Exploring the experience of finding out you have parkinsonism: What helps at this time?

Heather Langham, Trainee Clinical Psychologist

Supervised by Dr Elizabeth Baikie, Consultant Clinical Psychologist

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Older Adults Clinical Psychology Service, NHS Lothian

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Abstract

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Background

Diagnosing parkinsonism can be challenging for clinicians and patients, but it provides an opportunity to enhance patients' future health-related quality of life. This service evaluation aimed to assess whether current recommendations were being met and to explore what patients find helpful.

Methods

A survey was provided to patients with parkinsonism, exploring their experience of receiving their diagnosis, information provision and support options. The role of a "Decision Navigator" was explained, with patients' views sought on this.

Results

32 surveys were completed by patients with parkinsonism of 0-16 years' duration. They reported that appointments were an appropriate length and described clinicians positively, but information provision was limited. While the support offered was well received, this appeared to be focused on patients more than their family and friends. Prompt information and support were among factors that patients identified as being helpful. Over half would have liked a separate member of staff to accompany them throughout this time to help them process a diagnosis, particularly where personal resources were limited.

Discussion

The findings suggest that clinicians handle diagnosis consultations well, but information provision could be enhanced. Ensuring patients feel supported and trialling offering a guidance and

support from a member of staff throughout this process could also improve patients' experiences of this time.

Introduction

Parkinsonism

Parkinsonism is a term used to describe a number of conditions that share similar "motor" symptoms, including slowed movement along with rigidity, tremor and/or postural instability (SIGN, 2010). The most common of these conditions is idiopathic Parkinson's disease, often referred to as Parkinson's (Parkinson's UK, 2011). This is a chronic and progressive neurological condition (NICE, 2006) in which a range of non-motor symptoms are also frequently experienced. These include gastrointestinal and autonomic symptoms, pain, sexual dysfunction and dysosmia. Sleep disturbance and depression are common, with anxiety, cognitive impairment and psychosis experienced at a lower prevalence (Brod *et al.*, 1998; Chaudhuri *et al.*, 2006). Both motor and non-motor symptoms have been found to have a negative impact on people's health-related quality of life (Duncan *et al.*, 2013; Muller *et al.*, 2013). Whilst a choice of medication aimed to reduce the impact of the motor symptoms is available, it can have adverse side effects and/or reduce in efficacy over time (Jancovik & Stacy, 2006; SIGN, 2010). The prevalence of parkinsonism is estimated as 100-180 cases per 100,000 people (DWP).

Challenges of diagnosis

Providing a diagnosis of a significant health condition such as parkinsonism has its challenges for clinicians (e.g. Buckman, 1994; Miranda & Brody, 1992; Shaw *et al.*, 2013). These can include fearing various consequences, such their patients' reactions, being blamed, not having sufficient knowledge and concern regarding showing their own emotions (Buckman, 1994). Assuming simulated breaking of bad news is representative of real life experience, the anticipation and early stages of delivering a serious diagnosis is a stressful experience for many (Shaw *et al.,* 2013). It appears that communicating bad news in an "affective" manner, by expressing concerns and reassurances, may lower clinicians' stress levels (Van Dulmen *et al.*, 2007) although more research appears to be needed to gain a clearer understanding of this. Specific to Parkinsonism, the lack of a cure and the complications associated with the use of medications (Jancovik & Stacy, 2006; SIGN, 2010) may make this a particularly difficult experience (Pinder, 2002). Diagnosing Parkinson's can be a complex process (EPDA, 2012; Koller & Montgomery, 1997), with the identification of this diagnosis experienced as a time of "maximum theoretical coherence" for some clinicians (Pinder, 2002). Exploration of GPs' experiences of diagnosing Parkinson's revealed that they experienced relief when this diagnosis was identified and viewed it as less calamitous than some other conditions (Pinder, 2002). The progressive nature of the condition was considered to allow time for adjustment and when it occurred in relatively older patients, it appeared to be considered as an unfortunate part of the ageing process. However, these viewpoints conflict with patients' experiences.

Experience of receiving a diagnosis

In contrast, patients' experiences of receiving a diagnosis of Parkinson's have been described as a time of "maximum experiential incoherence" (Pinder, 2002). This experience has been likened to a bomb dropping (Phillips, 2006), due to the shock of this, its implications for one's future life and resulting strong emotional impact. Anxiety about one's future and potential loss of independence as functioning declines appear to be common concerns (Pinder, 2002), with people sometimes trying to "guard" themselves from this to an extent. Receiving a diagnosis does however enable people to more easily explain symptoms they have experienced and where uncertainty has been prolonged, it can be experienced as a relief (Pinder, 2002). This range of reactions, from shock to relief and varying levels of denial has been described for other health conditions (e.g. Watson *et al.*, 2006; Yardley *et al.*, 2001). Receiving such a diagnosis can be considered as the start of a grieving process (Kübler-Ross, 1969) for one’s loss of health and in some cases one’s role.

