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Health related quality of life in children with spina bifida in Uganda

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A B S T R A C T

Background: Studies on health related quality of life (HRQOL) of children with disabilities in low income countries are limited.
Objective: To inform interventions for children with spina bifida in low income countries, HRQOL of children with spina bifida and siblings, predictors, relationships between HRQOL and parental stress in Uganda were examined.
Methods: Demographic, impairment, daily, social functioning data, and HRQOL using the KIDSCREEN-10 were collected from 39 children, 33 siblings, and 39 parents from a cohort of families of children with spina bifida. T-tests, correlations, analysis of variance and regression analysis were used to compare means between children with spina bifida and their siblings, understand relationships between variables, and identify predictors of HRQOL.
Results: Children with spina bifida ($N = 39$) had lower HRQOL compared to their siblings ($N = 33$) ($t = -3.868$, $p < .001$ parental; $t = -3.248$, $p = .002$ child ratings). Parents ($N = 39$) indicated higher parental stress for their child with spina bifida ($t = 2.143$, $p = 0.036$). HRQOL child outcomes were predicted by the presence of hydrocephalus ($\beta = -.295$, $p = 0.013$) for children with spina bifida, and daily functioning levels ($\beta = .336$, $p = 0.038$), and parental support ($\beta = .357$, $p = 0.041$) for siblings specifically. Parent rated HRQOL outcomes were predicted by parental distress ($\beta = -.337$, $p = 0.008$), incontinence ($\beta = .423$, $p = 0.002$), and daily functioning levels ($\beta = .325$, $p = 0.016$) for children with spina bifida.
Conclusions: To improve HRQOL investment in neurosurgical care, community based rehabilitation, incontinence management, and parental support are required. A combination of child friendly semi-structured and creative research methods are recommended to study HRQOL.

Introduction

Spina bifida

Spina bifida is a congenital neural tube defect.[1] The majority of persons born with spina bifida have some degree of paralysis, which affects mobility as well as bowel and bladder control[1]; 66% of children with spina bifida in Uganda develop hydrocephalus.[2] Most children with spina bifida need neurosurgery to close the back to prevent infections; those with hydrocephalus need surgery to drain cerebral spinal fluid to prevent secondary impairments.[3,4]

Children with spina bifida in Uganda

In Uganda an estimated 1400 children are born with spina bifida annually.[5] National spina bifida prevalence and incidence data does not exist; infant mortality is 43, under five 64, and child mortality 22 per 1000 live births.[6] As governmental health and social support are very limited, families and private non for profit organisations are the main providers of care, and developed low cost interventions.[7]

Health related quality of life

Health related quality of life (HRQOL) refers to an individual's perception and subjective evaluation of their health and well-being within their unique cultural environment. Huber (2011) proposed to define health as: “the ability to adapt and to self manage, in the face of social, physical and emotional challenges”.[8] This definition is

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relevant in studying HRQOL of children with spina bifida in Uganda, who may not achieve a state of complete wellbeing as defined by the World Health Organization,[9] but do have the ability to adapt and self-manage in situations of exclusion, discrimination, and poverty.

In this study we compare HRQOL of children with spina bifida and their siblings, using the KIDSCREEN-10 item questionnaire for parents and children,[1011] and examine the relationship between parental stress and HRQOL.

Methods

Study design

This was a cross sectional study of the HRQOL of a cohort of children with spina bifida aged 8–14 years (N = 139). The children earlier received neurosurgical care at a neurosurgical hospital in Eastern Uganda and were followed up during outreach clinics. Inclusion criteria for the sampling was that the child lived in the central region (N = 78) and had a sibling in the same age range living in the same home, attending day school (N = 45). Parents of the selected 45 children were approached between September 2014 and June 2015; 40 agreed to participate (response rate 88.9%).

Demographic and disability data and scales to measure daily, social, parental functioning and HRQOL were collected from and administered to 39 parents, 39 children with spina bifida and 33 siblings. In total 6 siblings were unable to participate, and one family moved to another region during the study. The assessments were conducted in Luganda, the local language spoken in central Uganda.

Ethical considerations

Ethical approval and research clearance were obtained from Ghent University, Belgium, the Uganda Virus Research Institute, and the Uganda National Council for Science and Technology. Informed consent in English or Luganda was obtained from all parents, and assent from children where possible.

