Title: Implementation of the Needs Assessment Tool for Interstitial Lung Disease Patients (NAT:ILD): Facilitators and Barriers.

Short title: NAT:ILD Implementation

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ABSTRACT

A Needs Assessment Tool was developed previously to help clinicians identify the supportive/palliative needs of people with interstitial lung disease (ILD) (NAT:ILD). This letter presents barriers and facilitators to clinical implementation. Data from: i) a focus group of respiratory clinicians; ii) an expert consensus group (respiratory and palliative clinicians, academics, patients, carers), were analysed using Framework Analysis.

Barriers related to resources and service reconfiguration, and facilitators to clinical need, structure, objectiveness, flexibility and benefits of an "aide-memoire". Identified training needs included communication skills and local service knowledge. The NAT:ILD was seen as useful, necessary and practical in everyday practice.

Keywords*:* interstitial lung disease, needs assessment tool, qualitative research, palliative care, supportive care, caregiver, carer.

KEY QUESTIONS

INTRODUCTION

- **What is the key question?**
  The Needs Assessment Tool:Interstitial Lung Disease (NAT:ILD) could help respiratory clinicians identify and triage the supportive and palliative care needs of people with interstitial lung diseases and their families, but we need to understand the challenges and potential solutions regarding implementation in everyday clinical practice.
- **What is the bottom line?**
  The NAT:ILD was seen as useful, necessary and practical, but service reconfiguration and training in specific areas such as communication skills and psycho-spiritual assessment are requirements for successful implementation.
- **Why read on?**
  People with ILD, and their families, remain disadvantaged with regard to accessing generalist or specialist palliative care; the NAT:ILD may provide a way to address this issue, but consideration is needed with regard to service implementation.

The Needs Assessment Tool:Progressive Disease-Cancer (NAT:PD-C) was developed to help non-palliative care clinicians identify supportive and palliative needs of people with cancer and their informal carers. It reduced unmet needs without increasing consultation time [1]. In response to unmet supportive and palliative care needs of people with interstitial lung disease (ILD) [2,3] and national guidance [4] the NAT:PD-C was adapted for people with ILD (NAT:ILD) [5]. It prompts clinicians to assess in four sections the holistic needs of patient well-being (1 section), their informal carers' needs (2 sections) with additional prompts for information needs and triage for specialised palliative care.

We aimed to identify facilitators and barriers affecting potential clinical implementation of the NAT:ILD.

METHODS

We used a qualitative approach, with a focus group and an expert consensus group [5].

Participants and sampling strategy

Focus Group

A convenience sample of ILD clinicians at one tertiary referral centre were invited. The clinical service had links with the palliative care breathlessness intervention service but a palliative specialist was not part of the ILD multidisciplinary team (MDT).

Expert Consensus Group

Participants, from hospital and community settings, comprised: ILD and general respiratory clinicians (doctors, nurses, physiotherapists); patients and carers; and research team members.

Data collection

The facilitator (MJ) led both groups through the tool to explore face and content validity. Unprompted comments about implementation arose during discussion, then broad questions were asked about factors which would facilitate or hinder implementation in clinical practice (facilitated by AP). Groups were video and audio-recorded and contemporaneous field notes taken (JB).

Analysis

Framework Analysis was used [6] with anonymised transcripts coded (CR, AP), an analytical framework developed and themes generated. Video-observations using cognitive mapping [7] and field notes helped interpretation. Data were managed using NVivo Software (QSR International Pty Ltd. Version 10, 2012). The pragmatic sample size achieved coding and thematic saturation.

Ethics

This was part of a larger adaptation and validation project, approved by NRES (14/NE/0127) and each institution. Focus group participants gave written consent; this was not required for the expert consensus group.

RESULTS

Sample characteristics

Eight clinicians took part in the focus group: three consultants, three specialist respiratory trainee physicians (five to eight years post-qualification), an ILD respiratory nurse specialist and a specialist physiotherapist. The expert consensus group consisted of clinical academics (n=4), physicians (n=5), nurses (n=3), patients (n=4) and carers (n=2). [5]

Each lasted approximately 90 minutes.

