Title: Psychometric properties of the Needs Assessment Tool - Progressive Disease Cancer in UK Primary Care

First and corresponding author

Dr Victoria L Allgar

Hull York Medical School

University of York

Heslington Lane

York, YO10 5DD

T: 44 (0) 1904 321786

F: 44 (0) 1904 321696

Victoria.allgar@hyms.ac.uk

Co-authors (in order)

Dr Hong Chen

Hull York Medical School

Allam Medical Building

University of Hull

Hull, HU6 7RX

T: 44 (0) 1482 463124

F: 44 (0) 1482 464705

Hong.Chen@hyms.ac.uk

Dr Ed Richfield

Leeds Teaching Hospitals NHS Trust

Elderly Medicine

Great George Street

Leeds, LS1 3EX

T: 44 (0) 113 2064133

edrichfield@nhs.net

Professor David Currow

Faculty of Health

University of Technology Sydney

PO Box 123

Broadway NSW 2007

Australia

T: 61 (8) 7221 8235

david.currow@uts.edu.au

Professor Una Macleod

Hull York Medical School

Allam Medical Building

University of Hull

Hull, HU6 7RX

T: 44 (0) 1482 463482

F: 44 (0) 1482 464705

una.macleod@hyms.ac.uk

Professor Miriam J Johnson

Hull York Medical School

Allam Medical Building

University of Hull

Hull, HU6 7RX

T: 44 (0) 1482 463309

F: 44 (0) 1482 464705

Miriam.Johnson@hyms.ac.uk

Abstract

**Background**: The assessment of patients’ needs for care is a critical step in achieving patient-centred cancer care. Tools can be used to assess needs and inform care planning. The Needs Assessment Tool: Progressive Disease- Cancer (NAT: PD-C) is an Australian oncology clinic tool for assessment by clinicians of patients’ and carers’ palliative care needs. This has not been validated in the UK Primary Care setting.

**Aim:** To test the psychometric properties and acceptability of a UK primary-care adapted NAT:PD-C.

**Design:** Reliability: NAT: PD-C -guided video-recorded consultations were viewed, rated and re-rated by clinicians. Weighted Fleiss’ kappa and PABAK statistics were used. Construct: During a consultation GPs used NAT:PD-C, patient measures (Edmonton Symptom Assessment Scale; Research Utilisation Group Activities of Daily Living; Palliative care Outcome Score; Australian Karnofsky Performance Scale) and carer measures (Carer Strain Index; Carer Support Needs Assessment Tool). Kendall’s Tau-b was used.

**Setting/Participants:** General medical practitioners (GPs), nurses, patients and carers were recruited from primary care practices.

**Results:** Reliability: All patient wellbeing items and 4/5 items in the carer/family ability to care section showed adequate inter-rater reliability. There was moderate test-retest reliability for 5/6 in the patient wellbeing section and 5/5 in the carer/family ability to care section. Construct: There was at least fair agreement for 5/6 of patient wellbeing items; high for daily living (Kendall’s Tau-b =0.57, p<0.001). The NAT:PD-C has adequate carer construct validity (5/8) with strong agreement for 2/8. Over three-quarters of GPs considered the NAT: PD-C to have high acceptability.

**Conclusion:** The NAT PD-C is reliable, valid and acceptable the UK primary care setting. Effectiveness in reducing patient and carer unmet need and issues regarding implementation are yet to be evaluated.

Keywords

Primary health care

General practice

Palliative care

Needs assessment

Unmet need

Cancer

Introduction

The World Health Assembly has called for improved access to palliative care as a core component of health systems, emphasising primary and community/home-based care.1 National Palliative and End of Life Care Partnership2 outlined the need for systematic ways of reaching those with advanced disease, effective assessment and decision making, care coordination, planning and delivery.

