



Supportive care, Early Diagnosis and  
Advanced disease research group

# Defining the ILD palliative care patient, what tools are in the box?



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# Outline

- Before we start – clearing up misunderstandings
- Why palliative care?
- Who for?
- How can we tell?
- The Needs Assessment Tool: Interstitial Lung Disease (NAT:ILD)

# Misunderstandings

- End of life care
- Terminal care
- Care of the dying
- Palliative care
- Supportive care
- Patient-centred care

# What is palliative care?

- “... an *approach* that improves the quality of life
- ... *relief of suffering* by means of ...
- *assessment and treatment of pain and other problems*; physical, psychosocial and spiritual....”

WHO 2002

European Declaration on Palliative Care 2014

# What is palliative care?

- aims to help patients live as actively as possible until death;
- uses a team approach
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life

WHO 2002

European Declaration on Palliative Care 2014

# Why palliative care?

- Interstitial lung diseases (ILD) have a high symptom burden and with the most prevalent form, a poor prognosis.
- There is often poor communication and coordination of care, especially surrounding end of life
- Despite national guidelines, routine assessment of palliative needs is rare.
- Only 3% accessed palliative care in a recent IPF registry report

Spiteri M, Chair BLDRSC. The British Thoracic Society Interstitial Lung Disease Registry Programme Annual Report 2014/15. 2015 Nov. BRITISH THORACIC SOCIETY REPORTS

# Chronic Breathlessness Syndrome

- An international Delphi consultation
  - Consultation to define areas for the survey (n=17)
  - Three Delphi survey rounds (n= 34; n=25; n=29)
- A new clinical syndrome...”breathlessness that persists despite optimal treatment of the underlying pathophysiology and results in disability”
- Implications:
  - Legitimises it as something for patients to bring to clinical attention
  - Gives clinicians a framework for assessment
  - Encourages access and use of breathlessness management interventions
  - Raises awareness from research funders to the general public

Johnson MJ *et al* Eur Resp J 2017

# Defining the Palliative Care ILD Patient

- The symptomatic
- Those likely to be progressive, even if relatively asymptomatic at presentation
- Challenging – those with non-IPF fibrosis who might stabilise, but may progress from the outset
- Challenging – those who have been stable, but who are now deteriorating
- Challenging – those with pulmonary function responding to treatment

Kreuter M *et al.* Lancet Respiratory Medicine 2017 *in press*



# Prognosis based? Needs based ?

- Prognosis is relevant
  - Spotting those for whom early palliative care is warranted
- Prognosis is a barrier
  - If waiting for “end-of-life”
- Needs based is relevant
  - Throughout the disease course
- Needs based allows
  - Basic palliative care by ILD team and primary care
  - Intermittent access to specialist palliative care when needed

# Prognosis – the “holy grail”

- If we wait until deterioration is:
  - incontrovertible,
  - completely obvious,
  - irreversible,
  - no chance of stabilisation or improvement
- The patient will be dead

# Palliative care from whom?

COUGH – 78% (68 to 87)

BREATHLESSNESS – 82% (74 to 91)

HEARTBURN – 38% (19 to 58)

REGURGITATION – 36% (21 to 51)

- Basic skills to **assess** and **manage** these top 4 should be mandatory for every ILD clinician
- Basic skills to **identify** and **triage** other concerns should be mandatory for every ILD clinician
- Clinical pathways with specialist palliative care and primary care should be established

# Palliative care from whom?

Specialist palliative care for all is unnecessary and unsustainable

# How to identify and triage concerns – a new tool in the tool box

## The NAT:ILD team

- University of Hull Wolfson PCRC:
  - Jason Boland, Simon Hart, Carla Reigada, Una Macleod, Miriam Johnson
- Brompton and Harefield NHS Trust:
  - Joy Ross, Athol Wells, Bajwah, Sabrina
- University of Manchester:
  - Janelle Yorke, Gunn Grande
- University of York:
  - Caroline Fairhurst, Martin Bland
- University of Technology, Sydney:
  - David Currow

# Needs Assessment Tool: progressive disease in cancer (NAT:PD-C)

- One-page valid, reliable and clinically acceptable tool for assessment of patients' and caregivers' palliative care needs across a broad range of domains.
- Use by hospital based oncology clinicians
- Differentiates between need manageable by the usual care team and that which needs specialist palliative care referral .
- Shown to reduce patient reported unmet need
- Adapted and validated for people with ILD

Waller A, *et al* Palliative Medicine, 2008;22: 956–964.