Main findings

Two main themes were identified: clinical issues (Table 1) and practical issues (Table 2).

Clinical issues

Issues relating to the clinical interaction between patient and clinician could influence the willingness or ability of clinicians to use the tool. These were: gaining better knowledge about patient and carer particularly in the "non-medical" aspects; inadequate communication skills to assess psycho-social concerns and whether or not the NAT-ILD was beneficial for patients (Table 1).

Table 1. Clinical issues.

Theme 1: Clinical		
Sub-Theme	**Descriptor**	**Quotes**
Knowledge about the patient and carer*	Identify a broad range of unknown patient and carer issues	"…have I asked in this area of physical problems, have I asked in the area of psychological symptoms, have I looked to see if they've got any spiritual assessments…" (Expert Group, P2)
	Reminder to assess "non-medical" issues	."… but when you go through the list you realise that there's someone with massive information needs and huge potential legal issues that no, nobody registered" (Focus Group, P4)
	Facilitate *action* and *involvement* of other professionals.	"If people open up there's suddenly a need to spend some time on the phone, there's other people in the clinic, if you don't have a nurse specialist that has some time to do that you really are a bit stuck. I think it's embarrassing when you have to stop and say I can't, I

		can't do any more in clinic, go back to the GP, go back to the social worker…" (Focus Group, P6)
	Recognition that the effects of ILD permeate all domains of life	"I mean the tool itself is … actually trying to make sure that the, all the kind of concerns and the domains they might have been covered and identified and referred to the right people, that somebody is dealing with it…" (Expert Group, P2)
Communication ****	Unprepared/lacking in skills to explore some areas e.g. spiritual dimension.	"If I was going to tick a box, box about spiritual or existential concerns related to any of those points … I wouldn't have a first clue what to do about that,..." "...we're really good at looking for the things we think we can do something about …" (Expert Group, P3)
NAT:ILD Benefits for patients and services*	Tool is a clear, useful "aide-memoire" to *ask* and then ensure *action* to address concerns and thus improve care.	"I mean the tool itself is broader than just [trying to manage] the unscheduled admissions… actually trying to make sure that the, all the kind of concerns and the domains they might have been covered and identified and referred to the right people, that somebody is dealing with it…" (Focus Group, P2)
	Tool could identify training needs, service development requirements and help optimise use of additional resources	"...that gives an idea of what resources you'll need to [address] and commission." (Expert Group, P1)

***** Increased willingness to use the tool in practice

** Caused concerns to use the tool in practice, but not seen as insurmountable with training

Practical Issues

Facilitators which increased willingness to use the tool included (1) the tool being clear, concise and a consultation guide rather than a questionnaire or outcome measure**,** and (2) training to address skill gaps in holistic assessment (Table 2).

Barriers included service structures, (time constraints), and resources (multi-disciplinary team availability). Cultural competence, whereby routine enquiry about psychosocial and spiritual wellbeing is legitimised, was highlighted together with training to enable holistic assessment (Table 2).

