

# How People Living with Parkinson's Disease in Four European Countries View Occupational Therapy

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## ABSTRACT

### INTRODUCTION

People with Parkinson's (Parkinson's) disease experience diverse symptoms that impact on many aspects of daily life. Occupational therapy (OT) aims to optimize independence, coping, and social participation and can make a valuable contribution to management of the condition.

### METHOD

A prospective study was undertaken using an anonymous, open Web-based questionnaire, devised to explore the experiences and opinions of OT among a group of people living with Parkinson's in Norway, Slovenia, Sweden, and the United Kingdom.

### RESULTS

The views of 230 respondents with many of the typically recognized demographic and clinical features of Parkinson's populations were collected. The need for help in daily life was commonly reported, encompassing activities related to self-care, productivity, and leisure. Approximately half the people surveyed (54%) reported having seen an occupational therapist since their diagnosis. The location, frequency, and duration of interventions varied considerably between the four countries. The content of OT was diverse and included assistance for using arms and hands, carrying out daily activities, and concerned receipt of advice about aids, equipment, environmental adaptations, further support and services, and education about Parkinson's. Among the people who had received OT, there was a high level of consensus that they would recommend it to others with Parkinson's.

### CONCLUSION

In this sample, differences in OT services for people with Parkinson's were reported. Where OT services were received, it was seen as an important intervention. Further studies with a larger sample and involving more countries are needed to verify and build-on these findings.

**Keywords:** Parkinson's disease, occupational therapy, survey, patients' view, European countries

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### INTRODUCTION

Occupational therapy (OT) is commonly perceived by the general public and by many health care professionals in rather narrow terms, as being primarily about the assessment and provision of adaptive aids and equipment. However, current concepts of OT encompass a much broader approach. Contemporary OT practice aims to enable people (with Parkinson's disease [Parkinson's], or any condition causing difficulties with carrying out everyday tasks and activities) to seize, take possession of, or occupy the spaces, time, and roles of their lives<sup>1</sup>. The act of occupying space relates to the actions that people must perform to occupy their homes, their workplaces, and the places where they engage in social, recreational, or leisure pursuits. Occupying time relates to being engaged in purposeful and personally meaningful mental, physical, or social acts or tasks. When considering the life roles occupied

by people with Parkinson's, occupational therapists reason about ways to enable the broad range of daily activities that people with Parkinson's must enact to be able to live their lives in their own chosen ways.

A diverse array of issues associated with Parkinson's itself and its management, affect the usual or expected physical, social, and mental well-being of people with the condition. People with Parkinson's are significantly and often adversely influenced by conditions of the built environment, and in addition their symptoms often fluctuate throughout the day, as well as over the course of the disease,<sup>2</sup> causing problems with carrying out daily activities to manifest over time in a highly individualized manner. This is particularly relevant to daily life as Parkinson's affects many aspects of both motor and non-motor functioning.<sup>3,4</sup> It is increasingly recognized that cognitive dysfunction is common in the early stages of

Parkinson's and can occur before pharmacological treatment is commenced in some cases. This can significantly affect many aspects of daily life including work, relationships, and social life.<sup>5,6</sup> Fatigue (physical, mental, or both) and possibly also depression may further increase the burden of living with the condition and thus negatively affect participation in occupational roles and social activities.<sup>7,8</sup> To enable adaptation and facilitate the development of life skills and supportive resources required to cope with emerging challenges or reduced abilities related to living with Parkinson's—the OT process addresses both motor and non-motor issues. For example, fatigue management and application of cognitive strategies are becoming an important part of OT interventions for people with Parkinson's.<sup>9,10</sup> Although Parkinson's is not in itself a terminal condition, from the time of diagnosis, its progressive and increasingly complex nature calls for proactive multidisciplinary management and a rehabilitative approach, as reflected by recommendations 77–81 of the 2006 Parkinson's Guidelines that were commissioned by the National Institute for Clinical Excellence Guidelines (NICE).<sup>9</sup>

