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

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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 Tools^{3, 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 $\geq 93\%$ 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, Kruskal 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 follows 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 (9.5 and 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 46.1 years (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/or educational 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.

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

Competing interests: None declared

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Table 1: Inter-rater reliability and test-retest results

Question	Number of observations	Inter-rater reliability			Weighted kappa
		Distribution of categories			
Section 1: Priority referral for further assessment		No	Yes		
1.1 Does the patient have a carer readily available if required?	95	17.9%	82.1%		
1.2 Has the patient or carer requested a referral to a Specialist Palliative Care Service (SPCS)?	82	82.9%	17.1%		
1.3 Do you require assistance in managing the care of this patient and/or family?	87	69.0%	31.0%		
Section 2: Patient wellbeing		None	Some/ potential	Significant	
2.1 Is the patient experiencing unresolved physical symptoms?	120	5.8%	54.2%	40.0%	
2.2 Does the patient have problems with daily living activities?	119	22.7%	47.9%	29.4%	
2.3 Does the patient have psychological symptoms that are interfering with wellbeing or relationships?	117	45.3%	51.0%	13.7%	
2.4 Does the patient have concerns about spiritual or existential issues?	109	69.7%	23.0%	7.3%	

2.5 Does the patient have financial or legal concerns that are causing distress or require assistance?	108	86.1%	11.1%	2.8%	
2.6 From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?	108	66.7%	29.6%	3.7%	
Section 3: Ability of carer to care for patient		None	Some/ potential	Significant	
3.1 Is the carer or family distressed about the patient's physical symptoms?	110	43.6%	34.6%	21.8%	
3.2 Is the carer or family having difficulty providing physical care?	107	64.5%	27.1%	8.4%	
3.3 Is the carer or family having difficulty coping?	106	51.9%	36.8%	11.3%	
3.4 Does the carer or family have financial or legal concerns that are causing distress or require assistance?	100	87.0%	13.0%	0.0%	
3.5 Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?	103	67.0%	25.2%	7.8%	
Section 4: Carer/family wellbeing		None	Some/ potential	Significant	
4.1 Is the carer or family experiencing physical, psychosocial or spiritual problems that are interfering with their wellbeing or functioning?	97	54.6%	42.3%	3.1%	

4.2 Is the carer or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?	90	70.0%	27.8%	2.2%	
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NB. In interpreting the kappa statistics: < 0.2 as indicating poor or slight agreement, between 0.21 and 0.40 as fair agreement, between 0.41 and 0.60 as moderate agreement, and between 0.61 and 0.80 as good or substantial agreement.

Table 2: Summary of clinician responses to the NAT: PD-C (N-39)

Section 2: Patient wellbeing	None	Some/ potential	Significant	Missing
2.1: Is the patient experiencing unresolved physical symptoms?	5 (13%)	24 (62%)	10 (26%)	0 (0%)
2.2: Does the patient have problems with daily living activities?	15 (38%)	16 (41%)	8 (21%)	0 (0%)
2.3: Does the patient have psychological symptoms that are interfering with wellbeing or relationships?	29 (74%)	8 (33%)	2 (8%)	0 (0%)
2.4: Does the patient have concerns about spiritual or existential issues?	32 (82%)	3 (8%)	1 (3%)	3 (8%)
2.5: Does the patient have financial or legal concerns that are causing distress or require assistance?	37 (95%)	2 (5%)	0 (0%)	0 (0%)
2.6: From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?	33 (85%)	3 (8%)	1 (3%)	2 (5%)
2.7: Does the patient require information about either: the prognosis, the cancer, treatment options, financial/Legal issues, medical/health/support services or social/emotional issues.	10 (26%)			
Section 3: Ability of carer to care for patient	None	Some /potential	Significant	Missing

3.1: Is the carer or family distressed about the patient's physical symptoms?	18 (46%)	20 (51%)	0 (0%)	1 (3%)
3.2: Is the carer or family having difficulty providing physical care?	32 (82%)	5 (13%)	0 (0%)	2 (5%)
3.3: Is the carer or family having difficulty coping?	25 (64%)	12 (31%)	1 (3%)	1 (3%)
3.4: Does the carer or family have financial or legal concerns that are causing distress or require assistance?	34 (87%)	3 (8%)	0 (0%)	2 (5%)
3.5: Is the family currently experiencing problems that are interfering with their functioning or interpersonal relationships, or is there a history of such problems?	33 (85%)	2 (5%)	1 (3%)	3 (8%)
3.6: Does the carer require information about: the prognosis, the cancer, treatment options, financial/Legal issues, medical/health/support services and/or social/emotional issues.	5 (13%)			
Section 4: Carer/family wellbeing	None	Some /potential	Significant	Missing
4.1: Is the carer or family experiencing physical, psychosocial or spiritual problems that are interfering with their wellbeing or functioning?	27 (69%)	10 (26%)	0 (0%)	2 (5%)
4.2: Is the carer or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?	27 (69%)	6 (15%)	0 (0%)	6 (12%)

