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Effects of an educational program for selfmanagement, on functional independence of adolescents with spina bifida

Background: The number of children with spina bifida (SB) who survived reaching adulthood increased significantly and their adolescence transition is a major concern. The purpose of this study is to develop and evaluate an educational program that promotes selfmanagement competencies and facilitate their transition to adulthood.

Methods: An intervention based on psychoeducational strategies was embedded within a summer camp experience (7 Sessions). 56 adolescents with SB, aged between 10 to 18 years preformed the program and assess their effect on functional independence, self-concept and self-esteem. With a before (T1) and after (T2 and follow-up T3) design, the analysis was performed using the program IBM SPSS Statistics 20, ANOVA repeated measures.

Results: The adolescents made significant gains on functionality, cognitive and motor domains with moderate to high effect sizes observed. In the motor domain, we emphasize the improvement on self-care

and emptying dimension (bowel and bladder).

Conclusions: The program had greatest impact in the motor domain of the functionality (self-care, elimination, transfers), which remains six months later. This program produces better effects on young people aged between 10 and 12 years without previous experience on camps, regardless the gender, level of injury, presence of hydrocephalus or the type of auxiliary gait devices they use. In general, the results support that the experience improves the self-management competences and the functionality of youth with SB and, suggest that the program was highly effective.

Biography

Maria Isabel Dias da Costa Malheiro is an Assistant Professor at the Nursing College of Lisbon, Child and Adolescent Department. She has completed her Doctorate in Nursing at the Lisbon University, Master's in Special Education, Faculty of Human Motricity and Graduate Nurse, Specialist in Child and Pediatric Health Nursing. She has started to work in the hospital since 1988, Neonatology, Pediatrics, Child Development Center. She was the Member of the Spina Bifida Center at Garcia de Orta Hospital until 2002. Since 2002, she has joined the academic career at Nursing College of Lisbon as an Assistant Professor. She collaborates with the Spina Bifida and Hydrocephalus Portuguese Association since 2002, was Vice-President from 2005 to 2013. She was the Coordinator of the project training camp - educational program for self-management on adolescents with spina bifida/spinal cord injury 2011, 2012, 2013, 2014, 2015 and 2016.

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