

Resilience and family quality of life in parents of children with developmental disabilities: a South African pilot study

Authors: S. Moodley¹, K. Reichmuth¹, M. Hendricks¹, K.A. Donald^{1,2}

Affiliations: 1. Department of Paediatrics and Child Health, University of Cape Town
2. Neuroscience Institute, University of Cape Town

Background: Children with developmental disabilities require medical, therapeutic, psychological, social, financial and educational support which are limited in majority world countries, creating complexity to attaining best potential in every child. Their quality of life is affected by this. Protective factors that determine quality of life are linked to parent resilience. The COVID-19 pandemic disabled access to the support networks that were established prior to the pandemic.

Objective: The study was conducted to understand the quality of life of children with developmental disabilities and the relationship to parent resilience during the pandemic, on a cohort of parents from across South Africa.

Methodology: This was a quantitative study. Doctors affiliated to the Department of Child health at University of Cape Town and Shonaquip Social Enterprise (SSE) Parent Network, a disability focused organization in the community collaborated to reach families of children with disabilities in the community. The study was conducted after the third wave of infections in South Africa when the number of infections and restrictions were at its lowest. (27 October to 30 November 2021). Parents were introduced to the study on their social media support session and invited to participate. Telephonic interviews were set up at the parent's preferred time and reminders were sent. Parents had access to the study telephone and whatsapp number as well as an email address, in reschedule.

Tools:

The Connor Davidson Resilience scale: This 10- item has a clear reflection of the ability to bounce back from the variety of challenges that can arise in life. It has been shown to be appropriate for use within different cultures and has been used extensively in epidemiological studies (Riopel 2020).

The Beach Family Quality of life questionnaire: This is a 25-item inventory with a 5 point Likert type scale on 5 domains of family quality of life which includes: parenting, family interaction, emotional wellbeing, physical / material wellbeing and disability related support. (Beach Center on Disability 2006)



Ethical considerations: Parents of children with disabilities are a high-risk population due to the excessive emotional burden of stress that they endure. To ensure that our research did not add to this burden, we accessed parents that were linked to a support group in the community and set up interviews with them outside of the hospital setting at a convenient time for the family to engage.

Results: Thirty parents within the SSE parent network were being trained to lead small groups within their communities by SSE facilitators. Thirteen mothers (mean age 39 years, range 30-64 years) participated in the study, with (n=6, 46%) mothers reporting unemployment.

Mothers reported only 15% (n = 2) of fathers were involved in their children's care. Dependent children (mean age 12 years, range 4-27 years), lived with cerebral palsy, epilepsy, intellectual disability, Down syndrome, autism, and albinism. Mothers who were employed, had a college education, paternal support for their children, and had children returning to school, scored higher on the resilience scale (third quartile) compared to those who did not (first quartile). Resilience and family quality of life were correlated. Depression, stress, and loneliness were reported in parents scoring lower in the resilience scale. Two mothers commented that 'no one asks me how I am.'

Discussion: Parents from this support network across South Africa described socioeconomic challenges whilst caring for their children without the role of a father in their children's lives. They were not able to cope during the pandemic and that affected the quality of life of their children and family. Older parents reported less mental health concerns than younger parents caring for children with severe disabilities. Families without access to digital media are presumed to have faced worse socioeconomic challenges and may have needed more support services to impact their quality of life. Holistic approaches to care at all consultations with the child should screen maternal wellbeing and strengthen referral for psychosocial support that enable families to work through their challenges, particularly in resource limited settings where there are more barriers to caring for the child with a disability.

Conclusion: Poor socio-economic factors and poor maternal mental health negatively affect resilience in mothers of children with disabilities and thus the quality of life of the child. Interventions that include psychosocial support, could enhance their ability to cope thus strengthening the environment of children with disabilities.

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References:

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