



Assessing carer needs in chronic obstructive pulmonary disease

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Abstract

Informal carers play a key role in supporting patients with chronic obstructive pulmonary disease (COPD), particularly when disease is advanced. They also enable delivery of healthcare professional advice. There is a well-established impact of the caring role on carers in both the generic and COPD-specific literature. The needs of carers of patients with COPD are both generic to the caring role and disease specific. Healthcare professionals and health systems supporting patients with COPD need to actively identify and support carers. Carer assessment enables unmet needs to be identified and appropriately addressed. Assessments should consider carers' support needs, their caring capacity and practices, and carers own clinical needs. This narrative review outlines considerations for the assessment process including what should be assessed, who should conduct assessment and what should happen as a result of assessment.

Keywords

Carers, COPD, assessment, needs, person-centred care

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Introduction

Reliance on informal carers by individuals with chronic obstructive pulmonary disease (COPD) is common.¹ The physical effects and functional limitations that COPD patients face daily, particularly in advanced disease, require support from others.^{2,3} Carers (family members and friends in a supportive role) have been described as 'potential agents of change that can facilitate and enhance adherence of COPD management behaviours'⁴ (pp. 1588) and provide helpful insights on patients' limitations.² However, carers of patients with COPD provide support beyond enabling delivery of healthcare provider recommendations⁵ – they provide the majority of physical and psychological support to enable patients to complete basic activities of daily living in order to function,⁶ for example, bathing, dressing, housework and shopping. That supportive input can also include overnight vigilance. But carers can also be over protective,⁷ leading to patient frustration,⁸ and can make patients more dependent.^{2,9–11}

The impact of the caring role on carers' own physical and mental health is well established in both the generic and the COPD-specific carer literature.^{12,13} Carers of patients with COPD report anxiety, depression, fatigue, strain, social isolation, uncertainty, confusion, powerlessness, helplessness, loss of freedom, relationship difficulties, loss of intimacy, psychological distress, resentment, sleep disturbance, guilt and boredom.^{2,3,6,7,14–31} Personal, relational and cultural factors can significantly affect the balance between coping capacity and illness burden, increasing the risk of carer vulnerability.¹⁷ Carers are patients too³² and have their own support needs. Both the health effects

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of caring and existing health problems in carers have implications for healthcare professionals in assessing and meeting carers' needs.³³ Healthcare professionals have a role in recognizing the needs of carers of patients with COPD and facilitating responses;³⁴ lack of professional support is a source of stress for carers of patients with COPD.³⁵

What are carers' needs?

Much of the literature on defining need relates to societal or community level needs assessment rather than needs of individuals. Conceptualizations of need at the individual level, such as Bradshaw's,³⁶ have been discussed elsewhere in relation to carers.¹³ Carer needs can be broadly classified into two types: direct needs (support the carer may need for themselves) and enabling needs (support the carer may need to enable them to care).³⁷ Both types of need are frequently unmet.

The evidence base for unmet carer needs in relation to caring for someone with advanced COPD is growing¹³ and includes the need for knowledge and strategies to support the patient and manage the caring role and to manage feelings of helplessness and powerlessness.^{6,15,24} Currow et al.'s analysis of the South Australian Omnibus reported that over a third of bereaved carers of someone with end-stage lung disease reported unmet needs (109/290; 38%) including for support with physical care (17%), information about the future course of the illness (11%) or service availability (11%), support with symptom control (11%) and emotional support for their patient (11%).³⁸ Similarly, Farquhar et al.'s prospective UK study of current carers of patients with advanced COPD (the Living with Breathlessness Study) found that more than half wanted more support with knowing what to expect in the future, and more than a third with understanding COPD, knowing who to contact when concerned, having time for themselves in the day or dealing with their feelings and worries.³⁹ Around a fifth wanted more support with practical help in the home, equipment to help care for their relative, looking after their own health and talking with their relative about their condition.³⁹

Are there COPD-specific carer needs?

