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Parkinson's disease palliative care needs assessment tool: adaptation and psychometric testing

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Rapid identification of palliative care needs in Parkinson's disease: adaptation and psychometric testing of the Needs Assessment Tool: Parkinson's disease.

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ABSTRACT

Objective:

Parkinson's disease is a progressive, life limiting disease, which benefits from structured palliative care. Systematic recognition and triage of needs helps facilitate care, allows focused referral to Specialist Palliative Care and aids sustainability of services.

Existing palliative care tools for Parkinson's are patient / caregiver completed and focus on quantification rather than identification of need. The Needs assessment tool: progressive disease-cancer was designed for rapid identification of unmet needs in cancer. We describe adaptation and psychometric testing of the tool for Parkinson's disease (NAT:Parkinson's disease).

Methods:

Set in secondary care, Parkinson's disease outpatients clinics in the UK this study included people with Parkinson's, age > 18, including all disease stages. People with atypical Parkinsonian syndromes excluded.

Adaptation using systematic review and focus groups.

Construct validity tested in 50 consecutive patients against established patient and caregiver measures, analysed with Kendall's Tau B.

Inter-rater reliability, using video consultations, in broad range of clinicians involved in PD care using a weighted kappa. 0–0.2 = slight, 0.21–0.40 = fair, 0.41–0.60 = moderate, 0.61–0.80 = substantial, and p<0.05 indicative of statistically significant agreement.

Results:

Validity was substantial for 2, moderate for 5 and fair for 4 constructs.

Inter-rater reliability was substantial for 1, moderate for 3 and fair for 6 constructs. Two constructs failing to demonstrate fair reliability did show very high percentage agreement.

Conclusion:

Findings support the suitability of the NAT:Parkinson's disease for everyday clinical use in the identification and triage of unmet palliative need for people with Parkinson's disease.

Key messages:

What was already known?
PD has significant palliative burden.
Sustainable services require triage of unmet need

What are the new findings?
NAT:Parkinson's disease adapted for PD

A valid and reliable bedside tool for assessment and triage of PD palliative care needs.

What is their significance?
Clinical – Facilitates systematic identification of unmet needs in everyday clinical practice
Research – Aids development of integrated care models

BACKGROUND

Parkinson's disease (PD) is a common, life limiting neuro-degenerative condition, with a prevalence of 24.7/10,000 in the UK[1]. The burden of palliative care needs in Parkinson's Disease are similar to those in advanced malignancy [2]and amyotrophic lateral sclerosis[3]. Integrated palliative care services for Parkinson's Disease are developing, but will depend on consistent identification and triage of unmet need, leading to focused referral to Specialist Palliative Care (SPC) to ensure service sustainability[4].

Patient reported outcome measures (PROMs) have been adapted for PD, to quantify palliative care needs [5][6]. PROMs, by their nature, require patients to be able to engage with the assessment, with sufficient time, support and cognitive capacity. As such they may not be used routinely in clinical practice (refs) and clinicians and patients may not agree on how they should be employed in PD (Damman). Clinician reported tools (CRT), may place less burden on the patient, but still require time to complete, capture a different perspective, and may be less useful for subjective patient experience. Although the recently developed Palliative Outcome Scale for Parkinson's Disease (POS-PD) can be completed by a clinician as a proxy measure, we are unaware of existing tools for PD which fulfil the requirement to rapidly identify and triage, systematically and in routine clinical practice, those at risk of unmet need in order to facilitate focused management and referral.

The Needs Assessment Tool: Progressive Disease in Cancer (NAT:PD-C) was developed for malignant conditions as a clinician consultation guide, which establishes the level of clinicians' concern regarding unmet palliative needs. Covering caregiver and patient domains[7][8], each construct stands alone, with no composite score. Where concern exists, users are prompted to triage according to their ability to address and the need for external assistance. As such, it is neither PROM nor CRT, but rather a prompt for systematic appraisal of concern during a routine consultation and identify those likely to need further, more detailed assessment and measurement of any concerns.