A systematic review of cancer patient needs assessments commissioned by the Cancer Action Team, UK,3 defines a needs assessment tool as that which provides a consistent and comprehensive system to prompt discussion of a patients’ range of support and care needs; helps professionals triage tailored action and is useful for audit and service planning.3-5

Despite a number of Needs Assessment Tools3, 6 available for people with cancer, few are designed for use *by clinicians* to identify and triage of palliative care needs of cancer patients in the busy clinical setting. Structured tools can reduce inequalities as they prompt discussion between patients, families and clinicians, provide a strategy for triaging people according to need, prioritise resources and identify areas for improvement.7

The Needs Assessment Tool – Progressive Disease Cancer (NAT: PD-C) is an Australian one-page psychometrically valid, reliable and clinically acceptable clinician-completed tool for assessment of patients’ and carers’ palliative care needs across a range of domains in the oncology clinic.4, 7-9 The NAT:PD-C has four sections to prompt clinicians to assess holistic needs: priority prompts for specialised palliative care (3 items), patient well-being (6 items), ability of the carer/family to care for the patient (5 items), and carer well-being (2 items). The completed tool provides a profile of documented concerns matched with planned actions (“directly managed”, “refer to other team member”, “refer to specialist palliative care”) and may act as a referral form. Therefore the tool differentiates between need that can be addressed by the usual care team and that which requires referral for specialist palliative care.

As NAT: PD-C was developed and validated in Australia, its transferability to the UK cannot be assumed, and although primary care practitioners were involved in content validity testing it has not been formally tested in primary care.8 We therefore have adapted and tested the psychometric properties of the NAT:PD-C in UK primary care. This paper presents the inter-rater and test-retest reliability, construct validity and acceptability of the NAT: PD-C in this setting.

**Methods**

**Modification of the instrument**

Items and prompts of the original tool were revised using current literature relating to supportive and palliative needs of cancer patients and carers as appropriate to the UK social and cultural context. An expert group, consisting of the research team, patient and carer representatives, and primary health care staff (doctors, practice nurses, district nurses, community palliative care nurse specialists), reviewed each aspect of the adapted NAT: PD-C for content and relevance for UK practice.

**Procedures**

Clinicians (general medical practitioners [GPs] and nurses), patients and family carers were recruited from primary care practices in North and East Yorkshire and Humber, England. Participants could contribute to either reliability or construct testing or both. Palliative care clinical nurse specialists were excluded. Eligible patients were consenting adults with a confirmed diagnosis of incurable cancer and able to complete study measures. Patients undergoing palliative chemotherapy, radiotherapy or other cancer treatments were eligible. Family carer participants were those identified by the patients who were willing to participate. Clinician training to use the NAT:PD-C comprised a brief (10-15 minute) explanation of the tool and how to use it in a clinical consultation by a member of the research team.

**Measures**

Measurement of the extent to which clinicians assign the same score to the same item is called inter-rater reliability. Nine video-recorded NAT:PD-C guided clinical consultations were made by two GPs trained to use the NAT:PD-C, one from each of two practices. This allowed presentation of identical clinical information on multiple occasions to multiple raters without adding to participant burden. Some consultations were conducted at the patient’s home and other in the surgery. A range of tumour types and stages were represented and some had family carers present.

Participating clinicians individually rated at least one video-consultation for patient and carer needs using the NAT:PD-C. Videos were viewed and rated, either in groups or one-to-one facilitated by a researcher, or by accessing the video through a secure online service. For the test-retest reliability, clinicians were invited to re-rate the same video at least two weeks later. This method is one of the simplest ways of testing the stability and reliability of an instrument over time.

Construct validity refers to how well a test or tool measures the construct that it was designed to measure. In this paper we have explored how well the NAT: PD-C items correlate with other previously validated questionnaires that measure the same construct (convergent validity). Clinicians conducted a NAT:PD-C guided single clinic consultation with a participating patient and carer (if present). Consultations could be held in the surgery or patient’s home according to need and preference. Clinicians were encouraged to conduct the consultation as usual but to refer to the tool as an “aide-memoire”.

