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Evaluation of transition services for young people with cystic fibrosis in Southeast London

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Abstract

We report a project being launched to evaluate transition services for young people with Cystic Fibrosis (CF) living in Southeast London, UK, and attending either King's College Hospital (KCH) or University Hospital Lewisham (UHL).

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CF is Britain's most common autosomal recessive genetic disorder; currently over 7,500 people live with the condition. Historically, children with CF did not survive childhood. As with many other chronic illnesses of childhood onset, survival age is increasing in CF such that all children now born with the disease are expected to reach early adulthood, although with increased age come a host of medical complications such as osteoporosis and infertility, and social dilemmas such as disclosing the disease to potential partners and employers. The growing number and increasing age of young people means that paediatricians, the traditional carers for these patients, must hand over to colleagues in adult services who include a wide range of professionals in each patient's care. Key staff working in CF services comprise community and hospital nurses, doctors, social workers, dieticians, respiratory technicians, physiotherapists, psychologists and CF team co-ordinators.

In an attempt to smooth the upheaval for patients moving from paediatric to adult care, multidisciplinary transition services have been developed (Viner, 1999). Transition clinics hold the potential to address the many physical, emotional, family and wider social issues that become pertinent when children reach adolescence, although the best ways to deliver effective and appropriately timed transition services that are tailored to individual need are not clear. KCH team members hold paediatric 'shared care' clinics with ten local hospitals in Southeast London, Kent and East Sussex. In the year of their 16th birthday, young people can choose to attend the adolescent or adult clinic at KCH, and continue with either their local paediatric or adult team according to local policy. At UHL, the adult respiratory consultant meets patients in the paediatric clinic twice before patients move to the adult clinic. Due to smaller patient numbers, no outreach service is provided. At present, little is known about these young people's perceptions, experiences and outcomes.

The research represents the first stage in evaluating these transition clinics. Through interviews and questionnaires with patients, we aim to gain insight into young peoples' experiences of transition services and to identify factors relating to the structure and process of services that are perceived to either promote or inhibit support for patients. The views of key health professionals regarding the effectiveness of current service provision to young people with CF will also be sought through individual interviews with team members.

We also aim to determine the factors (including personal preferences and interpersonal dynamics) associated with outcomes in the provision of health care for young people with CF at transition from paediatric to adult services. We aim to use these findings to produce an information pack for families at both clinics to inform and reconcile differences in their expectations of adult care with the actual service they are provided. Our findings will be widely reported in multiprofessional journals. We are confident that by evaluating local CF transition services, multidisciplinary services for young people with chronic diseases can be improved.

Reference

Viner R. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood*, 81, 271 – 275.