

Enabling support for carers of patients with COPD: Morag Farquhar & Denise Naus
Hand-out for INSPIRED workshop breakout session 10th Feb 2015

Breakout session outline

Carer burden in advanced COPD is known to be considerable. Carers enable patients to be cared for (and often to die) in their place of choice. Yet this caring role comes at a cost: there is a long established literature on the impact of the caring role on the physical and psychological health of carers, and even on their mortality. The rhetoric of policy is that informal carers should be supported, but there is little guidance on how this should be achieved in practice. Using both robust research evidence and the voice of carer experience this breakout session will outline the support needs of carers in advanced COPD, introduce two tools for use in clinical practice to enable identification of carer support needs and invite your questions and reflections.

Importance of carers

Carers play a crucial role in providing end of life care to relatives, reducing formal care costs (1-2) and contributing to the social care economy. In COPD they provide complex personal care (e.g. washing, dressing, managing symptoms by administering medication or oxygen) as well as practical and emotional support. Their roles are multiple (3-5), often requiring overnight vigilance (3-6).

Impact of the caring role on carers of patients with COPD

Carers experience substantial effects on their health (7), but the reality of caring for a person with COPD often means putting their own health second (3). An ongoing UK longitudinal study of trajectories of need in patients and carers living with advanced COPD (the Living with Breathlessness study: LWB) identified a median caregiving duration of seven years and worse anxiety/ depression than population norms: 10% probable clinical depression and 27% probable clinical anxiety (8).

Carer experiences and needs specifically in relation to breathlessness include anxiety/ emotional distress (4-6, 9-11), isolation (6-7), restrictions (3-7, 9-10), lack of knowledge and strategies, helplessness and powerlessness (5-7), and lack of support/ assistance (3, 5-6). Carers can experience uncertainty and lack confidence in caring tasks and situations; the burden of responsibility can be intolerable. Healthcare professionals receive appropriate training on managing patient needs, but many carers receive no such guidance and feel ill-prepared to care (12-15). This has psychological consequences (e.g. carer anxiety), and impacts on their confidence (16) and ability to ask for help.

Carers' support needs

Carers are often ambivalent about their own needs, putting patients' needs before their own, which can result in neglect of their own health. They often remain unnoticed or invisible (17-18). In the LWB study, carers had unmet direct (support for self) and enabling (support to care) support needs, and were unprepared for many aspects of the caring role (8). More than half wanted more support with knowing what to expect in the future, and more than a third with understanding their relatives illness, knowing who to contact when concerned, having time for themselves in the day and dealing with their feelings and worries (8). More than half felt unprepared for finding out about and setting up services, and more than a third felt unprepared for getting help and information from the health system, for the stress of caregiving and for responding to and handling breathlessness (8).

Carers also report a lack of information about COPD itself, including knowledge of the illness trajectory and palliative care (5). They experience feelings of uncertainty regarding deterioration in patient health, what the future holds and fear associated with acute exacerbations (7). They want support to better manage patient symptoms such as breathlessness (6, 19) and some need the relief and support of respite (20).

Nearly two thirds of carers in the LWB study were unable to identify a key healthcare professional for their caring role (8) reflecting the lack of knowledge of, and access to, professional services identified in earlier studies (3, 5, 19, 21). COPD carers tend only to actively seek professional help during acute episodes (5-6). A recent study (22) revealed that carers of patients with severe COPD are neither acknowledged nor supported by healthcare systems and that they could be supported in their role through acknowledgement, facilitating recognition of patient changes and enabling creative adaptive responses for carers.

Supporting carers

We need to be dramatically better at supporting carers as well as patients. Identifying carers is the first step in offering them support.

- 1) Identify carer(s) – note that they may not identify themselves as “carers”
- 2) Acknowledge their role and reassure them about what they are doing well
- 3) Identify need for more support (and *desire* for more support)
- 4) Prioritise needs (*with* carer – as the greatest need may not be their highest priority)
- 5) Address priority need (or signpost/ refer-on) & re-assess

Two possible tools for use in clinical practice to identify carer support needs

There is an important distinction between tools that identify *indicators* of need (aspects of an individual’s experience that *suggest* a need for support) and tools that can be used to identify direct support needs (areas needing assistance) (23-24).

- 1) Carers Support Needs Assessment Tool (24-25; demonstrated on breakout session show-card)
 - Evidence-based carer-completed tool designed for use in clinical practice that focuses on supporting carers to identify unmet support needs - areas where they need help/require further assessment
 - Originally developed for carers of patients with cancer at end of life but successfully used with carers of patients with advanced COPD in a research context (8)
 - 14 support domains: 7 direct support (support for self) & 7 enabling (support to care)
 - All items start with: “Do you need more support with...” e.g. “Do you need more support with looking after your own health?”
 - Four response categories: No/ A little more/ Quite a bit more/ Very much more
 - Clinical use: UK training model is (i) one day training session for a manager and at least one champion per service (depending on service size), using a train the trainer model; (ii) materials for those delivering the original training, a training pack for those trained to take away, presentations to use, exemplars to use, sets of questions likely to be asked and responses to give; (iii) one hour Webex support sessions once a month for three months.
 - Professor Kelli Stadjuhar (University of Victoria) using CSNAT with Canadian clinical teams in home-based palliative care
 - Dr Ewing & Prof Grande (UK CSNAT team) and Prof Stadjuhar aware there may be interest from INSPIRED for Canada-based training; Prof Stadjuhar may be able to facilitate this
 - Website: <http://csnat.org/> (to request CSNAT Inspection Copy & permission to use)
- 2) Preparedness for Caregiving Scale (26)
 - Identifies how prepared carers are for caring role
 - 8 core items; LWB study added 2 extra items specific to COPD: breathlessness & fatigue (8)
 - All items start with: “How well prepared do you think you are...” e.g. “How well prepared do you think you are to take care of your relative’s physical needs?”
 - Five response categories: Not at all/ Not too well/ Somewhat well/ Pretty well/ Very well.

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How prepared you are

Please tick the box that most closely represents how you feel now, for each statement below.

| How well prepared do you think you are... | Not at all | Not too well | Some what well | Pretty well | Very well |
|---|------------|--------------|----------------|-------------|-----------|
| .. to take care of your relative's physical needs? | | | | | |
| .. to respond to and handle your relative's breathlessness? | | | | | |
| .. to respond to and handle your relative's fatigue or tiredness? | | | | | |
| .. to take care of his or her emotional needs? | | | | | |
| .. to find out about and set up services for him or her? | | | | | |
| .. for the stress of caregiving? | | | | | |
| .. to make caregiving activities pleasant for both you and your relative? | | | | | |
| .. to respond to and handle emergencies that involve him or her? | | | | | |
| .. to get the help and information you need from the health care system? | | | | | |
| .. overall, to care for your relative? | | | | | |

Farquhar et al's with permission adaptation for COPD (for Living with Breathlessness study) of Preparedness for Caregiving Scale (Archbold et al 1990)

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