Systematic identification and triage of palliative care needs of patients and family carers

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Overview

Why bother? The needs assessment tool in progressive disease Adaptation, validation and testing Implementation
Why bother?

• People with advanced illnesses, and carers have well described needs which affect their quality of life and experience of care
• All domains including information and legal & financial
• Identification of needs
  • Identify those not being addressed
  • Patients’ priority and perception
  • Required level of assistance
• More likely to be detected through systematic assessment than through patient response to open question.
Open question or systematic approach

- 200 patients referred to palliative care
- Average volunteered symptoms = 1
- Average with systematic assessment = 10
- 52% rated moderate or severe
- 53% distressing.

- 69% of 522 severe symptoms were not volunteered
- 79% of 1,393 distressing symptoms were not volunteered.

Assess needs in everyday clinical practice

• A needs based approach to care
• Avoids the pitfalls of prognosis approach
• Use of a tool can:
  • standardise assessment and triage of patient and carer concerns
  • Appropriate, timely use of limited services e.g. specialist palliative care
  • identify supportive and palliative care training needs in the usual hospital and primary care teams
  • identify service resource gaps.

• Access to supportive and palliative care services
  • according to the complexity and severity of needs
  • independent of diagnosis or prognosis

Two pronged attack...

• The needs assessment tool places responsibility *with the clinician*

• Identifies those who need further assessment

• Actively assesses needs of family or friend carer as part of the assessment

• Ensures an action plan, including referral(s) if necessary, is made

• Provides an environment where patients are encouraged to complete and present patient-report measures

• Creates an expectation that patient-report measures will be addressed
Overview

The needs assessment tool in progressive disease
Needs assessment tool: progressive disease (cancer)

A practical emphasis: consistency to an inconsistent assessment

### SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the patient have a caregiver readily available if required?</td>
<td></td>
<td></td>
<td>If yellow boxes are ticked, consider</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>assessment by SPES</td>
</tr>
<tr>
<td>Has the patient or caregiver requested a referral to a specialist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>palliative care service (SPCS)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you require assistance in managing the care of this patient and/or</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)

<table>
<thead>
<tr>
<th>Question</th>
<th>Level of Concern</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
<td>Managed by another care team member</td>
</tr>
<tr>
<td></td>
<td>Some/Potential</td>
<td>Managed by another care team member</td>
</tr>
<tr>
<td></td>
<td>Significant</td>
<td>Managed by another care team member</td>
</tr>
<tr>
<td>Is the patient experiencing unresolved physical symptoms (including</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>problems with pain, sleeping, appetite, nausea, bowel, breathing or</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>fatigue)?</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>Does the patient have problems with daily living activities?</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>Does the patient have psychological symptoms that are interfering with</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>wellbeing or relationships?</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>Does the patient have concerns about spiritual or existential issues?</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>Does the patient have financial or legal concerns that are causing</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>distress or require assistance?</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>From the health delivery point of view, are there health beliefs,</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>cultural or social factors involving the patient or family that are</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>making care more complex?</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>Does the patient require information about:</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>the prognosis, The cancer, Treatment options, Financial/legal issues,</td>
<td></td>
<td>Directly managed</td>
</tr>
<tr>
<td>Medical/health/support services, Social/emotional issues</td>
<td></td>
<td>Directly managed</td>
</tr>
</tbody>
</table>
### SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)

<table>
<thead>
<tr>
<th>Who provided this information? (please tick one)</th>
<th>Level of Concern</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Caregiver</td>
<td>Both</td>
</tr>
</tbody>
</table>

1. Is the caregiver or family distressed about the patient’s physical symptoms?
2. Is the caregiver or family having difficulty providing physical care?
3. Is the caregiver or family having difficulty coping?
4. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?
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?
6. Does the caregiver or family require information about (tick any options that are relevant):
   - The prognosis
   - The cancer
   - Treatment options
   - Financial/legal issues
   - Medical/health/support services
   - Social/emotional issues

**COMMENTS:**

### SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)

<table>
<thead>
<tr>
<th>Who provided this information? (please tick one)</th>
<th>Level of Concern</th>
<th>Action Taken</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Caregiver</td>
<td>Both</td>
</tr>
</tbody>
</table>

1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning?
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning?

**COMMENTS:**

### IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION

1. Referral to: (Name) ______________________________
2. Referral to: (Specialty) General practitioner | Medical oncologist | Social worker | Psychologist | Other __________
   Radiation oncologist | Haematologist | Specialist palliative care service
   Public health | Community health
3. Priority of assessment needed: Urgent (within 24 hours) | Semi-Urgent (2-7 days) | Non-Urgent (next available)
4. Discussed the referral with the client. Yes | No
5. Client consented to the referral. Yes | No
6. Referral from: Name: ___________________________  Position: ___________________________  Signature: ___________________________

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Effective and acceptable?