Diagnosis and future wellbeing

Given the difficulties associated with providing and receiving a diagnosis of parkinsonism, it seems important to identify whether these can be eased in any way. A multinational survey of people with Parkinson’s disease (GPDSSC, 2002) identified an exciting finding for those providing a diagnosis of Parkinson’s and follow-up support. Patients’ “satisfaction with the explanation of the condition at diagnosis” was found to have a statistically significant effect on their future health related quality of life. Therefore, although it can be stressful to provide a diagnosis of Parkinson’s, this can be viewed as a key opportunity to help improve patients’ future health related quality of life.

Current recommendations for diagnosis

Girgis & Sanson-Fisher (1998) provide detailed guidance regarding how best to break bad news to patients, developed from the views and experience of clinicians and patients. These include preparing the person for the possibility of bad news in advance, providing the option of having family/friends present, as well as having another professional present with whom the person can meet after their appointment. They recommend tailoring the amount of information provided to the person’s wishes, considering whether they cope by seeking lots of information or by avoidance (Eheman *et al.*, 2009). Ensuring this information is clear and simple, plus arranging follow-up meetings so the patient can seek more information later if they wish, is noted as important. Encouraging the person to express their feelings and responding empathetically is also advised. These recommendations are echoed by other guidance in this field (e.g. Baile *et al.*, 2000; Vandekieft, 2001), but as noted in Ptacek & Eberhardt's (1996) review, such suggestions generally arise from clinicians' rather than patients' opinion.

Specific to Parkinson's, NICE (2006) recommend the use of communication aimed to enable patients to participate in choices about their care. It is recommended that carers and relatives are involved where the patient agrees, with information tailored to the individual and provided in both oral and written forms. These guidelines also suggest that clinicians should be realistic but show some optimism and that patients should be provided with a contact point. However, these recommendations are based on expert committee reports and/or clinical experience, rather than empirical studies. The more recent SIGN recommendations (2010) are based around themes arising from qualitative studies of patients' experiences. These focus on the areas of "good" communication, information provision that is appropriate for the patient's needs and from reliable sources, consideration of the needs of the patient's family and/or carers and discussion of non-motor symptoms. It is however important to note that the impact of implementing such recommendations is not known. This is not exclusive to parkinsonism; a review of the evidence base for breaking bad news in cancer found that less than 2% of publications were "rigorous intervention studies" that explored the patient outcomes of their use (Paul *et al.*, 2009). Even then the randomised controlled trials that were undertaken often used insufficient sample sizes and had inconsistent findings (Walsh *et al.*, 2010). This suggests that more careful investigation of the effects of individual aspects of these recommendations is needed to aid our understanding of their effectiveness.

Decision Navigator

One intervention to aid provision of a diagnosis, which has been tested through a randomised controlled trial, is the use of a “Decision Navigator”. This involves a professional acting as a “navigator”, who received training to enable them to meet with patients prior to their appointment to support them to develop a list of questions they wished to be addressed. They accompanied patients to their appointment and provided them with a recording and typed summary of this afterwards. Its use with patients with prostate cancer (Hacking *et al.*, 2013) was found to result in significantly higher levels of decisional self-efficacy reported by patients both after their appointment and six months later. Patients' level of decisional conflict was significantly lower than a control group after their consultation and their level of regret regarding the treatment decision made was significantly lower. All patients who used the “Decision Navigator” reported finding it helpful. Although used in a different field, it seems possible that a similar role may be beneficial for the process of diagnosis of parkinsonism. Although there are not imminent decisions to be made when receiving a diagnosis of parkinsonism, the level of support and guidance offered before, during and following a diagnostic appointment would enable some of the recommendations previously outlined to be met. These include enabling patients to participate in choices about their care whilst also preparing them in advance for the possibility of bad news.

Aims of study

Despite these limitations of current recommendations made in formal guidelines, along with relevant literature regarding breaking bad news, they do provide a guide for clinical practice. This service evaluation aimed to explore the experiences of patients with parkinsonism within secondary care services in NHS Lothian, to see whether these recommendations are implemented. Specifically, it aimed to explore patients' experience of their clinicians' communication, information provision and support options offered. It also hoped to identify patients’ views of what they have found helpful and seek any recommendations they may have to further improve the service. This would enable the service to be developed to meet patients’ needs, rather than what clinicians consider to be patients’ needs (Ptacek & Eberhardt, 1996), in case these differ. It also aimed to explore patients’ views on the role of a “Decision Navigator” (Hacking *et al.*, 2013) during the diagnosis of parkinsonism.