Awareness of the scope of OT, accessibility to OT treatment, and the level of OT provision available to people with Parkinson's differs considerably between countries in Europe and across the globe.<sup>11</sup> In Sweden, OT services are delivered both within hospitals and in the community and are easily accessed. If patients cannot leave their homes, OT services can be received at home. Norwegian OT services work in a similar way. In the United Kingdom, OT is also delivered in a variety of hospital and community settings and is informed by Recommendation 80 of the NICE guidelines relating to Parkinson's disease.<sup>9</sup> Recently published Best Practice Guidelines specifically concerning people with Parkinson's receiving OT are also now available to support evidence-based OT practice.<sup>10</sup> In the Slovenian health system, OT is available almost entirely in hospital settings, with a corresponding lack of community-based OT services.

It is increasingly common for patient feedback surveys to be used to provide healthcare professionals with invaluable data and information to inform the review, planning, and update of healthcare services.<sup>12</sup> This survey focused on asking people with Parkinson's about their experiences and opinions of OT, regardless of whether they had actually received OT services. The Web-based questionnaire survey was used to collect data concerning the perception and availability of OT among a diverse group of people with Parkinson's at different stages of the condition. In addition, details relating to the content of OT practice as perceived by Parkinson's patients themselves have been captured to improve our understanding of contemporary patient experiences.

## METHOD

### Study Design

This was a prospective study using an anonymous, open Web-based questionnaire (e-survey) devised to explore the experiences and opinions of OT among people with Parkinson's. The

use of an online questionnaire is of particular advantage when the sample is geographically dispersed as in this case, where the employment of e-surveys is especially economical.<sup>13</sup> This was to be an anonymous, voluntary, online questionnaire, accessed through the European Parkinson's Disease Association (EPDA) and the four national PD associations. None of the questions were seen to be particularly intrusive and thus the need to seek ethical approval was not considered to be required.

### Participants

We invited people with Parkinson's and their families living in Norway, Slovenia, Sweden, and the United Kingdom to respond to the questionnaire. The sample was therefore derived on the basis of incidental self-selection and willingness to participate. It was beyond the scope of the questionnaire to record whether respondents were people with Parkinson's or others acting on their behalf. No payment or other rewards were offered to participants in the survey.

### Questionnaire

A bespoke questionnaire was developed for the purpose of this survey with a total of 34 questions divided in four sections: Section 1—*Demographic data* (10 questions) details about age, gender, marital status, level of education, and occupational status; Section 2—*Clinical data* (4 questions) details about duration of Parkinson's, presence of a range of motor and non-motor symptoms, and data about the physical effects of Parkinson's. Options to describe the physical effects of Parkinson's were based on the Hoehn and Yahr scale, modified for self-rating by a Slovenian neurologist specializing in movement disorders; Section 3—*Impact of Parkinson's* (6 questions), included questions about managing daily life in terms of daily activities, leisure, and help required in daily life; Section 4—*Experience of occupational therapy* (14 questions) explored access to OT, as well as the timing, content, and perception of OT interventions.

### Procedure

The Checklists for Reporting Results of Internet E-Surveys (CHERRIES) was used as a framework for this open survey.<sup>14</sup> The questionnaire was developed by the EPDA working with people with Parkinson's and three occupational therapists from Slovenia, Sweden, and the United Kingdom, respectively, with additional input from a Slovenian neurologist specializing in movement disorders.

Introductory information described the role of OT and its relevance to people with Parkinson's. The questionnaire was developed in English and translated into three additional languages, Norwegian, Slovenian and Swedish by the national Parkinson's organization native speakers. Occupational therapists in the respective countries that had experience of working with people with Parkinson's were asked to check for accuracy. Additionally, the Slovenian version was blind-back translated to ensure clarity. The question format was also reviewed by people with Parkinson's to ensure ease of

completion; the online form was designed to enable accessibility (particularly for those who have tremor).

Web pages were set up on the EPDA website to provide access to the survey in English, Norwegian, Slovenian, and Swedish. This was promoted through the member organizations and healthcare professionals as well as occupational therapists within their respective countries.