Many of these needs are not specific to caring for someone with COPD but are generic caring needs; this is in part because most patients with advanced COPD are likely to have other comorbid conditions

also requiring informal carer support. However, COPD is a relatively unpredictable long-term illness with evident emotional consequences, creating challenges for carers.^{12,40-42} The impact of some of these generic needs, and responses to some of those needs, may therefore be COPD specific, or at least specific to those living with progressive debilitating conditions that are characterized by acute exacerbations. For example, in terms of impacts of unmet need, carers (and patients) live with a fear of breathlessness²⁹ and a fear of acute exacerbations;²⁴ that fear can drive demand for emergency healthcare which can be distressing,^{17,43-45} may be costly⁴⁶ and may not always be warranted.^{43,47} In terms of responses to unmet need, there may be COPD-specific responses to generic needs such as lack of information, for example, by enabling carer access to pulmonary rehabilitation sessions or by providing one-to-one education on the management of breathlessness.^{8,48}

Caring for someone with a slowly progressing condition such as COPD means that the caring role is not only prolonged¹ but it is also changing – particularly as symptom exacerbations occur more frequently in advanced disease.^{2,41} Although there may be long periods of stability, patients exacerbate and their need for carer support changes.^{34,49} Farquhar et al. found the caring role in advanced COPD to be nonstatic: three-quarters (73%) of current carers reported that the amount of caring they gave had changed over time and two-thirds (66%) reported that the type of care they gave had changed.³⁹ The role increases quantitatively (i.e. the number of hours caring) but also, potentially, in its complexity; it can therefore increase carer burden as the disease, and its impact on the patient, progresses. This can happen over a prolonged period of years while the carer themselves is ageing, potentially with (progressive) health issues of their own.⁵⁰ Likewise, while patients' physical and emotional functioning deteriorate during an exacerbation, they can also recover (although not necessarily to the same level of functioning as before); therefore, the caring role may change again.

The nature of conditions such as COPD, which fluctuate and which are hard to prognosticate, means that this changing caring role is also unpredictable. Predicting exacerbations (and their impact) is difficult; therefore, predicting changes in the caring role (both in relation to the types of support given to the patient and when that support will be required for the carer) is also difficult. Just as patients are not always aware of the progressive nature of impacts of COPD,

carers may not be aware of this in relation to either the patient or the impact on themselves and their own role. The challenge of prognostication, even in advanced COPD,⁵¹ is a challenge not only for health-care professionals⁵² but for carers (and patients) too.⁸ The trajectory of the caring role in COPD is thus hard to predict which makes timely and repeated identification and response to unmet carer needs essential.

Most COPD carers live in the same household as patients and are spousal.^{16,19} This potentially brings an added dimension to carer need, and therefore assessment, relating to the quality and maintenance of the patient–carer relationship, for example, Simpson et al. reported emotional control attitudes in patients with negative impacts on relationship dynamics and identity¹⁷; similarly, Meier et al. reported impacts on couples' quality of life⁵³ and Rosa et al. note that spousal carers, in particular, may need professional support to better manage daily life as a couple.³ Some studies of caring in COPD have identified a deepening of spousal relationships,¹⁸ the rewarding nature of caring¹⁶ and its potential for personal growth,⁷ but identifying carers requiring more intensive assessment and support may be helpful.^{32,35} Further, given the physical and psychological impact of symptoms in COPD, and the resultant need for support from a carer, the patient–carer dyad should perhaps be considered the unit of care (for assessment and support). This may also facilitate advance care planning that rarely occurs in COPD.⁵⁴

What should be assessed?

Assessment in its broadest sense occurs to guide action and (informed) decision-making or to provide rationale for actions taken and decisions made. Clinical and supportive interventions are rarely delivered to patients in the absence of prior patient assessment; the same should be true of carers. There is a small but growing literature on carer interventions, yet the literature on carer assessment is scant.

Although focused on patients rather than carers, the outline for needs assessment found in the Single Assessment Process in the United Kingdom is worth exploring as an overarching framework for carer needs assessment. It includes seven key issues to consider when examining need:⁵⁵

- the nature of the presenting need,
- the significance of the need for the older person,

- the length of time the need has been experienced,
- potential solutions identified by the older person,
- other needs experienced by the older person,
- recent life events experienced by the older person, and
- the perceptions of family members and carers.