Methods

Ethical approval

The South East Scotland Research Ethics Service confirmed that NHS ethical review was not required. Ethical approval for the service evaluation was granted by the University of Edinburgh's Health & Social Science Research Committee. The NHS Lothian Quality Improvement Approval Team provided approval to undertake the evaluation.

Participants

Participants were individuals with parkinsonism, who opted to take, complete and return a survey. This was provided to them when attending their appointment with the Parkinson's Nurse Specialist, Neurology, Medicine for the Elderly Parkinson's Specialist or Older Adult Clinical Psychologist services within NHS Lothian. Clinicians were advised to only offer the survey to patients who had capacity to consent to participate and who were aware of their diagnosis of parkinsonism.

Measures

A 31-item survey was developed, which aimed to explore various factors reported to influence the experience of receiving a parkinsonism diagnosis. These included how prepared they were to receive such news, information provision, support options and staff responses. Participants were encouraged to share what they had found helpful and any suggestions for improvement to the process. The role of a "Decision Navigator" was outlined, with participants asked to consider whether they thought this would have been helpful at this time.

Procedure

115 packs of the survey, participant information leaflet and prepaid envelopes were distributed to the Parkinson’s Nurse Specialists, Neurology, Medicine for the Elderly Specialist and Older Adult Clinical Psychology departments within NHS Lothian, along with staff information sheets. Clinicians discussed the survey with patients who met eligibility criteria for participation and provided a survey pack to those who were interested in taking part.

Participants were able to complete the survey anonymously and return it by post, which meant that their clinicians would not be aware of their responses nor whether they chose to participate or not. Given the difficulties with writing commonly experienced by people with parkinsonism (e.g. Morris, 2000), the option to telephone the Clinical Psychology department to provide responses verbally was also offered. Were this to occur, the Clinical Psychology department would have been aware of those who chose to participate in this way, but only the lead researcher (who no longer worked in the department) would know of their individual responses. It was hoped that this approach would ensure that patients would not feel pressured to participate and would feel able to respond honestly about their experiences.

After just under three months, responses were collated and descriptive statistical analyses were undertaken for the quantitative sections. Thematic analysis (Braun & Clarke, 2006) was used to analyse the qualitative sections of the survey (i.e. comments).

Results

Response rate

32 responses were received. 12 survey packs were returned undistributed to the department; assuming the rest were provided to patients eligible for participation, this results in a response rate of 31%. Some questions were omitted by respondents, so the percentages reported below are calculated based on the number of respondents for that particular question, rather than the total number of participants.

Demographics

Table 1 summarises participants' demographics. 20 participants were male, with participants' mean age being 72 years. The length of time since diagnosis ranged from 0 to 16 years, with a mean duration of 6 years. Of the participants who could recall which professional provided their diagnosis, over three-quarters had seen a neurologist to receive/confirm this diagnosis, with the remainder receiving it from their GP. The majority (almost three-quarters) of respondents had been diagnosed within NHS Lothian secondary care services. 13% received this diagnosis at their GP practice whilst 16% were diagnosed elsewhere (in a private or different health board's hospital). As not all participants received their diagnosis in NHS Lothian secondary care services, the findings from both the overall sample are reported below, directly followed by the outcome of responses provided by just those who received their diagnosis in NHS Lothian secondary care services (where this differs). This enables the secondary care services within NHS Lothian to be evaluated as intended, whilst also reflecting the experiences of all participants.

Experience of receiving diagnosis

Nearly three-quarters of respondents reported that they had known why they were going to see the professional from whom they received their diagnosis of parkinsonism (71% overall; 74% of respondents who received diagnosis in NHS Lothian secondary care services). Around one quarter (27%/24%) would have liked to have received more information about their appointment prior to attending, but only a minority (10%/14%) would have liked to have spoken to a staff member before this. Most participants (88%/87%) reported that the length of their appointment was "about right". All participants indicated that the professional providing the diagnosis was at least one of the following three characteristics: understanding, sensitive or respectful, with 44% (57%) reporting that they found the professional to be all three of these. The remainder of participants only endorsed one of the three characteristics. Almost all participants (94%/91%) felt that they could ask questions during the appointment. Almost one quarter of respondents would have liked to talk to someone after their appointment (23%/24%); slightly more (28%/30%) would have liked to have had somewhere to sit quietly afterwards. These were not mutually exclusive for all participants. Table 2 provides a breakdown of proportions of responses for each relevant item.

