critical not only in helping patients come to terms with their diagnosis but also in developing the tools to meet these challenges [12]. A lack of knowledge can also have consequences. Numerous studies, for example, have documented a high proportion of patients with erroneous understanding about the curative potential of palliative chemotherapy that decide to undergo it expecting a cure of their malignancy [13]. KnowPD was designed to quantify gaps in patient knowledge of Parkinson's disease with the ultimate goal of informing the development of appropriate educational interventions.

Collectively, our results reveal pervasive misconceptions regarding PD treatment and symptomatology in a patient population that overwhelmingly self-described as being knowledgeable about the disease. The high level of perceived PD knowledge did not correlate with demographic variables such as gender, whether care was primarily provided by a movement disorder specialist, or education level, consistent with prior work that looked at patient characteristics associated with incorrect beliefs regarding

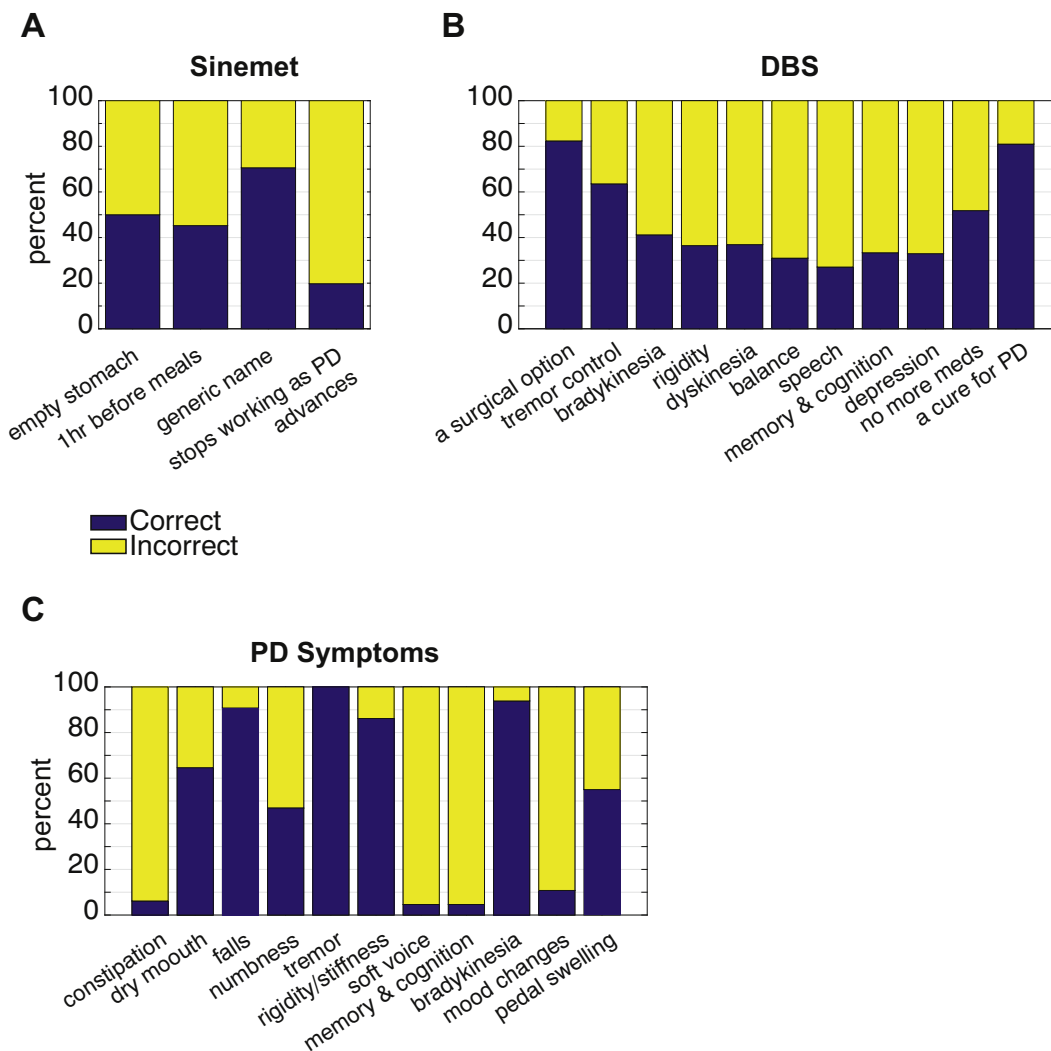


Fig. 2. Patient knowledge of PD by specific domain. Percent of correct (blue) versus incorrect (yellow) responses to questions pertaining to Sinemet (A), deep brain stimulation (DBS, B), and Parkinson disease symptoms (C).