The NAT:PD-C is valid and reliable[8][9], with reportedly little impact on consultation times[10] and its use shown to reduce unmet need. It has subsequently been adapted for both heart failure[11] and

Interstitial lung disease[12]. The NAT:PD-C has one page of clinician completed areas of enquiry and a second page of supporting information. It may be used as a clinical consultation guide during a single routine appointment without the need for a separate contact, or over a number of shorter contacts. It covers four broad domains: priority referral for more detailed assessment; patient wellbeing; ability of caregiver / family to care for patient; caregiver / family wellbeing.

With growing recognition of the need for integrated palliative care services for people with Parkinson's disease, a tool such as this could play a crucial role in navigating the chronic / palliative interface (lanoix). It may have an important role in complementing existing PROMs, acting as a trigger for subsequent referral and quantitative review with PROMs (ref), as a triage for those requiring more in-depth assessment to support sustainable services, or indeed in parallel with PROMS by identifying areas for focus, where detailed holistic assessment is sought in a single consultation. We therefore adapted the NAT:PD-C for use in Parkinson's disease and evaluated its validity and reliability in a broad population of people living with and caring for Parkinson's Disease.

METHODS

1. Adaptation

A systematic review and synthesis of qualitative literature, focused on palliative needs within the patient experience, was used to identify unmet palliative care needs in Parkinson's disease[13]. In addition, we conducted a primary qualitative study exploring palliative care experience in PD, building on the themes from the systematic review and including caregivers both independently and as proxy representatives[13]. These data were used to adapt the NAT:PD-C.

In phase 1, the qualitative data were mapped against existing domains of the NAT:PD-C (see supplementary tables). Data could be allocated to more than one domain where appropriate. Data unrelated to existing NAT domains were grouped separately. Domains and the constructs within them were adapted to include all the Parkinson's disease specific unmet needs and where necessary, new domains were created. This iterative process was conducted by the primary researcher (ER), with review by a second researcher (MJ) to ensure agreement.

In phase 2, the adaptation was taken to an expert stakeholder panel for further modification and examination of face and content validity. The panel consisted of two neuropalliative specialists (dual expertise in neurology and palliative care) from the United States and Canada, consultant physicians in palliative care, movement disorders and geriatrics from the UK, professors of palliative care with expertise in tool adaptation from the UK and Australia.

2. Validity and Reliability

2.1 Face and content validity

As this is a clinician consulting tool, face and content validity were examined (including for omissions to be rectified) by an international expert panel, drawn from a range of clinical backgrounds. (Box 1). Suggested changes were incorporated into the final version of the tool.

2.2 Construct validity and inter-rater reliability

Setting

Testing was conducted at a district general hospital in the north of England, serving a mixed population of urban and rural patients.

Participants

    a)   Construct validity

Eligible patients were consenting adults (18+ years) with clinically confirmed idiopathic Parkinson's disease (all stages), attending clinic and able to complete study measures. Carers were eligible if nominated by the patient as the key provider of informal care, consenting and able to complete study measures. Their decision to participate did not affect the enrolment of the care recipient.

Patients were excluded if they had an atypical parkinsonian syndrome, there was clinical uncertainty regarding diagnosis, or severe communication difficulty making participation impossible practically. Consecutive patients were recruited through the general movement disorders clinic. Accompanying carers were offered a separate information sheet and recruited in the same manner.

    b)   Reliability

Participants included a broad range of clinicians involved in the care of people with Parkinson's disease, covering a range of specialties (Neurology, Elderly Medicine, Palliative care) and clinical roles (Consultant, Specialist registrar [qualified doctor undergoing specialist training], Nurse Specialist). They were recruited through local special interest and training groups, from District General Hospital, Teaching Hospital, Hospice and community settings

Data collection

    a)   Construct validity

Patients (+/- carer) were invited to attend a consultation with a clinician specialising in movement disorders (ER), who was trained in the use of the NAT-Parkinson's. Prior to attending the consultation, patient participants completed the Parkinson's Disease Questionaire-39 (PDQ-39) and carers the modified-Caregiver Strain Index (m-CSI), sent to them by post. The Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS) was completed face to face on arrival to clinic. The research nurse assisted participants with completion of measures ahead of clinic if required.

