

The Health Related Quality of Life of children living with a physical disability attending Physiotherapy at Meerhof School in the North West Province.

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ABSTRACT

Background and purpose: Understanding Health Related Quality of Life (HRQoL) is important to therapists working in special schools in order for them to treat their learners holistically. The main purpose of the study was to describe the HRQoL of learners living with a physical disability attending physiotherapy at Meerhof School in the North West Province.

Methods: A quantitative descriptive cross-sectional study design was used by making use of the KINDL[®] interview questionnaire which consists of a 12-item Likert Scale. The sample in this study comprised of 30 learners presenting with physical disabilities attending physiotherapy at Meerhof School.

Results: Participants' ages ranged between six and 20 years with a mean age of 13. The majority of the participants were male (77%), and most of the children reported to have two siblings (33%). From the six domains of the KINDL[®] questionnaire, the Family and Friends domains were the highest with mean scores of 91.7% and 89.4% respectively. The mean scores of both Personal and Emotional well-being domains ranked lowest with scores of 78.9% and 78.3%. The total HRQoL scores of the learners were exceptionally high with an average score of 84.2%.

Conclusion: Despite their disabilities, learners with physical disabilities at Meerhof School reported a high level of HRQoL.

Keywords: Health-related quality of life, physiotherapy, Meerhof school, KINDL[®] questionnaire

Background and introduction

Health-related quality of life (HRQoL) in children includes concepts of illness, functional status, mental health and comfort but also parental impact and family functioning (Vargus-Adams, 2005). The International Classification of Function and Disability (ICF) describes a person's functioning as a dynamic interaction between his or her physical well-being and contextual factors, such as environmental and personal factors. These contextual factors may have a positive or a negative influence on the activities of daily living (ADL) (Gordeev, Maksymowych, Evers, Ament, Schachna & Boonen, 2010). Law, Hanna, Anaby, Kertoy, King and Xu (2014) emphasise that HRQoL encompasses functioning and participation in ADL as well as the influence on their family's psychosocial well-being. As a result, the relationships that learners have with their family and friends, the environment at home and at school, how they see the world as well as their involvement in decision making can all influence their daily functioning (Dyches, Smith, Korth, Roper & Mandleco, 2012). Family relationships include being accepted, feeling involved in decision making and being nurtured. Patients living with disabilities who report an environment in which their family members demonstrate behaviour such as over-reacting and over-compensating for their condition appear to have poor functional outcomes (Jensen, Moore, Bockow, Ehde & Engel, 2011).

By making use of HRQoL instruments, physiotherapists can determine which domains are most affected by learners' disabilities, and adjust their treatment plans accordingly. A number of generic HRQoL instruments have

been developed for children and adolescents (Eser, Yuksel, Baydur, Erhart, Saatli, Cengiz Ozyurt et al., 2008). Physiotherapists can use these outcome measurement tools to assess the HRQoL of children in order to gather evidence to assist them in their intervention strategies. The use of such tools could have a positive influence on learners' HRQoL (Carlson, Shields, Yong, Gilmore, Sakzewski & Boyd, 2010). However, the use of these instruments in special schools in South Africa appears limited.

In a recent study conducted in Cape Town by Jelsma and Ramma (2010), the EQ-5D-Y was used to determine HRQoL amongst learners attending open and special schools. In their study, learners with disabilities did not perceive their HRQoL to be any worse than that of their able-bodied counterparts, although they did recognise their limitations in everyday functioning. Jelsma and Ramma (2010) confirms that the HRQoL of learners is an important outcome measure for intervention and should be utilised more often as an outcome measure at schools for learners with special needs.

