

**VISOKA ZDRAVSTVENA ŠOLA V CELJU**

**DIPLOMSKO DELO**

**ZDRAVSTVENA NEGA MLADOSTNICE Z RETTOVIM SINDROMOM**

**NURSING CARE OF AN ADOLESCENT WITH THE RETT  
SYNDROM**

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## IZVLEČEK

**Uvod:** Rettov sindrom je zapletena genetična nevrološka motnja v razvoju, ki se začne v zgodnjem otroštvu in je značilna predvsem za deklice. Zahtevna zdravstvena nega oseb s tem sindromom mora biti individualna in celostna, medicinske sestre pa pri takšni negi nujno potrebujejo posebna znanja. Pri ugotavljanju zdravstvenih in negovalnih potreb tesno sodelujejo tako s starši otrok, kot z ostalimi zdravstvenimi strokovnjaki.

**Namen:** Namen diplomskega dela je predstavitev Rettovega sindroma in zdravstvene nege pri mladostnici s tem sindromom, ki biva v institucionalnem varstvu.

**Metode dela:** V teoretičnem delu diplomskega dela so bili podatki zbrani s pomočjo domače in tuje strokovne in znanstvene literature ter s pomočjo bibliografskih baz COBISS in CINAHL. V empiričnem delu je bila uporabljena kvalitativna metoda in izdelana študija primera mladostnice z Rettovim sindromom. V ta namen sta bili pregledani njena zdravstvena in negovalna dokumentacija. Instrumenta raziskave sta bila tudi strukturirana intervjuja z medicinsko sestro, ki pri mladostnici izvaja zdravstveno nego, in z materjo mladostnice.

**Rezultati:** Najpogostejše negovalne diagnoze, ki jih pri mladostnici ugotavljajo medicinske sestre, so: popolna nesposobnost izvajanja osebne nege, prehranjevanja in uživanja tekočin, samostojnega premikanja in spreminjanja položajev, najtežavnejši med vsemi pa sta deklinična nezmožnost besednega sporazumevanja z okolico in težko prepoznavanje njene nebesedne govorice, kar posledično vodi v bistveno zmanjšano kakovost njenega življenja ter okrnjene socialne stike. Zaradi dobrega poznavanja bolezni s strani dekletove matere, njenega zglednega sodelovanja z osebjem, ki se ukvarja z njo, le-ta kljub vsem primanjkljajem zadovoljivo vzdržuje preostale življenjske funkcije.

**Razprava in sklep:** Medicinska sestra, ki pri mladostnici izvaja zdravstveno nego, pozna značilnosti tega sindroma in pri njej najpogosteje ugotavlja negovalne diagnoze, ki so navedene tudi v strokovni literaturi. Pri izvajanju aktivnosti zdravstvene nege upošteva njene individualne potrebe, vendar je pri tem bolj usmerjena v deklinične telesne težave, ki jih tudi sistematično rešuje, manj pa je osredotočena na njeno psihično počutje in čustvene potrebe, čeprav ravno ti področji potrebujejo največ pozornosti. Delo z mladostnico je oteženo zaradi njene nezmožnosti komunikacije, zato jo medicinska sestra pozorno opazuje in je pri delu z njo potrpežljiva in empatična. Individualni načrt zdravstvene nege sproti prilagaja njenim potrebam, kar ob dodatnem strokovnem znanju zahteva tudi veliko praktičnih izkušenj.

**Ključne besede:** Rettov sindrom, medicinska sestra, mladostniki, zdravstvena nega.

## **ABSTRACT**

**Introduction:** Rett Syndrome is a complicated genetic neurological disorder in development. It starts in early childhood and it is typical mostly of girls. The demanding nursing-care of the people suffering from this syndrome has to be individual and whole. The nurses who carry it out have to have special knowledge and competence. When establishing the nursing-care needs of an individual, the nurses cooperate closely with the parents of the children suffering from RS as well as with the rest of the health specialists.

**Purpose:** The purpose of this diploma paper is to present Rett Syndrome and nursing-care of a young girl suffering from this syndrome. She is institutionalized.

**Methods of work:** In the theoretical part, the data were gathered using Slovenian and foreign scientific literature and the bibliographical data bases: COBISS and CINAHL. In the empirical part, the qualitative method and an elaborate study were used in the case of the girl suffering from Rett Syndrome. For this purpose her health and nursing-care documentations were examined. The research tools also included two structured interviews which were carried out with the nurse who does the nursing-care work and the girl's mother.

**Results:** The most frequent nursing-care diagnoses are: total inability to do personal hygiene, to eat, to drink, to move and to change positions. The two most problematic diagnoses are the girl's inability to communicate verbally and the vagueness of her non-verbal communication. Thus the quality of her living and her social contacts is greatly reduced. The girl's mother has a lot of knowledge about the illness and she cooperates with the medical staff most effectively, so the girl's other vital functions are satisfactory despite all the deficiencies.

**Discussion and conclusion:** The nurse, who performs nursing-care with the girl, knows the characteristics of the syndrome and she frequently recognises the nursing-care diagnoses which are also listed in expertise manuals. When carrying out the activities, the nurse pays attention to the patient's individual needs, but she is more focused on the physical problems, which she systematically solves, than the psychological state and the emotional needs, although the latter two require most attention. The work is especially demanding because of her inability to communicate, that is why the nurse practices most careful monitoring, patience and empathy. The individual plan is adjusted to the patient's needs which demand expert knowledge as well as a lot of practical experience.

**Key words:** Rett Syndrome, nurse, adolescent, nursing-care.