treatment for terminal cancer patients [13]. There is no evidence in the literature, as far as the authors are aware, that demonstrate that level of education, disease duration, and patient age correlate with knowledge of PD. In fact, the intuition that even level of education correlates with disease knowledge is undermined by our data and demonstrates the value of surveys such as KnowPD in dispelling incorrect notions about barriers to health care literacy. However, we cannot exclude the possibility that a degree of the misconceptions emanates from some level of cognitive decline that does not impair the patient's ability to complete the survey.

As it stands, the identification of any potentially addressable factor that might underlie the discrepancy remains a subject of future work. Even investigation of the provenance of a patient's current knowledge of PD is difficult and unreliable; patients would have likely been exposed to information provided by a physician, nurse, or in the form of a pamphlet, online resource, community resources such as support groups, or even the leaflets that might accompany medications. We attribute this to specific limitations in our survey, namely our small sample size, sample diversity (for example, the majority of patients are primarily seen by movement disorders specialists and have a college education), and lack of other demographic variables to explore. Another recognized limitation is that this survey did not collect nor control for if a subject was 'on' when the survey was completed; this would be helpful in future research.

The fact that misconceptions persisted even if patients had personal familiarity with the specific medications and therapy modalities about which they were being queried also suggested that experience was insufficient to dispel factually incorrect notions about the disease and raised concerns about the efficacy of the informed consent process. We investigated "ideal" characteristics of potential cost-effective interventions that could improve the delivery of information to patients and bridge the knowledge gaps. Among the more popular were electronic media, lunch lectures, yearly conferences, and the increased involvement of nurse practitioners and physician assistants. These recommendations form the basis of quality improvement projects currently in preparation.

5. Conclusion

Knowledge can help patients beyond the quotidian struggles. Awareness about disease progression and the potential necessity to amend or augment pharmacotherapy may encourage treatment adherence and timely decision-making about preparations for the future. We found that patient outlook correlated with self-reported knowledge about PD. This emphasizes the need to assess patient understanding of disease and develop interventions to correct deficiencies in a manner that preserves hope, eliminates false expectations, and maximizes patient involvement in disease management. This survey represents an advance towards this goal.