# Adaptation, face and content validation

Adapted NAT:PD-C to look for needs in ILD

- 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\*

**Needs Assessment Tool: Interstitial Lung Disease**

Name: \_\_\_\_\_  
(or attach address label)

Please complete all sections  
Guidance for completion on reverse  
Date: / /

Section 1a: Red Flags - If present, be alert to seek palliative care need.	Y	N	Directly Managed	Refer to other team member	Refer to SPCS
<b>Red flag symptoms</b>					
Clinical evidence of right heart failure					
Deteriorating Performance Status					
Has the patient or carer had repeated unscheduled contact with hospitals?					
Failure to attend clinic today?					
<b>Section 1b: Priority referral for further assessment:</b>	Y	N	Directly Managed	Refer to other team member	Refer to SPCS
No care?					
Patient or carer request referral to SPCS?					
Ym request assistance of SPCS?					

Comments: \_\_\_\_\_

Section 2: PATIENT WELLBEING: "Does the patient have.....?"	Level of Concern			Action Taken		
Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/>	None	Some/Potential	Significant	Directly Managed	Refer to other team member	Refer to SPCS
Unresolved physical symptoms (including SOB/cough/mucous/leg oedema, haemoptysis/poor appetite, fatigue/inconcomitant breathlessness, constipation, pain, confusion, voice, slow mouth, mobility, self-image or any?)						
Unresolved psychological symptoms (loss quality of life? Problems with daily living activities?)						
Spiritual or existential concerns (issues about the meaning of life and suffering)						
Work, financial or legal concerns?						
Health beliefs, cultural or social factors making care delivery complex?						
Information needs: Prognosis <input type="checkbox"/> Diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Support services (social/emotional issues) <input type="checkbox"/>						

Comments: \_\_\_\_\_

Section 3: ABILITY OF CARER OR FAMILY TO CARE FOR PATIENT: "Do the Carer / Family.....?"	Level of Concern			Action Taken		
Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/>	None	Some/Potential	Significant	Directly Managed	Refer to other team member	Refer to SPCS
Distressed about the patient's symptoms?						
Having difficulty providing physical care?						
Having difficulty coping with the patient's psychological symptoms?						
Concerned about financial or legal issues?						
Experiencing problems that are interfering with inter-personal relationships or functioning, or is there a history of such problems?						
Information needs: Prognosis <input type="checkbox"/> The diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Support services (social/emotional issues) <input type="checkbox"/>						

Comments: \_\_\_\_\_

Section 4: CARER/FAMILY WELLBEING: "Carer or family experiencing....."	Level of Concern			Action Taken		
Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/>	None	Some/Potential	Significant	Directly Managed	Refer to other team member	Refer to SPCS
Unresolved psychosocial problems or feelings (loneliness, depression, anxiety, frustration) that are interfering with their wellbeing or functioning?						
Grief over the future death of the patient?						

Comments: \_\_\_\_\_

**IF FURTHER ASSESSMENT REQUIRED, PLEASE COMPLETE THIS SECTION:**

liaison with \_\_\_\_\_

Referral to (Name) \_\_\_\_\_ Patient aware of referrals: Y  N

Speciality: R.D Nurse Specialist  Spiritual Care  Psychology  OT  PT  Copy to GP: Y  N

Social Services  Specialist Palliative Care  Local specialist R.D Clinic  Other

Priority of assessment needed: Urgent (within 24 hours)  Semi-urgent (2-7 days)  Non-urgent (next available)

Boland, J *et al.* Journal of Palliative Medicine, 2016;19(5):549-55

# Adaptations

## Section 1a: Red Flags – If present, be alert for unmet palliative care need:

### Red flag symptoms

Clinical evidence of right heart failure

Deteriorating Performance Status

Has the patient or carer had repeated unscheduled contact with hospitals?

Failure to attend clinic today?



# Adaptations

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

## Section 2: PATIENT WELLBEING (*“Does the patient have.....”*)

Who provided this information?

Patient  Carer  Both

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*)?

Unresolved psychological symptoms / loss quality of life?

Problems with daily living activities?

Spiritual or existential concerns (*issues about the meaning of life and suffering*)

Work, financial or legal concerns?

Health beliefs, cultural or social factors making care delivery complex?

**Information needs:** Prognosis  Diagnosis  Treatment options  Financial/legal issues

# Adaptations

- Assessment of family members providing care
- Role of caregivers in clinical consultations

Section 3: ABILITY OF CARER OR FAMILY TO CARE FOR PATIENT ( <i>"Is the Carer / Family....."</i> )						
Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/>	None	Some/ Potential	Significant	Directly Managed	Refer to other team member	Refer SPCS
Distressed about the patient's symptoms?						
Having difficulty providing physical care?						
Having difficulty coping with the patient's psychological symptoms?						
Concerned about financial or legal issues?						
Experiencing problems that are interfering with inter-personal relationships or functioning, or is there a history of such problems?						
Information needs: Prognosis <input type="checkbox"/> The diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Support services (social/emotional issues) <input type="checkbox"/>						

Comments:

Section 4: CARER/FAMILY WELLBEING " <i>Carer or family experiencing....."</i>	Level of Concern			Action Taken		
	None	Some/ Potential	Significant	Directly Managed	Refer to other team member	Refer SPCS
Unresolved psychosocial problems or feelings ( <i>loneliness, depression, anxiety, frustration</i> ) that are interfering with their wellbeing or functioning?						
Grief over the future death of the patient?						