ER used the NAT-Parkinson's as an "aide memoire" during the consultation, but otherwise conducting the consultation as usual, then completed the tool post-consultation to summarise participants' needs.

    b)   Reliability

In order to minimise patient burden and present identical clinical information to multiple raters, 10 NAT-Parkinson's directed clinical consultations were video-recorded. Videos included patients at all stages of Parkinson's disease (Hoehn and Yahr 1-5). Participating clinicians received a short training session from ER, (10-15 minute) including an explanation of the tool and how to use it in a clinical consultation, and then independently completed the NAT-Parkinson's on at least two of the 10 video-recorded consultations. Data collected September 2013 – September 2014.

Sample size and statistical analysis

    a) Construct validity

Given the difficulty of estimating sample size for tests of agreement, we used computer simulations, based around the published qualities of NAT:PD-C[11] and the comparator tools[14][15]. A sample of 50 patients was estimated to give 98% power to detect significant agreement in the correlation between the NAT-Parkinson's items and the comparator tools completed by participants. Kendall's Tau-b analyses were completed using SPSS IBM version 21. Kendall's Tau-b range from –1 to +1 indicating positive or negative agreement, where 0 represents no agreement. Empirically, the following were assumed: 0–0.20 as poor/slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1 as almost perfect agreement, with $p<0.05$ indicating sufficient evidence of statistically significant agreement.

    b) Reliability

We estimated that 100 paired assessment ratings (10 separate consultations rated by 10 separate assessors) would provide enough variability of raters and clinical presentations, to provide a valid test. Agreement between raters was assessed using weighted kappa, using the statistical package STATA version 14, where kappa was assigned a linear weighting. Again, we assumed the following: kappa 0–0.20 as poor/slight, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80 substantial, and 0.81–1 almost perfect agreement[16][17].

Ethics

The study was approved by the Regional Ethics Committee (REC number: 13/YH/0006), the Research and Development board and was included in the NIHR study portfolio (Portfolio number: 12774).

RESULTS

    1. **Adaptation**

Supplementary file 1 details the changes made to the NAT:PD-C during phase 1 and phase 2 of the adaptation process. A number of key features, felt to be fundamental to the fidelity of the tool were not altered including: i) the breadth of the tool with sections for patient, caregiver and family needs, ii) tiered level of concern *(0= none, 1= some / possible, 2 = significant)* iii) tiered levels of interventions *(direct intervention by assessor, by another team member, or referred to external services)*, and iv) overall document size which facilitates rapid application in clinical practice.

Domain 1: Priority referral criteria

Addition of Red Flag prompts

A new "red flags" category identifies sub-groups at greater risk for unmet palliative care need, placed at the beginning of the document and intended to heighten awareness during the assessment.

Domain 2 Patient wellbeing

Significant adaptations in this domain included:

2.1 Physical symptoms. Motor symptoms are the defining characteristic of Parkinson's disease, while non-Motor features are myriad and associated with even greater burden [18]. Supporting documentation now reflects the presence of prominent Parkinson's disease specific symptoms (e.g. freezing, dyskinesia, urinary difficulties, drooling).

2.2 Psychological symptoms. This construct was expanded to include neuro-psychiatric issues which are prominent in Parkinson's disease and cause significant distress [19]

2.6 Health beliefs. This section was altered to highlight the difficulty in perception of palliative or hospice care amongst Parkinson's disease patients and carers, as well as the issue of "downward comparison", both of which act as barriers to support.

2.7 Information. Adapted to reflect the difficulties associated with information management, with specific prompts regarding the prognosis of Parkinson's disease, which is often poorly understood and discussion of which is encouraged in national guidelines [20].

Domain 3: Ability of caregiver to care for patient

3.1 Distress at physical symptoms. This section was expanded to reflect the significant burden of non-motor and neuro-psychiatric symptoms in Parkinson's disease and the resultant distress for caregivers [21].