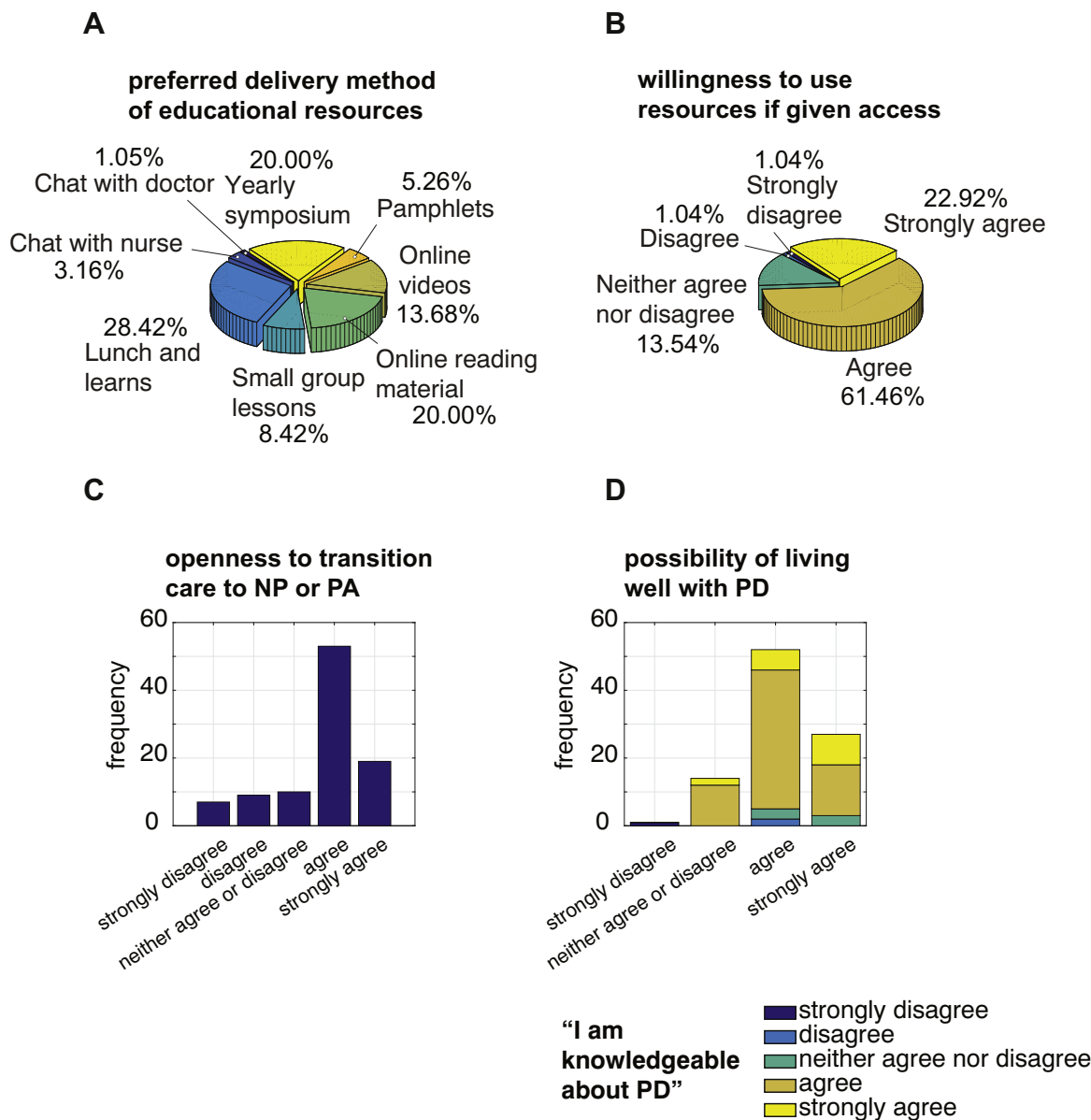


Fig. 3. Educational interventions by patient preference and future outlook. Distributions of preferred educational delivery methods (A) and patients' willingness to use them (B). (C) Patient openness to transition care to other provider types. (D) Responses to the statement of whether it is possible to live well with PD.

Declaration of competing interest

No specific funding was received for this work. The authors declare that there are no conflicts of interest relevant to this work and no additional disclosures to report.

Acknowledgments

None.

Authors' roles

MRS—Survey construction, patient recruitment, data collection, data analysis, preparation of manuscript, editing of manuscript, response to reviewer comments.

EJC—Survey construction, patient recruitment, data collection, preparation of manuscript, editing of manuscript.

TH—Survey construction, IRB preparation.

PK—Survey construction, patient recruitment, data collection, editing of manuscript.

DMO—Survey construction, IRB preparation, data collection, data analysis, editing of manuscript.

SS—Survey construction, IRB preparation, data collection, data analysis, editing of manuscript.

SC—Survey construction, IRB preparation, patient recruitment, data collection, editing of manuscript.

Ethical compliance statement

This study was approved by the Institutional Review Board at the University of Texas Southwestern Medical Center (IRB No. STU 112015-096).

To reduce risk for loss of confidentiality, verbal consent was used and no personal health or identifiable information was collected. Subjects were provided with a short summary of the study aims on the first page of the survey where they were again notified that participation was voluntary.

The survey was accessed only after subjects affirmed voluntary participation. Completion of the survey affirmed consent.

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.prdoa.2020.100038>.

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