In Slovenia where access to the Internet was limited, a paper version was prepared and distributed during the annual meeting of Trepetlika, the Slovenian Parkinson's disease organization. Responses provided via this paper version were entered by two students onto the Web-based questionnaire forms and double checked for accuracy prior to submission.

The online form was coded to prevent duplicate data being submitted. Data collection took place between February 2 and May 31, 2009. Descriptive statistics were used for analysis.

## RESULTS

A total of 230 questionnaires were submitted with no forms being incomplete (100% completion rate). Of the respondents 53% were male and the average age of all the respondents was 64.2 years (range 21–86). Duration since diagnosis of Parkinson's ranged from 1 to 25 years, with a mean of 7 years (Table 1). Forty-five percent of all the respondents had received education beyond 18 years of age (range from 23% of respondents from Slovenia, 54% UK, 62% Sweden, 83% Norway). Eighty-one percent of the sample were married or in a long-term relationship and 15% reported having dependent children. Eighty percent of respondents were either retired or had no paid work, but 16% were engaged in part-time or full-time work. Respondents reported many of the common motor and non-motor symptoms of Parkinson's (Figure 1). They were represented from all five stages of disease severity as measured by self-assessed staging of Parkinson's, modified for self-rating, using the Hoehn and Yahr Scale (H&Y) (Table 2, Figure 2). A substantial number of the survey respondents reported requiring help in daily living activities in the areas of self-care, productivity, and leisure (Figure 3).

In total, just over half (54%) of our sample of 230 people with Parkinson's reported having seen an occupational therapist since the diagnosis of their condition. OT appointments occurred in variety of settings, mainly in people's own

homes, or in Parkinson's clinics and rehabilitation units (Table 3). In all four countries there was a high level of consensus among participants who had received OT that they would recommend OT to other people with Parkinson's (range by individual countries was from 84% in Sweden, 85% in the UK, 95.9% in Slovenia, to 100% in Norway). Patients who had received OT reported feeling that their first OT appointment was timed "just right" in half of all cases (51%—ranging from 38% in Slovenia up to 62% in Sweden). A small minority of patients expressed feeling that OT had been initiated too early (8% in total), ranging from 0% in Norway and Slovenia, to 5% in the United Kingdom and 18% in Sweden. Around 35% of all the respondents felt that OT had been initiated "too late," ranging from 16% in Sweden, 20% in Norway, 30% in the United Kingdom up to 59% in Slovenia.

More than half of all respondents (61%) did not purchase equipment without the advice of an occupational therapist. In the United Kingdom, the ratio between buying equipment with or without the advice of an occupational therapist was 3:1 in favor of those who received advice from an occupational therapist. In Sweden and Slovenia, there was a tendency to buy aids and equipment without the advice of an occupational therapist. Equipment recommended by an occupational therapist was generally not paid for (directly). This is due to such costs being covered by health insurance, or provision "free at the point of delivery" by a statutory health or social service.

