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Sestrinska uloga u procesu palijativne zdravstvene njege pedijatrijskih onkoloških pacijenata

Nursing role in the process of palliative care for pediatric oncology patients

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Sažetak

Unatoč sve većem napretku u liječenju malignih bolesti kod djece, neke bolesti ipak nije moguće izliječiti i smrtni je ishod neminovan. Razvojne osobitosti djece te ovisnost o roditeljima zahtijevaju potpuno drugačiji pristup skrbi u odnosu na odrasle pacijente. Iako se palijativna skrb za odrasle i za djecu temelji na istim načelima ublažavanja patnje i usmjerenosti na kvalitetu života, važno je osvijestiti različitost potreba odraslih i djece te im adekvatno pristupiti. Medicinska sestra kao član multidisciplinarnog tima koji je tijekom 24 sata uz pacijenta ima krucijalnu ulogu u prepoznavanju fizičkih i emocionalnih simptoma bolesti i njihovom upravljanju uporabom različitih metoda i alata. Osim za dijete, dijagnoza maligne bolesti vrlo je stresna i za cijelu obitelj djeteta. Važno je da medicinska sestra koja sudjeluje u skrbi ima dobro razvijene komunikacijske vještine udružene s empatijom kako bi adekvatno mogla pružati podršku obitelji oboljelog djeteta tijekom trajanja bolesti i nakon djetetove smrti. Uz emocionalnu inteligenciju i kompetencije koje ima, važno je da medicinska sestra „ide ukorak s vremenom" kako bi na svojem radnom mjestu pružala visokokvalitetnu skrb pomoću najnovijih smjernica i tehnologija.

Ključne riječi: palijativna skrb, medicinska sestra, neugodni simptomi

Kratak naslov: Palijativna zdravstvena njega djeteta

Abstract

Despite significant advances in the treatment of malignant diseases in children, some illnesses remain incurable, and death becomes inevitable. The developmental characteristics of children and their dependence on parents require a completely different approach to care compared to adult patients. Although palliative care for adults and children is based on the same principles of alleviating suffering and focusing on quality of life, it is important to recognize the different needs of adults and children and address them appropriately. As a member of the multidisciplinary team which is with the patient 24 hours a day, the nurse plays a crucial role in recognizing the physical and emotional symptoms of the illness and managing them using various methods and tools. The diagnosis of malignant disease is extremely stressful not only for the child but also for the entire family, so the nurse involved in care must have well-developed communication skills combined with empathy to adequately provide support during the illness and after the child's death. In addition to emotional intelligence and the competencies they possess, nurses need to keep up with time to deliver high-quality care using the latest guidelines and technologies in their workplace.

Keywords: palliative care, nurse, distressing symptoms

Short title: Pediatric palliative care

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Uvod

Maligne bolesti danas predstavljaju vodeći uzrok smrtnosti u dječjoj populaciji, čineći ih jednim od najtežih izazova s kojima se suočava pedijatrijska zdravstvena skrb. Napretkom suvremene medicine velik broj bolesti uspješno se liječi, međutim kod određenog broja djece izlječenje ipak nije moguće postići [1]. Osim onkološke skrbi, djeci je potrebna skrb koja će biti usredotočena na ublažavanje fizičkih simptoma bolesti i terapije, ali i psihološke patnje i stresa koji se javljaju [2]. Kako bi se zadovoljile ove potrebe, razvila se palijativna skrb čija je filozofija pružanje suosjećajne skrbi s velikim naglaskom na kvalitetu života i smanjenje patnje [2]. Pedijatrijska se palijativna skrb prema Svjetskoj zdravstvenoj organizaciji definira kao „aktivna i potpuna skrb o djetetovu tijelu, njegovu umu i duhu te uključuje i podršku obitelji" [3]. Iako se palijativna skrb za odrasle i za djecu temelji na istim bioetičkim načelima, važno je osvijestiti da djeca nisu mali odrasli i da im je