Information provision

Table 3 summarises participants' experiences of information provision. Over a fifth (22%/26%) of participants did not report being told information about their condition. Just over a quarter (28%/30%) indicated that they had been given written information about this, with 22% provided with a relevant website address; in all but one case this was supplementary to information provided verbally. When grouping together the two, to consider information given or a way of accessing information, around half (47%/52%) received written information and/or a website address. Just over a third (38%/35%) were given a contact name in case of future queries. The majority of all respondents who did receive information reported that they understood all or most of it (87%/90%). Just over half of respondents (55%) described the information they received as “excellent” or “good”, while around a third (39%/32%) described the information provided as “adequate”. Around two-thirds (68%) thought the amount of information received was “about right”; with the remainder reporting that they would have liked to have received more information. Around two-thirds (69%/65%) forgot some of the information they received during their appointment.

Support

Around three-quarters of participants (78%/74%) were aware that they could bring someone to their appointment. Around two-fifths (41%/39%) were accompanied to their appointment; around one third (32%/36%) of those who attended alone reported that they had not been aware that they could bring someone. Half (50%/57%) were asked about what support they had from family or friends. The majority of respondents (72%/81%) were informed about a support group that they could access. Just under one third (32%/27%) of respondents had accessed a support group; 50% (60%) of these had been informed about a support group during their diagnosis appointment. Just over a third (35%) of all respondents were told how their family/friends could access support; this fell to a quarter of participants receiving a diagnosis in NHS Lothian secondary care services (25%).

As all participants were patients in NHS Lothian secondary care services, the experiences of support experienced by all participants will next be reported. A high proportion (86%) of all respondents had used the Parkinson’s Nurse Specialists service. Of those who had, all reported that they had found the service to be at least one of the following three characteristics: understanding, sensitive or respectful, with 46% reporting that they found the service to be all three of these. Half of participants reported having found other services to be helpful; these included other health professionals along with exercise classes and groups specifically for people with parkinsonism. These findings are summarised in Table 4.

Reflections

Participants were asked to comment on whether there was anything they had found helpful at the time of diagnosis. Over two thirds (72%) responded to this question. Five themes were identified from the responses provided (see Table 5). Some participants appeared to feel that nothing had helped them at this time, in some cases noting that this was due to the nature of the diagnosis. For others it appeared that just having an understanding of the cause of the symptoms they had noticed was in itself helpful. Another theme was that being made aware that the condition was typically slow to progress and that they had time to live their life still was reassuring. Being able to access information and receive support from others (professionally and through friends and family) were also helpful for people at this time

Participants were also asked to provide suggestions of anything that could have been done differently to make things easier for them at the time of diagnosis; 84% provided responses. Some participants could not identify anything additional that they thought would have helped at this time, while others commented that the timing of the diagnosis could have been better. A strong theme that arose was that they wished to have not been “left in limbo” – this occurred when participants had long waits between appointments and input, along with not having their information and support needs met.

Decision Navigator

Most participants (94%) told us whether they would or would not have liked a Decision Navigator when they were diagnosed, with over half (55%) of respondents reporting that they would have liked this role. One theme arising from comments provided is that this would help with preparing for and processing their diagnosis. This would also have met the needs of participants who reported having wished for more information prior to their appointment and having wanted to talk to someone afterwards. Another theme arising from the comments was of individuals feeling that they did not need this, but that this was due to their own resources, be this support from others or the personal ability to manage. The responses to this item are outlined in Table 6.

Discussion

The participants in this survey ranged from individuals diagnosed within the last few years to people who have been living with a parkinsonism diagnosis for many years. This range makes it more challenging to use the responses from those diagnosed within secondary care services in NHS Lothian as an evaluation of these services in their *current* form. The number of participants who had been diagnosed within the last two years was too small to allow meaningful conclusions to be drawn from this sample. However, the responses do enable exploration of whether key areas identified as being important in the provision of a parkinsonism diagnosis have tended to be fulfilled within NHS Lothian secondary care services. They are also useful in providing a general understanding of people's experiences and identifying areas for further improvement to services.

Comparing participants' experience to what is reported to help

There are many positive factors to take from the responses to the survey. Participants generally reported that the appointment in which they received their diagnosis was of the right length and that they could ask questions. All respondents indicated that the clinician providing their diagnosis was understanding, sensitive or respectful. This suggests that despite the difficult nature of the appointment (Buckman, 1994; Pinder, 2002), clinicians are able to tailor their approach and the length of their appointment appropriately. It was noted that respondents either selected all three of these attributes or only one; it is unclear whether the participants who endorsed just one of these may have thought they could only select one of the three characteristics.

