Cost of Poverty and Deprivation on Health Outcomes of Children with Cystic Fibrosis: Is it Time to Re-think Medical Based Tariffs for Cystic Fibrosis Care?

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Objectives: Cystic fibrosis [CF] tariffs in the UK are dictated by the annual banding of patients based on a nationally agreed medical criteria. This process takes no account of the known adverse impact of poverty and deprivation on long term health trajectories in CF. We aimed to assess whether the medical based tariff allocated to CF children in our clinic reflected the level of additional support mandated using a validated safeguarding risk assessment [SRA].

Methods: We analysed our CF population [n=37] in 2018 from health records using the SRA tool incorporating risks in children and young people; parents and carers; and family and environment. There were 4 levels allocated with low risk 1 to high risk 4 each showing the extra support needed. We used level 2 and above as a marker of deprivation and compared this their medical banding [1,1a,2, 2a,3,4,5] and recorded the main themes of SRA concerns and extra support needed by the CF team given above the normal care.

Results: 53.1% [n=19] of our population had a SRA level 2 and above with 9 level 2; 7 level3 and 3 level 4. Significant SRA concerns were in the child or young person in 38%; parent and carer 57%; and family and environment 4.7 %. The main themes were poverty; substance misuse; mental health issues; chronic illness in carers; smoking; chronic neglect e.g. poor clinic attendance and concordance with treatment; unemployment and poor housing. Contact time with CF nurse was significantly increased with SRA level 2 and above.

Conclusion Poverty and deprivation mandate extra resource to support children with CF. This is not presently reflected in the medically based CF tariff and so incorporation of SRA into the process of tariff allocation seems a useful way to target resources to those with most need.