Table 3: Summary of patient responses for Palliative care Outcome Score (POS) and Edmonton Symptom Assessment System (ESAS)

	Mean (SD), Median (Min, Max) OR N (%)
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Palliative care Outcome Score (POS)*	
1: Have you been affected by pain?	
Not at all, no effect	10 (26%)
Slightly - but not bothered to be rid of it	13 (33%)
Moderately - pain limits some activity	9 (23%)
Severely - activities or concentration markedly affected	6 (15%)
Overwhelmingly - unable to think of anything else	1 (3%)
Missing	0 (0%)
2: Have other symptoms seemed to be affecting how you feel?	
No, not at all	15 (39%)
Slightly	13 (33%)
Moderately	8 (21%)
Severely	2 (5%)
Overwhelmingly	1 (3%)
Missing	0 (0%)
3: Have you been feeling anxious or worried about your illness?	
No, not at all	17 (44%)
Occasionally	7 (18%)
Sometimes - affects my concentration now and then	10 (26%)
Most of the time - often affects my concentration	4 (10%)
Can't think of anything else - completely pre-occupied by worry and anxiety	1 (3%)
Missing	0 (0%)
4: Have any of your family or friends been anxious or worried about you?	
No, not at all	13 (33%)
Occasionally	10 (26%)
Sometimes – it seems to affect their concentration	4 (10%)
Most of the time	11 (28%)
Yes, always preoccupied with worry about me	1 (3%)
Missing	0 (0%)
5: How much information have you and your family or friends been given?	
	32 (82%)

Full information or as much as wanted – always feel free to ask	1 (3%)
Information given but hard to understand	3 (8%)
Information given on request but would have liked more	0 (0%)
Very little given and some questions were avoided	3 (8%)
None at all – when we wanted information	0 (0%)
Missing	
6: Have you been able to share how you are feeling with your family or friends?	24 (62%)
Yes, as much as I wanted to	8 (20%)
Most of the time	5 (13%)
Sometimes	1 (3%)
Occasionally	1 (3%)
No, not at all with anyone	0 (0%)
Missing	
7: Have you felt that life was worthwhile?	
Yes, all the time	23 (59%)
Most of the time	7 (18%)
Sometimes	4 (10%)
Occasionally	1 (3%)
No, not at all	4 (10%)
Missing	0 (0%)
8: Have you felt good about yourself as a person?	
Yes, all the time	13 (33%)
Most of the time	15 (39%)
Sometimes	3 (8%)
Occasionally	5 (13%)
No, not at all	3 (8%)
Missing	0 (0%)
9: How much time do you feel has been wasted on appointments relating to your healthcare?	32 (82%)
None at all	6 (15%)
Up to half a day wasted	1 (3%)
More than half a day wasted	0 (0%)

Missing	
10: Have any practical matters resulting from your illness, either financial or personal	
Practical problems have been addressed and my affairs are as up to date as I would wish / I have had had no practical problems	23 (59%)
Practical problems are in the process of being addressed	10 (26%)
Practical problems exist which were not addressed	5 (13%)
Missing	1 (3%)
Edmonton Symptom Assessment System (ESAS)	
1: Pain	3.6 (3.0), 3 (0, 9)
2: Tired	6.1 (2.4), 6 (2, 10)
3: Nausea	0.8 (1.5), 0 (0, 6)
4: Depression	2.2 (2.9), 0 (0, 10)
5: Anxiety	3.3 (3.0), 3 (0, 8)
6: Drowsy	4.4 (3.2), 5 (0, 10)
7: Appetite	2.7 (3.3), 1 (0, 10)
8: Wellbeing	5.1 (2.8), 5 (0, 10)
9: Shortness of breath	4.8 (3.2), 5 (0, 10)
10: Other problem	3.8 (3.7)/ 3 (0, 10)

