

Kako starši in strokovni sodelavci vidijo postopke oskrbe kronično bolnih otrok v programih zdravljenja in rehabilitacije

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Uvod: V zadnjih desetletjih se je v postopkih zdravljenja in rehabilitacije kronično bolnih otrok uveljavil koncept obravnave, ki je usmerjena v družino (1). Želeli smo preveriti, kako starši in strokovni sodelavci ocenjujejo postopke oskrbe v programih zdravljenja in rehabilitacije. **Metode:** K sodelovanju v raziskavi smo povabili starše, katerih otroci so bili vključeni v postopke oskrbe v različnih zdravstvenih ustanovah leta 2010. K sodelovanju smo povabili tudi strokovne sodelavce iz istih ustanov. Za ocenjevanje smo uporabili Vprašalnik za ocenjevanje postopkov oskrbe (angl. Measures of Processes of Care, MPOC-20), ki so ga izpolnili starši, in Vprašalnik za ocenjevanje postopkov oskrbe, ki so ga izpolnili strokovni sodelavci (MPOC-SP) (2). Vprašalnik MPOC-20 vključuje 20 vprašanj (pet podlestvic), vprašalnik MPOC-SP pa 27 vprašanj o postopkih oskrbe (štiri podlestvice). Na vsako vprašanje je mogoče odgovoriti z oceno od 7 (v zelo veliki meri) do 1 (sploh ne). Na voljo je tudi ocena 0, ki pomeni, da na vprašanje ni mogoče odgovoriti. **Rezultati:** V raziskavo se je vključilo 235 staršev (80 odstotkov mater; 55 odstotkov otrok je bilo dečkov) in 67 strokovnih sodelavcev (14 zdravnikov, 14 fizioterapevtov, 18 medicinskih sester, šest delovnih terapevtov, tri učiteljice, sedem logopedov ter pet psihologov in socialnih delavcev, trije niso označili strokovne izobrazbe; povprečna starost strokovnih sodelavcev: 43,9 leta, povprečna delovna doba v timu za delo s kronično bolnimi otroki: 17 let). Starši so poročali o dobrih ocenah vedenja strokovnjakov. Povprečne ocene posameznih lestvic MPOC-20 so bile 5,83 (SD 1,10) za Koordinirano in celotno oskrbo, 5,62 (SD 1,12) za Spoštljivo oskrbo, 5,45 (SD 1,23) za Partnerstvo in omogočanje aktivne vloge, 5,33 (SD 1,61) za Posredovanje specifičnih informacij o otroku in 4,59 (SD 1,65) za Posredovanje splošnih informacij. Podobno so o svojem vedenju v postopkih oskrbe poročali tudi strokovni sodelavci: povprečna ocena 7,5 (SD 0,7) za Spoštljiv odnos do ljudi, 5,2 (SD 1,5) za Občutljivost v medosebnih odnosih, 4,8 (SD 1,5) za Posredovanje specifičnih informacij o otroku in 4,3 (SD 1,3) za Posredovanje splošnih informacij. Starši in strokovni sodelavci so menili, da sta v postopkih oskrbe najbolj pomanjkljivi prav posredovanje splošnih informacij in posredovanje specifičnih informacij o otroku. **Zaključki:** Starši in strokovni sodelavci so bili najmanj zadovoljni s posredovanjem informacij v postopkih oskrbe, zato bo v prihodnosti na tem področju treba pripraviti izobraževanje o postopkih oskrbe, ki so usmerjeni v družino, in izboljšati organizacijo dela.

Ključne besede: postopki oskrbe, starši, strokovni sodelavci, ocenjevanje, MPOC.

Processes of care for chronically disabled children: views of parents and care providers

Background: The model of family centred care has been implemented for the last decades for treatment and rehabilitation of chronically ill children (1). We wanted to explore how parents feel about services of care and how service providers report on their own behaviours in treatment programs and rehabilitation. **Methods:** We invited parents whose children were involved in the processes of care at different health care institutions in 2010. We invited also the service providers from the same institutions. Parents filled in the Measure of processes of care, MPOC-20 (2); service providers filled in the MPOC-SP (2). The questionnaire MPOC-20 consists of 20 questions (five subscales), while the MPOC-SP consists of 27 issues (four subscales). The items are answered on a 7-point scale ranging from 7 (»to a very great extent«) to 1 (»not at all«), with a 0 for »not applicable«. **Results:** 235 parents participated in the study (80% mothers, 55% of the children were boys) and 67 service providers (14 medical doctors, 14 physiotherapists, 18 nurses, six occupational therapists, three teachers, seven speech therapists and five psychologists and social workers. Three didn't mark their profession. The average age of service providers was 43.9 years. They served at their current position for the last 16.6 years (SD 8.1 years) and all of them were employed for a full time. Parents reported a quite high level of satisfaction with the processes of care. The mean scores were high on all the MPOC-20 scales except Providing General Information: mean scores were 5.83 (SD 1.10) for Coordinated and Comprehensive Care, 5.62 (SD 1.12) for Respectful and Supportive Care, 5.45 (SD 1.23) for Enabling and Partnership, 5.33 (SD 1.61) for Providing Specific Information about the Child and 4.59 (SD 1.65) for Providing General Information. Service providers reported similar results: the MPOC-SP mean subscale scores were 5.2 (SD 0.9) for Showing interpersonal sensitivity, 4.3 (SD 1.3) for Providing general information, 4.8 (SD 1.5) for Communicating specific information and 5.7 (SD 0.7) for Treating people respectfully. **Conclusion:** Parents and experts were least satisfied with providing of specific and general information, so in the future we have to prepare training on family centred services and improve the organization of work.

Key words: processes of care, parents, professionals evaluation, MPOC.

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