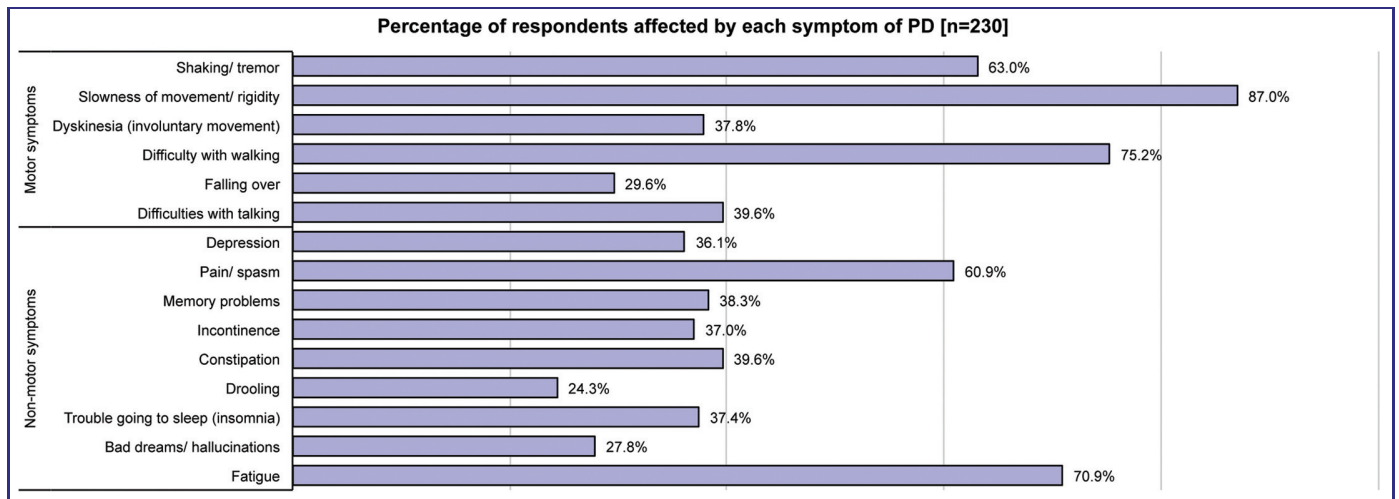
Questionnaire respondents (including both those who had received OT and those who had not) frequently indicated the types of OT content that they had received, or would like to receive, from the following options: using arms and hands, carrying out daily activities, advice about assistive aids, equipment, and environmental adaptations. Provision by occupational therapists of information about further services and support available, education about Parkinson's, and better management of activities at home were also mentioned by a minority of respondents (Figure 4).

## DISCUSSION

This study aimed to gather the views of people with Parkinson's in four European countries on the availability and perception of OT services. Overall, the demographic and clinical profile of the survey respondents was typical of many

Table 1. Response by Country of Residence

Country	Numbers by Country	Years with Parkinson's Median (Range)	Gender M/F (%M)	Had Seen OT Since Diagnosis of Parkinson's; N (% of Total Respondents per Country)
Norway	6	8.50 (3–17)	3/3 (50%)	5 (83.3%)
Slovenia	95	8.00 (1–25)	51/44 (53.7%)	49 (51.6)
Sweden	82	8.00 (1–24)	41/41 (50%)	50 (61%)
United Kingdom	45	4.00 (1–18)	25/19 (55.6%)	20 (44.4%)
Country not stated	2	5.50 (3–8)	2/0 (100%)	0 (0%)
Combined totals	230	7.00 (1–25)	122/107 (53%)	124 (53.9%)



**Figure 1.** Percentages of all respondents reporting motor and non-motor symptoms of Parkinson's. More than half of the respondents reported symptoms from five categories as follows: slowness of movement/rigidity, difficulty with walking, fatigue, shaking/tremor, pain/spasm.

Parkinson's populations. However, these respondents represent a small minority of the people living with Parkinson's in the countries surveyed, and our results should therefore be interpreted with caution in relation to this.

**Availability of Occupational Therapy (Seeing an OT Since Diagnosis—Where, When, How Often, If Payment Is Made)**

Respondents to this survey who had received OT reported receiving such services in a range of different settings. Across the countries surveyed, services for people with Parkinson's are delivered through specialist Parkinson's clinics and rehabilitation units, or in community settings including patient's own homes. In this subset of respondents, the main location of OT appointments was the home of the person with Parkinson's. This was especially evident in the United Kingdom (85%) and Norway (80%), but rarer in Sweden (32%) and virtually nonexistent in Slovenia (4%). In general, the trend was for OT services to be provided in the environment where patients live, which allows interventions to be tailored closely to individuals' actual lifestyle and their roles in their own home and community. In Slovenia, OT for Parkinson's patients is most often provided in a Parkinson's clinic. The next most common Slovenian OT settings are a rehabilitation unit, or a hospital. This is due to the fact that community OT