If we replace 'older person' with 'carer', and in the last bullet point replace 'carers' with 'the patient', then this framework could inform carer assessment and response:

- the nature of the presenting need,
- the significance of the need for the *carer*,
- the length of time the need has been experienced,
- potential solutions identified by the *carer*,
- other needs experienced by the *carer*,
- recent life events experienced by the *carer*, and
- the perceptions of family members and of *the patient*.

However, such a framework suggests that carers 'present'. There is well-established generic evidence that carers are reluctant to present unless it is a time of crisis,^{56,57} and this holds true in COPD;^{6,15} there is also evidence on why they do not present.¹³ One solution to this is for healthcare professionals to proactively identify carers, regardless of whether they have needs or not, and to then create or identify opportunities for assessing needs; to identify carers Farquhar has suggested simply asking patients 'who gives you help and support at home?'¹³ and Millington-Saunders suggests adding carer questions to chronic disease templates.⁵⁷ In a further adaption of the above framework, needs assessment it could then consider the following:

- the nature of needs,
- the significance of the needs for the carer – and which they would like to prioritize,
- the length of time the prioritized need has been experienced,
- recent life events experienced by the carer,
- potential solutions identified by the carer,
- the perceptions of family members and of the patient, and
- potential solutions agreed by the carer and healthcare professional.

Even if the carer currently has no needs, they may have needs in the future; having an established

relationship with a trusted healthcare professional may enable early identification of those needs and effective response.

There are essentially two perspectives on carer assessment: carer needs assessment from a social care perspective and carer needs assessment from a healthcare perspective. The focus in this article is the healthcare perspective: this could include assessment of carer support needs, assessment of carer caring capacity and practices, and clinical assessment of the carer.

Assessment of carer support needs

Carer assessment does occur but is often informal, taking the form of ‘doorstep conversations’³⁷ or relying on healthcare professional intuition rather than being a systematic process of assessment and response. Systematizing the process ensures carers are identified, recognized and acknowledged, and may legitimize for carers their entitlement to access support and facilitate recording of need and responsive actions.^{58–60} For example, Thomsen et al. reported that healthcare professionals found a systematic approach to carer bereavement risk assessment in palliative care (not in the context of COPD specifically) generated relevant information that was not previously available to them, despite their initial reluctance to such an approach.⁶⁰ Recognition of the carer and their role is increasingly being noted as important in COPD^{34,44,61}: at the simplest level, Philip et al. suggest that recognition could include simple verbal acknowledgement of their role and tasks.³⁴

Assessment of carer support needs should consider both types of carer need outlined earlier: direct needs (support the carer may need for themselves) and enabling needs (support the carer may need to enable them to care).⁶² Many research tools exist for identifying and characterizing carer experiences such as burden, but surprisingly few tools have been purposefully designed to identify carer need in clinical practice.⁶³ Two tools which have been designed to directly identify carer need in clinical practice include the Carers’ Alert Thermometer (CAT)^{64,65} and Carer Support Needs Assessment Tool (CSNAT).^{37,59,62,66}

The CAT is a professionally led screening or risk assessment tool to alert practitioners to carers who may benefit from formal needs assessment.⁶⁴ It comprises 10 questions that fall into two domains: the needs of carers in their caring role (enabling needs) and the carer’s own health and well-being (direct

needs). The CAT traffic light system classifies risk and provides a set of generic support responses for each alert area.⁶⁴ Further information and registration to use the CAT are available on the CAT website.⁶⁷

The CSNAT is an evidence-based tool designed for use in clinical practice. It differs from the CAT in that it is carer completed, focusing on supporting carers to self-identify their unmet support needs: areas where they need help or require further assessment.³⁷ CSNAT is a direct measure of carer support need which is integrated into a person-centred approach to practice. It consists of 14 questions (support domains): 7 relating to direct support needs (support the carer may need for themselves) and 7 relating to enabling needs (support the carer may need to enable them to care). By being self-completed, the tool enables carers themselves to consider areas where they feel they need more support and to then express and discuss these needs with a practitioner. That discussion, or needs-led conversation, includes carer prioritization of identified unmet needs and forms the basis for developing a plan of action tailored for that individual carer. Thus, the process of using the tool is practitioner-facilitated but carer-led, with carers themselves identifying their support needs and working with the practitioner to determine resulting supportive actions.⁶² The UK Living with Breathlessness Study successfully used the CSNAT with carers of patients with advanced COPD to identify their unmet needs in a research context.³⁹ Further information and registration to use the CSNAT (including information about CSNAT training) are available on the CSNAT website.⁶⁸