Introduction

Malignant diseases today represent the leading cause of mortality in the pediatric population, making them one of the most challenging issues faced by pediatric healthcare. With the advancements in modern medicine, a large number of diseases are successfully treated; however, for some children, achieving a cure is still not possible [1]. In addition to oncology care, children require care that focuses on alleviating the physical symptoms of the disease and treatment, as well as the psychological suffering and stress that arise [2]. To meet these needs, palliative care has been developed, with a philosophy centered on providing compassionate care, emphasizing quality of life, and reducing suffering [2]. Pediatric palliative care is defined by the WHO as "active and comprehensive care of the child's body, mind, and spirit, and it also includes support for the family" [3]. Although palliative care for adults and children is based on the same bioethical principles, it is crucial to recognipotrebno pristupiti na drugačiji način. Sama bolest i njezino liječenje uzrokuju širok raspon emocija kod djece, što zahtijeva adekvatno prepoznavanje i kvalitetne komunikacijske vještine svih djelatnika uključenih u djetetovu skrb. Jedna je od bitnih razlika i ovisnost o roditeljima, stoga je krucijalno u skrb za dijete aktivno uključiti njegovu obitelj, ali istovremeno biti osjetljiv i na njihove potrebe i probleme [4]. Medicinska sestra jedan je od najvažnijih članova tima koji skrbi za dijete. Kao osoba koja provodi najviše vremena uz dijete, od medicinske se sestre očekuje da preuzme različite „uloge“ poput savjetnice, pružateljice skrbi, zagovornice pacijentovih potreba i brojne druge [4]. Cilj je ovog članka istaknuti ključnu ulogu medicinske sestre u procesu pružanja palijativne skrbi djeci, ali i prikazati aktualne trendove te ponuditi konkretne preporuke za unapređenje prakse u ovom specifičnom području zdravstvene njege.

Ključne kompetencije i odgovornosti medicinske sestre

Djeca i njihovi roditelji najviše kontakata ostvaruju upravo s medicinskim sestrama, stoga je važna konstantna težnja k uspostavljanju odnosa s uzajamnim povjerenjem. Istovremeno provođenje mjera za izlječenje i produljenje života zajedno s mjerama za ublažavanje patnje i upravljanje simptomima, kod roditelja često dovodi do osjećaja neizvjesnosti te posljedičnog stresa, anksioznosti i smanjene predanosti postizanju postavljenih ciljeva. Od medicinske se sestre očekuje da bude sigurna u vlastite kompetencije koje su joj potrebne za provođenje visokokvalitetne palijativne skrbi; upravljanje simptomima, ublažavanje patnje, psihosocijalna podrška djetetu i njegovoj obitelji, komunikacijske vještine i upravljanje stresnim situacijama [5]. Palijativna se skrb uvodi već u vrijeme postavljanja dijagnoze, posebno kod malignih bolesti s niskom mogućnošću izlječenja [6]. Medicinske sestre ključne su pri utvrđivanju potreba pacijenata i njihovih obitelji. Da bi se postigla visoka kvaliteta u pružanju palijativne skrbi, važno je da njega bude prilagođena potrebama, vrijednostima, preferencijama pacijenta, ali i njegove obitelji [5, 6, 7]. Medicinska sestra planira zdravstvenu njegu i postavlja ciljeve u dogovoru s oboljelim djetetom i članovima njegove obitelji koje prethodno treba informirati o samoj bolesti, njezinoj prognozi te o prednostima i nedostacima svake potencijalne intervencije [4, 7]. U obitelji također treba pronaći osobu koja će biti odgovorna za donošenje važnih odluka ako dijete nije sposobno sudjelovati u istom [7].

Maligna bolest i terapijski postupci izazivaju niz neugodnih simptoma kod djece. Collins i suradnici u svojem su istraživanju koristeći MSAS 10–18 (engl. *Memorial Symptom assesment scale for 10 to 18 years old*) na uzorku od 160 djece utvrdili da su najčešće navođeni simptomi bili: bol, smanjena razina energije, pospanost, mučnina, kašalj, gubitak apetita i psihološke poteškoće [8]. Bol kao najčešći popratni simptom maligne bolesti i terapijskih postupaka vrlo je kompleksan simptom zbog svoje subjektivnosti, što od medicinskih sestara zahtijeva pažljivu procjenu. Prilikom procjene mogu se upotrebljavati različite skale poput: Comfort skale, FLACC skale, McGillova upitnika, QUESTT sustava i drugih [3].

ze that children are not simply small adults and that they require a different approach. The disease and its treatment cause a wide range of emotions in children, necessitating appropriate recognition and high-quality communication skills from all caregivers involved. One of the key differences is the child's dependence on parents, making it crucial to actively involve the family in the child's care while also being sensitive to their needs and challenges [4]. The nurse is one of the most important members of the team caring for the child. As the person who spends the most time with the child, the nurse is expected to take on various "roles", such as advisor, caregiver, advocate for the patient's needs, and many others [4]. This article aims to highlight the crucial role of the nurse in the process of providing palliative care to children, as well as to present current trends and offer concrete recommendations for improving practice in this specific field of healthcare.