* % may not sum to 100% due to rounding

Table 4: Summary of responses to the Carer Strain Index and Carer Support Needs Assessment Tool

Carer Strain Index (CSI)*	No	Yes	Missing
1: Sleep is disturbed	10 (46%)	12 (54%)	0 (0%)
2: It is inconvenient	18 (82%)	4 (18%)	0 (0%)
3: It is a physical strain	18 (82%)	4 (18%)	0 (0%)
4: It is confining	10 (46%)	12 (54%)	0 (0%)
5: There have been family adjustments	15 (68%)	7 (32%)	0 (0%)
6: There have been changes in personal	15 (68%)	7 (32%)	0 (0%)
7: There have been changes in other	20 (91%)	2 (9%)	0 (0%)
8: There have been emotional adjustments	17 (77%)	5 (23%)	0 (0%)

9: Some behaviour is upsetting	13 (59%)		9 (41%)		0 (0%)
10: It is upsetting to find...has changed	14 (64%)		8 (36%)		0 (0%)
11: There have been work adjustments	18 (82%)		4 (18%)		0 (0%)
12: It is a financial strain	18 (82%)		4 (18%)		0 (0%)
13: Feeling completely overwhelmed	15 (68%)		6 (27%)		1 (5%)
Carer Support Needs Assessment Tool (CSNAT)*	No	A little more	Quite a bit more	Very much more	Missing
1: Understanding your relative's illness	13 (59%)	7 (32%)	1 (5%)	1 (5%)	0 (0%)
2: Having time for yourself in the day	14 (64%)	8 (36%)	0 (0%)	0 (0%)	0 (0%)
3: Managing your relative's symptoms,	20 (91%)	0 (0%)	1 (5%)	0 (0%)	1 (5%)
4: Your financial, legal or work issues	20 (91%)	2 (9%)	0 (0%)	0 (0%)	0 (0%)
5: Providing personal care for your	18 (82%)	3 (14%)	0 (0%)	1 (5%)	0 (0%)
6: Dealing with your feelings and worries	16 (73%)	4 (18%)	1 (5%)	1 (5%)	0 (0%)
7: Knowing who to contact if you are	19 (86%)	1 (5%)	2 (9%)	0 (0%)	0 (0%)
8: Looking after your own health	18 (82%)	3 (14%)	1 (5%)	0 (0%)	0 (0%)
9: Equipment to help care for your relative	17 (77%)	5 (23%)	0 (0%)	0 (0%)	0 (0%)
10: Your beliefs or spiritual concerns	19 (86%)	2 (9%)	0 (0%)	1 (5%)	0 (0%)
11: Talking with your relative about his or	18 (82%)	3 (14%)	1 (5%)	0 (0%)	0 (0%)
12: Practical help in the home	16 (73%)	4 (18%)	1 (5%)	0 (0%)	1 (5%)
13: Knowing what to expect in the future	12 (54%)	7 (32%)	3 (14%)	0 (0%)	0 (0%)
14: Getting a break from caring overnight	19 (86%)	2 (9%)	1 (5%)	0 (0%)	0 (0%)
15: Anything else	15 (68%)	0 (0%)	0 (0%)	0 (0%)	7 (32%)

* % may not sum to 100% due to rounding

Table 5: Mapping of each tool with of responses to the NAT: PD-C; Section 2: Patient wellbeing and construct validity.

Concept measured	Corresponding NAT items: (levels of concern 0, 1, 2)	Comparator tool
Physical Symptoms	2.1: Is the patient experiencing unresolved physical symptoms?	Edmonton Symptom Assessment Scale: C of items 1: pain, 3: nausea, 6: drowsiness, and 9: shortness of breath.