However, the responses regarding information provision suggest that the secondary care services within NHS Lothian have not been meeting recommendations for information provision (NICE, 2006; SIGN, 2010). It appears remarkable that some individuals reported not having received any information verbally about parkinsonism, in some cases without receiving information in any other forms either. The information that *is* provided tends to be considered to be of an adequate or better standard and is understood by most. However, some participants would have liked to have received more information, with around a half receiving neither written information and/or a website link to access more information. Although the participants in this study had a wide range of duration of diagnosed parkinsonism, these findings were by no means limited to those who had received their diagnosis many years ago. The tendency to forget information received in such situations (e.g. Goodwin, 2000; Ley, 1979) was reflected in the findings from this survey. This is noted particularly when receiving bad news (Jansen *et al.*, 2008), which is thought to result from attentional narrowing (Christianson & Loftus, 1987; Kessels, 2003), with attention focused on the central, emotional aspect of information (i.e. the diagnosis of parkinsonism) rather than more peripheral details (e.g. potentially such as medication options and support). The difficulty of retaining information may be more pronounced in Parkinson's given the verbal memory encoding deficit observed in patients with recently diagnosed Parkinson's who have not commenced medication for this (Brønnick *et al.,* 2011). Providing reliable written information in addition to oral information (SIGN, 2010) appears to be a straightforward way to aid individuals to process and understand their diagnosis. Improved retention of information and higher satisfaction levels have been noted when this is undertaken with patients in other settings upon discharge from hospital (Johnson & Sandford, 2005).

The majority of participants had been informed how they could access a support group, but only in a minority of cases were they told about support for their family/friends. Most participants had used the Parkinson's Nurse Specialists service; those who had found that they were understanding, sensitive or respectful.

Helping further improve services in future

The themes identified from participants' responses provide an insight into the range of views reported. Points to note that could be used to shape services are that good, prompt information provision and support, from both professionals and family/friends, are viewed as helpful by many.

Decision Navigator

It seemed that having a member of staff in a similar role to that of a "Decision Navigator", for example as an "Appointment Navigator" would be a valued resource. Responses suggested that while some patients may not choose to utilise this, having this option in case of a lack of personal resources may still have been reassuring. Given the positive outcomes reported where this has been used in other services (e.g. Hacking *et al.,* 2013), although treatment decisions may not be as urgent or as varied as in some conditions, the help of this role in preparing and supporting individuals to process their diagnosis would be welcomed. The option of an "Appointment Navigator" would also aid services to better achieve recommendations by guidelines such as NICE (2006) regarding empowerment of patients and the provision of tailored information along with a contact point. The link between satisfaction of the explanation of condition provided at the time of diagnosis, with future health-related quality of life (GPDS, 2002), suggests an investment in this role could have long term benefit. This could be beneficial both to patients' wellbeing and potentially financially too, through decreasing the extent of poor health-related quality of life and resulting demand on services. Additionally, it would be useful to encourage patients to consider bringing someone to their appointment, given not all participants were aware they could and as having support from friends/family appears to essentially fulfil this role in some cases.

Summary of service implications

The findings of this service evaluation suggest that information provision should be improved to meet current guidelines, ensuring that both verbal and reliable written information is provided. Support options for patients' family and friends could also be discussed more frequently. Trialling the use of an "Appointment Navigator" appears to be an effective way of meeting current recommendations regarding delivering a diagnosis and would be welcomed by a large proportion of patients. The positive descriptions of clinicians, both those providing a diagnosis and those offering follow-up support, suggests combining these improvements with their competent interpersonal manner may help patients' future health-related quality of life to be enhanced (GPDSSC, 2002). This is clearly desirable in itself, but may also reduce subsequent demand on services.

Limitations of study

It is acknowledged that the use of self-report in this survey has its limitations. It is hoped that the anonymous nature of the survey reduced the likelihood of any social desirability bias affecting the accuracy of responses (Edwards, 1953). Although participants were given the survey by a clinician, in many cases this would not be the clinician who provided their diagnosis. Participants were informed that clinicians would not know whether they had gone on to complete and return a survey, nor have any way of identifying responses to individuals. This is therefore not anticipated to have affected response accuracy. A more problematic issue is that of memory distortion (e.g. McClelland, 1995; Schacter & Slotnick, 2004), given that for some participants it had been many years since they had received their diagnosis of

Parkinsonism. Their memories of their experiences of receiving this diagnosis may have been affected by more recent interactions with clinicians, plus their level of adjustment to their condition may also influence their recall of this time (e.g. Levine & Safer, 2002; Safer *et al.*, 2010).

It is also not possible to know whether patients who did not wish to participate had substantially different experiences to those who did. Additionally, as the survey was devised solely for this study, its reliability and validity is not known. Despite these limitations, it provides a useful and interesting insight into the experiences of those diagnosed with parkinsonism. This evaluation highlights strengths within NHS Lothian secondary care services along with areas for improvement.

