

VISOKA ZDRAVSTVENA ŠOLA V CELJU

DIPLOMSKO DELO

**AKTIVNOSTI ZDRAVSTVENE NEGE OSEB S
CRI DU CHAT SINDROMOM**

**NURSING CARE ACTIVITES FOR PERSONS WITH
CRI DU CHAT SYNDROME**

Študentka: MARTINA KRIŽNIK JEZERNIK

Mentorica: pred. IVANKA LIMONŠEK, dipl. m. s., univ. dipl.org.

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IZVLEČEK

Uvod: Osebe s Cri du Chat sindromom imajo skupne značilnosti, ki jih ločijo od ostalih in ki jih opredeljujejo. Zaradi številnih zdravstvenih problemov potrebujejo skrbno zdravstveno nego. Pogosto so vključeni v ustrezne institucije. Pomembno je sodelovanje zdravstvenega in multidisciplinarnega tima ter staršev. Komunikacija med njimi in starši mora temeljiti na medsebojnem zaupanju. Starši so tisti, ki se prvi soočijo z drugačnostjo otroka.

Namen: Namen diplomskega dela je predstaviti in opisati značilnosti oseb s Cri du Chat sindromom. Namen je predstaviti zdravstveno nego in aktivnosti zdravstvene nege pri osebah s Cri du Chat sindromom ter opisati značilnosti življenja oseb s Cri du Chat sindromom.

Metode dela: Raziskovalna metodologija je temeljila na zbiranju podatkov iz zdravstveno negovalne dokumentacije, na opravljenem strukturiranem intervjuju delavcev negovalnega tima in razgovora z delavci širšega ali multidisciplinarnega tima. Opravljen je bil razgovor s starši otroka s Cri du Chat sindromom.

Rezultati: Rezultati raziskave so pokazali, da imajo osebe s Cri du Chat sindromom veliko zdravstvenih problemov. Zaradi tega je potrebno izdelati individualne načrte zdravstvene nege po procesni metodi dela. Izkazalo se je, da ima oseba s Cri du chat sindromom največ problemov pri hranjenju, spanju, gibanju in vedenju.

Sklep: Zdravstvena nega oseb s Cri du Chat sindromom je zahtevna, potrebno je imeti veliko znanja, empatije in izkušenj. Vsi, ki se vključujejo v delo, morajo vzpostaviti visok nivo sodelovanja in timskega dela.

Ključne besede: Cri du Chat sindrom, zdravstveni problemi, zdravstvena nega, medicinska sestra, institucija, multidisciplinarni tim, starši.

ABSTRACT

Introduction: People with Cri du Chat syndrome share common characteristics that distinguish them from others and define them. Due to numerous health problems they need careful nursing. They are often included in the relevant institutions. It is important cooperation between nursing team and parents. Communication between team and parents should be based on mutual trust. Parents are the ones which are first confronted with otherness of their child.

Purpose: The purpose of this study is to present and describe the characteristics of people with Cri du Chat syndrome. The purpose is to present the nursing care and nursing care activities for people with Cri du Chat syndrome and describe the life characteristics of persons with Cri du Chat syndrome.

Methods: The research methodology was based on data collection from health care documentation, performed a structured interview with workers of a nursing team and discussion with the workers of the wider multidisciplinary team. There has been an interview with the parents of a child with Cri du Chat syndrome.

Results: The results showed us that persons with Cri du Chat syndrome have many health problems. There must be made individual care plans for processing working method. It turns out that person with Cri du chat syndrome has the most problems with feeding, sleep, movement and behaviour.

Conclusion: Health care of people with Cri du Chat syndrome is difficult, it is necessary to have a lot of knowledge, understanding and experience. All those involved in the work should establish a high level of cooperation and teamwork.

Keywords: Cri du Chat Syndrome, health problems, nursing care, a nurse, an institution, a multidisciplinary team, parents.