Key Competencies and Responsibilities of the Nurse

Children and their parents have the most contact with nurses, making it important to constantly strive to establish a relationship based on mutual trust. Simultaneously implementing measures for curing and prolonging life, together with measures for alleviating suffering and symptom management, often leads to uncertainty among parents, resulting in stress, anxiety, and reduced commitment to achieving set goals. Therefore, the nurse is expected to be confident in her competencies, which are necessary for providing high-quality palliative care: symptom management, alleviation of suffering, psychosocial support for the child and their family, communication skills, and handling stressful situations [5]. Palliative care is introduced as early as the time of diagnosis, especially in cases of malignant diseases with a low chance of cure [6]. Nurses are, therefore, in a crucial position when it comes to identifying the needs of patients and their families. To achieve high-quality palliative care, care must be appropriate to the needs, values, and preferences of the patient and their family [5, 6, 7]. The nurse plans the healthcare and sets goals in agreement with the sick child and his family members, who should first be informed about the disease, its prognosis, and the advantages and disadvantages of each potential intervention [4, 7]. It is also necessary to identify a family member responsible for making important decisions if the child cannot participate in the process [7].

Malignant diseases and therapeutic procedures cause a range of unpleasant symptoms in children. In their study, Collins and colleagues, using the MSAS 10-18 (Memorial Symptom Assessment Scale for 10 to 18 years) on a sample of 160 children, found that the most commonly reported symptoms were pain, decreased energy levels, drowsiness, nausea, cough, loss of appetite, and psychological difficulties [8]. Pain, as the most common accompanying symptom of malignant disease and therapeutic procedures, is a very complex symptom due to its subjectivity, which requires careful assessment by nurses. Various scales can be used for assessment, such as the Comfort Scale, FLACC Scale, McGill Pain Questionnaire, QUESTT System, and others [3].

Sve se više govori o pozitivnim učincima koje terapija glazbom može imati na poteškoće koje se javljaju zbog bolesti i terapijskih postupaka poput boli, problema sa spavanjem, anksioznosti i depresije. Istraživanje provedeno u kirurškoj i pedijatrijskoj jedinici intenzivne skrbi (engl. *SICU/PICU*) dviju bolnica u SAD-u dovelo je do saznanja da terapija glazbom može poslužiti kao alat u terapiji neugodnih simptoma. Pacijenti i djelatnici koji su sudjelovali u skrbi naveli su pozitivan učinak glazbene terapije na olakšavanje boli te na spavanje. Također, primijećen je i blagotvoran učinak na smanjenje anksioznosti i depresije koja je česta kod pacijenata koji se nalaze u završnom stadiju života [9].

Osim fizičkih simptoma, česte su i različite psihološke reakcije na bolest i umiranje. Saznanje o malignoj bolesti djeteta kod obitelji izaziva poprilično šok. Dijete bez obzira na svoju dob shvaća da se u njegovu životu događa velika promjena. Uobičajenu svakodnevicu zamjenjuje boravak u bolnici te različiti dijagnostički i terapijski postupci koji mogu biti prilično neugodni. Budući da ovakav tempo izaziva stres, važno je da medicinska sestra djetetu osigura stalnu podršku i uključenost roditelja koji mogu najbolje procijeniti djetetovo ponašanje i pružiti mu utjehu [10].