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Appendices

Appendix 1: Table

Table 1. Participant demographic information

Item	**Overall sample**			**Only those diagnosed at a NHS Lothian hospital**		
	n	**%**	**Other***	***N***	**%**	**Other***
Total responses received:	32			23		
Gender:						
Male	20	62.5		14	60.9	
Female	12	37.5		9	39.1	
Age (years):						
<59	4	12.5		2	8.7	
60-64	4	12.5		4	17.4	
65-69	5	15.6		5	21.7	
70-74	5	15.6		3	13.0	
75-79	4	40.6		3	13.0	
80-84	7	21.9		4	17.4	
85-89	3	9.4		2	8.7	
Mean *(SD)*			72.1 *(10.1)*			71.3 *(9.1)*
Duration of diagnosis (years):						
0-4	12	37.5		8	34.8	
5-9	10	31.3		8	34.8	
10-14	5	15.6		2	8.7	
15-19	2	6.3		2	8.7	
Did not report	4	12.5		4	17.4	
Mean (of responses)*(SD)*			5.9yrs *(4.3)*			5.7yrs *(4.4)*
Professional delivering diagnosis:						
Neurologist	20	71.4		15	78.9	
GP	5	57.1		2**	10.5	
(Neurologist and GP indicated – not included in above categories)	3	10.7		2	10.5	
Where neurologist reported to be involved:	23	82.1		17/19**	73.9/82.6**	

Did not report/ can't remember	4			4		
Location diagnosed:						
NHS Lothian hospital	23	72		23	100	
GP practice	4	13		N/A		
Other	5	16		N/A		

*Excluding non-respondents for item **Reported received diagnosis from GP, but also reported being diagnosed in NHS Lothian secondary care services (specifying a particular hospital). Assumed diagnosis confirmed by neurologist.

Table 2. Experience of receiving diagnosis

Item	**Overall sample**		**Those diagnosed at a NHS Lothian hospital**	

	n	**%***	***n***	**%***
Knew why seeing professional:				
Yes	20	71.4	14	73.7
No	8	28.6	5	26.3
Did not respond	4		4	
Would have liked more information prior to appointment:				
Yes	8	26.7	5	23.8
No	22	73.3	16	76.2
Did not respond	2		2	
Would have liked to have spoken to staff member before appointment:				
Yes	3	10	3	14.3
No	27	90	18	85.7
Did not respond	2		2	
Length of appointment:				
Too long	0	0.0	0	0.0
About right	28	87.5	20	87.0
Too short	4	12.5	3	13.0
Professional providing diagnosis was:				
Understanding	25	78.1	17	73.9
Sensitive	17	53.1	13	56.5
Respectful	18	56.3	13	56.5
All three	14	56.3	13	56.5
Only one of above endorsed	18	44.8	10	43.5
Felt could ask questions during appointment if wanted:				
Yes	30	93.8	21	91.3
No	2	6.3	2	8.7
Would have liked to talk to someone straight after their appointment:				
Yes	7	23.3	5	23.8
No	23	76.7	16	76.2
Did not respond	2		2	
Would have liked to have had somewhere to sit quietly after their appointment:				
Yes	9	28.1	7	30.4
No	23	71.9	16	69.6
Someone to talk to <u>and</u> somewhere to sit quietly?				
Both	4	12.5	4	17.4
Only one	6	18.8	4	17.4
Neither	17	53.1	13	56.5
‘No’ for sit quietly, talk to item not responded to	2	6.3	2	8.7

*Excluding non-respondents for item

Item	**Overall sample**		**Those diagnosed at a NHS Lothian hospital**	
	n	**%***	***n***	**%***
Told information about condition:				
Yes	25	78.1	17	73.9
Did not indicate	7	21.9	6	26.1
Given written information:				
Yes	9	28.1	7	30.4
Did not indicate	23	71.9	16	69.6
Given a DVD:				
Yes	1	3.1	1	4.3
Did not indicate	31	96.9	22	95.7
Provided with website address (linked to condition):				
Yes	7	21.9	5	21.7
Did not indicate	25	78.1	18	78.3
Given a contact name in case of future queries:				
Yes	12	37.5	8	34.8
Did not indicate	20	62.5	15	65.2
*Understood information?***				
All of it	12	40.0	10	47.6
Most of it	14	46.7	9	42.9
Some of it	0	0.0	0	0.0
Didn’t understand very much of it	2	6.7	1	4.8
Didn’t receive any information	2	6.7	1	4.8
Removed from analysis**	2		2	
How rated information received:				
Excellent	5	16.1	4	18.2
Good	11	35.5	7	31.8
Excellent and good selected	1	3.2	1	4.5
Adequate	12	38.7	7	31.8
Poor	2	6.5	2	9.1
Did not respond	1		1	
Would have liked more or less information provided?				
More	10	32.3	7	31.8
Neither – about right	21	67.7	15	68.2
Less	0	0.0	0	0.0
Removed (for selecting 2 options)	1		1	
Did you remember what you were told after the appointment?				
All of it	10	31.3	8	34.8
Some of it	18	56.3	13	56.5
Very little	4	12.5	2	8.7

Table 3. Information provision

*Excluding non-respondents for item
**Removing responses from participants whose responses were contradictory

Table 4. Support options.

