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 Bhatnagar[1], Nancy Bhardwaj[1], Barry Linnane[2], Mary Herzig[3], Muireann Ni Chroinin[4], David Mullane[4], Desmond Cox[5], Paul McNally[5], Sheila Javadpour[5], Basil Elnazir[6], Peter Greally[6], Fiona Healy[7], Michael Williamson[7], Dubhfeasa Slattery[7], Laura Kirwan[8], Gillian Lancaster[9], Claire Glasscoe[9], Ricardo Segurado[1], Kevin W Southern[9], Patricia Fitzpatrick[1]

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