

Dimenzije kakovosti zdravstvene obravnave otrok/mladostnikov s posebnimi potrebami

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Raziskovalno vprašanje (RV): Velik delež svetovne populacije ima neko vrsto oviranosti. Zaposleni v zdravstvu morajo pri obravnavi pacienta upoštevati vse dejavnike, ki na pacienta in njegove bližnje vplivajo, prav tako pa morajo delovati skladno s posameznikovimi individualnimi potrebami.

Namen: Namen raziskave je opredeliti dimenzije zadovoljstva s kakovostjo zdravstvene obravnave na podlagi ugotovitev različnih avtorjev in hkrati definirati dejavnike, ki vplivajo na to, v kolikšni meri so starši otrok in mladostnikov s posebnimi potrebami oz. oviranostmi zadovoljni s kakovostjo zdravstvene obravnave njihovih otrok in mladostnikov.

Metoda: Raziskava temelji na sistematičnem pregledu obstoječe literature. Iskanje strokovnih in znanstvenih člankov odprtega tipa je potekalo v iskalnih bazah Springerlink, Science Direct, ProQuest, PubMed in Scopus. Časovni okvir iskanja so bile objave v obdobju med leti 2012 in 2023. Iskalni niz je ponudil 106 takšnih člankov. V nadaljnjo obravnavo smo vključili le članke, v katerih različni avtorji prikazujejo dejavnike, ki pozitivno oziroma negativno vplivajo na zadovoljstvo staršev z zdravstveno obravnavo njihovega otroka oziroma mladostnika s posebnimi potrebami. Kriterijem je ustrezalo 57 člankov. Rezultati glavnih ugotovitev so prikazani v tabelah.

Rezultati: Zaznani dejavniki, ki pozitivno vplivajo na zadovoljstvo staršev, so dostopnost obravnave, sodelovanje strokovnjakov in staršev, ustrezna komunikacija, aktivnosti za zmanjšanje anksioznosti staršev, na pacienta osredotočena oskrba in individualni pristop, neomejeni obiski, uporaba prilagojenega načrta zdravstvene obravnave, uporaba novosti, permanentno izobraževanje in usposabljanje zdravstvenih delavcev, uvedba koordinatorjev obravnave ter merjenje zadovoljstva staršev. Med zaznanimi negativnimi dejavniki so nepostavitev medicinske diagnoze, neprilagodljivost zdravstvenega osebja glede na nastalo situacijo, pomanjkljivo znanje in specifično znanje zdravstvenih delavcev, pomanjkljiva podpora ob prehodu iz mladostniške v odraslo dobo, pomanjkljiva komunikacija v procesu

obravnave ter med različnimi ustanovami in različnimi strokovnjaki, nedotakljivost določenih tem, pomanjkanje kontinuitete procesa obravnave in koordinacije pri delu, ne osredotočenost na paciente ter nedostopnost storitev.

Organizacija: Članek predstavlja doprinos k razumevanju pomembnosti spremljanja zadovoljstva staršev otrok in mladostnikov s posebnimi potrebami, ki so uporabniki zdravstvenih storitev. Rezultati naše raziskave prikazujejo pozitivne vplive tako na otroke in mladostnike, na njihove starše kot tudi na zdravstvene delavce, ki sodelujejo v procesu obravnave. Prikazani negativni vplivi pa dajejo idejo za razmislek, kako naprej, da bo delo še bolj kakovostno opravljeno.

Družba: Podane ugotovitve so lahko v pomoč vodstvu zdravstvenih ustanov pri iskanju rešitev za izboljšanje zadovoljstva staršev otrok in mladostnikov s posebnimi potrebami.

Originalnost: Gre za prvo tovrstno raziskavo v slovenskem prostoru.

Omejitve/nadaljnje raziskovanje: Raziskava je omejena na pregled obstoječe literature v elektronskih podatkovnih bazah. Rezultati raziskave podajajo idejo in osnovo za nadaljnje raziskovanje, kjer bi lahko v naši raziskavi dobljene rezultate implementirali na zdravstveno ustanovo in tam izvedli raziskavo o zadovoljstvu z zdravstveno obravnavo te populacije.

Ključne besede: posebne potrebe, otroci in mladostniki, zdravstvena obravnava, kakovost, zadovoljstvo, starši, na pacienta osredotočena zdravstvena obravnava.

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The Dimensions of Quality of Healthcare of Children/Adolescents with Disabilities

Research Question (RQ): A large percent of world's population has some kind of a disability. Healthcare workers have to take into consideration all of the factors that have an impact on the patient and his family and also consider individual needs of the patient.

Purpose: The aim of the study is to identify the dimensions of satisfaction with the quality of healthcare based on the findings of different authors, and at the same time to define the factors that influence the extent to which parents of children and adolescents with disabilities are satisfied with the quality of healthcare provided to their children and adolescents.

Method: The research is based on a systematic review of the existing literature. A search for peer-reviewed and open-access scientific articles was conducted in SpringerLink, Science Direct, ProQuest, PubMed and Scopus. The time frame of the search was publications between 2012 and 2023. The search offered 106 such articles. For further consideration we included articles in which different authors reported factors that positively or negatively influence parents' satisfaction with the healthcare of their child and adolescent with disabilities. 57 articles met the criteria. The results of the main findings are shown in the tables.

Results: The perceived factors that have a positive impact on parental satisfaction are accessibility of care, cooperation between professionals and parents, adequate communication, activities to reduce parental anxiety, patient-centred care and individual approach, unrestricted visits, use of a personalised care plan, use of innovations, continuous education and training of health professionals, introduction of care coordinators and measurement of parental satisfaction. Among the negative factors perceived are the lack of medical diagnosis, the inflexibility of healthcare workers to the situation, the lack of knowledge and specific skills of healthcare professionals, the lack of support for the transition from adolescence to adulthood, the lack of communication in the treatment process and between different institutions and different professionals, the intangibility of certain topics, the lack of continuity in the treatment process and coordination at work, the lack of focus on the patient and the lack of accessibility of services.

Organization: This article contributes to the understanding of the importance of monitoring the satisfaction of parents of children and adolescents with disabilities who are users of healthcare services. The results of our research show positive impacts on children and adolescents, their parents and the healthcare professionals involved in the healthcare

process. The negative impacts shown give an idea of how to think ahead to improve the quality of work.

Society: The findings may help the management of healthcare institutions to find solutions to improve the satisfaction of parents of children and adolescents with disabilities.

Originality: It is the first study of its kind in Slovenia.

Limitations / further research: The research is limited to a review of existing literature in electronic databases. The results of the survey provide an idea and a basis for further research, where the results obtained in our study could be implemented in a healthcare facility and a survey on satisfaction with the healthcare of this population could be conducted there.

Keywords: disabilities, children and adolescents, healthcare, quality, satisfaction, parents, patient-centred-care.

Andreja Vovk graduated from the Faculty of Health Sciences in Ljubljana, majoring in nursing, in 2001 and obtained her master's degree in nursing from the Faculty of Health Care Angela Boškin Jesenice in 2020. Since 1996, she has been employed at the University Medical Centre Ljubljana, department of Gynaecology and Obstetrics, and currently performs the duties and tasks of a consultant in the field of quality and development in healthcare and midwifery and coordinator of the quality management system. She is a quality systems manager, external and internal auditor according to ISO 9001, lecturer on quality and safety topics and head of the quality and safety module at the Nurse and Midwifery Organization of Ljubljana.