A questionnaire for measuring HRQoL in children and adolescents, the KINDL[®], was developed by a German psychologist, Dr. Ulrike Ravens-Sieberer in the year 2000 to explore those areas of life mostly affected by illness or disability. It has been tested in a number of studies involving over 3000 healthy and chronically ill children (Ravens-Sieberer & Bullinger, 2000). A study conducted on a sample of 1501 grade four and grade eight learners attending a school in Germany, found that psychosocial strain, presence of disease or disability and school absenteeism were

negatively associated with quality of life (QoL) ratings. The mean total HRQoL score amongst both healthy and chronically ill learners was 74.5%. Unfortunately, the study did not distinguish between the scores of healthy and chronically ill learners (Ravens-Sieberer, Gortler & Bullinger, 2000). In South Africa, a similar study was conducted, but using a different questionnaire, the EQ-5D-Y. This study found that the mean total HRQoL score amongst healthy and chronically ill children (n=258) was 77.3% (Wille, Badia, Bonsel, Burstrom, Cavrini, & Devlin, 2010), a similar finding to that of the study by Ravens-Sieberer et al.(2000) using the KINDL[®] questionnaire. Wille et al. (2010) also did not differentiate between the scores of healthy and chronically ill children.

Despite the fact that many learners in this country undergo rehabilitation, including physiotherapy, their level of HRQoL is currently unknown. Although Jelsma and Ramma (2010) have investigated the HRQoL of learners in Cape Town, it appears from the lack of literature on HRQoL of disabled learners in Gauteng and the North West Province, that no similar studies have been conducted in these regions of South Africa.

The objectives of the study were therefore to determine the HRQoL of children attending physiotherapy at Meerhof School in the North West Province. Six domains were explored using the KINDL[®] questionnaire: Physical well-being, Emotional well-being, Self-esteem, Family, Friends and Everyday functioning.

Implementing the KINDL[®] questionnaire or other similar instruments could assist physiotherapists in making appropriate changes to individual learners' treatment plans in order to address their specific needs in a more holistic manner. Furthermore, results from HRQoL instruments are able to provide valuable guidance and information to therapists at special schools regarding learner progress. Therapists can exploit this information in identifying learners who need referral to other members of the healthcare team such as psychologists and social workers. Once the correct measures have been taken, HRQoL can be re-assessed to establish whether learners' perceived QoL has improved over time. Physiotherapists therefore need to consider all factors that may influence the HRQoL of a patient living with a disability, as any of these factors may influence their rehabilitation.

Methodology

In this study a quantitative descriptive cross-sectional study design was applied. Meerhof School is situated in Hartebeespoort, in the North West Province in South Africa and caters for learners between the ages of five and 20 years who have various mental and physical disabilities. Those who attend physiotherapy at the school comprised the target population (N=190). Learners were included if they presented with a physical

Data collection method and instrument

Data was collected at Meerhof School during August and September 2013.

The KINDL[®] Questionnaire for Measuring HRQoL in Children and Adolescents, first developed by Bullinger, Mackensen and Kirchberger (1994) in the German language and then translated to English by Ravens-Sieberer and Bullinger (1998a & 1998b), was used in the study. The questionnaire was translated into Afrikaans and back translated into English. The tool was tested for its face and content validity in a pilot study. During the construction of the original KINDL[®] questionnaire the German researchers measured the reliability of the instrument. The Cronbach's alpha measure of consistency for the overall scale scored high, with a coefficient of $\alpha = 0.80$ (Ravens-Sieberer & Bullinger, 2000).

The KINDL[®] questionnaire consists of two versions: one that is completed by participants

disability between the ages of five and 20 years, and attended physiotherapy on a weekly basis at Meerhof School during 2013. Physical disabilities included severe head injuries, juvenile arthritis, muscular dystrophy, paraplegia, quadriplegia, spina bifida and a variety of congenital or acquired cerebral palsy conditions. A purposeful sampling technique was applied: all learners who met the inclusion criteria and provided the informed consent form signed by their parents/legal guardians were included in the sample (n=30).

themselves and secondly the interview questionnaire where the researcher asks the questions and then captures the participants' answers. The interview questionnaire works well especially for participants younger than 8 years of age. In this study the interview version was used. Each questionnaire consists of six domains: Physical well-being of the child, Emotional well-being, Self-esteem of the child, Family, Friends, and Everyday functioning (Ravens-Sieberer & Bullinger, 2000) with two Likert scale questions per domain (total of 12 questions). Each question has three options, namely: 1=never; 2=sometimes and 3=very often which accumulates to a total score of 36. Some of the values had to be reversed during data capturing following the guidelines provided in the KINDL[®] manual (Ravens-Sieberer & Bullinger, 2000).

