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P182-What sources of information do patients report being most important in decision making? Results from a multicentre questionnaire-based study

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Introduction

People with advanced kidney disease have a number of different renal replacement treatment options to consider. People acquire information from a variety of different sources, including from discussions with healthcare professionals, 'patient information leaflets', and online information presented on the websites of national kidney organisations and patient charities. Many NHS and charitable organisations have put significant effort into the production of written and multimedia patient information resources, but it is unclear if patients find these helpful. This study aimed to identify which sources of information on renal replacement therapies patients find most helpful.

Methods

This study was undertaken at 14 renal units in the UK. A previously developed and validated questionnaire was posted to adults who received a kidney transplant at the study sites between 1/4/13 and 31/3/17. Reminders were sent to non-responders after 4-6 weeks. Participants could complete a paper or online version. In addition to demographic data, the questionnaire collected data on which sources of information on renal replacement therapy participants had found most important. Participants were asked to select all deemed important from a list of 10 different sources. Basic descriptive statistical tests (chi², linear regression tests for linear trend) were performed to look for differences in preference across different patient groups.

Results

1239 questionnaires were returned from 3172 patients (39% response). 93.8% of respondents reported that 'a discussion with a health care professional' was an important source of information on their treatment options. The importance of this source varied with age, with older recipients reporting it as less valuable than younger people (p value for trend < 0.001). 63.6% found 'written information provided by a hospital' helpful, but this varied with socioeconomic position: more socioeconomically deprived participants found it less useful than people who were less deprived (p value for trend with IMD quintile 0.003). 46.6% found 'a discussion with a friend or family member' was useful in making treatment decisions, but again this varied with age: 66.2% of 20-29 year olds found this important compared to 34.0% of 70-79 year olds, p value for trend 0.03. Only 33.4% of people found 'health related or other websites' useful. Younger people were more likely to report that websites were a useful source when compared to older respondents (p value for trend < 0.001) but even amongst the youngest group (20-29 year olds) only 43.2% reported finding them helpful.

Discussion

Amongst kidney transplant recipients, face-to-face discussions with healthcare professionals are the most important source of information to patients, not matched by other resources (written, online). Only a minority of participants reported that online resources were important sources of information, despite this being where a lot of attention is focused and where multimedia resources are made available. There was evidence of variation in source preference with age and socioeconomic position, highlighting the need for tailored personalised education and transplant preparation. A renewed focus on healthcare communication rather than reliance on other resources is suggested.