Perceived environmental barriers and supports to home, community and school participation for children with spina bifida

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Introduction

Participation is defined as involvement and engagement in all life situations and is seen as an essential condition for children's development [1]. Children with spina bifida (SB) have multiple medical problems and are at risk of decreased participation.

The International Classification of Functioning, Disability and Health model identifies participation as a complex phenomenon that is affected by the interaction of body structures and functions with environmental and personal factors. Environmental barriers and supports serve as significant mediators between child/personal factors (e.g., health condition, functional issues) and participation outcomes [2].

Enhancing the participation of children with SB requires knowledge about perceived environmental barriers and the impact of varied environmental contexts on the child's ability to participate in activities of their choice.

Objective

The study aimed to comprehensively describe parents' perception of environmental barriers and supports to home, community, and school participation for children with SB.

Methods

➢ Quantitative cross-sectional study of nationally representative sample
➢ Participants – Lithuanian children with SB aged 5 to 18 years
➢ Measures:
  ✓ Participation and Environment Measure for Children and Youth (PEM-CY) [3]
  ✓ Clinical data collection instrument designed by the study author
➢ Statistics
  Descriptive - to analyze supports and barriers
  Multiple linear regression analyses - to identify the impact of health condition and functional issues on perceived environmental supports and barriers

Results

Supports and barriers to home participation

- The highest overall impact of supports was associated with home followed by the preschool/school and the community. The most frequent environmental supports were the time that family members spend with the child, and the child's ability to access personal transportation to access preschool/school and community activities.

- The highest overall impact of barriers was evident in the community followed by the preschool/school and home. The most common barriers to participation were the lack of programs and services to support the child's participation at preschool/school and the community, the lack of public transportation to get to preschool/school and the community activities, the physical demands of typical preschool/school and community activities.

- Functional abilities and SB-related health problems significantly influenced perception of the impact of environmental barriers. Children with limited ability to walk experienced greater perceived barriers at home while intellectual disability was associated with higher number of barriers at preschool/school and the community. Urinary incontinence also significantly influenced perceptions of the impact of environmental barriers.

Conclusions

- Data of the study indicate the presence of multiple environmental barriers to recreational, community, and school participation, thus opening up opportunities for multiple points of entry to facilitate change.

- More attention to environmental modifications (especially for children who have lower level of cognitive abilities and/or urinary incontinence) as primary targets of interventions aimed at promoting participation should be paid. A child's functional abilities often could not be changed, however, in most circumstances, participation could be enhanced by minimizing disabling gaps between a child's capabilities and the social and physical demands of the environment.

References