Data analysis

All the results were captured in Microsoft Excel and SPSS version 20 for further analysis. Data analysis for the total score and sub-scales for the questionnaire was executed as published in the KINDL[®] manual. The total score was calculated out of 100. The raw data was used to determine the total KINDL[®] score as well as the domain score, corresponding to the mean percentage for each domain (Ravens-Sieberer & Bullinger, 2000) as depicted in Table 1.

Demographic details of the patients were summarised descriptively and categorical data was summarised by percentage calculations and proportions. Continuous variables were

summarised by reporting on means and standard deviations or medians and ranges. Measures of association were determined by means of the applicable statistical test and p-values of ≤ 0.05 were considered to be significant.

Results of the KINDL[®] questionnaire when used with chronically ill children in earlier studies have shown that the measure is able to distinguish between the level of impairment of HRQoL in children with different diseases and disabilities, both on a sub-scale level and in terms of its total score (Ravens-Sieberer & Bullinger, 2000).

Ethical considerations

Ethical clearance was granted in June 2013 (MREC/H/132/2013: UG) by the Medunsa Research and Ethics Committee (MREC) of the University of Limpopo. Permission to conduct the study at Meerhof School was obtained from the Meerhof School Board in February 2013. All participants, their parents or caregivers and the physiotherapists involved were given the relevant information prior to the study in order to make an informed decision as to whether to participate or not. Letters containing information on the study as

well as the consent forms were sent to each participant's home, allowing the parents or caregivers enough time to go through the documentation on their own prior to making their decision. All participants were required to return the informed consent form, completed by their parents or caregivers and granting permission for their child's participation in the study. The learners willing to participate also signed an assent form before the interviews were conducted. All information was treated as confidential and the completed consent forms as well as questionnaires were stored securely by the researcher in a locked filing cabinet.

Results

Demographic Data

The 30 participants' ages ranged from six to 20 years, with a mean age of 13. The majority of the participants were males (77%) and most of the participants reported to have two siblings (33%).

Domains of KINDL[®] questionnaire

Responses for the domains are portrayed in Table 1. Responding to questions relating to their physical health, almost half of the participants (47%) reported not feeling ill at school, but interestingly enough more than one third (37%) reported that they experienced headaches sometimes during the week. On emotional well-being participants also scored high, as the majority (57%) stated that they felt happy and laughed regularly. This links with most learners feeling proud of themselves and contented as well as feeling pleased with themselves most of the times.

Furthermore, participants seem to experience good parental relationships as this was the highest reported domain (80%) followed by the

Friends domain at 76.7%. The Everyday functioning domain involving school activities, when combining the sometimes and often responses, indicated that the majority of participants coped well with assignments (93.3%).

From Table 1 it is clear that learners' total KINDL[®] scores were relatively high, indicating an overall good HRQoL. There were only two participants who scored low scores of 63.9% and 69.4% respectively. The average HRQoL score for all the learners was 84%, the highest score by one learner was 97.2% followed by three learners who scored 94.4%.

The only significant measure of association was the Spearman Correlation coefficient, as reflected in Table 2. The rho value was 0.372 and a statistically significant p-value of 0.043 was found. This implies that there was a positive but moderate correlation between the number of siblings a learner had and the total KINDL[®] score.

Discussion

The HRQoL tools such as the KINDL[®] measures the extent to which health impacts and individual's ability to function and their state of well-being and general satisfaction with the physical, psychological and social domains of life (Boyer et al., 2006). The sample (n=30) from this study compares well to those used in similar studies by other researchers (Ravens-Sieberer & Bullinger, 2000). The age range of participants in this study ranged from six to 20 years and 77% were males. Jelsma and Ramma (2010), in a South African study, reported a similar ratio of percentages in males (74%) versus females (26%). A study conducted by Wille et al. (2010) used learners between the ages of eight and 18 years, which was similar to the age range of participants in the present study.

