Impact of newborn screening on outcomes and social inequalities in cystic fibrosis: A UK Registry based study

Daniela K Schlüter, Carol Dryden, Kevin W Southern, Peter J Diggle, David Taylor-Robinson
Centre for Health Informatics, Computing and Statistics (CHICAS), Lancaster Medical School, Lancaster University, Lancaster, United Kingdom, LA1 4YW

Department of Paediatrics, University Hospital Wishaw, Netherton Street, Wishaw, Lanarkshire, ML2 0DP

Department of Women's and Children's Health, University of Liverpool, Liverpool

Department of Public Health and Policy, University of Liverpool

Objectives

Previously we have demonstrated that infants with CF from socio-economically disadvantaged areas in the UK have worse early outcomes than those from more affluent areas. In the present study, we used data from the UK CF Registry to examine the impact of newborn bloodspot screening (NBS) on clinical outcomes and health inequalities in children with CF born in the new millennium.

Methods

We obtained data on 4117 individuals with CF born between 2000 and 2014 who are captured in the UK CF Registry. Clinical outcomes were the trajectories of percent predicted FEV_1 ($ppFEV_1$) from age five, weight and body mass index (BMI) z-scores from age one, and time to chronic Pseudomonas Aeruginosa (PA) infection. We developed longitudinal models for $ppFEV_1$, weight, and BMI and a time-to-event model for PA infection to assess the association of NBS with outcomes and potential interactions with childhood socio-economic conditions (SECs), measured by the index of multiple deprivation, whilst adjusting for sex, number of F508del copies, birth cohort, ethnicity, and pancreatic insufficiency.

Results

Complete data for the analysis of the effect on lung function, weight, BMI and time to chronic PA infection were available for 2267, 3424, 3410 and 3428 individuals, respectively. About one third of the individuals were diagnosed by NBS. NBS was associated with a shallower rate of lung function decline (0.45; 95%CI 0.13 to 0.76 per year), and higher average weight trajectory intercept (0.14; 95%CI 0.06 to 0.23 standard deviations). We found no significant association of NBS with the intercept for lung function or BMI; or with longitudinal trajectories of weight and BMI. There was no significant interaction between NBS and childhood SECs. Evaluation of the PA outcome is ongoing.

Conclusions

Analysis of data from a large national CF Registry shows that NBS is associated with better lung function and increased weight for all children with CF, but it has not narrowed health inequalities.