THE PSYCHOLOGICAL IMPLICATIONS AND HEALTH RISKS OF CYSTIC FIBROSIS PRE AND POST CFTR MODULATOR THERAPY

Rebecca Keyte¹, Helen Egan¹, Michail Mantzios¹

1. Dept. of Psychology, School of Social Sciences, Birmingham City University, Birmingham, UK

Objectives: Cystic Fibrosis (CF) is entering a period of personalised medicine, with modulator therapies promising to revolutionise care. Whilst individuals are reporting anecdotally the life changing effects of modulator drugs, the associated psychological implications is an under-researched area, resulting in a limited understanding on what life is like today for individuals with CF. In order to meet the needs of the growing CF population, qualitative research to underpin psychological interventions to support wellbeing is vital.

Method: Thirteen adult participants prescribed Kaftrio have been recruited (5 male, age range 23-40 years) from the UK (11 participants), USA (1 participant) and Germany (1 participant), with a median FEV₁ 63% predicted. Recruitment is still open; in total twenty participants will be recruited. Qualitative semi-structured interviews provide an interpretive perspective regarding the impact of modulator therapies.

Results: Preliminary findings highlight the optimism the CF community hold regarding modulator therapies, with participants reporting Kaftrio has exceeded expectations, transforming their identity. Participants' illness identity, which has restricted their ability to live a "normal life", has been (somewhat) lifted, with participants discussing career ambitions, travel desires, and family planning which pre-Kaftrio felt unrealistic.

Conclusion: An appreciation of a "normal life" post-modulator therapy is paramount, with participants reporting adherence and non-engagement with health risk behaviours despite not experiencing CF complications. There was the consensus that future CF generations who grow up with modulator therapies will not appreciate the revolutionary impact of these therapies, and are therefore vulnerable to non-adherence and health risk behaviours. These findings will inform interventions enabling clinicians to offer more effective support in encouraging positive health and lifestyle choices in this new era of CF care.