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Cystic Fibrosis Research News

Title:

Limitations to providing adult cystic fibrosis care in Europe: results of a care centre survey

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What was your research question?

The goal of this survey was to identify existing services available to adults living with CF throughout Europe.

Why is this important?

The number of adult people with CF is on a steady rise, with a recent paper projecting a 75% growth over the next decade. There is growing concern that with this influx the adult care centers will not be able to meet the needs of their patients.

What did you do?

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A joint Taskforce was organised by the European Respiratory Society and the European Cystic Fibrosis Society to explore the provision of care for adults with cystic fibrosis throughout Europe. A small working group of clinicians and patient representatives from seven different European countries (both Western and Eastern Europe) designed a survey to distribute to cystic fibrosis centres and clinics, assessing the current level of service. The survey was available on-line or via email.

What did you find?

Three hundred surveys were distributed with a 33% response rate (86 separate replies from Western Europe, 12 separate replies from Eastern Europe). We found that CF training opportunities for clinicians and support staff are limited in Europe. While adult specific CF care has been identified, teams continue to be supported by paediatric colleagues and many adults are still being admitted to paediatric wards for inpatient therapies. Additional concerns were identified through the survey, such as delivery of service, infection control and access to medications. Furthermore, poor personnel resources impacted access to comprehensive multidisciplinary teams, effecting overall care. In some centres, service delivery, particularly infection control and access to some CF medication is insufficient and in many places poor personnel resources limits access to comprehensive multidisciplinary teams.

What does this mean and reasons for caution?

While this survey provides some pertinent information regarding adult CF care in Europe, it is biased to Western Europe due to limited contact details and paucity of adult CF centres in Eastern Europe. Due to the imbalance of responses it is difficult to truly assess the situation, particularly in Eastern Europe. It is surmised from this survey that most centres provide an adult service with an MDT team and home IV therapy, however this may be misrepresented by the west where adult patient numbers are greater.

What's next?

This survey shows an urgent need to develop resources for adult CF care, in both physical space and by appropriately training all clinicians involved in the multi-disciplinary care team.

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http://www.ncbi.nlm.nih.gov/pubmed/?term=Limitations+to+providing+adult+cystic+fibrosis+care+in+Europe%3A+results+of+a+care+centre+survey