S obzirom na sve veći priljev stranog stanovništva, bitno je na umu imati različita kulturna i vjerska uvjerenja te navike pacijenata. Rasne i etničke razlike značajno utječu na pristup pacijenata palijativnoj skrbi, manifestirajući se putem raznolikih preferencija i očekivanja vezanih za skrb na kraju života. Primjerice, pacijenti iz kulturološki različitih sredina mogu imati oprečne stavove prema analgeziji; dok jedni preferiraju maksimalno ublažavanje boli, drugi mogu biti suzdržani prema uzimanju analgetika zbog različitih vjerskih ili kulturalnih razloga. Također, vrste intervencija koje pacijenti smatraju prihvatljivima te količina informacija koje žele imati o svojoj bolesti često se razlikuju. Na primjer, neki pacijenti žele znati sve o svojoj bolesti i prognozi, dok neki preferiraju da se informacije filtriraju kroz članove obitelji ili druge autoritete u zajednici. Komunikacija između djelatnika koji sudjeluju u skrbi te pacijenata i njihovih obitelji također je različita; u nekim kulturama izravan i otvoren pristup može se smatrati neprimjerenim, dok se u drugim kulturama cijeni otvorenost i jasna komunikacija. Osim toga, uloga obitelji u donošenju odluka može značajno varirati, posebno kod djece različite životne dobi. U nekim se kulturama ističe autonomija, međutim, neke kulture preferiraju kolektivno donošenje odluka o postupcima koji će se provoditi kod pacijenta. Pojam patnje također se oprečno shvaća. Jedni patnju vide kao neizbježan, pa čak i duhovno značajan aspekt života, a drugi žele spriječiti bol i patnju pod svaku cijenu [11]. S obzirom na navedene razlike, svim djelatnicima koji skrbe za pacijenta treba biti prioritetno razumijevanje i poštivanje zahtjeva pacijenta bez obzira na različite stavove [4].

Sve intervencije koje medicinska sestra provodi kod djeteta popraćene su komunikacijom, bilo verbalnom ili neverbalnom, stoga su dobre komunikacijske vještine sestre iznimno važne, posebno kod ovako osjetljive skupine pacijenata. Saznanje o ozbiljnoj bolesti kod djeteta izaziva stres i nelagodu, no poželjno je s djetetom razgovarati o bolesti onoliko koliko dijete dozvoli i koliko je spremno na to. Prije razgovora o bolesti, potrebno je procijeniti koliko dijete

There is increasing discussion about the positive effects that music therapy can have on the difficulties that arise due to illness and therapeutic procedures, such as pain, sleep problems, anxiety, and depression. A study conducted in the Surgical and Pediatric Intensive Care Units (SICU/PICU) of two hospitals in the United States found that music therapy can serve as a tool in the treatment of unpleasant symptoms. Patients and healthcare professionals involved in care reported a positive effect of music therapy on pain relief and sleep. Additionally, a beneficial effect on reducing anxiety and depression, which are common in patients in the terminal stages of life, was also observed [9].

In addition to physical symptoms, various psychological reactions to illness and dying are also common. Learning about a child's malignant disease causes considerable shock within the family. Regardless of their age, the child understands that a significant change is occurring in their life. The usual daily routine is replaced by hospital stays and various diagnostic and therapeutic procedures, which can be unpleasant. Given that this pace can be stressful, the nurse needs to provide the child with constant support and involve the parents, who can best assess the child's behavior and provide comfort [10].

Considering the increasing influx of foreign residents, it is important to keep in mind different cultural and religious beliefs and habits of patients. Racial and ethnic differences significantly influence patients' access to palliative care, manifesting through diverse preferences and expectations related to end-of-life care. For example, patients from culturally diverse backgrounds may have differing attitudes toward analgesia; while some prefer maximum pain relief, others may be hesitant to take analgesics for various religious or cultural reasons. Additionally, the types of interventions patients consider acceptable and the amount of information they wish to have about their illness often vary. For example, some patients want to know everything about their disease and prognosis, while others prefer that information be filtered through family members or other community authorities. Communication between caregivers and patients, and their families, also varies; in some cultures, a direct and open approach may be considered inappropriate, while in others, openness and clear communication are valued. Furthermore, the role of the family in decision-making can vary significantly, especially when it comes to children of different ages. In some cultures, autonomy is emphasized, while others prefer collective decision-making about the procedures to be carried out for the patient. The concept of suffering is also understood differently. Some view suffering as an inevitable and even spiritually significant aspect of life, while others aim to prevent pain and suffering at all costs [11]. Given these differences, it should be a priority for all caregivers to understand and respect the patient's requirements, regardless of differing attitudes [4].