has not been developed yet in Slovenia. The frequency of OT intervention varied considerably across the sample and a higher frequency was mainly related to OT occurring during a hospital in-patient stay, followed by annual or 6 monthly OT intervention (the question asked was—How often do you see an occupational therapist?—Which could have been interpreted in various ways. For example, once a year may be related to a one-off OT session, or perhaps to a “short course” of OT intervention at 12 monthly intervals). In the four countries covered by the survey, OT is provided as part of a national health or medical insurance system and is therefore free of charge. In Sweden, however, 32% of respondents reported having paid for OT, although there is no private OT in Sweden for the purpose of treating people with Parkinson's. One explanation could be that the question was interpreted differently in Sweden where the National Health Service is subsidized by patients, who pay up to a certain amount to be eligible for ongoing free health care for a year.

**Content of Occupational Therapy (OT Received/Wanted/ Needed)**

This sample of people with Parkinson's expressed issues relating to their performance of meaningful activities and occupations in areas of self-care, productivity, and leisure.

**Table 2.** Self Reported Staging of Parkinson's, Modified for Self-Rating, from the Hoehn and Yahr scale

Physical Effects of Parkinson's	Country of Residence, N = 230 (% for Category of Effects, by Country)					Total
	Norway	Slovenia	Sweden	United Kingdom	Not stated	
H&Y stage 1: affects one side of body	2 (33.3%)	13 (13.7%)	3 (39%)	12 (26.7%)		59 (25.7%)
H&Y Stage 2: affects both sides of body	3 (50%)	7 (7.4%)	12 (14.6%)	4 (8.9%)	1 (50%)	27 (11.7%)
H&Y Stage 2.5: no balance problems	0 (0%)	6 (6.3%)	7 (8.5%)	2 (4.4%)	1 (50%)	16 (7%)
H&Y Stage 3: some balance problems but still independent	0 (0%)	22 (23.2%)	26 (31.7%)	20 (44.4%)		68 (29.6%)
H&Y Stage 4: severe balance problems but need no assistance	1 (16.7%)	39 (41.1%)	2 (2.4%)	4 (8.9%)		46 (20%)
H&Y Stage 5: cannot sit or stand independently	0 (0%)	8 (8.4%)	3 (3.7%)	3 (6.7%)		14 (6.1%)



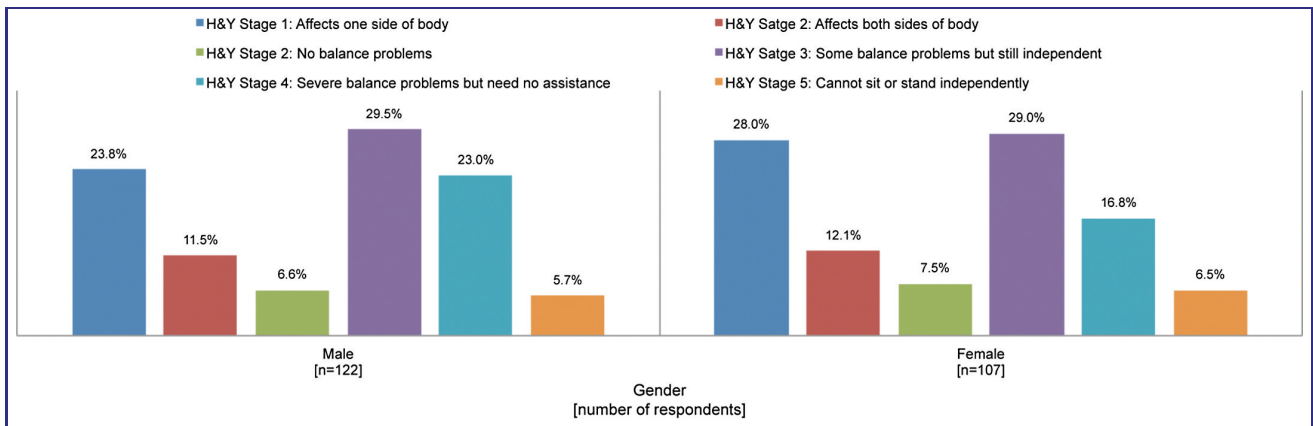


Figure 2. Percentage of respondents by gender of self-reported staging of Parkinson's, modified for self-rating, from the Hoehn and Yahr scale.

