

## Abstract Preview - Step 3/4

- print version -

---

Topic: 11. Nursing / Psychosocial Issues

**Title: My quality of life or yours? The discrepancies between parent and child reported quality of life scores**

Author(s): [H. Douglas](#)<sup>1,2</sup>, M. Bryon<sup>2</sup>, S. Ledger<sup>1</sup>, E. Main<sup>1</sup>

Institute(s): <sup>1</sup>University College London, Great Ormond Street Institute of Child Health, London, United Kingdom, <sup>2</sup>Great Ormond Street Hospital for Children NHS Trust, London, United Kingdom

**Text: Objectives:** Understanding how an individual perceives their health-related quality of life (HRQoL) is vital in both clinical care and health-related research. A parent or carer (P/C) of a child or young person (CYP) with CF often acts as advocate. It is important to measure perceptions in both the P/C and CYP. This study compared CFQ-R scores reported by CYP with those of their P/C.

**Methods:** The CFQ-R was completed by 71 children (6-17yrs) and their P/Cs at baseline, 12 and 24-months as part of the INSPIRE-CF trial. Scores from CYP and P/C in CFQ-R domains common to all versions were compared (Physical, Emotional, Eating, Body image, Treatment burden, Respiratory and Digestion).

**Results:** 205/213 data sets were analysed (4 CYP withdrew before 2<sup>nd</sup> test). Magnitude and direction of differences between P/C and CYP CFQ-R scores in each domain were consistent at each time point, so were analysed together.

Scores from CYP and P/C were within 5 points of each other in different domains between 15-41% of the time, with agreement being least likely for Treatment Burden and Emotion. Average differences were high in Treatment burden (P/C:59, CYP:71 (mean difference±SD) 12±24.5), Emotion (P/C:82, CYP:75, -6.4 ±17.6), Eating (P/C:83, CYP:88, 5.2±20.2) and Body image (P/C:77, CYP:86, 10±23) domains, with P/C's scoring more than CYP for Emotion only. Paired scores differed by >25 points between 20-24% of the time. Differences for Physical (P/C:89, CYP:86, -3.2 ±14), Respiratory (P/C:83, CYP:81, -1.8±13.7) and Digestion (P/C:87, CYP:87, 0.5±22) domains were small, with paired scores differing by >25 points 9%, 9% and 19% respectively .

**Conclusion:** HRQoL perceptions from P/C's and CYP were discrepant overall but more likely to be similar for domains relating to symptoms and physical fitness. Larger and more frequent differences occurred in psychological domains such as body image and emotion. The significant disparity must be taken into consideration when assessing CFQ-R scores.

**Preferred Presentation Type:** No Preference

---

Conference: 40th European Cystic Fibrosis Conference · Abstract: A-850-0011-00435 · Status: Submitted

[Print](#)

[Back](#)