After the consultation patients completed the Edmonton Symptom Assessment Scale (ESAS) (a patient-reported tool with a 0-10 numerical rating scale for the assessment of ten common symptoms),10 Research Utilisation Group Activities of Daily Living (RUG-ADL)11 (a 4-item clinician/researcher completed scale measuring four activities of daily living), Palliative care Outcome Score (POS)12 and Australian Karnofsky Performance Scale (AKPS) (a palliative modified version of the original scale.13 The carers (if present) completed the Care Strain Index and Carer Support Needs Assessment Tool (CSNAT).4 GPs completed a Likert scale about the acceptability of the NAT:PD-C in clinical practice.

**Statistical analysis**

Inter-rater reliability was assessed using unweighted and weighted Fleiss’ kappa statistics.. Disagreement weights were used with 0.0 for agreement, 1.0 for a difference of one category (0 vs. 1 or 1 vs. 2) and 2.0 for a difference of two categories (0 vs. 2). Test-retest reliability was assessed using a kappa statistic was used to assess agreement and interpreted alongside percentage agreement.14 At least fair agreement was considered evidence of adequate reliability. Data simulations provided a sample size of 100 views to detect a kappa statistic of at least moderate to substantial agreement (within +/- 0.1, based on a 90% confidence level).

For the construct validity testing of the NAT: PD-C, the NAT:PD-C and comparator scores are presented as n (%) and mean (sd) median (minimum, maximum). Data simulations provided a sample size of 38 required to provide ≥93% power to detect a relationship between the NAT:PD-C and the physical symptoms domain of the Palliative care Outcome Scale (POS) (at least a value >0.3 [fair agreement]). The assessment of correlation between the patient NAT:PD-C items (NAT:PD-C Section 2) and the patient-reported comparator tools was assessed using Kendall’s Tau-b correlation coefficients. This allows comparison between the NAT:PD-C items, which produce an ordinal score, with the tools: ESAS, RUG-ADL and POS and the p-values are quoted. Cohen’s kappa was used to compare NAT:PD-C item 2.7 (information needs). To assess the relationship between the level of concern NAT:PD-C daily living item and both the total RUG-ADL score and the AKPS, Kruskall Wallis tests were used.

The prevalence and bias adjusted kappa (PABAK), Cohen’s kappa and percentage of agreement were used to assess whether responses were similar between the NAT: PD-C items relating to the ability and wellbeing of the carer (NAT:PD-C Sections 3 and 4) and appropriate CSI and CSNAT items measuring similar concerns/support needs. For each NAT:PD-C item, the agreement between none or at least some concern was calculated. At least fair agreement for PABAK was considered evidence of adequate reliability.

To assess the acceptability of the NAT:PD-C the n (%) for each category is presented.

All analyses were undertaken on STATA/SE 14 (StataCorp LP) and a p-value of <0.05 was considered to indicate statistical significance. The paper followings the GRRAS checklist for reporting of studies of reliability and agreement.15

Ethical approval from the NRES Committee London - Bloomsbury (REF:13/LO/1229) and intuitional permissions were obtained prior to data collection.

**Results**

**Reliability assessment of the NAT: PD-C**

Fifty five GPs and seven nurses provided 121 tests (GPs: mean age 40.3 (10.0), women 29 (53%); nurses: mean age 44.6 (13.1), 6 (86%) women. Clinicians had 13.1 (9.5and 13.7 (6.7) mean years of experience respectively. Table 1 shows the inter-rater and test-retest reliability of the adapted tool.

TABLE 1 HERE

**Inter-rater reliability**

There was at least fair reliability for all items in Section 2 in assessing patient wellbeing, with moderate inter-rater reliability for 2/6 items: daily activities (Kappa: 0.50) and psychological symptoms (Kappa: 0.46).

In Section 3, assessing the ability of the carer/family to care for the patient, there was at least fair reliability for 4/5 items with moderate inter-rater reliability for the “difficulty coping” item (Kappa: 0.47). There was fair inter-rater reliability for carer/family wellbeing item of grief (Kappa: 0.21)..

**Test-retest reliability**

Twenty one GPs and six nurses undertook 46 re-tests. The mean time between viewings was 32 (17.9) days. The results show at least moderate reliability for 5/6 patient wellbeing items and 5/5 for the ability of carer to care for patient. In the section assessing carer’s well-being there was substantial inter-rater reliability for the carer or family experiencing grief item (Kappa: 0.70).