• When used monthly by clinicians
• Significant reduction in health system & information; patient care & support needs.
• NAT-PD had a high rate of completion; identified needs consistent with those self-reported by patients; did not alter consultation length.
• Care with implementation or;
  • delivered without explanation or in jargonistic terms,
  • not integrated into the consultation.
  • most content related to physical health issues.

Waller A et al. JPSM 2012; 43: 569 - 581
Lambert S et al. Journal of Psychosocial Oncology, 2018 36:1, 82-96,
Overview

Adaptation, validation and testing
Programme of work

• NAT for people with Parkinson’s Disease (NAT:Parkinsons)
  • Adapted and psychometrically tested (reliability and face, content and construct validation)

• NAT for cancer in UK primary care (NAT:Cancer)
  • Adapted and psychometrically tested (reliability and face, content and construct validation)
  • Early testing (feasibility of a main trial) completed and proposal for funding for main trial submitted

• NAT for people with interstitial lung disease (NAT:ILD)
  • Adapted and psychometrically tested (reliability and face, content and construct validation)
  • Initial implementation study completed and reported
  • Application for testing in preparation
Process for adaptation and face/content validation

• Cultural relevance
  • Is the patient of Aboriginal or Torres Strait Islander descent?
  • Does the family live more than 50km from the primary service provider?
• Disease-specific
• Update

• Literature
  • Parkinson’s; ILD; cancer
• Focus groups (carers, patients, clinicians)
  • Parkinson’s; ILD*
• Expert consensus
  • Parkinson’s; ILD*; cancer

*also explored issues in relation to implementation
Expert group - NAT:cancer

**Expert Group Meeting:**
- 3 GPs
- 1 practice nurse
- 1 community matron
- 3 patient and carer representatives

**Minor change to the tool:**
- Physical symptoms: problems with skin and appliances (stoma bags)
- Activities of daily living: difficulty with medication and medical regimes
- Legal concerns: power of attorney
- UK related support material
  “Does the patient or family have logistical difficulties accessing services (e.g. due to distance, transport, cost)?“
NAT:ILD adaptation

• From ILD literature
• 4 focus groups
  • 11 patients, 4 carers, 8 clinicians*
• Expert consensus group*
  • 3 academics, 9 clinicians, 4 patients and 2 caregivers
• Workshop*
• Use in everyday practice*

Adaptations
• Respiratory symptoms (especially cough) and concerns about sexual activity were highlighted

<table>
<thead>
<tr>
<th>Section 2: PATIENT WELLBEING</th>
<th>(“Does the patient have……”)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who provided this information?</td>
<td></td>
</tr>
<tr>
<td>Patient ☐</td>
<td>Carer ☐</td>
</tr>
<tr>
<td>Unresolved physical symptoms (including SOB/cough/mucous; leg oedema, heartburn/reflux/poor appetite, fatigue/insomnia/daytime drowsiness, constipation, pain, cognition, voice, sore mouth, mobility, self-image or sex)?</td>
<td></td>
</tr>
<tr>
<td>Unresolved psychological symptoms / loss quality of life?</td>
<td></td>
</tr>
<tr>
<td>Problems with daily living activities?</td>
<td></td>
</tr>
<tr>
<td>Spiritual or existential concerns (issues about the meaning of life and suffering)</td>
<td></td>
</tr>
<tr>
<td>Work, financial or legal concerns?</td>
<td></td>
</tr>
<tr>
<td>Health beliefs, cultural or social factors making care delivery complex?</td>
<td></td>
</tr>
<tr>
<td>Information needs: Prognosis ☐</td>
<td>Diagnosis ☐</td>
</tr>
</tbody>
</table>
Important finding

• Family and friend carers in particular welcomed this joint approach

• Usual experience:
  • Sit in a corner of the clinic room and be ignored
  • Clinicians don’t tap into a valuable source of information about the clinical state of the patient
  • Clinicians don’t assess whether they can still provide care, or whether they are about to fall to bits
Inter-rater and test-retest reliability assessment

- 9 videos of a patient/carer assessed by a GP using the NAT-cancer
- 9 patients, +/- carers
- 2 GPs
- 49 GPs/6 nurses

Analysis: Fleiss kappa (Bland modified)
Inter-rater and test-retest reliability - cancer