*Excluding non-respondents for item

Item	**Overall sample**		**Those diagnosed at a NHS Lothian hospital** (n= 19)	
	n	**%***	***n***	**%***
Aware could bring someone to their appointment?				
Yes				
No	25	78.1	17	73.9
	7	40.6	6	26.1
Attended appointment alone?				
Yes	19	59.4	14	60.9
No	13	40.6	9	39.1
Attended appointment alone...				
...and were aware they could bring someone	13	68.4	9	64.3
...and were not aware they could bring someone	6	31.6	5	35.7
Asked about what support they have from family & friends?				
Yes	15	50.0	12	57.1
No	15	50.0	9	42.9
Did not respond	2		2	
Informed about a support group they could access:				
Yes	21	72.4	17	81.0
No	8	27.6	4	19.0
Did not respond/unsure	3		2	
Accessed a support group?				
Yes	10	32.3	6	27.3
No	21	67.7	12	72.7
Did not respond	1		1	
Of those who accessed a support group, had they been informed about a support group in their appointment?				
Yes	4	50.0	3	60.0
No	4	50.0	2	40.0
Unable to conclude	2		1	
Told how family/friends could access support?				
Yes	10	34.5	5	25.0
No	19	65.5	15	75.0
Did not respond	3		2	
Used the Parkinson's Nurse Specialist service?				
Yes	24	85.7	16	76.2
No	4	14.3	3	14.3
Did not respond/contradictory responses with other answers	4		2	
(Of those responding yes^) *Found PNS to be:*				
No. relevant respondents:	24		16	
Understanding	19	79.2	11	68.8
Respectful	16	66.7	10	62.5
Sensitive	11	45.8	5	31.3
All three	11	45.8	5	31.3
Only one of above endorsed	13	54.2	11	68.8
Found other services helpful?				
Yes	12	50.0	7	
No	12	50.0	10	41.2
Did not respond/unclear	8		6	58.8

Table 5. Themes arising from exploration of what has and could help (all participants).

Question	**Overall *n***	**% of all survey respondents**	**Themes described from responses**
We know that finding out you have parkinsonism can be a very difficult time. Is there anything that you found particularly helpful at this time?	23	71.9	o “Nothing can help” o “Finally I know what is wrong” o “Having time to still live life” o “Accessing information” o “Being supported by others”
Was there anything that could have been done differently that you think would have made this time easier for you?	27	84.4	o “Nothing” o “More considerate timing”” o “Not being left in limbo” – *the latter with the following sub-themes:* • “Receiving quicker follow-up” • “Feeling more supported”

Table 6. Views of “Decision Navigator” role.

Question	**Overall *n***	**% ***	**Those diagnosed at a NHS Lothian hospital *n***	**% ***	**Themes described from responses (overall)**
Some services have trialled using a “Decision Navigator”. This is a member of staff who meets with you before your appointment. This provides you with the opportunity to talk through what you would like to discuss at the appointment and make a note of any questions you may have. The Decision Navigator can then attend the appointment with you and take notes. After the appointment, they can sit with you and talk through what was discussed. Do you think you would have liked to have had a Decision Navigator when you were diagnosed?					o “Decision Navigator would help me to prepare for and process diagnosis” o “Did not personally need” – *the latter with the following sub-themes:* • “The service I received was good enough” • “I had personal/external resources that helped instead (but Decision Navigator would be useful if I did not)”.
Yes	17	54.8	12	54.5	
No	13	41.9	9	40.9	
Don’t know	1	3.2	1	4.5	
Did not respond	1		1		

*Excluding non-respondents for item

Appendix 2: Survey

Exploring the experience of finding out you have Parkinsonism: What helps at this time?

Thank you for considering completing this survey. Please note that if you choose to complete and return this survey, your consent to participate in this service evaluation is assumed. Your responses will help us to highlight what may be helpful for people finding out they have Parkinsonism in future. You will not receive any further contact and no identifiable information will be included when the findings of the survey are reported. You are free to stop completing it at any time and you may choose to not provide a response to some of the questions if you wish. To preserve your anonymity, please do not put any information on the survey that could identify you (for example, your name).