Identifying and assessing carers’ perceptions may provide opportunities to provide support through addressing misperceptions. Healthcare professionals can facilitate the recognition of changes that have occurred in the patient’s condition (and their implications), enabling creative adaptive responses for carers.³⁴ Nakken et al. suggest that assessing carer’s perceptions of the patient’s health is an important factor given that carers subjective burden is a major determinant of the impact of caring in COPD,² for example, Al-Gamal et al. reported that spouses who perceive patient breathlessness as more severe were more likely to experience higher levels of psychological distress⁶⁹ and Gabriel et al. identified that the perception of the possibility that patients may have a painful death associated with asphyxia was a main cause of emotional distress for carers of patients with COPD.⁷

Braine and Wray also advise identifying carers' wider support networks and any sense of isolation.⁷⁰ This might include exploration of where friends and family live and the frequency and type of contacts. They also suggest that it is equally important to establish if these relationships are positive, as divergent or strained relationships may place additional demands on the carer.⁷⁰ Carers of patients with COPD who perceive less support from family and friends are more likely to experience loneliness and depression.⁷¹

Assessment of caring capacity and caring practices

The capacity of carers to provide appropriate care is rarely considered. In an ideal world, assessment would occur before it can be assumed that the carer is able to provide competent care in the context of safe care for themselves or the patient.⁷⁰ However, the 'start' of the caring role is rarely a distinct 'event' in a condition with progressive impact such as COPD, and the pool of people available to take on the caring role is usually limited and can change. The possibility of adaptation (practical, psychological and planning) appears to be important in sustaining the ability to provide care over the long term has been noted.³⁴ Similarly, the role of resilience in enabling and sustaining the caring role in chronic conditions such as COPD is gaining traction³: this may be resilience at the individual carer level or in the wider family (or friends) at a network level.

Assessing (and addressing) carers capacity to care may enable the caring role through positive feedback⁷ (e.g. encouraging appropriate carer responses to patient need) but may also be important in establishing carers' understanding of COPD and their resulting expectations of the patient.⁷² It can also facilitate early identification of any misguided practices⁷⁰ (e.g. discouraging activity for fear of aggravating breathlessness) or unsafe practices that could be detrimental to either the patient or the carer. Hsiao et al. found that older Taiwanese family carers required more education regarding medications and preventive care in COPD than younger carers.⁷³

Research tools, such as the Preparedness for Caregiving Scale (PCS),⁷⁴ may have utility in assessing how prepared or confident the carer feels within their role. The PCS comprises eight core items to identify how prepared carers are for the caring role (e.g. 'How well prepared do you think you are to take care of your relative's physical needs?'), with five response categories: not at all/not too well/somewhat well/

pretty well/very well. Farquhar et al. used the PCS in the UK Living with Breathlessness Study with carers of patients with advanced COPD successfully in a research context, adding two extra items specific to COPD (with the permission of the PCS developers) relating to carers preparedness to manage breathlessness and to manage fatigue.³⁹ Henriksson et al. evaluated the PCS in a palliative care population and suggested it may have utility in clinical practice given its brevity, usefulness, validity and reliability: responses could be used to provide a basis for, and initiate, a deeper dialogue concerning family carers' feelings of preparedness and their needs.⁷⁵

Although not in relation to COPD, Swetenham et al.'s study of palliative care clinics found that carers and patients appreciate being separated in the clinical setting as it provided time and privacy to reveal fears.⁷⁶ Using tools such as the PCS and CSNAT could facilitate this, giving carers an opportunity to independently consider their needs and communicate them to healthcare professionals.

Identification of misguided or unsafe practices is more difficult. Here, healthcare professionals may have to rely on their clinical skills, picking up cues from observed practices or discussions which touch on caring practices with either the carer or the patient. Similarly, healthcare professionals need to be alert to identifying abuse or neglect⁷⁰ to ensure safeguarding in relation to both patient and carer safety. Braine and Wright's suggestion of assessment of the caregiving situation through separate conversations with the patient and carer⁷⁰ may facilitate this.

