Poster 117

CAREGIVER BURDEN DUE TO PULMONARY EXACERBATIONS (PEx) IN CYSTIC FIBROSIS (CF): A SURVEY OF CAREGIVERS OF PAEDIATRIC PATIENTS WITH CF IN THE UK, IRELAND, AND GERMANY

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INTRODUCTION

- The impact of disease on caregivers of children with CF is not well understood
- This impact on caregivers may change when children with CF are hospitalized to treat pulmonary exacerbations (PEx)
 - PEx are acute worsenings of symptoms that happen to people with CF and may result in hospitalization
- This study is the first to quantify the impact on caregiver productivity, mental health, physical health, and social/family functioning during PEx-related hospitalization and after the child's recovery from PEx

OBJECTIVES

This study aims to:

- Describe the impact of caring for children with CF on caregivers, and
- Describe the impact when children are hospitalized for PEx and need intravenous (IV) antibiotics

CONCLUSIONS

- Caregivers of children with CF experience higher impact on their mental health, work productivity, and social/emotional wellbeing when their children are hospitalized for pulmonary exacerbations compared with when they have recovered from pulmonary exacerbations
- Reducing pulmonary exacerbations in children may reduce the impact on mental health, work productivity, and social/emotional wellbeing experienced by caregivers while caring for their children with CF

METHODOLOGY

TWO TIMEPOINTS (T1/T2)

NUMBER OF CAREGIVERS (N) AND COUNTRIES

CAREGIVER SURVEY

INCLUSION/EXCLUSION CRITERIA







Caregivers Children



• P values are used to determine the statistical significance of study results. In this study P values of <0.05 were considered significant and are marked by an asterisk (*) in this poster • For additional details on the methodology, refer to the expanded methodology section at the bottom of this poster

RESULTS



• Percent predicted forced expiratory volume in 1 second (ppFEV₁) measures the amount of air blown out in 1 second into a spirometer, as a percentage of the average amount blown out by someone with similar age, sex, and body type

VALIDATED INSTRUMENTS



HOURS OF CARE IN LAST 2 WEEKS



T1: During child's hospitalization for PEx T2: After child's recovery from PEx

* statistically significant difference between T1 and T2



of caregivers experienced 82vs 58% impact on spending quality time with partners

of caregivers experienced 73vs46% impact on participating in social activities*





of caregivers felt afraid of losing their job because of their child's CF

57%

of caregivers

child's CF

altered their job

or career choice

because of their



Unpaid Assistance from Friends and Neighbours



T1: 8.1 hours | T2: 0.6 hours



* statistically significant difference between T1 and T2

 Caregivers reported higher impact on social and emotional life when their children are hospitalized for pulmonary exacerbations compared with when they have recovered from pulmonary exacerbations. This includes spending quality time with partners, planning outings, and taking care of their health and other children/family members

91% of caregivers changed from working full time to part time, reduced hours, or stopped working because of their child's CF

Impact on caregiver career categories are not mutually exclusive. Impact on caregiver career results are not from a validated questionnaire and were collected only at T1.

• Caregivers reported that their child's CF had a high impact on their career over time. This includes many caregivers who changed from full-time to part-time or stopped working because of their child's CF



Housekeeper or Childcarer





Paid Assistance from Clinical Caregiver T1: 0.1 hours | T2: 0.2 hours

LIMITATIONS

- The range of recall periods may affect the validity of the results due to recall bias
- Generalization to larger population of CF caregivers may be limited
- The results of the study should be interpreted with caution due to small sample size

AUTHOR DISCLOSURES

TT is an employee of Vertex Pharmaceuticals Incorporated and may own stock or stock options in that company. ES is a former employee of Vertex Pharmaceuticals Incorporated and may own stock in that company. **JGM** has received compensation for lectures, advisory boards, and an investigator-initiated study grant from Vertex Pharmaceuticals Incorporated, all outside of the submitted work. DWC and MD have no conflicts of interest to disclose. **MF** is a consultant to Vertex Pharmaceuticals Incorporated.

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EXPANDED METHODLOGY

Study Design

• A prospective, observational study of primary caregivers of children (2-17 years) with CF in Europe being treated at Birmingham Children's Hospital, Birmingham, UK, Jena University Hospital, Jena, Germany, and Our Lady's Children's Hospital, Dublin, Ireland Data were collected through a self-reported survey completed at 2 time points - T1: during acute intravenous antibiotics treatment associated with the child's pulmonary exacerbation-related hospitalization - T2: after the caregiver reported the child in a well-health state following intravenous antibiotics completion (\geq 4 weeks from T1)

Study Population

• Primary caregivers were self-identified and recruited during T1 The primary caregiver was the individual principally responsible for assisting the child with CF with their daily activities and treatment management

• The following were excluded from the study:

- Caregivers of children currently on cystic fibrosis transmembrane conductance regulator modulator (CFTR) therapy
- Caregivers of children experiencing their first ever pulmonary exacerbationrelated hospitalization

Measures

- 2 validated instruments were used to assess the impact experienced by caregivers
- 12-item Short Form Survey (SF-12), General Health Status - Work Productivity and Activity Impairment: Specific Health Problem (WPAI:SHP)

 Additional questions, complementary to the 2 validated instruments, were used to assess the impact on the caregiver's career (only collected at T1), and family, social, and emotional impact

and 1 spouse of a CF patient was consulted to develop the additional questions **Statistical Methods** • Data were summarized using means and standard deviations (SD) for continuous

- A 9-member panel consisting of 5 caregivers of CF children, 3 adult CF patients,

- variables and frequency and percentage for categorical variables
- Validated instruments were scored according to developer guidelines
- Paired t test was used on values for continuous variables, and McNemar's test was used for comparing binary variables between time points (T1 and T2)
 - Only paired responses between T1 and T2 were used to make comparisons between the 2 time points

• All statistical tests were 2-sided; *P* values were not adjusted for multiple testing and results were considered statistically significant at P < 0.05



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