Study tools

To measure factors which influence HRQOL, we collected demographic data and selected tools which measure physical, daily, and social functioning as well as parental stress and perceived support.

Data on demographic and impairment specific variables such as the presence of hydrocephalus, neurosurgical treatment and rehabilitation services received, and incontinence management were collected from parents.

The presence of a househelper or other adult at home involved in the care of the child alongside the primary caregiver was registered as a measure of perceived support. Membership of a parent support group was documented as another form of support.

Physical functioning was measured in terms of general health, mobility, incontinence, and secondary disabilities through file review and interviews with parents and the child's community based rehabilitation (CBR) worker. Mobility assessment measured whether a child was able to sit or walk independently, and was using assistive devices.[12] A selection of 10 items of The Vineland Adaptive Behaviour Scales (VABS) Daily Living Skills subscale and 6 items of the VABS Social Skills subscale relevant to the Ugandan setting were used.[13] Items included measures of daily functioning tasks such as removing a jumper, fetching water and dressing independently, social communication and interaction with peers. Items were scored 2 (behaviour is usually performed), 1 (sometimes performed), or 0 (never performed). The reliability of the daily functioning and social outcomes subscales of the VABS were good with a Cronbach's alpha of .82 and .79.

To measure parental stress the Parental Stress Index Short Form (PSI/SF) consisting of 36 items scored on a 5 point Likert scale was used. The items are divided over 3 subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child. A total stress score is computed from the three subscales and indicates the overall level of parental stress.[14] Cronbach's alpha for the PSI/SF was 0.85.

To measure HRQOL we used the KIDSCREEN-10 parents and children's questionnaires.[10] The KIDSCREEN-10 was earlier used to measure HRQOL of adolescents living with HIV in central Uganda and had a Cronbach's alpha of 0.70[11]. Our KIDSCREEN outcomes were normally distributed, with a Cronbach's alpha of .74 for the parents' version, and .71 for the children's questionnaire. Factor analysis showed a Kaiser-Meyer-Olkin sampling adequacy of .724 and a significant Bartlett's Test of Sphericity ($p < .001$).

Data analysis

Basic demographic, impairment, daily and social functioning data, and records of the parental stress and HRQOL scores were written out during assessments, and entered into a SPSS16 database. The sub-total scores for the VABS subscales, PSI-SF, and KIDSCREEN-10 were calculated to compare means of the scores between the children with spina bifida and their siblings using SPSS16. Bivariate correlations between continuous variables and the main outcomes were calculated. Analysis of variance tests were used to test for difference in HRQOL scores between children and siblings, and scores rated by parents and children. Factors predicting HRQOL were investigated by stepwise regression analysis.

Study sample

In total 39 children with spina bifida (myelomeningocele) (56.4% male, 43.6% female), 33 siblings (43.6% male, 56.4% female), and 39 parents (79.5% mothers, 12.8% fathers, 5.1% grandmothers, and 2.6% others) participated in this study. The average age of the children with spina bifida was 9.4 (SD = 1.63), and 9.9 years (SD = 1.60) for siblings. Parents' ages ranged from 30 to 49 years with an average age of 37.1 (SD 4.3) years. The majority completed primary education (74.4%) and was married (76.9%). The household size ranged from 3 to 13 with an average of 6.8 persons per household (SD = 2.31), with on average 4.3 children (SD 2.2) and 2.3 adults (SD 1.0) per household. The average monthly household income was 82 euro (range 24–306 euro). All siblings were in primary school, whilst 17.9% (7) of the children with spina bifida were not in school. All children with spina bifida had undergone surgery (myelomeningocele closure); among children with both spina bifida and hydrocephalus 33.3% had undergone endoscopic third ventriculostomy and 44.4% had ventriculo-peritoneal shunts placed. The majority of the children with spina bifida (94.9%) received rehabilitation services after surgery. Gross motor skill outcomes were grouped into: children who can walk independently (41.0%), children who use assistive devices to walk (48.7%), children who cannot walk and do not use assistive devices to ambulate (10.3%). In total 32 children (82.1%) with spina bifida were incontinent; 81.3% of them practised catheterization.

Results

Parental and child ratings on the KIDSCREEN-10 were significantly higher for siblings compared to children with spina bifida ($t = -3.868$, $p < .001$ parental; $t = -3.248$, $p = .002$ child ratings).

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