

## Publication

### Adult patients' experiences of symptom management during pulmonary exacerbations in cystic fibrosis: A thematic synthesis of qualitative research

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**Objective** The aim of this review was to describe how patients experience an exacerbation of cystic fibrosis in terms of symptom management. **Methods** A systematic literature search was performed in MEDLINE, CINAHL, EMBASE, PSYCINFO and ASSIA. Studies were included that contained any direct quotes or summaries of quotes from patients with cystic fibrosis aged 16 or older and were related to symptom experience and management during an exacerbation. **Framework analysis**, guided by Symptom Management Theory, was used to present the findings. **Results** The review included 18 qualitative studies. In addition to physiological symptoms, patients highlighted the significant role of psychological symptoms. Delayed help-seeking was a common first response. Participants choose their self-management strategies taking both physiological and psychological symptoms into account. Maintaining normality was an important short-term outcome for patients, leading to conflict with health professionals. Patients' symptom management during exacerbation was greatly influenced by the structure of cystic fibrosis care. **Discussion** Our findings provide an initial understanding of factors influencing patient self-management during an exacerbation. The transferal of these findings into clinical practice will provide a basis for shared goal setting and intervention planning. In addition, our findings have implications for future development of patient-reported outcome measures and intervention research.

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