• 9/13 items at least fair agreement
• 4 items moderate agreement
  • 2.2 problems with daily living activities?
  • 2.3 psychological symptoms?
  • 2.4 spiritual or existential issues?
  • 3.3 difficulty coping?
• Other 4 items - >97% agreed no significant concern
Reliability Results - ILD

• 53 clinicians (32 doctors, 18 physiotherapists, 2 clinical physiologists, 1 nurse)
  • 64 first views across 10 videos
  • 21 test-retest observations on four videos

Inter-rater reliability
• 11 (69%) NAT:PD-ILD items reached at least fair agreement (weighted kappa >0.2)

Test-retest reliability
• Five items exhibited at least moderate agreement (weighted kappa >0.4)
Comment

- Subjective and broad constructs e.g. “Is the patient experiencing unresolved physical symptoms?”
- Assessed in a clinical consultation; in-depth assessment is not the focus
- Clinicians (doctors and nurses) with a range of clinical experience:
  - 10 – 15 minutes training. Although this is adequate for initial use, a learning effect is likely.
- Training did not include palliative care training or communication skills
Construct validity

Use the NAT to assess a patient/carer in a consultation

Complete an acceptability scale

patient/carer complete comparative questionnaires

Cancer (n=39): AKPS, ESAS*, POS*, RUG-ADL, CSI*, CSNAT*  
ILD (n = 65): AKPS, SGRQ-I*, CSI*, CSNAT*
<table>
<thead>
<tr>
<th>NAT Cancer items: “Does the patient have...”</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Unresolved physical symptoms?</td>
<td>p=0.027</td>
</tr>
<tr>
<td>2. Problems with daily living activities?</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>3. Psychological symptoms that are interfering with wellbeing or relationships?</td>
<td>p=0.012</td>
</tr>
<tr>
<td>4. Concerns about spiritual or existential issues?</td>
<td>p=0.009</td>
</tr>
<tr>
<td>5. Financial or legal concerns that are causing distress or which require assistance?</td>
<td>p=0.177</td>
</tr>
<tr>
<td>6. Patient health delivery...health beliefs, cultural or social factors</td>
<td>p=0.842</td>
</tr>
<tr>
<td>7. Require information?</td>
<td>p=0.249</td>
</tr>
</tbody>
</table>
### Patient Wellbeing

<table>
<thead>
<tr>
<th>NAT: PD-ILD “Does the patient have...”</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Unresolved physical symptoms</td>
<td>p=0.10</td>
</tr>
<tr>
<td>2. Unresolved psychological symptoms / loss quality of life?</td>
<td>p=0.001</td>
</tr>
<tr>
<td>3. Problems with daily living activities?</td>
<td>p&lt;0.001</td>
</tr>
<tr>
<td>4. Spiritual or existential concerns?</td>
<td>p=0.33</td>
</tr>
<tr>
<td>5. Work, financial or legal concerns?</td>
<td>p=0.04</td>
</tr>
<tr>
<td>6. Health beliefs, cultural or social factors making care delivery complex?</td>
<td>p=0.02</td>
</tr>
</tbody>
</table>

Johnson MJ, et al Thorax 2018 *Online first*
Testing - CANASSESS:PC trial

Research question:
Is a cluster Randomised Controlled Trial (cRCT) to test the routine use of the NAT:PD-C in primary care to reduce unmet patient and carer needs feasible?

Study design:
2-arm cluster Randomised Controlled Trial (cRCT) with parallel process evaluation

6 month recruitment period (40 - 60 recruits across 4 practices)

Completed 44
Does the NAT work?
does it make a difference to patients and carer outcomes

• Don’t know yet
  • NAT-cancer
  • Need 62 practices across Y&H and Sunderland
  • 4 “hubs” with 16 practices each; 20 patients per practice over 24 months
  • Application submitted

• NAT-ILD
  • Application in process, national collaboration
  • Incorporate further implementation work and exploration as to how to maximise mutual benefit of clinician needs assessment and patient-report
Overview

Implementation
Challenges and facilitators to NAT:ILD implementation in clinical practice

• Symptom management training and communication skills

• Reconfiguring
  • Skill mix and clinical pathways,
  • MDTs with palliative care input,
  • Change in priorities; legitimise time “upfront” to save later

Reigada C et al Thorax 2017
• SUMMARY
• Needs assessment must be systematic
• The NAT is a clinical consultation guide for everyday use
• Complimentary to patient-reported measurement
• Thought regarding implementation required
• Full testing awaited

• Professor of Palliative Medicine
• miriam.johnson@hylms.ac.uk