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Original article

## Impact of End-Stage Kidney Disease on Academic Achievement and Employment in Young Adults: A Mixed Methods Study

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## A B S T R A C T

**Purpose:** Young adult kidney patients are at an important stage of development when end-stage kidney disease (ESKD) may adversely influence progress in education and employment. This study is designed to assess the impact of ESKD on education and employment outcomes in young adults.

**Method:** This cross-sectional study was a mixed methods design. Education and career achievements in young adults with ESKD were recorded quantitatively using a questionnaire survey (n = 57): 14 of 57 representative participants were subsequently selected for semistructured interview.

**Results:** Questionnaire survey was conducted in 57 young adults (median age 25): 8.8% (n = 5) were predialysis; 14.0% (n = 8) dialysis; and 78.9% (n = 45) were kidney transplant recipients. Median school-leaving age was 16 (interquartile range = 15–19). Of 57 young adults, 10 (17.5%) were still studying, 43 (75.4%) had completed education, 34 (59.7%) were employed (23 full time and 11 part time), and 19 (33.3%) were unemployed. Twenty-seven of 45 transplanted patients were employed (60.0%). Of these 27, 21 were full time (77.8%). Five of eight dialysis patients were employed: only one of eight was full-time employed (12.5%). Themes impacting on education and employment included low energy levels, time missed, loss of self-esteem, and feelings of loneliness and isolation, which may progress to depression and recreational drug use. Lack of understanding from educators and employers resulting in lost work, and career ambitions changed or limited because of dialysis.

**Conclusions:** Dialysis has a major negative impact on education and reduced employment rates of young adults. There is a general lack of understanding among educators and employers of the impact of ESKD. Low energy levels, lack of self-esteem, and depression are key factors. There is a need for health care providers to recognize this issue and invest in supporting young adults with ESKD.

**IMPLICATIONS AND CONTRIBUTION**

End-stage kidney disease and dialysis has a negative impact on education and employment for young adults. Integrated dialog with educators and employers and psychosocial and targeted peer support can be valuable tools to help young adults come to terms and cope with the negative psychological aspects of end-stage kidney disease.

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End-stage kidney disease (ESKD) indicates loss of independent renal function such that the affected individual needs to be supported by either dialysis or kidney transplantation. ESKD is a

significant problem in young adult patients (aged 18–30 years) with a current United Kingdom (UK) prevalence rate of 2% of the ESKD population. While many patients transition from pediatric to adult care, 50% of the young adult patient population will present for the first time to an adult kidney unit [1]. In adult renal services, there is little differential in management according to patients' age, resulting in the isolation of many young adults

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among a large group of older patients (median age 65 years) [2]. Young adult patients with ESKD are at a critical stage in education and/or employment pathways. Unfortunately, in many cases, their progression may be slowed or halted because of the impact of their ESKD.

While adhering to dialysis or immunosuppressive therapy, young adult patients must cope with changing life roles, developing education and employment opportunities, and the physical and mental development associated with adolescence [3]. Self-management is of key importance in the treatment of chronic illnesses [4]. The young adult is at a critical point in the evolution of self-management skills required by ESKD patients.

Literature related to education in young adults with ESKD is limited; children with chronic kidney disease are at continued risk of neurocognitive impairment and lower intelligence quotient scores [5,6], resulting in grade retention, school absenteeism, and learning disabilities [7].

Patients with ESKD aged between 18 and 30 years achieve less developmental milestones compared with young adults growing up with other chronic illnesses. Only 60.5% have a first paid job at the age of 18 years (or younger) compared with 79.9%–93.4% in other illnesses or 87.4% in healthy peers [8].

Little is known about what determines low employment rates in young adults with ESKD; evidence on the impact of ESKD on young adult educational achievements and employment is scarce. The aim of the study was to address the following research questions: first, what is the spread of education and career achievement in young adults with ESKD aged 16–30 years in a UK population? Second, is there a difference between aspired and attained educational, vocational and career progression? If so, what is the scale of this difference? Additionally, what are the perceived barriers and facilitators of successful progression in education and employment? Finally, what initiatives and support programs do young adults with ESKD feel should be considered as a means of supporting them in their educational and vocational achievements?