All interventions that the nurse performs with the child are accompanied by communication, whether verbal or nonverbal, making good communication skills of the nurse extremely important, especially with such a sensitive group of patients. Learning about a serious illness in a child, regardless of age, causes stress and discomfort, but it is desirado sad zna i koliko toga želi znati kako bi sestra znala uputiti dijete u ono što ga čeka u budućnosti. U razgovoru je potrebno upotrebljavati jasne pojmove prilagođene dobi i djetetovu shvaćanju, a nakon svakog razgovora s djetetom važno je procijeniti koliko nas je dijete razumjelo, ali i kako se osjeća [12]. Osim kod oboljelog djeteta, dijagnoza maligne bolesti izaziva snažan stres i kod roditelja. Weiss i Feister (2018) ističu važnost rane komunikacije s roditeljima, osobito u slučajevima *longshot* terapije (*longshot* – terapijski postupci koji nemaju učinka, ali roditeljima pružaju nadu) koji dovode do tzv. faze *fantazije* kod roditelja koju karakteriziraju česta emocionalna i etička razmatranja. Idealan razgovor s roditeljima uključuje iskreno iznošenje informacija koje roditeljima omogućava ispravno donošenje odluka. Pretjeran i neutemeljen optimizam, kao i uskraćivanje informacija, potrebno je izbjegavati [13].

Briga oko teško bolesnog djeteta često može biti emotivno i fizički iscrpljujuća za roditelje i ostale članove obitelji. Osim na tjelesne i psihološke aspekte, ozbiljna bolest djeteta utječe i na odnose u obitelji [3]. Da bi roditelji djetetu mogli pružati najbolju moguću skrb, važno je kod njih osvijestiti da je i njima potreban odmor i predah od svakodnevnih aktivnosti. Primjena *skrbi radi predaha* roditeljima omogućuje prije svega odmor, ali i mogućnost za obavljanje vlastitih životnih obaveza. Ovakav oblik pomoći nude hospiciji, stacionarne jedinice, dnevni boravci, a organizacija je moguća ovisno o zahtjevima roditelja, odnosno pružatelja skrbi [4, 13]. Istraživanje autorice Davies i suradnika iz 2004. godine ukazalo je na pozitivan učinak skrbi radi predaha na djecu, roditelje, ali i na braću i sestre bolesnog djeteta. Oboljela djeca istaknula su relaksaciju i užitak, učenje, socijalizaciju te osjećaj slobode. Roditeljima je odgovarao osjećaj slobode, udobnosti, vrijeme za sebe, dok su braća i sestre istaknuli osjećaj važnosti i toga da je netko usmjeren i na njih [14].

Unatoč profesionalnim naporima zdravstvenih djelatnika, smrtni je ishod kod neke djece neminovan kraj bolesti. Kad se približi kraj djetetova života, medicinske sestre trebale bi odvojiti umiruće dijete od ostalih pacijenata, a roditelje informirati na vrlo empatičan način kako bi što bezbolnije prihvatili novonastalu situaciju. Iako se dijete više aktivno ne liječi, svakako je potrebno učiniti sve da bi se djetetu olakšala patnja i umanjili svi popratni neugodni simptomi [4].

Smrt djeteta za roditelja zasigurno je jedan od najtraumatičnijih događaja čije posljedice traju dugo nakon same smrti [4]. Žalovanje je prirodan proces koji se javlja kod svake osobe koja je izgubila nekoga ili nešto do čega joj je bilo stalo. Uloga zdravstvenih djelatnika, a posebno medicinskih sestara, jest da roditeljima osvijeste da je žalovanje proces koji se treba dogoditi i u kojem se prolazi kroz određene faze. Bez obzira na različite savjete i preporuke, najvažnije je roditeljima pružiti potrebnu podršku i razumijevanje tijekom tog izuzetno teškog i emotivnog perioda života [12].

Tehnološke inovacije

Napredak u tehnologiji transformirao je naše živote i olakšao obavljanje svakodnevnih aktivnosti uporabom pa-

ble to talk to the child about it as much as they allow and are ready for. Before discussing the illness itself, it is necessary to assess how much the child already knows and how much they want to know so that the nurse can understand how much to inform the child about what lies ahead. It is essential to use clear terms adapted to the child's age and level of understanding, and after each conversation with the child, it's important to assess how much they understood and how they felt [12]. The diagnosis of a malignant disease also causes significant stress in parents. Weiss and Feister (2018) emphasize the importance of early communication with parents, especially in cases of 'longshot' therapy (longshot - therapeutic procedures that have little chance of success but provide hope for the parents), which leads to the so-called 'fantasy phase' for parents, characterized by frequent emotional and ethical considerations. An ideal conversation with parents involves the honest presentation of information that allows them to make informed decisions. Excessive and unfounded optimism, as well as withholding information, should be avoided [13].