3.5 Problems with inter-personal relationships. Adapted to reflect the patient / carer dyad and challenges outside relationships.

3.6 Information. Includes the concept of "discordant dyads" where information needs differ between patient and caregiver.

Domain 4: Carer / family wellbeing

4.1 Problems that are interfering with wellbeing or functioning. The spiritual and existential impacts of caring, particularly the need to redefine one's self and one's roles are now represented in the section on carer wellbeing. Positive and negative impacts of care role and the need to respond / support, are reflected in the prompt; *"Do the family / care currently feel that caring has a net positive or negative affect for them personally and their relationship with the patient*

Changes to structure

In response to the expert groups, changes were made to aid ease-of-use and comprehensiveness of the user guidance. The appearance of the tool was altered, with streamlining of the triage section and introduction of question stems, reducing word count and enhancing usability.

2.1 Construct validity

We recruited 50 people with Parkinson's disease, (26 men, mean age 73 years [range 59 to 86]; 24 women, mean age 76 [60 to 89]), of whom 28 (56%) had a carer (more common for male patients:

65%). All Hoehn and Yahr stages were represented within the sample, with stage 2 being most frequent (see Table 1).

Table 1 - Hoehn and Yahr stage by sex

		Male	Female
	Stage 1	3	3
	Stage 2	11	11
H+Y	Stage 3	10	5
score	Stage 4	2	2
	Stage 5	0	1
Gender		26 (52%)	24 (48%)
Carer		17 (65%)	11 (46%)

Correlations were statistically significant for most constructs (Table 2). There was substantial correlation (>0.6) for two constructs (Activities of daily living and carer distress), moderate (0.4-0.6) for five constructs (*Patient:* physical, psychological, spiritual, *Carer:* physical difficulty, Difficulty coping) and fair (0.2-0.4) for four (*Patient*: health beliefs, *Caregiver*: interpersonal difficulties, *Family*: wellbeing, grief).

The constructs relating to financial and legal concerns were not included in this analysis, as no comparator tool was identified.

Table 2: Correlation between NAT-Parkinson's construct and comparator

NAT: Parkinson's Construct	Comparator item[a] (From MDS-UPDRS, PDQ-39, mCSI)	Kendall's Tau B result	P Value
2.1 Patient physical	PDQ (Mobility)	0.51	<0.001
2.2 Patient psychological	PDQ (Emotion)	0.55	<0.001
2.3 Patient ADL	MDS-UPDRS Part 2	0.62	<0.001
2.4 Spiritual	PDQ (Emotion)	0.42	<0.001
2.6 Health beliefs	PDQ (support)	0.26	0.042

3.1 Carer distress	m-CSI	0.63	<0.001
3.2 Carer difficulty (physical)	m-CSI	0.48	0.004
3.3 Carer difficulty (coping)	m-CSI	0.46	0.005
3.5 Carer difficulty inter-personal	m-CSI	0.32	0.046
4.1 Carer/family wellbeing	m-CSI	0.36	0.025
4.2 Grief	m-CSI	0.28	0.093

[a] m-CSI (Modified Caregiver Strain Index), PDQ-39 (Parkinson's Disease Questionnaire-39), MDS-UPDRS (movement disorder society adaptation of Unified Parkinson's Disease Rating Scale).

In each case we anticipated a convergent relationship between the NAT construct and the comparator tool.

2.2 Inter-rater reliability

To achieve 100 video assessments, 34 raters were recruited, from movement disorders specialists (n = 5), elderly medicine (with Parkinson's disease training) (n = 20) and palliative medicine (n = 5) (consultant and registrar level), as well as Parkinson's disease nurse specialists (n = 2) and palliative neurology nurse specialists (n = 2). Each rater assessed between two and four consultations.

Inter-rater reliability was substantial for one construct (Carer distress), moderate for three constructs (Patient: financial difficulty, Carer: physical difficulty, difficulty coping) and fair for six constructs. Three constructs (Patient: health beliefs, Carer: financial, Family: Grief) failed to demonstrate at least fair agreement, although in two of the three cases, percentage agreement was almost 100% (Table 3). This anomaly is a feature of kappa, and thus the kappa must be interpreted alongside percentage agreement[22].