These domains are core areas of OT practice, and according to Kielhofner,<sup>15</sup> occupation encompasses a wide range of “doing” that occurs in the context of time, space, society, and culture. Deane et al.<sup>16,17</sup> undertook two surveys of approximately 150 occupational therapists in the United Kingdom to gain data on current practice and to develop a consensus as to best practice of OT when treating people with Parkinson's. The two surveys showed with a clear consensus at the time of data collection—that “Parkinson's requires lifelong provision of occupational therapy within multidisciplinary teams.” Despite this, occupational therapists who responded to the surveys reported that OT was usually provided over a relatively short period of time, after which the person with Parkinson's was usually discharged.<sup>16,17</sup> Occupational therapists who responded to Deane et al.'s surveys, also reported a tendency for occupational therapists treating people with Parkinson's to focus on self-care goals. However, Deane et al. also highlight the need for occupational therapists to focus on the wider social and psychosocial aspects of occupation in addition to selfcare goals. Since the publication of these two surveys, Deane has subsequently also summarized the four main roles that occupational therapists assumed when treating people with Parkinson's as being: problem solver,

educator, networker, and supporter (personal communication, March 12, 2010).

In our sample of people with Parkinson's, of those who had received OT, about 30% had received OT intervention corresponding to the roles of problem solver (using arms and hands, carrying out daily activities) and educator (advice about or supply of assistive aids, equipment, or environmental adaptations). The main needs expressed by respondents who had not received OT, were for the roles of networker and problem solver, for example, in relation to adjusting to the effects of Parkinson's on their work. The greatest reported requirement or need for OT was expressed in relation to the roles of networker, problem solver, and educator (eg, concerning provision of information about further support and services available, and assistance in managing activities at home).

Assistive aids and equipment to help manage problematic elements of daily life for people with Parkinson's was further explored within the respondents who had received OT. More than half of all the respondents (61%) did not purchase equipment without advice from an occupational therapist. Overall, it was not very common for respondents to purchase equipment without OT advice, but there was considerable

