

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in Younger Children: A Qualitative Analysis of Families' Experiences of the Condition and Perspective on Treatment

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Abstract : Background: Paediatric chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME) is characterised by persistent, disabling fatigue. Health services see patients below the age of 12. This age group experience high levels of disability, with low levels of school attendance, high levels of fatigue, anxiety, functional disability and pain. CFS/ME interventions have been developed for adolescents, but the developmental needs of younger children suggest treatment should be tailored to this age group. Little is known about how intervention should be delivered to this age group, and further work is needed to explore this. Qualitative research aids patient-centered design of health intervention. Methods: Five to 11-year-olds and their parents were recruited from a specialist CFS/ME service. Semi-structured interviews explored the families' experience of the condition and perspectives on treatment. Interactive and arts-based methods were used. Interviews were audio-recorded, transcribed and analysed thematically. Qualitative Results: 14 parents and 7 children were interviewed. Early analysis of the interviews revealed the importance of the social-ecological setting of the child, which led to themes being developed in the context of Systems Theory. Theme one relates to the level of the child, theme two the family system, theme three the organisational and societal systems, and theme four cuts-across all levels. Theme1: The child's capacity to describe, understand and manage their condition. Younger children struggled to describe their internal experiences, such as physical symptoms. Parents felt younger children did not understand some concepts of CFS/ME and did not have the capabilities to monitor and self-regulate their behaviour, as required by treatment. A spectrum of abilities was described; older children (10-11-year-olds) were more involved in clinical sessions and had more responsibility for self-management. Theme2: Parents' responsibility for managing their child's condition. Parents took responsibility for regulating their child's behaviour in accordance with the treatment programme. They structured their child's environment, gave direct instructions to their child, and communicated the needs of their child to others involved in care. Parents wanted their child to experience a 'normal' childhood and took steps to shield their child from medicalization, including diagnostic labels and clinical discussions. Theme3: Parental isolation and the role of organisational and societal systems. Parents felt unsupported in their role of managing the condition and felt negative responses from primary care health services and schools were underpinned by a lack of awareness and knowledge about CFS/ME in younger children. This sometimes led to a protracted time to diagnosis. Parents felt that schools have the potential important role in managing the child's condition. Theme4: Complexity and uncertainty. Many parents valued specialist treatment (which included activity management, physiotherapy, sleep management, dietary advice, medical management and psychological support), but felt it needed to account for the complexity of the condition in younger children. Some parents expressed uncertainty about the diagnosis and the treatment programme. Conclusions: Interventions for younger children need to consider the 'systems' (family, organisational and societal) involved in the child's care. Future research will include interviews with clinicians and schools supporting younger children with CFS/ME.

Keywords : chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME), pediatric, qualitative, treatment

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