**Construct validity testing**

Seventeen GPs (mean age 46.1years (10.7) years, range 28-63; 69% men) completed at least one NAT:PD-C assessment with a patient. Thirty-nine people with advanced cancer participated (mean age 74.0 years [SD: 13.6], range 20–93 years; 56% men). Twenty-two carers (mean age 68.6 years (SD: 12.7), range 44–83; 38% men) completed at least one item of the comparator scales.

Thirty-seven (95%) of patients had a carer available, 7 (18%) patients and/or carer had requested a referral to SPCS and 9 (23%) clinicians stated that they required assistance in managing the care of the patients and/or family. The distribution of scores of the NAT: PD-C are shown in Table 2. The average total RUG-ADL score was 5.33 (2.26), 4 (4, 11) and the average score for AKPS was 64.9 (14.1), 60 (40, 90). Descriptive summaries for patient-reported questionnaires are shown in Table 3 and carer-report questionnaires in Table 4. and 4.

TABLE 2 HERE

TABLE 3 HERE

TABLE 4 HERE

The mapping of each item in Section 2, assessing patient wellbeing, with the items from the patient-reported questionnaires that measure the same construct, are shown in Table 5.

The NAT:PD-C has at least fair agreement (>0.3) for 5/6 the patient wellbeing domains. There was high moderate agreement for daily living and the RUG-ADL total score (0.57, p<0.001). The patient item “daily living” was positively correlated with the RUG-ADL total score . The mean RUG-ADL score for patients with no NAT:PD-C identified concerns with daily living ability was statistically significantly lower compared with scores of those with “some” or “significant” concerns (4.13 (0.52) *vs* 4.94 (1.91) *vs* 8.38 (2.33); p=0.044). The AKPS was significantly lower for participants with greater NAT-identified needs (p<0.001).

TABLE 5 HERE

The mapping of each item in Sections 3 and 4 of the NAT:PD-C, in assessing carer ability and wellbeing, with the items from the carer-reported questionnaires that measure the same construct are shown in Table 6. The NAT:PD-C has adequate construct validity (5/8); 3/8 of the carer domains showing moderate agreement (providing physical care (PABAK: 0.59), coping with psychological problems (PABAK: 0.48) and carer experiencing unresolved psychosocial problems or feelings (PABAK: 0.50) and strong agreement 2/8 for information needs (PABAK: 0.69) and impending grief (PABAK: 0.65).

TABLE 6 HERE

**Acceptability of the tool**

Over three-quarters (15 (88%)) agreed or strongly agreed that the NAT:PD-C was acceptable to use within a UK primary care clinical setting and 2 (12%) were neutral.

**Discussion**

**Main findings/results of the study**

The NAT:PD-C showed adequate inter-rater reliability and construct validity given the broad constructs assessed and the broad clinical experience represented. The strength of associations were similar to testing of the original NAT:PD-C and the versions adapted for heart failure and interstitial lung disease.16

The constructs of patient-reported and other measures used as comparator tools are related but different to assessment of need, therefore it is not surprising that relatively few items rated as moderate or strong agreement. Similarly, some NAT:PD-C carer items overlap with concerns within CSI and CSNAT, but are not directly comparable. The original NAT-PD-C, with similar psychometric properties to those reported here, resulted in reduced patient and carer needs when applied in practice.17 This is the key factor in any clinical tool.

The outcomes being measured are subjective and very broad in most categories. For example, “Is the patient experiencing unresolved physical symptoms?” covers a large range of issues more fully identified in the suggested areas of concern. This design is deliberately broad enough to capture as many concerns as possible, assessed in the context of a “screening” consultation so as to keep this as near daily clinical practice as possible. This is a strength in a clinical setting. It could be seen as a weakness for a standardised *measurement* tool as it does not have the exactness to give good Tau or kappa values across the board.