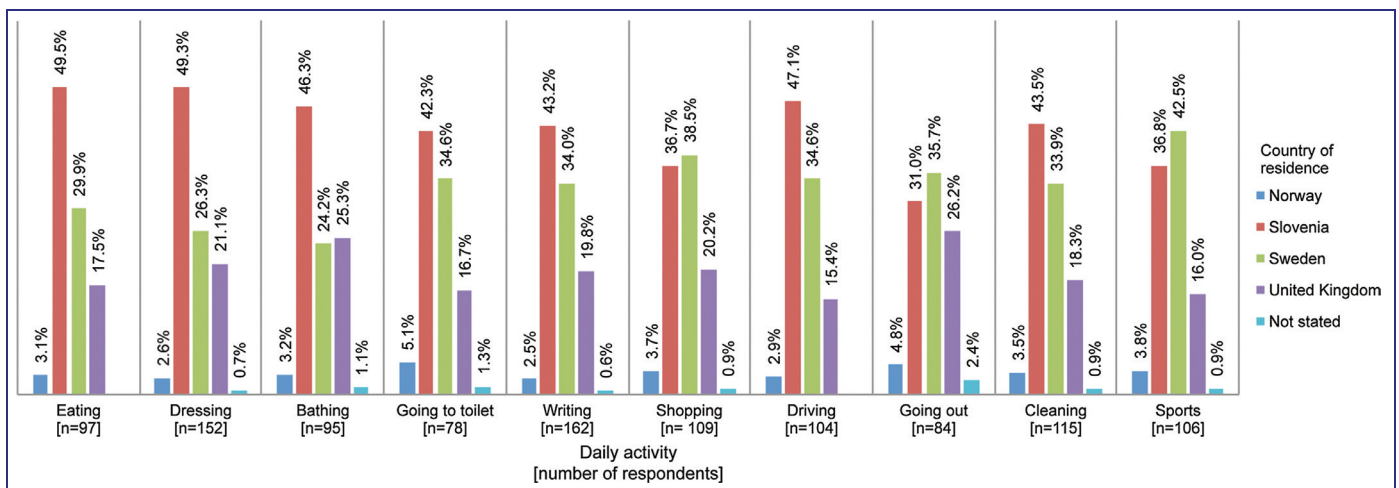


Figure 3. Percentage of respondents reporting daily activities affected by Parkinson's, by country of residence.

**Table 3.** Location of OT Appointments, Illustrating Variation by Country, of the Place in Which OT Was Received.

Location of OT Appointments	Country of Residence				Percentage of all Respondents (%)
	Norway	Slovenia	Sweden	United Kingdom	
In own home	80%	4.1%	32%	85%	31.5%
In hospital	0%	10.2%	22%	15%	15.3%
In a rehabilitation unit	0%	34.7%	32%	15%	29%
In a Parkinson's clinic	0%	55.1%	14%	15%	29.8%
During an Out-patient visit	0%	0%	14%	0%	5.6%
Not stated	20%	0%	6%	0%	3.2%

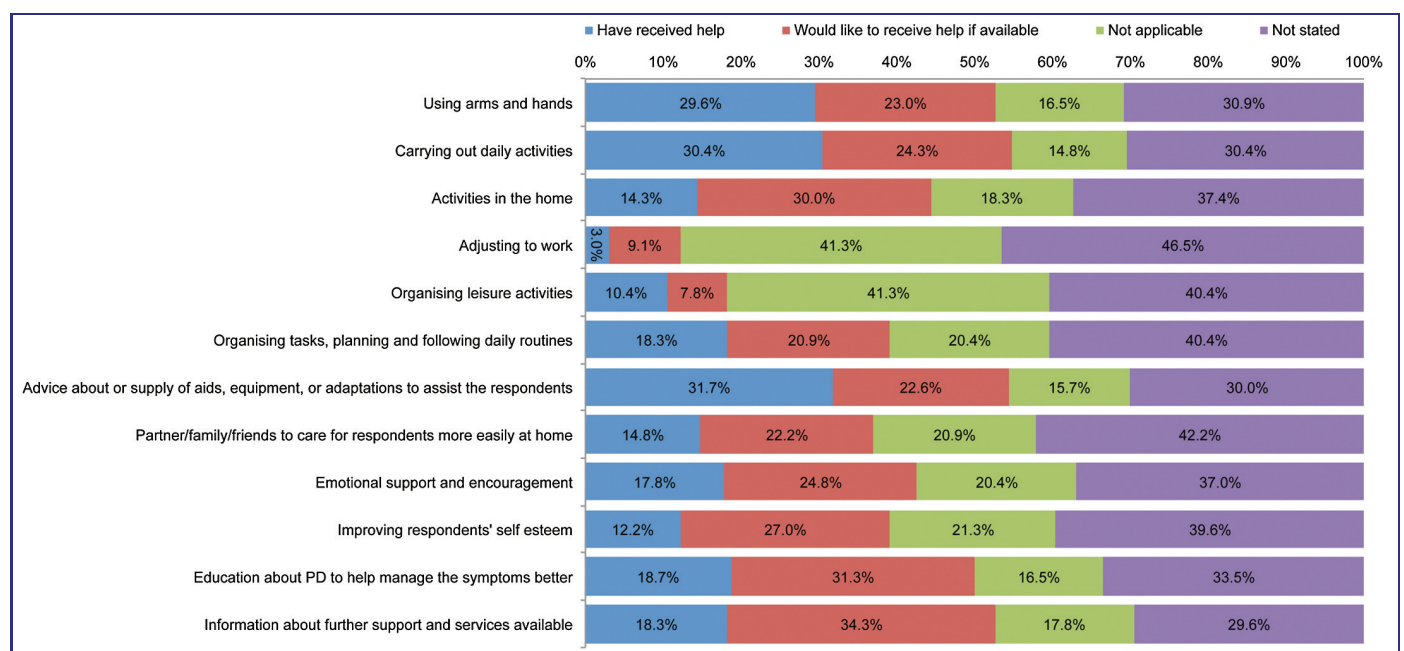
variation on this between the four countries. In the United Kingdom, it was more common for respondents to have received OT advice, where as in both Sweden and Slovenia the tendency was to buy aids and equipment without advice from an occupational therapist.