Concept measured	Corresponding NAT items: (levels of concern 0, 1, 2)	Comparator tool
		POS: Combination of POS1: have you been affected by pain? and POS2: have other symptoms been affecting how you feel?
Physical functioning	2.2: Does the patient have problems with daily living activities?	RUG-ADL total score AKPS
Psychological symptoms	2.3: Does the patient have psychological symptoms that are interfering with wellbeing or relationships?	Edmonton Symptom Assessment Scale: Combination of items 4: depression, 5: anxiety and 6: feeling of wellbeing. POS: Combination of POS3: feeling anxious or worried about your illness?, POS7: have you felt that your life was worthwhile? and POS 8: have you been satisfied about yourself as a person?
Psycho-spiritual symptoms	2.4: Does the patient have concerns about spiritual or existential issues?	POS: Combination of POS3: feeling anxious or worried about your illness?, POS7: have you felt that your life was worthwhile? and POS 8: have you been satisfied about yourself as a person?
Psycho-social functioning	2.5: Does the patient have financial or legal concerns that are causing distress or require assistance?	POS 10: Have any practical matters resulted from your illness, either financial or personal?
	2.6: From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?	POS: Combination of POS 4: have any of your family or friends been anxious or worried about you? and POS6: have you been able to share how you are feeling with your family or friends?
Information requirements	2.7: Does the patient require information about either: the	POS 5: How much information have you or your family or friends been given?

Concept measured	Corresponding NAT items: (levels of concern 0, 1, 2)	Comparator tool
	prognosis, the cancer, treatment options, financial/Legal issues, medical/health/support services or social/emotional issues.	

NB. For this analysis, the three levels of concern in the NAT:PD-C were grouped into 0='None' versus 1='Some/potential' + 'Significant'; the CSI responses were coded 0 for 'No' and 1 for 'Yes'; and the four CSNAT item responses were categorised into two groups (0='No' versus 1='A little more' + 'Quite a bit more' + 'Very much more').

Table 6: Mapping of each tool with of responses to the NAT: PD-C Section 3: ability of carer or family to care for the patient and Section 4: Carer/family wellbeing

Corresponding NAT items: (levels of concern 0, 1, 2)	Comparator items from CSI and CSNAT (sum of scores for items listed) or POS question.	Kendall's Tau- correlation coefficient OR Kappa, p-value n
Section 3: Ability of carer to care for patient		
3.1: Is the carer or family distressed about the patient's physical symptoms?	CSI9: Some behaviour is upsetting, CSII13: Feeling completely overwhelmed and CSNAT3: Managing your relative's symptoms, including giving medicines	Kappa=0.11, p=0.9 n=19
3.2: Is the carer or family having difficulty providing physical care?	CSI3: It is a physical strain, CSII13: Feeling completely overwhelmed, CSNAT3: Managing your relative's symptoms, including giving medicines, CSNAT5: Providing personal care for your relative, CSNAT9: Equipment to help	Kappa=0.37, p=0.0 n=19

	care for your relative and CSNAT12: Practical help in the home	
3.3: Is the carer or family having difficulty coping?	CSI8: There have been emotional adjustments, CSI9: Some behaviour is upsetting and CSI13: Feeling completely overwhelmed POS 4: Over the last 3 days, have any of your family or friends been anxious or worried about you?	Kappa=0.31, p=0.1 n=20 Kendall's Tau-b correlation coefficient=0.21, (p=0.152) n=20
3.4: Does the carer or family have financial or legal concerns that are causing distress or require assistance?	CSI11: It is a financial strain and CSNAT4: Your financial, legal or work issues	Kappa=0.10, p=0.1 n=21
3.5: Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?	CSI4: It is confining, CSI5: There have been family adjustments, CSI6: There have been changes in personal plans, CSI7: There have been emotional adjustments, CSI9: It is upsetting to find...has changed so much from his/her former self, CSI10: There have been work adjustments, CSNAT2: Having time for yourself in the day and CSNAT11: Talking with your relative about his or her illness.	Kappa=0.02, p=0.6 n=21
3.6: Does the carer require information about: the prognosis, the cancer, treatment options, financial/Legal issues, medical/health/support services or social/emotional issues.	POS 5: Over the last 3 days, how much information have you and your family or friends been given?	Kappa=0.22, p=0.1 n=21
Section 4: Carer/family wellbeing		
4.1: Is the carer or family experiencing physical, psychosocial or spiritual	CSI1: Sleep is disturbed, CSI2: It is inconvenient, CSI7: There have been emotional adjustments, CSI13: Feeling completely	Kappa=0.23, p=0.2 n=19

<p>problems that are interfering with their wellbeing or functioning?</p>	<p>overwhelmed, CSNAT6: Dealing with your feelings and worries, CSNAT8: Looking after your own health, CSNAT10: Your beliefs or spiritual concerns and CSNAT14: Getting a break from caring overnight</p>	
<p>4.2: Is the carer or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?</p>	<p>CSNAT13: Knowing what to expect in the future when caring for your relative</p>	<p>Kappa=0.39, p=0.0 n=17</p>