Table 3: Kappa by NAT-Parkinson's disease domain

NAT Section	Proportion of observations equal to:			Weighted	
				kappa	SE
	0	1	2		
NAT 2.1 Physical	2%	49%	49%	0.39	0.05
NAT 2.2 Psychological	28%	54%	18%	0.33	0.06
NAT 2.3 ADL	34%	52%	14%	0.27	0.06
NAT 2.4 Spiritual	56%	38%	6%	0.21	0.06

NAT 2.5 Financial	89%	6%	5%	0.54	0.26
NAT 2.6 cultural	70%	29%	1%	0.11	0.10
NAT 3.1 Carer distress	59%	37%	4%	0.55	0.81
NAT 3.2 Carer physical	66%	27%	6%	0.45	0.12
NAT 3.3 Coping	67%	33%	0%	0.40	0.10
NAT 3.4 Carer financial	96%	4%	0%	0.03	0.54
NAT 3.5 Interpersonal	66%	33%	1%	0.19	0.11
NAT 4.1 Carer wellbeing	74%	26%	0%	0.28	0.12
NAT 4.2 Grief	93%	7%	0%	−0.01	0.34

Concern regarding unmet palliative care need: 0 = no concern, 1 = some concern, 2 = significant concern

DISCUSSION

The NAT tool was successfully adapted for people living with Parkinson's disease (NAT:Parkinson's) and deemed to have face and content validity by a panel of experts. Adaptations focused on highlighting patients particularly at risk of unmet need, and inclusion of specific issues resulting from the clinical features of Parkinson's disease, particularly motor, non-motor and neuropsychiatric problems. Domains relating to informal caregivers were felt to be very pertinent in helping to address perceived neglect despite serious and prolonged burden of care.

Psychometric testing confirms acceptable and useful construct validity and inter-reliability for NAT-Parkinson's disease with the psychometric properties of the NAT-Parkinson's being similar to the original NAT:PD-C, its adaptation for UK primary care[9], and other adaptations (NAT-ILD[23] and NAT-HF[11]). The broad constructs in the NAT-Parkinson's are designed to help better communication between clinician and patient, support decision making and provide a useful prompt for everyday clinical practice.

Relation to other studies and implications for clinical practice

A number of patient-reported palliative care assessment tools, for people with Parkinson's, have now been described[24]. The NAT:Parkinson's is distinct in a number of respects: 1) it is the only one to be clinician rated, reducing patient burden and increasing utility in everyday practice – there are a multitude of clinical tools for Parkinson's Disease, few of which are routinely used outside of research; 2) it facilitates rapid identification and triage, rather than quantification of unmet needs, thereby triggering action; 3) it includes patient, carer and family needs in a single assessment.

Integrated models have been proposed to tackle the demand for palliative care both in Parkinson's disease and non-malignant disease more widely. The NAT:Parkinson's may be best positioned at the interface between chronic and palliative care services, to rapidly identify and triage unmet need, facilitating patients movement between chronic and palliative services as need dictates and thus removing the barrier of prognostic-based referral approaches. Quantitative assessment tools, used after the initial identification of need, may complement the NAT:Parkinson's, in such a model. Importantly, PROMs may worsen patient outcome if they are not integrated with an assessment by the clinician. (ref) Depending on the model of care, it could also be used alongside patient-report measures, where these are brought to the consultation with a NAT-trained clinician; the NAT and patient-report measures being used together to profile the needs and inform the management plan.

Published experience of related tools supports the potential of the NAT:Parkinson's. The NAT:PD-C, which had similar psychometric properties, has been shown to reduce unmet palliative care need[25], without increasing consultation time in the oncology clinic. A recent landmark trial of integrated palliative care versus usual care for people with Parkinson's, used the NAT:Parkinson's to identify the study population (people likely to benefit from palliative care)[26]. The trial showed improvement in quality of life in the intervention group whereas the control group's quality of life deteriorated. Greater improvement was noted in non-motor symptoms, motor symptom severity, completion of advance directives, caregiver anxiety, and caregiver burden in the intervention group than in the control group at 12 months. Thus, it could play a valuable part in improving patient outcomes by triggering appropriate action, within an integrated system, as well as identifying unmet need.