Table 2. Practical issues

Theme 2: Practical		
Sub-Theme	**Descriptor**	**Quotes**
Facilitators		

Tool design	Focus on issues relevant to the patient and carer. A guide to consultation.	"…this is a prompt to say have you asked about this area of a patient's wellbeing, because these are the sorts of things that people forget, they don't ask systematically about psychological symptoms, they don't ask systematically about activities of daily living, or spiritual concerns …" (Expert Group, P1)
Training	Recognition of training needed to implement this tool.	"I think it's a training need perhaps for the doctors doing this and knowing these things are probably relevant for a range of sub-specialties in respiratory medicine..." (Focus Group, P2). "I would like us to discuss what type of skills would be needed or what type of resources you may need to ask as part of putting this into practice" (Expert Group, P6);
Barriers with potential solutions		
Structure and Resources	Challenge of current team dynamics and hospital logistics	"…I don't know, is it [the NAT:ILD] something you do when it's triggered by a hospital admission, or is it something that's triggered by your unscheduled (…) is it something that's done routinely at new patients every six months, I don't know, when would it?!" (Focus Group, P2)
	Lack of human resources, focus on clinic activity (e.g. 15 min *per* consultation)	"…but it would mean significant modification of the way we do our consultation" (Focus Group, P4)
	Comparative lack of key members of the multi-disciplinary team	"I think, you know, every chronic disease clinic should have a psychologist attached…" (Focus Group, P1) "...but also economic stratification. So the ones that are severe are probably going to have greater needs for medical resources, as well as the social care…" (Focus Group, P1)
Cultural Competence	Culture change needed for routine enquiry about psychosocial and spiritual wellbeing	"…in the TB clinic actually with lots of different backgrounds, and there, there are people from all over the world who often have much stronger faith beliefs than we do UK…" (Focus Group, P4) "…I mean from a trainee point of view, this would mean integrating these patient wellbeing questions into our consultation …would mean significant modification of our consultation models…" (Expert Group P4)
Training	Importance of awareness of ILD impact on patients' and carers' lives but poorly equipped to address non-medical issues.	"So we should maybe learn, look at some of the other specialties and see how they've done it" (Expert Group, P3)
	With training and practice in the use of the tool could complete a holistic framework (including spiritual needs) but is likely to increase consultation time	"…initially we find ourselves asking a lot of questions which are probably not relevant (…) you probably could avoid some of those bits and probably integrate lessons like this … even then it's difficult in a fifteen minute consultation..." (Expert Group, P1)

Reflections from video recordings

There were few blocking body postures even when discussing barriers, reflecting the overall wish of participants to find solutions. The exception was when discussing time constraints of busy clinics; a sense of resignation or nihilism was shown by some participants until challenged and solutions proposed by others in the group.

DISCUSSION

The NAT:ILD was seen as a practical way to address the unidentified, unaddressed serious palliative and supportive care concerns of patients and carers. Participants identified gaps in clinical and communication skills, limited resources and need for culture change. Implementation challenges were delineated, but presented alongside potential solutions. The greatest concerns related to confidence and time constraints to assess psychosocial and spiritual need.

People with ILD have significant palliative and supportive care needs [2] for which there are effective interventions [8]. Despite this, palliative care access is rare; only 3% in a recent interstitial pulmonary fibrosis registry report [9].

Multi-disciplinary care and excellent communication skills are the accepted service model for cancer services. Communication skills training delivers sustainable improvements in clinical practice [10] but is not standard for respiratory clinicians unlike oncology and palliative teams in the UK.

Organisational and logistic factors were barriers to implementation. A change in service configuration to inter-disciplinary clinics would be optimal. The NAT:-ILD may provide a

tool to support implementation of new practices into daily care, catalyse service configuration change to a more patient-centric approach and facilitate multi-professional working.

Strengths and limitations

Audio and visual recording helped interpretation of responses, particularly whether barriers were potentially surmountable.

As with all qualitative work, findings should be interpreted within the service context; this team liaised regularly with the palliative care breathlessness clinic. Other services may be less confident identifying symptoms without such support.

No clinician had used the NAT:ILD in practice. A subsequent dissemination workshop including clinicians with experience in practice upheld the findings (data available on request).

Implications for clinical practice

These clinicians were aware of the wider impact of ILD on patients and their carers. Discomfort assessing psychosocial and spiritual concerns stemmed from feeling: i) unsure what/how to ask ii) ill-equipped to manage emerging problems. Training in assessment, a basic palliative approach and communication skills, and service reconfiguration with identification of referral pathways for specialist concerns is needed. A team relationship with palliative care services would be an initial step in mutual education, training and support leading to a positive culture change.

CONCLUSION

Participants recognised that the NAT:ILD could help improve care of patients and carers, but were concerned about limited time and skills. Participants identified solutions including

training in psychosocial/spiritual assessment and symptom management, support from other disciplines (palliative care and psychology), and MDT engagement, and ways to overcome some barriers within resources. However, service development and additional resources may be required for optimal implementation of the NAT:ILD.

DECLARATION OF CONFLICTING INTERESTS

The authors declare that there is no conflict of interest.

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The tool is available through the NICE website:

https://www.nice.org.uk/guidance/cg163/resources/needs-assessment-toolprogressive-disease-interstitial-lung-disease-natpd-ild-2665699597**FUNDING**

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