

Chapter 21

Coping and Transition in Young People With Chronic Kidney Disease (CKD) – Maintaining Best Practice: Paediatric Nephrology

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ABSTRACT

Most young people coping with Chronic Kidney Disease (CKD) know that over time this disease can affect their physical health, lifestyle and psychological wellbeing. Transition services and experiences differ; some young people also have better coping strategies than others. This article explores 1) whether there is a need for a transition reorganization to maintain best practice for young people with CKD and 2) what would make more effective coping and transition research for the future. Three coordinated meetings took place inviting young people to contribute their insights on transition and coping questions. 1) Twelve (12) young people from the Renal Patient Support Group (RPSG) online invited (mean age = 15 years), 2) Nine (9) young people attended a Medicines for Children Research Network (MCRN) Young Person's Advisory Group (YPAG) at the Birmingham Children's Hospital, UK (mean age = 14 years) and 3) Nine (9) from the MCRN YPAG meeting at Great Ormond Street Hospital, London UK (mean age = 15 years). Young people's contribution can be summarized: 1) The 'rounded experiences' before, during and after transition of young people with CKD are still required, 2) It is important to see if there is an association between positive coping and smoother transition, 3) Need to appreciate care needs to be better integrated for young people ahead of their transition to achieve best practice and 4) Supporting young people with CKD to build aptitudes is important so they become independent and cope with their health. An overall transition guideline and reorganization that factors in coping strategies should be prompted in future research for teams supporting the care for young people to maintain best practice.

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INTRODUCTION

An estimated total of 861 young people under 18 years with CKD were receiving treatment at paediatric nephrology centres in the UK in 2012. At the census date, 80.2% had a functioning kidney transplant, 10.6% were receiving Renal Replacement Therapies (RRTs) such as Haemodialysis (HD) and 9.2% were receiving Peritoneal Dialysis (PD). Patients aged 16–18 years may receive their medical care either in a paediatric or in an adult nephrology centre. As data was incomplete for the 16 to 18 year old adolescent patients, they have been excluded from the majority of subsequent analyses (particularly when describing incidence and prevalence rates). There were 679 young people under 16 years of age receiving RRT in the UK in 2012.

No young people received a transplant and the majority of patients were being treated with PD (57.1%). This contrasts with older patients in the 12 to 15.99 year age group where 85% had a functioning graft and similar proportions were on HD and PD. Subsequent analysis of RRT modality by gender and ethnicity showed no difference. However, as absolute sub-group numbers are small, caution is needed in conducting any comparative analyses. There were 117 patients under 18 years of age who commenced RRT at paediatric renal centres in 2012. Analyses are restricted to the 108 patients who were under 16 years of age.

AIM

This article seeks to identify 1) is there is a need for a transition reorganization to maintain best practice for young people in CKD and 2) what would make more effective coping and transition research for the future.

CHRONIC KIDNEY DISEASE (CKD)

Chronic Kidney Disease (CKD) is a long-term condition and has been described as the gradual, and usually permanent, loss of kidney function over time (Fogo 2007). Literature has explored different concepts of coping (Muhammad et al. 2012a) and a review has summarized how young people cope with CKD (Muhammad et al. 2012b). Positive coping may also be important potentially allowing a smoother transition. More recent research has informed that coping in young people needs to be better understood (In press, Muhammad et al. 2015). There is also evidence to suggest that rates of acute rejection are higher when young people transition from paediatric renal care to adult renal services (Harden et al. 2012). By implementing an integrated transition clinic, coupled with improving healthcare experiences, can improve young people's adherence to regular medication as judged by reduced transplant failure rates (Harden et al. 2012).

The ability to treat young people with chronic disease, coupled with the inability to offer an absolute cure, causes ongoing complications in young people with CKD (Fowler and Baas 2006; Eiser and Jenney 2007; Eiser et al. 1999). There are good examples of toolkits and frameworks allowing commissioners and providers to evaluate quality criteria or generic standards for health services for young people with a range of health conditions (including the Department of Health, Quality Criteria for Young People

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