Strengths and limitations

A major strength is the diverse group of participants, reflecting all disease stages and including patients according to ability to consent, rather than a cognitive assessment score. This inclusive approach optimised the ability of those with early cognitive impairment to participate, supporting the external validity of our results, for everyday clinical practice. This is significant in light of the calls for palliative interventions to be available for people with Parkinson's at all stages[20] and that people at early stage disease (Hoehn and Yahr 1+2) are often under-represented in palliative care research[26].

We acknowledge the limitations of comparing a clinician consultation guide such as the NAT:Parkinson's with PROMs. We prioritised the use of validated PD tools acknowledging that neither PROMs nor CRTs would provide a perfect comparator.

The difference between PROMs and clinician assessment, and the broad nature of constructs within the NAT:Parkinson's inherently leads to weaker correlations; for example, the construct of unmet need in the domain "persistent physical symptoms" is much broader than enquiry about specific symptoms. In addition, patient report symptoms, quality of life measurements and needs assessment are overlapping but are different entities[27]. Clinical assessment, such as that supported by the NAT:Parkinson's, is inexact and varies between clinicians but is nevertheless considered to be a core clinical skill.[28] The inter-rater reliability of clinicians doing the same clinical examination is commonly in the range of fair to poor and therefore it is unsurprising that few of our comparisons reach strong agreement. However this broad nature of assessment embedded in the NAT:Parkinson's is likely a strength in a clinical context. The trial by Kluger[26] and colleagues provides evidence that the NAT:Parkinson's tool is able to identify those most likely to benefit from specialist

palliative care. It should not be seen as a measurement tool, but as a communication and decision tool, prompting more in-depth exploration (with measurement) as necessary.

A limitation is that comparator scales designed to measure palliative care outcomes in Parkinson's disease were not available at the time of this study. Since the start of this project Parkinson's disease specific adaptations of the POS (POS-S PD[6]) and ESAS (ESAS-PD[2]) have been published, which may have been better suited as comparator tools.

Inter-rater reliability is an important aspect of clinician facing tools and we demonstrated only moderate or fair agreement for the majority of constructs. It is important to note that a wide range of clinical raters were deliberately included, in order to strengthen external validity. This is likely to have reduced levels of agreement, particularly for sub-sections of the tool more familiar to palliative specialists. Including different levels of clinical seniority and both doctors and nurses[29] is also likely to have increased the variation between raters[29]. Rating an observed clinical encounter does not take into account the dynamic and interactive nature of clinical consultation. Therefore, although observing videos was the best available method, it limits the ability of the rating clinician to follow up verbal or non-verbal cues or apply their own consultation style. In clinical practice a learning effect is likely for any clinician[30], and we anticipate greater reliability in a stable, trained team.

This study did not examine test-retest reliability, this is an area that could be examined in future work. However, much of the variability of test re-test is also present in inter-rater variability, so good inter-rater is likely to indicate good test re-test[31]. The NAT:Parkinson's disease was used within the recent successful trial of integrated palliative care for PD, to identify people who may benefit. The study reports that those with higher levels of clinician concern as rated by the NAT:Parkinson's disease, had greater benefit from intervention. This suggests discriminant validity and could be the focus of future work.

We did not examine the implementation implications, but it should be noted that the need for additional symptom assessment and management skills, communication skills and the support of a palliative care team has be noted with regard to implementing the NAT-HF [32] and NAT-ILD[33].

Conclusion

The NAT:Parkinson's is a reliable and valid for the rapid identification and triage of unmet palliative care needs in Parkinson's Disease. It offers a significant alternative to existing tools, being clinician completed, and suitable for everyday use in the identification and triage of unmet patient *and* carer needs. It is a useful addition to the clinical armoury to promote timely access to both general and specialist palliative care, according to need, as a routine reality for this neglected group of patients.

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