12.04 The changing challenges to the parents of growing children with Cystic Fibrosis in Ireland:
The Irish Comparative Outcome Study of Cystic Fibrosis (ICOS)

Rini Bhatnagar¹, Nancy Bhardwaj⁴, Barry Linnane², Mary Herzig³, Muireann Ni Chroinin⁴, David Mullane⁴, Desmond Cox⁵, Paul McNally⁵, Sheila Javadpour⁵, Basil Elnazir⁶, Peter Greally⁶, Fiona Healy⁷, Michael Williamson⁷, Dubhfeasa Slattery⁷, Laura Kirwan⁸, Gillian Lancaster⁹, Claire Glasscoe⁹, Ricardo Segurado¹, Kevin W Southern⁹, Patricia Fitzpatrick¹

¹University College Dublin, School of Public Health, Physiotherapy and Sports Science, Dublin, Ireland, ²University Hospital Limerick, Limerick, Ireland, ³University Hospital Galway, Galway, Ireland, ⁴Cork University Hospital, Cork, Ireland, ⁵Children’s Health Ireland at Crumlin, Dublin, Ireland, ⁶Children’s Health Ireland at Tallaght, Dublin, Ireland, ⁷Children’s Health Ireland at Temple Street, Dublin, Ireland, ⁸Cystic Fibrosis Registry of Ireland, Dublin, Ireland, ⁹University of Liverpool, Department of Women's and Children’s Health, Liverpool, United Kingdom

Corresponding Author:
Rini Bhatnagar: https://orcid.org/0000-0002-2653-783X
Email: rini.bhatnagar@ucdconnect.ie

Background: Children with Cystic Fibrosis (CWCF) require continuous care and treatments that are labour-intensive and time-consuming for parents. This study aims to evaluate caregiver burden of parents of CWCF recruited to ICOS study, a census-based historical cohort study of CF.

Methods: This is the first population-based study to use the newly validated Challenge of Living with CF-Short Form (CLCF-SF) generated from a larger psychometric tool "CLCF", selecting 15 items whilst not losing validity as a measure of caregiver burden. This study involves parents of CWCF born July 2008-June 2023. Comparisons were based on child’s age (<60 months/“younger group” (mean=44 months) vs ≥60 months/“older group” (mean=129 months)) at time of questionnaire completion.

Results: 173 parents participated. Among all parents, marginal to great difficulty was reported managing CF demands (28%) and family handling challenges (43%); 77% had difficulty establishing CF care routine, issues managing oral medication (27%), nebulisers (47%) and physiotherapy (42%). Significantly more parents of older children struggled with extra expenses (54.1% vs 35.3%; p=0.024) reported that their children were easily upset (54.9% vs 37.3%; p=0.034) and moody (50% vs 25.5%; p=0.003). Among all parents, significantly more whose children were on CFTR modulator therapy reported their child’s moodiness than those who were not (50.6% vs 33.7%; p = 0.025).

Conclusion: Our findings suggest greater caregiver burden in parents of older CWCF and a need for more support in establishing CF care routine.

Keywords: Cystic Fibrosis, CLCF-SF, caregiver

Funding: This study is funded by Health Research Board (ILP HSR 2019-005)

Conflict of interest: Authors declare no conflict of interest