The positive but moderate correlation between participants' number of siblings and the total KINDL[®] score could be attributed to the influence of contextual factors. According to Solish, Perry and Minnes (2010) activity participation should not only be defined as the level of participation, but also investigate with whom children participate. In children with physical and/or mental disabilities siblings and parents play a major role. Parents and siblings are a vital component of the family centred care approach that addresses the health care needs of children with cerebral palsy (King, Teplicky, King & Rosenbaum, 2004; Baker, Haines, Yost, DiClaudio, Braun & Holt; 2012). This model recognises that each family is unique and different. Moreover, the family is a constant in the child's life and knows best the abilities and needs of their children with cerebral palsy. Therefore, for the child to

function optimally there has to be a coherent supportive family and community structure (King et al., 2004).

Contextual factors including the family and the child's environment has an influence on various domains which constitutes their HRQoL. The concept of HRQoL is inherently subjective because it requires an individual to provide a unique appraisal of his/her unique awareness and experience regarding the impact of a disease on his/her life including their functioning and emotional state (Gold, Mahrer, Yee & Palermo, 2009). HRQoL in children includes concepts of illness, functional status, mental health and comfort but also parental impact and family functioning (Vargus-Adams, 2005). In the case of paediatric patients HRQoL is also influenced by aspects such as the ability to participate in peer groups and keep up with developmental activities (Grootenhuis, De Boone & Van der Kooi, 2007). The relatively high scores of learners from Meerhof School in the personal well-being domain, particularly their physical health, could be attributed to various contextual factors. According to the researchers, these factors include the environment, education structure (special school), family as well as community support as reflected in their responses for Family and Friends domains respectively.

In the emotional domain, participants scored higher than in the physical well-being domain. The overall mean in the emotional domain compared well to a study conducted in Asia that found a mean percentage of 76.7% (Wee, Ravens-Sieberer, Erhart & Li, 2007). However when it comes to self-esteem this study's participants performed much better than those

reported in Wee et al. 2007 which was 44%. Learners in this study felt proud and pleased with themselves, despite their physical impairments. In a study by Grootenhuis et al. (2007) amongst children with neuromuscular diseases, similar observations were made. The finding of this study was further supported by Jensen and colleagues (2005) as well as Bendixen, Senesac, Lott and Vandenborne (2012) who reported good mental and emotional outcomes among children with neuromuscular diseases and Duchenne muscular dystrophy respectively.

Children participating in this study had exceptional interaction with their parents, caregivers and siblings. The significant role of family in the HRQoL for children is portrayed by the highest mean percentage as depicted in Table 1. This mean percentage of the family domain was higher than the 71.9% found by Wee et al. (2007). Potter, Cantarero and Wood (2012) emphasised that the child's perception of their QoL is influenced by the support they receive from their neighbourhood and community. Palisano, Chiarello, King, Novak, Stoner and Fiss (2012) highlighted that "home and community participation of children with physical disabilities is an important outcome of rehabilitation" (p. 1041). This is an important consideration for rehabilitation therapists working with children in the school environment.

Learners value interaction with friends as important second to family. The Friends domain portrayed higher scores for playing with friends than getting along. Once more the overall Friends domain score was higher than the 66.2% score observed by Wee et al.

(2007). Grootenhuis et al. (2007) emphasised that the paediatric HRQoL is influenced by aspects such as the ability to participate in peer groups and keep up with developmental activities.

In the Everyday functioning domain Wee et al. (2007) found a mean percentage of 59% which is relatively low compared to participants from this study. The researchers hypothesised that this difference could be attributed to variations in the educational environment and structure, rehabilitation and the social support received by the two groups. Palisano et al. (2012) support this notion as they posit that the influence of multiple child and family determinants are important factors that impact on the participation of children in everyday activities.

