

Tackling the rhetoric: an evidence-based support needs tool to enable supportive care in advanced non-malignant disease

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Background

Problem:

- Delivery of supportive and palliative care to patients with advanced non-malignant diseases such as COPD is hampered by the challenge of prognostication and unpredictability of disease trajectories

Possible solution:

- An alternative approach is delivery of care and support in response to patient-identified need

Aim

- This study aimed to develop a support needs tool for patients with advanced COPD, to enable patients to identify and express their support needs

Methods

Two stage qualitative study:

Stage 1: Identification of domains of support need in advanced COPD via:

- rapid review of literature
- analysis of qualitative data from the Living with Breathlessness Study (n=20 purposively sampled patients with advanced COPD)
- focus groups (n=3) with patients with advanced COPD

Stage 2: Development of the Support Needs Approach for Patients (SNAP) tool

- formulation of identified domains of need into questions (tool items)
- review and refinement of draft tool in stakeholder workshops (n=5; with patients, community respiratory team, and primary care practices) to establish acceptability and suitability for clinical practice

Results

The developed SNAP tool is:

- provided by the clinician but completed by the patient
- asks patients to consider whether they need more support in relation to 16 broad areas (domains) of support need

Stakeholders:

- described the range of evidence-based domains of support need as **comprehensive**, and the layout as **patient-friendly**
- broadly endorsed SNAP tool and approach, but concerned about number of domains, time required within the consultation, and meeting patient expectations. (These issues will be tested in a future study)

Extract from draft SNAP tool showing some example items (Farquhar, Gardener & Ewing: July 2016)

I do think it's a good idea because when you go in (to an appointment) for your ten minutes you're worried and then you might forget what you came for in the first place. So if that was ticked off that would give you a [reminder]

(Patient)

I think it's very good ... when you are looking through the list and you sort out what really is your main concern

(Patient)

I think you'd find a problem with the doctor having enough time to give you any of this help and go through the questions, because they're looking at their watch

(Patient)

How are you?

We would like to know what support you need. Please tick the box that best represents your needs now, for each statement below.

| Do you need more support with... | No | A little more | Quite a bit more |
|--|----|---------------|------------------|
| .. understanding your illness | | | |
| .. getting out and about | | | |
| .. having a healthier lifestyle (e.g. keeping active or eating well) | | | |
| | | | |
| | | | |

It's just the patient being in charge of what they want to do, you know.... It's not about us, it's about the patient

(Community Respiratory Team members)

I think it works nicely because we're trying to encourage patients to self-manage so it kind of supports that.

We send out invitations for COPD annual reviews anyway, written invitations; it would be very easy to say, "Please could you have a look at the enclosed [...] and bring it with you because it will help us solve problems."

(GP)

If you're getting them to fill this in they (the patients) will then have certain expectations as to what you're actually able to achieve and their expectations may be higher than our facilities ... to actually facilitate that change

(GP)

Conclusions

- The SNAP tool has potential to help patients with advanced COPD, and other non-malignant diseases, identify and express their support needs to enable delivery of supportive care.
- Follow-on work is testing tool validity and feasibility of the approach.