## Methods

This mixed methods cross-sectional study combined quantitative and qualitative research methodology. Patients were eligible if aged 18–30 years, in the predialysis phase, on dialysis or transplanted, and were willing to provide informed consent, having demonstrated sufficient cognitive and linguistic capacity to do so and participate. All participants received a patient information sheet to read in advance of consenting and signing a specific study consent form. Ethical approval was obtained through dual application to the UK national clinical research ethics system and a nominated ethics committee.

A transplant physician (P.H.) screened patients for eligibility. When written consent had been obtained, patients completed the questionnaires during clinic visits. Subsequently, selected participants were approached for interview. Interviews were conducted during clinic or home visits.

The quantitative part aimed to gather demographics of our patient population and understand the spread of educational and vocational achievements. A set of 5-point Likert scales, ranging from “I strongly disagree” to “I strongly agree,” were developed to evaluate statements referring to satisfaction with education level or job content and the impact of ESKD and therapy on education and employment. Subsequently, we reduced the Likert scales to 3-points ranging from “I agree” to “I disagree”, having

combined these categories with their “strongly” counterparts. The Likert scales were reduced from 5 to 3 points because of the relatively small sample size that clarified the range of opinion between agreement and disagreement of each statement. Responses were summarized using percentages or median values.

After completion of the quantitative stage, a subset of survey participants were selected for a semistructured interview, to gain an in-depth understanding of their educational and vocational experiences [9,10]. Stratified sampling was performed according to predetermined criteria of age, gender, ethnicity, and treatment modality [11], to provide a representative sample of the young adult UK ESKD population. Patients were subdivided according to initial pediatric or adult presentation of care.

We followed a predetermined and piloted interview framework; the interviews were audio recorded and transcribed verbatim. Content analysis was systematically performed, following sequential flow to delineate patterns in perceptions by compressing text into content categories based on explicit rules of coding [11]. We did not use any coding software or programs. Themes were counted in terms of their mention “in general”, in terms of “education effect” and “employment effect,” and as having either a positive or negative effect.

Each theme mentioned could only be counted once per interview to prevent over emphasis of individual themes. Tables of theme occurrences per interview were subdivided between participants presenting before and during adulthood to explore whether separate issues existed for these different groups. To assure reliability, all interviews were coded by a second researcher independently and read by three researchers to rule out interpretation bias.

## Results

### Participant demographics

Sixty-four young adult patients, of 112 potential participants from the clinic, with advanced kidney failure or ESKD completed the survey (57.1%). Those who declined their involvement, cited reasons of either time unavailability, general lack of interest, or unwillingness to commit to the prospect of a face-to-face interview involving discussions of personal issues. Seven patients, aged >30 years were excluded. Reflecting the local and UK demography of young adult ESKD patients, 80.7% of those surveyed were male, 87.7% (n = 50) were white, 3.5% (n = 2) black African, 3.5% (n = 2) Pakistani, 1.8% (n = 1) Chinese, and 3.5% (n = 2) of mixed race. Of them, 47.4% had initially presented to pediatric renal services, transferring to adult care; 52.6% presented directly initially to adult care. Kidney disease was detected between the age of 0–5 (40.4%), 6–10 (3.5%), 11–19 (45.6%), and 20–29 years (10.5%). The etiology of ESKD was congenital (35.1%), glomerulonephritis (22.8%), unknown (22.8%), obstruction (14.0%), and diabetes mellitus (5.3%). The median age of our population was 25; 40.3% still lived with parents, 36.8% cohabiting, and 15.7% were living alone. Of our sample, 38.6% developed ESKD and underwent renal replacement therapy during the first decade, 45.6% during adolescence (aged 11–19 years). Of our sample, 8.9% were predialysis with a mean estimated glomerular filtration rate (Modification of Diet in Renal Disease Study Equation) of 26 mL/minute, 12.3% on hemodialysis (HD), and 1.8% receiving peritoneal dialysis (PD); 78.9% were kidney transplant recipients.

Of our sample, 71.4% interviewees were male; median age 23.5 years; 71.4% transplanted, 28.6% HD. Of those transplanted,

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