

Improving the care of young adults and adolescents with Kidney disease: Results of a patient survey

Dr Behrouz Nezafat Maldonado¹, Dr Sarah McCloskey¹, Dr Shalabh Srivastava^{1,2}, Dr Saeed Ahmed¹

¹South Tyneside And Sunderland NHS Foundation Trust, Sunderland, United Kingdom, ²Newcastle University, Newcastle, United Kingdom

Background

Transition is described as “the purposeful, planned process that addresses the medical, psychosocial and educational needs of young people and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems”¹.

It is recognised that this period can be fraught with difficulties and require additional support. In addition, young adults and adolescents have complex care needs that differ from the older population.

Policy initiatives around transition and young adult’s services have become increasingly common in order to implement, improve and standardise care. The Department of Health guideline “Transition: getting it right for young people”² and Royal College of Paediatrics and Child Health “Facing the Future”³ reports highlight the standard for ongoing health needs of children and young people.

Methods

We carried out a survey of Young People known to Renal Service at our unit that serves a population of 750000 patients. All patients aged 18-25 who had contact with renal services between September 2018-September 2019 were invited to participate. The survey was sent by post with a stamped return envelope and via a text system which provided a weblink. Patients attending clinic were also approached.

Our aims were to explore young adult patients’ experience with the renal service in line with current recommended standards⁴ and understand the barriers for engagement with adult services and potential targets for service improvement.

Results

108 patients were identified as having ongoing follow up with Renal services in the 12 month period. 18 patients returned the survey. The average age was 22 years and 8/18 were in full-time employment. 44% (13/18) of participants left school at age 16 or younger.

16/18 of the patients attended general nephrology clinic, 1 attended haemodialysis clinic and 1 was a patient of the low clearance clinic (patients with persistent eGFR <20 or pre-dialysis). On average, the cohort attended 3 appointments in 12 months (range 0-10). 6 patients had transitioned from children services to adult services.

The clinic environment scored 4/5 on average. Communication between adult team, the patient and their family was rated 4/5. All participants were aware of the department’s confidentiality policy.

Providing age appropriate information, access to text service reminders for appointments and having a written health care plan together with access to mental health support workers, were the highest rated interventions to improve patient experience.

2 patients suggested a dedicated 18-25 years clinic as an intervention that would improve their experience.

Conclusion

There is a need for further improvement in the care that young adults receive, especially those with a recent diagnosis or patients that have transitioned. Patient involvement in service development is pivotal in assuring it is fit for purpose.

A dedicated clinic for 18-25 years old patients together with a written care plan and age specific leaflets about their diseases may be the best interventions to meet the needs of this group. Work is under way to develop a transition process that incorporates these features into patient care and ensures active engagement of Paediatric and Adult Renal teams.