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EVALUTATION OF PROCESSES OF CARE IN A REHABILITATION PROGRAM FOR CHILDREN WITH DISABILITY AND EVALUATION OF SOME IMPACT FACTORS

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Katja Groleger Sršen received the European Academy of Rehabilitation Medicine Award for her doctoral thesis: Evaluation of processes of care in a rehabilitation program for children with disability and evaluation of some impact factors at the Medical Faculty, University of Ljubljana, Slovenia. Promotor: Professor Anton Zupan, Co-Promotor: Professor Gaj Vidmar. Chair of the Doctoral thesis committee: Professor. Helena Burger. The award was given to her during the congress of European Congress of Physical and Rehabilitation Medicine in Vilnius, Lithuania, May 3, 2018.

Original contribution to scientific knowledge:

- a comprehensive analysis of the impact of family characteristics, the health status of children and the treatment/(re)habilitation programs in various institutions, on the assessment of processes of care;
- the highlighted importance of a key worker;
- the role of some factors known to be associated with evaluating processes of care was confirmed;
- some of the new facts, in particular the declining scores of parents with the longer duration of the child's treatment programs and the difference between the parent's scores according to the specialist doctor, who is following-up the children;
- the 5-dimensional structure of the MPOC-20 questionnaire was confirmed, its improvements were proposed;
- the stability of the assessment with the MPOC-20 and MPOC-SP questionnaires over a period of one year was shown.
- Based on these results we will suggest improvements to the system of health care and rehabilitation of chronically ill or disabled children in terms of establishing the network of key workers and organising educational programs.

SUMMARY

A thorough knowledge of processes of care and their subsequent improvement is one of the possible strategies to reduce the psychosocial problems of parents of chronically ill children. Hence, we wanted to assess the influence of demographic factors, the health status of the chronically ill children and the characteristics of the different programs of (re)habilitation on the assessment of processes of care provided by the parents (using the Measure of Process of Care, MPOC-20, questionnaire). We were particularly interested in the possible impact of the presence of a key worker.

Firstly, we have checked the sensitivity, internal consistency and stability in time of the Slovenian translation of the MPOC-20 and MPOC-SP. Then we invited parents whose children had been referred to 8 Slovene health institutions (two at tertiary level, 8, and 6 at secondary level of health care) during the period from 1st January 2011 to 31st December 2011. We also invited the care providers from the same 8 institutions. Parents (care providers) filled in MPOC20 (MPOCSP). Parents also answered the question on how the processes of care reduced their stress and filled in the Client Satisfaction Questionnaire (CSQ-8). They were also asked to fill in the questionn-

aire on demographic data, health status and treatment programs and rehabilitation of their chronically ill child. Data collection was followed by statistical analysis (univariate analysis, regression models, Confirmatory Factor Analysis and Structural Regression Model).

Parents of 235 children (80% were mothers) and 67 care providers participated in the study. The parents reported high overall satisfaction with the processes of care. They were the least satisfied with the provision of general information and specific information about the child. Results were in excellent agreement with previous study results (referring to means scores and ranking order of MPOC-20 subscales). Less than half of parents reported the availability of key person (a person who guides the family within the healthcare system; helps to coordinate the healthcare; enabling parents via offering support, information and resources, based on their needs). We found the availability of the key worker in the healthcare system to be positively associated with higher scores on all MPOC-20 scales (confirmed by univariate analyses and the regression model). We also found positive influence of child's male sex on Providing general information Subscale scores (univariate analysis and regression model). Longer involvement in the treatment was statistically significantly associated with lower scores in Enabling partnership (EP), Coordinated and Comprehensive Care for Child and Family (CCC) and

Respectful and Supportive Care subscales (structural regression model). Parents whose children visit a PRM specialist assessed the Enabling and Partnership scale, in average, higher (suggesting that rehabilitation supports the active involvement of parents with the entire rehabilitation team of various experts or therapists). Based on structural regression model we decided to transfer Item 5 from the CCC to the EP scale. The proportion of the clarified variance was from 7% to 22%. Results confirmed also the sensitivity, internal consistency and stability in time of the Slovenian translation of the MPOC-20 and MPOC-SP.

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LIST OF ORIGINAL PUBLICATIONS

1. Groleger Sršen K, Vidmar G, Sočan, G Zupan, A. Parental evaluation of processes of care in relation to the child, parent and family characteristics. *Int J Rehabil Res* 2014; 37: 220–228.
2. Groleger Sršen K, Vidmar G, Zupan A. Validity, internal consistency reliability and one-year stability of the Slovene translation of the Measure of Processes of Care (20-item version). *Child Care Health Dev* 2015; 41: 569–580.
3. Sočan G, Groleger Sršen K, Vidmar G, Zupan A. Model-based validation of the Slovenian 20-item version of the Measure of processes of care. *European Journal for Person Centered Healthcare* 2017; 5(1).



Katja Groleger Sršen, Xanthi Michail (Chairperson of EARM), Henk Stam (Editor-in-Chief of JRM) and Agneta Andersson (Editorial Manager of JRM) at the prize award ceremony.