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Improving support of informal carers of respiratory patients

Morag Farquhar PhD MSc BSc (Hons)

Professor of Palliative Care Research

School of Health Sciences
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ
UK

M.Farquhar@uea.ac.uk

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Editorial

Informal carers are unpaid "lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management".[1] They may provide complex personal care, practical and/or emotional support, including overnight vigilance, reducing formal care costs. However, they can lack knowledge of, and access to, formal services, remaining unnoticed or invisible, only seeking professional help when in crisis.[2,3]

Carers need support to sustain their own health (support for self) and to boost their ability and confidence to care (support to care).[4] Improved carer support could not only improve their own health and wellbeing (carers are patients too), but bolster and sustain their support of the patient, which may ameliorate crises. Carers are thus both clients and co-workers of formal health and social care services,[5] with support needs that may require response by health and social care.

The caring role, its impact on carers and on carer needs, are widely acknowledged but relatively little attention has been paid specifically to carers of patients with respiratory conditions. This is surprising given that an estimated 77% of people with advanced COPD have carers.[6] Further, there may be specific needs related to the largely unpredictable long-term trajectory of many respiratory conditions which creates challenges for carers supporting those with progressive debilitating conditions that are characterised by acute exacerbations.[7]

In a recent publication in *Respirology*, Majellano et al report on the needs and wellbeing of carers of people with severe asthma or COPD.[8] Using questionnaires, tools and free text survey responses, they found many similarities between these two groups of respiratory carers both demographically and in terms of the impacts of caring, including impaired quality of life and the experience of having a range of unmet support needs. Interestingly, however, COPD carers provided more practical care than severe asthma carers and had significantly greater needs for *"having time for self"* (33% versus 13%, $p=0.006$):[8] this may in part be attributable to the likely co-morbidities of patients with COPD (with knock-on effects on the caring role), particularly when disease is advanced.

To identify these carers' unmet support needs, Majellano et al used the 14-question version of the Carer Support Needs Assessment Tool (CSNAT v2).[4,9] They found the most frequently identified areas of support need on the CSNAT v2 were *"knowing who to contact if you are concerned about your relative"* and *"knowing what to expect in the future when caring for your relative"* (Figure 2)[8] – what is notable about this is that these were the most common areas of need despite the longevity of these carers' caring roles in both conditions. It suggests a lack of needs identification and response by health care services.

It is also notable that, despite the CSNAT findings of high levels of unmet support need, the authors found that few support needs were reported by carers in their free-text responses on the survey.[8] This reflects the literature on carer ambivalence about their own needs, and their tendency to put patients' needs first.[3] The *way* we ask carers about their unmet support needs in clinical practice is therefore crucial.

Majellano et al note that their findings “identify an area for improvement in current practice”; they also rightly note the challenges for carers in verbalising their need and so suggest “incorporating simple tools… in the clinical setting”.[8] Again, the *way* this is done is practice is essential to achieving carer engagement and ensuring responses are appropriately tailored: carers should see this as an opportunity to explore and address their support needs rather than just the completion of a questionnaire or form with no clear purpose.

The fact that Majellano et al used the CSNAT to collect their data on support needs is notable as the CSNAT itself underpins an intervention designed specifically for this purpose: the CSNAT Intervention (CSNAT-I).[9] CSNAT-I is an evidenced-based person-centred intervention that facilitates tailored support for carers. It essentially comprises carer-completion of the CSNAT (the tool itself) and a needs-led conversation with a CSNAT-I trained clinician (training freely available online[9] and mandatory for the licence required to use the CSNAT in clinical practice). The needs-led conversation is key as the areas of support need identified by the CSNAT are very broad – the reason why one carer indicates a particular area of need may be very different to why another carer indicates that same area of need (and may vary within the same carer over time). The conversation is also designed to enable carers to consider what might help address their self-identified support needs: those supportive inputs can range from “simple” acknowledgement and active listening, through direct support from the clinician (e.g. the provision of information or education), to referral-on.

CSNAT-I is particularly appropriate for COPD carers as, since Majellano et al’s study was conducted, a new 15-question version of the CSNAT (the tool itself) has been developed and validated for patients with chronic progressive conditions (CSNAT v3), underpinned by development and validation work with COPD carers themselves.[10] The CSNAT was originally developed using data from carers of patients at the end-of-life, predominantly with a cancer diagnosis (versions 1-2).[3] Version 3 includes just one additional question relating to managing relationships (reflecting the impact of a longer-term caring role).

Majellano et al have thus provided clinicians with a much-needed impetus to improve support for these carers and, fortuitously, an evidence-based population-relevant mechanism to help achieve this is readily available in CSNAT-I.

Acknowledgments

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