Disability in children in low-income and lower-middle-income countries: a narrative review of parental and community perception and the psychosocial impact on the family

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Purpose

The purpose of this review is to explore the perceptions, the potential psychosocial impact on the caregiver and family, and treatment beliefs held by parents and community members of children with disabilities (CWD) in low-income countries (LIC) and lower-middle-income countries (LMIC). This will enable rehabilitation professionals to provide more culturally competent health care.

Introduction

- There are currently over one billion people, or 15% of the world’s population, living with a disability, and 60% of these live in developing countries.
- Anxiety levels increase in family members at the level of physical functioning of the child decreases. In LIC and LMIC, the impact on caregivers is even greater due to the everyday struggle just to make ends meet.
- The health of CWD is highly affected by the health and well-being of their primary caregiver. The cultural beliefs, traditions, and associated stigmas influence the perceptions of the disability held by communities. The level of stigma and discrimination community members place on families of CWD highly influence the caregivers burden and quality of life.
- Rehabilitation professionals have a responsibility to address societal barriers and stigma through advocacy, research, and action at the local and global level.

Methods

- Electronic literature search of PubMed, EMBASE, Scopus, and Global Health databases using search terms related to disability, perception, quality of life, and LMIC.
- Quality assessment performed on all included articles.
- Two authors independently searched the studies for main ideas and then combined their results to determine the overriding themes.

Full-text articles assessed for eligibility

- Inclusion criteria:
  1. Focused on a population in LIC or LMIC according to World Bank income classification.
  2. Published between 2004 and January 2014.
  3. Written in English.
  4. Focused on family or community perception or quality of life.
  5. Fit our exclusion of disability. A gross motor impairment or physical limitation that would be appropriate for the physical therapy intervention.
- Excluded studies focused on self-selection or immigrant populations.

Results

Map of LC and LMIC study settings

- Physical, mental, and emotional burden on the caregiver (n = 16):
  - Blame and guilt of the mother: Mothers blamed them for their wrongdoings, including extramarital affair, greed, dishonesty, denying people’s rights, or consuming intoxicants, which many believe led to them being punished with CWD.
  - Mental wellness: The negative impact of the community causes mothers to retreat into isolation, hiding their children from the community, due to fear of segregation and discrimination. The lack of acceptance and social interaction restrictions cause loneliness and increased stress on the community for CWD.
  - Effects on family unity: Mothers felt shame from their extended family, viewing CWD as a disgrace to the family. The study reported family support and cohesion typically increases with having CWD.
  - Physical burden: Caregivers reported musculoskeletal pain, sleep disturbances, or generally feeling unwell.

- Influence of religion and God (n = 15):
  - Gift from God: Caregivers believed that they were chosen to take care of a child with a disability, that though CWD are different, they are valuable.
  - Punishment from God: Some believed having CWD is punishment from God for wrongdoings and ways to test the caregivers.

- Superstitions and cultural beliefs (n = 12):
  - Traditional treatment and healer: Care from traditional healers included use of incantations, sacrifices, religious shrines, herbal medicines, strict dietary restrictions, massage of disabled limbs, and burying the child in the sand.
  - Witchcraft and curses: Families and community believe in curses brought upon CWD by lack of resources and poverty.
  - Evil spirits and ghosts: Multiple articles referred to the cause of disability being due to possession of a ghost or evil spirit, fate, or bad karma.

- Biological understanding of disability (n = 9):
  - Characteristics of caregivers: Education was not a direct link to the knowledge of caregivers on causes of disability. Younger mothers were more knowledgeable but still relied on the influence of the family.
  - Health of the pregnant mother: Factors affecting the health and physical well-being of the mother were cited as causes of disability. Including taking too much medication during pregnancy, not enough room in the womb, and poor nutritional state of the mother.

- Concerns for the growing CWD (n = 8):
  - Education and work: Many mothers expressed goals for the CWD to be independent in the home, as well as attend school and find work someday. Family and community members agreed it is possible for CWD to be positive contributors to society with extra love and efforts.
  - Marriage: Parents report fear of difficulty marrying off not only CWD, but also their siblings.
  - Safety against sexual abuse: Two articles, both from Pakistan, expressed concerns for their female child’s safety against sexual abuse.

Discussion

- Parents of CWD experience extreme psychological burden, yet few seek help, even if they recognize the effects on their mental and emotional health.
- Parents and community members may accept the science and biomedical explanation for how their child developed a disability, yet they may hold fast to traditional explanations to explain why their child has a disability. A family-centered approach is necessary to understand the different influences affecting the perception of CWD held by families and community members.
- Religious and spiritual factors highly influence perception of the cause of CWD in LIC and LMIC.
- Rehabilitation professionals trained in western medicine may overlook this aspect of care because it is less prevalent in many high-income countries.
- Increasing public awareness and understanding of disability while maintaining respect for cultural values could help challenge the negative stigma of the community and decrease emotional, mental, and physical burden on families.

Limitations

- Global health research lacks a widely implemented definition of disability, and most researchers did not provide the definition used in their studies.
- Description of and justification for methodology is inconsistent throughout the literature.
- The included studies represent only 10 out of 64 (12%) LIC and LMIC, which limits the ability to generalize results.

Conclusions

- Generalizations should not be made about the beliefs held by caregivers and community members in LIC and LMIC.
- Clinicians must seek to understand the perspective of each individual and for community in order to provide the most culturally competent care.
- The burden experienced by caregivers is often not addressed due to lack of resources and poverty.
- There is a limited amount of research in many geographic regions, revealing a need for further study on these topics.

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References