Clinical assessment of the carer

Carers are patients:³² patients who just happen to be in a caring role. Thus, they may require clinical assessment or screening just as any patient who is not a carer might. If the carer's role as a carer is unknown, clinical assessment would precede assessment of carer support needs if they presented with a clinical problem. If the carer's role as a carer is known, then clinical assessment may follow (or form a part of) assessment of carer support needs (either proactively or reactively). Clinical assessment may include areas related to impact of caring, for example, psychological health⁷⁷ or musculoskeletal injuries (from physically assisting and lifting). Tools suggested for this⁷⁰ include the Hospital Anxiety and Depression Scale.⁷⁸ Early recognition of the negative impacts of caregiving is beneficial in preventing the onset of major

health problems for carers and any adverse effects in relation to the patient.⁷⁰

Who should conduct assessments?

When outlining the general concept of carer assessment (not specific to COPD), Braine and Wright suggest that nurses working in all areas of practice, but especially in the community setting, are in pivotal position to get to know the family and carer.⁷⁰ However, carer identification and support is not just the remit of nurses. In terms of care settings in which patients with advanced COPD have the most healthcare professional contact, UK data suggest that primary and community care settings are the most common:⁷⁹ these may indeed therefore be the prime setting for proactively identifying and assessing carers. However, healthcare professionals in other settings should not assume that carer identification and assessment is being covered by others; if healthcare professionals have concerns in relation to either carer or patient welfare, a duty of care remains.⁶¹ Qualitative data collected from healthcare professionals for the UK Living with Breathlessness Study identified an unchecked assumption that carer support was covered by others.⁸⁰

What should happen as a result of assessment?

Responses to assessment should be agreed between the carer and the healthcare professional (and, where appropriate, the patient). Those responses will depend on the nature of the need as well as resources available. Responses can take the form of direct intervention by the healthcare professional facilitating the assessment (e.g. providing informational, practical or emotional support) or may involve harnessing additional support within the carer's existing networks, signposting to resources or services, or formal referral to other care professionals or services. Mapping potential voluntary and statutory resources is useful but requires vigilant updating and is a locality-based exercise as provision varies widely. And interventions may be delivered to the carer, to the patient-carer dyad or to the wider family or support network, again depending on need. However, the process of assessment, particularly if systematic and formalized, could be an intervention in itself, acknowledging the carer, their role and its challenges.

Assessment should not be a one-off event: it should be ongoing and integral and therefore involve

reassessment.⁷⁰ Changes in the patient's health may change treatment plans which carers may need to be made aware of in order to help enact them; changes in the patient's health may also impact on the carer's burden. Further, carers coping mechanisms may change with disease progression.⁸¹ In addition, changes in the carer's own health (or social circumstances) may impact on their ability to care. Carers may experience a decline in their own psychological and physical functioning towards the terminal stages of COPD.^{31,82} Reassessment not only provides an opportunity to identify and respond to any new unmet needs but to evaluate whether interventions provided were helpful.⁷⁰

The caring role changes as disease progresses, but it also ends. That end may or may not have been predicted in terms of its timing or location;⁴² also, it may or may not have happened in line with patient, or carer, preferences. Identifying and responding to any resulting difficulties in the grieving process are important.⁸³ These can manifest as unusual physical symptoms, or feeling excessively sad, angry, helpless, guilty or anxious, or as appetite or sleep disturbances, or difficulty in concentrating.⁷⁰ Thus, carer assessment, and response, potentially continues beyond the death of the patient. Sometimes, the first presentation of a carer to a healthcare professional can be after the patient's death.⁵⁷

Conclusion

Patients with COPD are often reliant on informal carers for help and support, particularly when disease is advanced. The impact of the caring role on individuals is well established, but the importance of their role in both supporting the patient and enabling delivery of healthcare professional advice is also known. Carers of patients with COPD have both generic and disease-specific needs. Healthcare professionals and health systems need to actively support carers of patients with COPD.^{22,84} This requires the identification of carers and appropriate assessment before identified unmet needs can be discussed and addressed by the carer and healthcare professional together. That assessment should consider carers' support needs, their caring capacity and practices and clinical needs.

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