Participation: what does it mean to clinicians and families?

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Introduction

“Participation” in a life situation

International Classification of Functioning for Children and Youth (WHO, 2007)

Children are ‘human beings’, rather than ‘human becomings’ for whom participation and quality of life are immediately important, and not just an aspiration for the future.

Colver, 2006

Background

- Participation is not fully understood within the healthcare context (Hoogsteen & Woodgate, 2010)
- 14 different participation outcome measures have been developed (Chien et al, 2014; Granlund, 2013)
- No one outcome measure fully represents participation (Schiariti et al, 2014; Adolfsson et al, 2013)
- The impact of equipment on participation is not known

Objectives

The purpose of the review was to examine the published literature to:

- Identify the determinants of “participation” in the context of the ICF-CY in studies involving clinicians or families of children aged 0-3 years
- Compare what “participation” means to clinicians and families
- Investigate the role of equipment on “participation”
Methods

Database searches

Keywords:
(particip* OR social participation OR activities of daily living/) AND (child, preschool/ OR infant/ OR toddler* OR disabled children/)

Inclusion criteria:
Quantitative or qualitative studies which included families of children in 0-3 age group range with physical disabilities; studies, reviews or clinical commentaries which describe determinants of participation in the context of the ICF-CY; studies which use participation outcome measures with the target group.

Exclusion criteria: Participation in either meanings; psychometric evaluations of participation outcome measures; diagnoses such as developmental coordination disorder, autism or traumatic brain injury; older children exclusively.

Methods

Database searches

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<tr>
<th>Database</th>
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Apply limits and de-dup: 3487 titles

Abstract and exclusion criteria: 241 titles

Article review, exclusion criteria and reference lists: 48 articles

13 articles

Results

Objective | No | Results
To identify the determinants of "participation" in the context of the ICF-CY in studies involving clinicians or families of children aged 0-3 years | 0 | No studies found including children aged 0-3 years
Investigate the role of equipment on "participation" | 0 | No studies found including equipment

Results

Objective | Theme | No | Results
Compare what "participation" means to clinicians and families | Research involving clinicians and determinants of participation in the context of the ICF-CY | 7 | Andrade et al (2012)
Bult et al (2011)
Chien et al (2014)
Coster & Khetani (2008)
Hoogsteen & Woodgate (2010)
Rosenbaum & Gomez (2011)
Palmers et al (2012)
Adolfsen et al (2013)
Axelsson & Wilder (2014)
Bult et al (2012)
Khetani et al (2013)
Thomas-Stonell et al (2009)
Thomas-Stonell (2013)

Research involving families and determinants of participation in the context of the ICF-CY | 6 |

Research involving families and determinants of participation in the context of the ICF-CY

Discussion

Research involving clinicians and determinants of participation in the context of the ICF-CY

- Clinicians understand the importance of participation and its complexity
- Focus on investigation, review or refinement of definitions and measurement
- Heavy reliance on the ICF-CY
- Concentration on measurement of body function, structure or activity limitations

Should such a “complex, nuanced phenomena” be considered more subjectively? (Hammel et al, 2008)

Discussion

Research involving families and determinants of participation in the context of the ICF-CY

- Some work grounded in ICF-CY and lacks family perspective
- Parents’ and clinicians’ expectations differed and parents noted twice as many participation-related outcomes (Thomas-Stonell et al, 2009)
- Thomas-Stonell et al developed FOCUS outcome measure based on content analysis of parents’ responses (Thomas-Stonell et al, 2013)
- Child Participation in Family Activities (Axelsson & Wilder, 2014) did not include subjects less than 5 years old

Are we getting closer to the heart of the matter? Difficulties with internal validity?
Conclusion

Where are the gaps?

- Focus on definitions and measurement in the absence of family involvement may risk missing the point
- A child with a disability is a major source of stress to which families must adjust (Mason & Pavia, 2006)
- Enabling active family participation could reduce later barriers (Bult et al, 2012; Raghavendra, 2013)
- Gaps relate to early intervention and family participation, as well as the impact of equipment – which may be a barrier as well as an enabler
- Further research is needed in these areas

References