Caring for a seriously ill child can often be emotionally and physically exhausting for parents and other family members. In addition to affecting physical and psychological aspects, a serious illness in a child also impacts family relationships [3]. For parents to be able to provide the best possible care for their child, they need to realize that they too need rest and a break from daily activities. The implementation of respite care primarily provides parents with rest but also the opportunity to attend to their own life obligations. This form of assistance is offered by hospices, inpatient units, and daycare centers, and it can be organized according to the requirements of the parents or caregivers [4, 13]. A 2004 study by Davies and colleagues highlighted the positive effect that respite care has on children, parents, and siblings of the sick child. The sick children reported experiencing relaxation and enjoyment, learning, socialization, and a sense of freedom. Parents appreciated the sense of freedom, comfort, and time for themselves, while the siblings mentioned feeling important and that someone was paying attention to them as well [14].

Despite the efforts of healthcare professionals, a fatal outcome is an inevitable end to the illness for some children. As the end of the child's life approaches, nurses should separate the dying child from other patients and inform the parents in a very empathetic manner to help them accept the new situation as painlessly as possible. Although the child is no longer actively being treated, it is essential to do everything possible to alleviate the child's suffering and minimize all accompanying unpleasant symptoms [4].

The death of a child is undoubtedly one of the most traumatic events for parents, and its effects last long after the death itself [4]. Grieving is a natural process that occurs in anyone who has lost someone or something they care about. The role of healthcare professionals, particularly nurses, is to help parents understand that grieving is a process that needs to happen and they go through certain phases. Regardless of the various advice and recommendations, it is most important to provide parents with the necessary support and understanding as they go through this extremely difficult and emotional period of their lives [12].

metnih telefona i digitalnih platformi. U medicini su nove tehnologije dovele do preciznije dijagnostike i poboljšane skrbi za pacijente u svim njezinim granama [15]. Iako je često uvriježeno mišljenje da se za pacijenta koji se nalazi na kraju života ne može ništa učiniti jer provedeni postupci neće dovesti do izlječenja, važno je osvijestiti potrebu za olakšanjem patnje i djelovanjem na neugodne simptome kod pacijenata u čemu uvelike može pomoći i uporaba „pametnih" alata [3, 15]. Uloga je medicinske sestre krucijalna kod uvođenja i promidžbe uporabe tehnologije u palijativnoj skrbi s obzirom na to da provodi najveći dio vremena s pacijentom.

Kao što je već navedeno, bol i ostali neugodni simptomi uvelike otežavaju svakodnevicu pacijenata i snižavaju kvalitetu života. Jedan od primjera dobrobiti tehnologije kod ovog problema jest razvoj web-sustava PediQUEST. Uloga ovog sustava prikupljanje je informacija o simptomima kod djeteta i njihovoj procjeni kvalitete vlastita života. PediQUEST se na početku testirao u tri velika centra za rak u SAD-u, što je ukazalo na poboljšanu komunikaciju između pacijenta i zdravstvenih djelatnika te, u konačnici, na bolje upravljanje neugodnim simptomima, kako fizičkim, tako i emocionalnim [15, 16]. Implementacija ovog sustava u specijalizirane i nespecijalizirane odjele koji pružaju palijativnu skrb na našem području zasigurno bi podigla kvalitetu skrbi na veću razinu.

Aplikacija poput *Pain Buddy* proširuje ovu funkcionalnost jer, osim što prati simptome koje djeca prijavljuju, pruža i mogućnost neposredne intervencije korištenjem farmakoloških, ali i nefarmakoloških metoda ublažavanja boli i drugih simptoma te poteškoća s kojima se djeca susreću [15].

