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P203 -Participant experiences and satisfaction from the CAVIAR study

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PARTICIPANT EXPERIENCES AND SATISFACTION FROM THE CAVIAR STUDY

Introduction

Surveys and questionnaires related to patient experience and satisfaction are seen as valuable source of information to assess and improve the quality of health care provided. With regards to health research, patient reported experience measures will give an insight into the process of how the study was delivered and what impact it had for participants. Unfortunately patient reported experience questionnaires are not routinely used in clinical trials involving kidney transplant population. This is important to guide future clinical trials, ensure that clinical research is patient-centred and to understand the interests of different stakeholders involved in research.

Methods

The aim of CAVIAR study was to compare whether a more pro-active versus passive interventional approach to modify lifestyle is associated with superior outcomes post kidney transplant. A total of 130 individuals were recruited and randomised of whom 103 completed the study. Active follow-up period for all patients lasted 6 months. In the end of the study participation a patient feedback form was sent to 119 patients. Feedback form was anonymous and sent via post together with stamped addressed envelope for easy return. Return destination was different to research team location to minimise the response bias. Feedback form consisted of seven sections: 1.) background, 2.) study visits, 3.) research staff, 4.) completing the study, 5.) top three reasons for participating in the study, 6.) things that didn't like about the study and 7.) free text comment section. Background section included information of gender, age, ethnicity and type of kidney transplant patient received. Likert scale was used in sections 2, 3 and 4 respectively. Statements in Likert scale were presented as positive statements. Results from Likert scale were analysed by measuring the most frequent responses. Sections 5 and 6 had optional pre-selected answers with free text comment area. Free text comments were analysed by identifying positive and negative themes emerging from the feedback.

Results

From 119 feedback forms 58 were returned (return rate 48.7%). A snapshot of responses provided is shown in the accompanying Table 1.

Most frequent positive themes emerging from free text comments were overall satisfaction with study delivery and support received during the study intervention. Surprisingly the main negative theme was related to the employment and the impact participation in the study had to the employment.

Conclusion

Patient reported experience measures after participation in clinical research is a valuable tool to gain deeper understanding of the process of study delivery and how it affects the everyday life for participants. In a clinical trial setting, the results from such feedback can be used to tailor clinical trials to be patient-centred with the aim to improve both participant recruitment and retention.