# Methods 1

- ILD clinicians in four ILD hospital clinic sites were trained to use the NAT:PD-ILD.
- Consecutive clinic attendees and carers were invited to participate.
- For consenting participants, clinicians conducted the consultation using the NAT:PD-ILD as a guide
- After the consultation
  - clinicians completed the NAT:PD-ILD,
  - patients completed the St. George's Respiratory Questionnaire (SGRQ-I)
  - carers completed the Carer Strain Index (CSI) and Carer Support Needs Assessment Tool (CSNAT).

# Results

## Participants:

- 68 patients were recruited (site 1 n=39; site 2 n=17; site 3 n=9; site 4 n=3).
- Mean age = 66 years (range 34 to 87)
- 62% were male (n=42).
- 45 (66%) patients had a carer (Spouses=82%; child=11%; other relative=4%; friend/neighbour=2%)
  - 27 completed the CSI
  - 29 completed at least one item of the CSNAT.
- 9 clinicians (6 doctors, 3 nurse specialists)

# Patient Wellbeing

NAT: PD-ILD	The SGRQ-I comparator	Kendall's Tau-b ( $\rho$ ) (p-value)
Patient wellbeing "Does the patient have..."		
<b>1. Unresolved physical symptoms</b>	Part 1 Q1-6; Part 2 Section 3 Q1 -6; and Part 2 Section 4 Q6	0.16 (p=0.10)
<b>2. Unresolved psychological symptoms / loss quality of life?</b>	Part 1 Q6; Part 2 Section 4 Q1 – 6; and Part 2 Section 7	0.32 (p=0.001)
<b>3. Problems with daily living activities?</b>	Part 2 Section 2 Q1-5; Part 2 Section 4 Q4+5; Part 2 Section 5 Q1-5; Part 2 Section 6 Q1-4; and Part 2 Section 7	0.36 (p<0.001)
<b>4. Spiritual or existential concerns?</b>	Section 4 Q2; and Part 2 Section 7	0.11 (p=0.33)
<b>5. Work, financial or legal concerns?</b>	Part 2 Section 1	0.34 (p=0.04)
<b>6. Health beliefs, cultural or social factors making care delivery complex?</b>	Part 2 Section 4 Q1-6	0.24 (p=0.02)

## NAT: PD-ILD Carer domains

		N	PABAK	Cohen's kappa	% agreed
<b>Ability of carer or family to care for patient</b> <b>“Is the carer/family...”</b>	7. Distressed about the patient's symptoms?	28	0.57	0.53	79
	8. Having difficulty providing physical care?	28	0.14	0.23	57
	9. Having difficulty coping with the patient's psychological symptoms?	28	0.36	0.36	68
	10. Concerned about financial or legal issues?	27	0.41	0.31	70
	11. Experiencing problems that are interfering with inter-personal relationships or functioning, or is there a history of such problems?	28	-0.57	-0.13	21
<b>Carer/family wellbeing</b> <b>“Carer or family experiencing...”</b>	12. Unresolved psychosocial problems or feelings?	27	0.04	0.17	52
	13. Grief over the future death of the patient?	26	-0.46	-0.10	27

# Inter-rater and test-retest reliability

- Video recordings of ten patient-clinician consultations
  - NAT:PD-ILD to guide assessment
- Clinicians trained to use the NAT:PD-ILD
  - rated the video-consultation
  - re-rated the same video two weeks later
- Weighted Fleiss' kappa, with quadratic weights, calculated for the ratings on 10 videos

# Reliability Results

- 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 clinic consultation, where 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

# Challenges and facilitators to NAT:PD-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

# Conclusions

- The vast majority of people with ILD have palliative care needs
- All ILD clinicians should be able to
  - Provide basic symptom management
  - Identify and triage other palliative care problems including psycho-spiritual
- Involvement of caregivers
  - Source of valuable information
  - Care needs in their own right
- The NAT: PD-ILD is valid and reliable to help identify and triage
- Training needed:
  - to assess patient symptoms at an earlier stage.
  - communication skills
- Focus must be on the disease *and* its effects