Jedno od novih područja u upravljanju boli kod djece jest i uporaba terapijskih igračaka. Igračke su oduvijek služile kao dobar način distrakcije pažnje prilikom provođenja neugodnih intervencija, ali i kao edukacijsko sredstvo kod različitih bolesti. Budući da tehnologija napreduje, igračke se izvrsno mogu iskoristiti kao terapeutska alternativa pri djelovanju na bol, stres, anksioznost i strah. Novije su igračke povezane s mobilnim aplikacijama koje putem igračke emitiraju vibracije i umirujuće zvukove s ciljem olakšanja simptoma bez uporabe farmakoloških metoda [15].

Zaključak

Uloga medicinske sestre u palijativnoj skrbi djeteta s malignom bolešću nezamjenjiva je i obuhvaća cjelovit pristup u upravljanju neugodnim simptomima koji se javljaju kao posljedica bolesti i terapijskih postupaka, a bitno snižavaju kvalitetu života djeteta. Osim usmjerenosti na potrebe djeteta, medicinska sestra skrbi i za potrebe roditelja i obitelji djeteta kojima je potrebna stalna emocionalna podrška za vrijeme trajanja djetetove bolesti, ali i nakon neminovne smrti djeteta u procesu tugovanja. Tehnološki napredak vidljiv je i u ovom segmentu zdravstva – olakšao je komunikaciju između pacijenta, roditelja i zdravstvenih djelatnika, ali i pružio uvid u olakšavanje negativnih posljedica bolesti. U budućnosti će ključnu ulogu u unapređenju palijativne zdravstvene njege zasigurno imati inovativni pristupi koji će omogućiti praćenje simptoma

Technological innovations

Advancements in technology have transformed our lives and made daily activities easier through smartphones and digital platforms. In medicine, new technologies have led to more precise diagnostics and improved patient care across in all branches [15]. Although it is often a common belief that nothing can be done for patients at the end of life because the procedures performed will not lead to a cure, it is important to recognize the need to alleviate suffering and address unpleasant symptoms in patients, where the use of 'smart' tools can be greatly beneficial [3, 15]. The role of the nurse is crucial in introducing and promoting the use of technology in palliative care, as they spend most of their time with the patient.

As already mentioned, pain and other unpleasant symptoms greatly hinder the daily lives of patients and lower their quality of life. One example of the benefits of technology in addressing this issue is the development of the web-based system PediQUEST. The role of this system is to collect information about symptoms in children and assess their quality of life. PediQUEST was initially tested in three major cancer centers in the United States, which indicated improved communication between patients and healthcare professionals and, ultimately, better management of unpleasant symptoms, both physical and emotional [15, 16]. The implementation of this system in specialized and non-specialized departments providing palliative care in our area would undoubtedly elevate the quality of care to a higher level.

Applications like Pain Buddy expand this functionality, as they not only track the symptoms reported by children but also provide immediate intervention options using both pharmacological and non-pharmacological methods for pain relief and other symptoms and difficulties that children encounter [15].

One of the new areas in pain management for children is the usage of therapeutic toys. Toys have always served as a good means of distraction during uncomfortable interventions, as well as an educational tool for various illnesses. As technology advances, toys can be effectively utilized as a therapeutic alternative to address pain, stress, anxiety, and fear. Newer toys are connected to mobile applications that emit vibrations and calming sounds through the toy, aiming to alleviate symptoms without the use of pharmacological methods [15].

Conclusion

The role of the nurse in the palliative care of a child with a malignant disease is irreplaceable and encompasses a holistic approach to managing the unpleasant symptoms that arise as a result of the illness and therapeutic procedures, significantly reducing the child's quality of life. In addition to focusing on the needs of the child, the nurse also cares for the needs of the parents and family, who require ongoing emotional support during the child's illness and after the inevitable death through the grieving process. Technological advancements have also touched this segment of i individualiziranu zdravstvenu njegu, dok će uloga medicinske sestre i dalje ostati ključna u pružanju stručne skrbi, empatije i stalne podrške oboljelom djetetu i članovima njegove obitelji.

Nema sukoba interesa.

healthcare, facilitating communication between the patient, parents, and healthcare professionals, while providing a new means of alleviating the negative consequences of illness. In the future, innovative approaches that allow for symptom monitoring and individualized healthcare will undoubtedly play a key role in improving palliative health care, while the nurse's role will continue to be central in providing expert care, empathy, and ongoing support to the sick child and his family members.

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