The NAT:PD-C is therefore best seen as a communication and decision tool where action is thereby triggered if more in-depth exploration is needed, rather than an outcome measurement. Formulation of a clinical diagnosis is an inexact science with considerable variation between clinicians.18 For example, the Kappa value for clinician-agreement about the presence of individual respiratory signs reaches fair to moderate agreement only,19, 20 but are nevertheless considered as core clinical skills. Agreement about groups of symptoms and signs are even more difficult to standardise.18

We deliberately included clinicians with a range of clinical experience to increase generalisability in daily practice. However, this brings further variation; one study of consultants and trainees conducting neurological examinations found senior neurologists inter-rater Kappa values ranged from 0.40 to 0.67 and from 0.22 to 0.81 for trainees.21 Some NAT:PD-C items with poor agreement may indicate clinicians’ lack of confidence in assessing this aspect of patient concern e.g. spiritual and existential concerns and may reflect an important area of clinician discomfort and/oreducational need rather than a weakness in the tool.

Inter-rater reliability was only fair for the item assessing carer distress about the patient’s physical symptoms. Carer reluctance to discuss these issues in great detail may have contributed to the results, since previous research has found that carers prefer to concentrate on the issues of the patient during consultations.4

**Strengths and weaknesses/limitations of the study**

Clinicians with a wide range of clinical experience were included to make this tool generalisable and the tool was assessed in a clinical primary care practice context. Paradoxically low values of kappa may occur when one of the categories is chosen by most observers for most participants.14 This was the case for items with lower weighted kappa statistics and the agreement level may be underestimated.

There were relatively small numbers of carers and may have been insufficient to demonstrate agreement.

The observational rather than participatory nature of the inter-rater video testing is likely to reduce the level of agreement as clinicians cannot “pick up the cue” and explore it in the consultation, limiting the clinician’s ability to refine their assessment.

The clinician participants rated the videos after approximately 10 – 15 minutes training only. A learning effect is likely and clinicians using the tool in daily practice will have more experience with using the tool than participants.

**Next steps**

To successfully implement the NAT:PD-C in clinical practice attention must be given to practical implications of training needs, and organisation of services. Implementation work conducted alongside another adaptation of the NAT:PD-C for people with interstitial lung disease22 identified the need, in addition to the initial training of how to use the tool, to provide training in communication skills and symptom management.23

There was stronger agreement for function than symptoms. Clinicians may be more likely to notice symptoms severe enough to cause disability. The poorer agreement for these items may therefore improve with training, and represent a lack of skills or confidence.

The tool is yet to be tested in a clinical trial to evaluate its use by clinicians in terms of impact on patient and carer experience. Further work is also needed to determine the most effective way to use this tool in practice.

**Conclusion**

The adapted NAT:PD-C is reliable and valid in the UK primary care setting and may be a useful resource for identifying patient and carer concerns and triage those appropriate for referral to other care team members or specialist providers.

**Funding:** Yorkshire Cancer Research

**Ethical approval:** NRES Committee London - Bloomsbury (REF:13/LO/1229)

**Competing interests:** None declared

**Acknowledgements:** This work was funded by Yorkshire Cancer Research (Award reference number HEND001). The authors thank The general medical practitioners [GPs] and nurses who viewed the video consultations; the GPs who undertook the NAT:PD-C assessments and helped with recruitment; and all the patients and family carers who gave up their time to take part in the study.

**References**

1. World and resolution HA. Strengthening of palliative care as a component of comprehensive care throughout the life course. In: ASSEMBLY S-SWH, (ed.). 2014.

2. Partnership NPaEoLC. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020. 2015.

3. Richardson A, Medina J, Brown V, et al. Patients' needs assessment in cancer care: a review of assessment tools. Support Care Cancer 2007; 15: 1125-1144. 2007/01/19. DOI: 10.1007/s00520-006-0205-8.

4. Waller A, Girgis A, Lecathelinais C, et al. Validity, reliability and clinical feasibility of a Needs Assessment Tool for people with progressive cancer. Psychooncology 2010; 19: 726-733. DOI: 10.1002/pon.1624.

