Divergence and convergence of viewpoints of children with cerebral palsy, caregivers, teachers and healthcare professionals in Sri Lanka on quality of life

S. Hettiarachchi\textsuperscript{1} & G. Kitnasamy\textsuperscript{2}

\textsuperscript{1}University of Kelaniya, Sri Lanka  
\textsuperscript{2}Cerebral Palsy Lanka Foundation, Sri Lanka

BACKGROUND

Quality of Life (QOL) is defined as a broad multidimensional concept, which incorporates subjective evaluations of both positive and negative aspects of life\textsuperscript{1}. Poor QOL in children with cerebral palsy is associated with the parent-child relationship, limited opportunities for social participation, limited access to healthcare services, psychological well-being and the child’s physical functioning\textsuperscript{2}. Within the research, QOL is associated more strongly with social and environmental factors and less with the impairment\textsuperscript{3}. Children have also been noted to rate their QOL higher compared to their primary caregivers\textsuperscript{4}, suggesting potentially divergent and convergent viewpoints among different stakeholders.

OBJECTIVES

The objective of this cross-sectional study was to describe the QOL of children diagnosed with cerebral palsy as reported by primary caregivers, healthcare professionals and/or educational professionals and the children themselves.

METHODS

Design: Mixed-methods study  
Participants: 10 children with cerebral palsy, 30 primary caregivers and 30 healthcare professionals  
Data collection method: Children: Sinhala and Tamil-translations of the CPQOL-Child and narratives of their artwork (with AAC support as required)  
Primary caregivers: Sinhala and Tamil-translations of the CPQOL-parent version; open-ended interviews with key informants  
Professionals (healthcare/education): Open-ended interviews  
Data analysis: CPQOL data were analyzed quantitatively. Thematic analysis of the qualitative interview data based on Framework Analysis\textsuperscript{5}.

RESULTS

Divergent findings

- PROFESSIONALS
  - Lack of access to formal and mainstream education
  - We have cognitive able students at our center but we have not been able to get them into mainstream schools. (P9-teacher)
  - Lack of access to multi-disciplinary care
  - Physio and OTs must work together with Speech Therapists to ensure good QOL during mealtimes. (P4-teacher)

- CHILD-CAREGIVER
  - Motor function associated with well-being and autonomy
  - I want to play cricket with my friends. Sometimes, I fall over. (P10)

CONCLUSIONS

The main divergent viewpoint was of children with cerebral palsy not associating severity of motor difficulties with their physical well-being in contrast to caregivers. The children noted higher QOL compared to caregivers, which is in line with previous research\textsuperscript{3}. That said, the CPQOL questionnaire was not able to fully capture the socio-cultural realities reported by the caregivers within the interviews.

References