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WHAT DO INFORMAL CARERS WANT TO LEARN ABOUT BREATHLESSNESS IN ADVANCED DISEASE AND HOW DO THEY WANT TO LEARN IT?

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Introduction Breathlessness is a distressing, disabling symptom of advanced disease with considerable impact on informal carers. We know that carers experience anxiety, isolation, restriction of activity, lack of support and powerlessness. Despite this knowledge the evidence-base for educational interventions to support informal carers and enhance their caregiving capacity is limited.

Aim(s) and method(s) To identify informal carer preferences for learning content and delivery modes of an educational intervention for carers on breathlessness in advanced disease. In-depth interviews with a purposive sample of 24 patient-carer dyads from two disease groups (cancer and COPD) to facilitate exploration of similarities and differences in education needs and preferences for differing disease trajectories. Analysed using a Framework approach.

Results There was a notable degree of overlap in content and delivery-mode preferences among informal carers across the two disease trajectories. Five areas of learning were salient for carers: understanding breathlessness (causes and experience); managing anxiety and panic; helpful and safe levels of activity; maintaining quality of life; and, knowing what to expect in the future. Intervention delivery-mode preferences included face-to-face group learning incorporating clinical-practitioner expertise and a supportive element through sharing experiences, 'work-arounds' and useful tips with peers. Carers generally wanted to learn with their patient so short sessions, not too early in the day, in venues accessible for breathless patients were important practical considerations.

Conclusions An evidence-based educational intervention needs to be broad in scope, incorporating both clinical-practitioner expertise and peer experience. It should also be flexible to accommodate a variety of delivery-mode preferences and personalised content.