5. Waller A, Girgis A, Davidson PM, et al. Facilitating needs-based support and palliative care for people with chronic heart failure: preliminary evidence for the acceptability, inter-rater reliability, and validity of a needs assessment tool. J Pain Symptom Manage 2013; 45: 912-925. 2012/09/25. DOI: 10.1016/j.jpainsymman.2012.05.009.

6. Carlson LE, Waller A and Mitchell AJ. Screening for distress and unmet needs in patients with cancer: review and recommendations. J Clin Oncol 2012; 30: 1160-1177. 2012/03/12. DOI: 10.1200/JCO.2011.39.5509.

7. Waller A, Girgis A, Johnson C, et al. Facilitating needs based cancer care for people with a chronic disease: Evaluation of an intervention using a multi-centre interrupted time series design. BMC Palliat Care 2010; 9: 2. 2010/01/11. DOI: 10.1186/1472-684X-9-2.

8. Waller A, Girgis A, Currow D, et al. Development of the palliative care needs assessment tool (PC-NAT) for use by multi-disciplinary health professionals. Palliat Med 2008; 22: 956-964. 2008/10/24. DOI: 10.1177/0269216308098797.

9. Waller A, Girgis A, Johnson C, et al. Implications of a needs assessment intervention for people with progressive cancer: impact on clinical assessment, response and service utilisation. Psychooncology 2012; 21: 550-557. 2011/02/25. DOI: 10.1002/pon.1933.

10. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991; 7: 6-9.

11. Fries BE, Schneider DP, Foley WJ, et al. Refining a case-mix measure for nursing homes: Resource Utilization Groups (RUG-III). Med Care 1994; 32: 668-685.

12. Hearn J and Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Qual Health Care 1999; 8: 219-227.

13. Abernethy AP, Shelby-James T, Fazekas BS, et al. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. BMC Palliat Care 2005; 4: 7. 2005/11/12. DOI: 10.1186/1472-684X-4-7.

14. Viera A and Garrett J. Understanding interobserver agreement: the kappa statistic. Fam Med 2005; 37: 360-363.

15. Kottner J, Gajewski BJ and Streiner DL. Guidelines for Reporting Reliability and Agreement Studies (GRRAS). Int J Nurs Stud 2011; 48: 659-660. 2011/03/03. DOI: 10.1016/j.ijnurstu.2011.01.017.

16. Johnson MJ, Jamali A, Ross J, et al. Psychometric validation of the needs assessment tool: progressive disease in interstitial lung disease. Thorax 2017 2017/11/17. DOI: 10.1136/thoraxjnl-2017-210911.

17. Waller, A., Girgis A, et al. Improving outcomes for people with progressive cancer: interrupted time series trial of a needs assessment intervention. Pain Symptom Manage 2012; 43: 569-581.

18. Joshua AM, Celermajer DS and Stockler MR. Beauty is in the eye of the examiner: reaching agreement about physical signs and their value. Intern Med J 2005; 35: 178-187. DOI: 10.1111/j.1445-5994.2004.00795.x.

19. Holleman DR, Simel DL and Goldberg JS. Diagnosis of obstructive airways disease from the clinical examination. J Gen Intern Med 1993; 8: 63-68.

20. Metlay JP, Kapoor WN and Fine MJ. Does this patient have community-acquired pneumonia? Diagnosing pneumonia by history and physical examination. JAMA 1997; 278: 1440-1445.

21. Shinar D, Gross CR, Mohr JP, et al. Interobserver variability in the assessment of neurologic history and examination in the Stroke Data Bank. Arch Neurol 1985; 42: 557-565.

22. Boland JW, Reigada C, Yorke J, et al. The Adaptation, Face, and Content Validation of a Needs Assessment Tool: Progressive Disease for People with Interstitial Lung Disease. J Palliat Med 2016; 19: 549-555. 2016/02/03. DOI: 10.1089/jpm.2015.0355.

23. Reigada C, Papadopoulos A, Boland JW, et al. Implementation of the Needs Assessment Tool for patients with interstitial lung disease (NAT:ILD): facilitators and barriers. Thorax 2017 2017/02/20. DOI: 10.1136/thoraxjnl-2016-209768.