

Cystic Fibrosis

GLACLP Annotated Bibliography by Sara Hall

Title: Health-related quality-of-life in children with cystic fibrosis aged 5-years and associations with health outcomes

Review: *The authors collected data from five-year-old patients enrolled in the Australasian Cystic Fibrosis Bronchoalveolar Lavage (ACFBAL) trial and their caregivers. They compared the child-reported and parent-proxy quality-of-life information, investigated health outcomes for children in the trial versus those receiving standard therapy and identified the need for the development of a preschool version of the current cystic fibrosis questionnaire.*

Year of Publication: 2020

DOI: 10.1016/j.jcf.2020.02.022

Age Group: Preschool

Keywords: cystic fibrosis, preschool, children, health-related quality of life, pulmonary, exacerbations, lung function

APA Citation: Cheney, J., Douglas, T.A., Gailer, N., Vidmar, S. & Wainwright, C. (2020). Health-related quality-of-life in children with cystic fibrosis aged 5-years and associations with health outcomes. *Journal of Cystic Fibrosis*, 19, 483-491.

<https://doi.org/10.1016/j.jcf.2020.02.022>

Title: An investigation on parenting stress of children with cystic fibrosis

Review: *This study used a Parenting Stress Index – Short Form questionnaire to gather information from children and adolescents living with cystic fibrosis and their parents. Taking a biopsychosocial approach, the authors aimed to investigate the degree of stress experienced by parents and the potential impact it has on family dynamics. They affirmed the value of providing psychological support to caregivers and their results indicated the need for further parent-child integrated interventions.*

Year of Publication: 2020

DOI: 10.1186/s13052-020-0795-7

Age Group: Toddler; Preschool; School Age; Adolescent

Keywords: parenting stress index, cystic fibrosis, child, clinical management, biopsychosocial model

APA Citation: Civitella, M.T., Continisio, G.I., Esposito, M.R., Gargiulo, G., Guillari, A., Raia, V., Rea, T., Sepe, A., Serra, N., Simeone, S. & Toscano, S. (2020). An investigation on parenting stress of children with cystic fibrosis. *Italian Journal of Pediatrics*, 46(33).

<https://doi.org/10.1186/s13052-020-0795-7>

Title: Thriving alongside cystic fibrosis: Developing a grounded theory of empowerment in children and young people with cystic fibrosis during key life transitions

Review: *Patient empowerment in children and young people living with cystic fibrosis is examined using a Grounded Theory method to interview and analyze data from patients, parents and professionals. The authors emphasized the complexity of and challenges with empowerment for this population; especially barriers to peer support due to the risks associated with cross-infection. The study resulted in theory development, provided implications for future research and highlighted effective empowerment strategies.*

Year of Publication: 2021

DOI: 10.1111/cch.12860

Age Group: Adolescent

Keywords: adolescents, children, cystic fibrosis, empowerment

APA Citation: Collado, M.D., Fairweather, N.H., Harris, S.A., Jones, F.W. & Shayle, A. (2021). Thriving alongside cystic fibrosis: Developing a grounded theory of empowerment in children and young people with cystic fibrosis during key life transitions. *Child: Care, Health and Development*, 47(4), 484-493. <https://doi.org/10.1111/cch.12860>

Title: Promoting emotional wellness in children with cystic fibrosis, Part I: Child and family resilience

Review: *This article focused on the vulnerabilities of children living with cystic fibrosis, the impact of chronic disease on the family system and social determinants of health. The authors discussed opportunities for the integration of proactive interventions beginning at birth and throughout childhood. They called for greater attention to the emotional wellness of children and their families and an emphasis on behavioral health promotion within the CF care model.*

Year of Publication: 2020

DOI: 10.1002/ppul.24958

Age Group: Infant; Toddler; Preschool; School Age; Adolescent

Keywords: child and family functioning, cystic fibrosis, parent mental health, wellness promotion

APA Citation: Boat, T.F., Christon, L.M., Filigno, S.S., Georgiopoulos, A.M., Mueller, A., Prieur, M.G. & Smith, B.A. (2020). Promoting emotional wellness in children with cystic fibrosis, Part I: Child and family resilience. *Pediatric Pulmonology*, 56(1), 97-106.

<https://doi.org/10.1002/ppul.24958>

Title: Moving toward patient autonomy: A case study of communication in adolescent cystic fibrosis care

Review: *This case study examined perspectives of the same incident shared by a patient and a child life specialist using a model called collaborative interpretation. The authors studied communication practices and barriers between adolescents living with cystic fibrosis and their healthcare providers. They recognized the crucial role of child life specialists in fostering the patient-provider relationship and underlined specific needs for adolescents undertaking a more active role in decision-making and management of their care.*

Year of Publication: 2018

DOI: <https://www.childlife.org/docs/default-source/publications/bulletin/aclp-bulletin-winter-2018.pdf?i=463803>

Age Group: Adolescent

Keywords: Healthcare communication, cystic fibrosis, adolescent, patient autonomy

APA Citation: Kim, L. & Young, A.J. (2018). Moving toward patient autonomy: A case study of communication in adolescent cystic fibrosis care. *ACLP Bulletin: Child Life Focus*, 36(1), 24-33. <https://www.childlife.org/docs/default-source/publications/bulletin/aclp-bulletin-winter-2018.pdf?i=463803>