With the exception of two learners, who had a mean score of 63.9% and 69.4% in total respectively, the general HRQoL of learners with disabilities who attended physiotherapy at Meerhof School was good, with an average of 84%. This HRQoL score is similar to the HRQoL score in the study conducted by Jelsma and Ramma (2010) in Cape Town, where participants scored an average of 83.2%, but it differs from the 65.5% score of the Singaporean sample (Wee et al., 2007). This could be attributed to the difference in cultures between South Africans and Singaporeans in as far as upbringing, family ties, community integration are concerned, as well as the difference in sample sizes used in the two studies.

Limitations

Caution should be taken when generalising results, as the study by Wee et al. (2007) in Singapore assessed 328 learners between the ages of eight and 16, while this South African study assessed only 30 participants.

Moreover, differences in personal factors such as relationships between the participants and their family and friends, cultural differences and even the difference in sample size might have influenced these results.

Recommendations

There has been little research done on children's perspectives of their health and QoL. Evidence suggests that children's views may differ from their parents', nurses and healthcare professionals (Noyes, 2006).

Therefore healthcare professionals and educators need to understand the critical factors that affect the QoL and in turn influence the level of care that the learners should receive (Abresch, Seyden and Wineinger, 1998).

In addition, the KINDL[®] questionnaire could be useful in schools as an outcomes measure to evaluate learners' progress, based on their HRQoL, and may provide guidance regarding domain(s) where improvement is desired. The

results could also help in the identification and referral of those learners who need the services of a social worker or psychologist.

In future studies on this topic, a larger sample should be used and the survey could be conducted at various schools. The KINDL[®] questionnaire could also be used to determine how the QoL of learners with a disability compares to that of children in mainstream schools (matched pairs) or community-based schools that might experience less community and parental support than Meerhof School. In any future studies, questionnaires and interview questions should be translated into local languages such as Setswana, Xhosa and Zulu.

Conclusion

Despite perceptions that learners living with a disability might have a low HRQoL, this study proved the contrary. The findings indicated that the majority of learners (93%) have a good HRQoL score. These findings suggest that learners at Meerhof School have an adequate support system that contributes to their high HRQoL scores. However, various contextual factors might have had an influence on HRQoL, warranting further investigation.

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Table 1: HRQoL scores for each domain of the KINDL[®] questionnaire

Domain	<i>During the past week...</i>	Never	Sometimes	Often	Mean Domain Percentage
Personal well-being	... I felt ill	14 (46.7%)	13 (43.3%)	3 (10.0%)	78.9%
	... I had a headache or tummy-ache	15 (50.0%)	11 (36.7%)	4 (13.3%)	
Emotional well-being	... I had fun and laughed a lot	1 (3.3%)	12 (40.0%)	17 (56.7%)	78.3%
	... I was bored	7 (23.3%)	11 (36.7%)	12 (40.0%)	
Self-esteem	... I was proud of myself	0 (0.0%)	12 (40.0%)	18 (60.0%)	86.7%
	... I felt pleased with myself	0 (0.0%)	12 (40.0%)	18 (60.0%)	
Family	... I got along well with my parents	0 (0.0%)	6 (20.0%)	24 (80.0%)	91.7
	... I felt good at home	0 (0.0%)	9 (30.0%)	21 (70.0%)	
Friends	... I played with friends	1 (3.3%)	6 (20.0%)	23 (76.7%)	89.4%
	... I got along well with my friends	1 (3.3%)	9 (30.0%)	20 (66.7%)	
Everyday functioning	... I coped well with the assignments set at school	2 (6.7%)	16 (53.3%)	12 (40.0%)	80%
	... I enjoyed school	4 (13.3%)	8 (26.7%)	18 (60.0%)	

Table 2: The Pearson's and Spearman Correlation Coefficients for Siblings vs Total KINDL® Scores

	Value	Asymp. Std. Error ^a	Approx. T ^b	Approx. Sig. ^c
Interval by Interval Pearson's R	.353	.120	1.996	.056 ^c
Ordinal by Ordinal Spearman Correlation	.372	.141	2.120	.043 ^c
N of Valid Cases	30			