**Perception of Occupational Therapy (Relevance of OT—Timeliness, Importance, Willingness to Recommend to Others with Parkinson's)**

According to published literature, OT intervention is most often delivered in the intermediate and later stages of Parkinson's (equating to H&Y Stages 3–5).<sup>18,19</sup> Although the H&Y scale “mixes pathology, with impairments and disabilities”<sup>20</sup> this widely used scale gives a quick and simple index of disease severity. In our sample, of the respondents who reported having received OT, 59% self-rated themselves as being at H&Y Stages 3–5, with the majority of these being at H&Y Stage 3. However, 41% of the respondents had received OT in the early phase of the condition, equating to H&Y Stages 1 and 2, with just over half of these being at H&Y Stage 1. In the early stages of Parkinson's, it is important that interests

and roles are maintained within and outside the home, including participation in employment, social activities, and driving.<sup>21</sup> Comorbidity, especially in the elderly population may also contribute to the impact of Parkinson's on the daily lives of people with the condition before reaching an advanced stage of the disease.<sup>22</sup> It is therefore likely to be of benefit to introduce OT early in the course of the disease as a form of secondary prevention, by focusing on proactive identification of emerging difficulties with daily tasks and acquisition of adaptive techniques to minimize activity limitations.<sup>23</sup>

Initiating an OT service was reported as being timed “just right” by half of the patients, however, around 35% reported that referral to OT had occurred “too late”. These results may reflect differences in OT referral practices between the four countries. In Slovenia, for example, OT is mainly introduced during an admission to a Parkinson's clinic, when disease progression has reached the intermediate or advanced stages. In Sweden and the United Kingdom, on the other hand, OT is introduced earlier, and in the case of young people with early onset Parkinson's, OT may even be initiated at the time of diagnosis. In all four countries, there was a high level of



**Figure 4.** OT areas the respondents reported that they received or would like help with (N = 230).

consensus among respondents who had received OT that they would recommend OT to other people with Parkinson's. The need for more OT involvement with people who are living with Parkinson's has been raised by other authors<sup>19,22,24,25,26</sup> and patient support organisations, although somewhat ironically the latest Cochrane review found that there is currently inadequate evidence to evaluate the effect of OT for people with Parkinson's.<sup>27</sup> Clearly, more research into the value and processes of OT for people with Parkinson's is required to substantiate evidence-based practice in this sphere.

## CONCLUSION

Among the respondents who did receive OT there was a very high level of consensus on the willingness to recommend OT to others living with Parkinson's. Our sample was self-selected and voluntary which may have created bias toward OT (volunteer effect)<sup>14</sup>; however, as only just over half (54%) of our sample had received OT since the diagnosis of their Parkinson's, our results are counterbalanced by and also capture the opinions and experiences of a significant proportion of individuals who had not experienced OT. This survey is based on a relatively small cohort that probably underrepresents some elements of the full spectrum of the Parkinson's population. It nevertheless adds details of the attitudes and experiences of people with Parkinson's, to the current paucity of evidence available to underpin the role of OT for people with the condition.

These survey results could be employed to promote awareness of what OT has to offer from the perspective of people with Parkinson's themselves. These findings could also be used to promote debate and to act as a driver for Parkinson's-oriented OT service developments and improvements, within the countries surveyed and even further afield.

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