Some of the questions will have boxes for you to tick if you agree. Others have space for you to write a comment if you wish.

……

I confirm that I have read and understood the participant information leaflet that accompanies this survey ☐

I understand that the anonymised findings of this survey will be available to patients and staff and may also be published ☐

Please tick if anyone is helping you to complete this survey:
Family member/friend ☐ Staff member ☐ Other ☐

……

Q1. What is your gender?

Male ☐

Female ☐

Transgender ☐

Q2. How old are you? ...... years old.

Q3. How old were you when you found out that you had Parkinsonism? .... years old.

Q4: Which professional told you that you had Parkinsonism?

Neurologist ☐
Geriatrician ☐
GP ☐
Can't remember ☐
Other ☐ (Please state) ....

Q5. Did you know in advance why you were going to see this professional?

Yes ☐
No ☐
Comment (optional) ....

Q6. Would you have liked more information about the appointment beforehand?

Yes ☐
No ☐
Comment (optional) ....

Q7. Would you have liked to have talked to a member of staff before the appointment?

Yes ☐

No ☐

Q8. Where was your appointment when you were you told that you had Parkinsonism?

Western General Hospital ☐

St. John's Hospital ☐

Liberton Hospital ☐

GP practice ☐

Other ☐

Q9. How would you describe the length of your appointment?

Too short ☐

About right ☐

Too long ☐

Q10. Was the professional who told you that you had Parkinsonism: *(Please tick any you agree with)*

Understanding ☐

Sensitive ☐

Respectful ☐

Q11. Did you feel you could ask questions if you wanted to?

Yes ☐

No ☐

Q12. Would you have liked to talk to anyone straight after the appointment?

Yes ☐

No ☐

Comment (optional) ……………………………………………………………….

Q13. Would you have liked to have had somewhere to sit quietly after the appointment?

Yes ☐

No ☐

Q14. Please tick the relevant box if any of the following happened at your appointment (when you were told you have Parkinsonism):

I was told information about this condition ☐

I was given written information about it ☐

I was given a DVD about it ☐

I was provided with a website address about it ☐

I was told about the Parkinson's Nurse Specialists service ☐

I was given the name of someone I could contact if I had any questions ☐

Q15. If you received information about your condition, did you understand it?

All of it ☐

Most of it ☐

Didn’t understand very much of it ☐

Didn’t receive any information ☐

Q16. How would you rate the information you received?

Excellent ☐

Good ☐

Adequate ☐

Poor ☐

Q17. Would you have liked to receive more or less information at this time?

More ☐

Less ☐

Neither – the amount of information I received was about right ☐

Q18. If you were told information about your condition at the appointment, did you remember what you had been told afterwards?

All of it ☐

Some of it ☐

Very little ☐

Q19. Did you attend the appointment by yourself?

Yes ☐

No ☐

Q20. Did you know you could bring someone to the appointment?

Yes ☐

No ☐

Q21. Were you told how your family/friends could access support?

Yes ☐

No ☐

Q22. Were you asked about what support you have from family and friends?

Yes ☐

No ☐

Q23. Were you told about any support groups you could access?

Yes ☐

No ☐

Q23. Have you accessed a support group?

Yes ☐

No ☐

Q24. Have you used the Parkinson’s Nurse Specialists service?

Yes ☐

No ☐

Q25. What influenced your decision to use this or not?

Please comment: ………………………………………………………………………….

Q26. Have you found the Parkinson's Nurse Specialists service to be any of the following? *(Please tick any you agree with)*

Understanding ☐

Respectful ☐

Sensitive ☐

Q27. Have you found any other services helpful in providing support?

Yes ☐

No ☐

If yes, which services? …………………………………………………………………..

Q28. We know that finding out you have Parkinsonism can be a very difficult time. Is there anything that you found particularly helpful at this time? …………………………………………………………………………….

………………………………………………………………………………………………

………………………………………………………………………………………………

Q29. Was there anything that could have been done differently that you think would have made this time easier for you?……………………………………………………………………………………

………………………………………………………………………………………………

………………………………………………………………………………………………

Q30. Some services have trialled using a ‘Decision Navigator’. This is a member of staff who meets with you before your appointment. This provides you with the opportunity to talk through what you would like to discuss at the appointment and make a note of any questions you may have. The Decision Navigator can then attend the appointment with you and take notes. After the appointment, they can sit with you and talk through what was discussed.

Do you think you would have liked to have had a Decision Navigator when you were diagnosed?

Yes ☐

No ☐

Comments ………………………………………………………………………………………

…………………………………………………………………………………………………

Thank you for completing this survey.

To return it, please post it in the stamped addressed envelope that was included with the survey.