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ENABLING PATIENT-CENTRED CARE IN ADVANCED COPD: IDENTIFYING CARE AND SUPPORT NEEDS

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Introduction Chronic obstructive pulmonary disease (COPD) is a chronic progressive condition with high symptom-burden, accounting for one death every 20 minutes in England and Wales. Patient-centred care takes into account patient needs and preferences but we lack fundamental research on needs in advanced non-malignant disease and the clinical practice tools required to enable such care.

Aim To describe unmet care and support needs in advanced COPD and identify mechanisms for need-identification to enable patient-centred care.

Method Mixed-method interviews with the population-based Living with Breathlessness study cohort of patients with advanced COPD, their informal carers and key clinicians. Validated patient measures of function, need and service use analysed using descriptive statistics. Purposively sampled multiple-perspective qualitative data on needs and experiences of care analysed using a framework approach.

Results 235 patients recruited: mean age 71.6 years (SD 10.3), 61% male, mean MMRC dyspnoea scale 3.68 (SD 1.04) and CAT 23.4 (SD 7.5). Patients identified symptoms unreported to clinicians and unmet needs for support with practical tasks, personal care, psychological support and information. Patients' ability to spontaneously articulate need was limited. Descriptions of service contacts could be characterised as predominantly reactive: "care" was invisible to some. Service contacts appeared to be driven by organisational and medical agendas rather than patient-centred.

Conclusion(s) Shifting the focus beyond organisational and medical agendas in advanced COPD to more patient-centred approaches requires the proactive identification of need, prompted by clinicians. This could be facilitated by a brief structured holistic tool, grounded in patient data, yet feasible for use in clinical practice.