“TEŠKO MI JE PALO ODVAJANJE OD OBITELJI, DRUŠTVA I ŠKOLE. NEDOSTAJAO MI JE MOJ DOM.” – “PREŽIVJETI” MALIGNU BOLEST IZ PERSPEKTIVE IZLIJEČENIH MLADIH OSOBA

‘’IT WAS HARD FOR ME TO BE SEPARATED FROM MY FAMILY, FRIENDS AND SCHOOL. I MISSED MY HOME” – HOW ‘’TO SURVIVE” A MALIGNANT DISEASE FROM THE PERSPECTIVE OF YOUNG PEOPLE WHO HAVE BEEN CURED

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Sažetak: *Cilj istraživanja bio je steći potpunije razumijevanje iskustva preživljenja maligne bolesti iz perspektive izliječenih mladih osoba. U istraživanju je sudjelovalo dvadesetero mladih koji su se liječili od nekog oblika maligne bolesti (akutne limfoblastične leukemije (ALL), meduloblastoma, osteosarkoma, Ewingova sarkoma, Non-Hodgkinova limfoma i aplastične anemije). Primijenjena metoda prikupljanja podataka bio je anketni upitnik, a dobiveni su podaci analizirani metodom tematske analize. Generirane su tri glavne teme istraživanja: 1) saznanje o bolesti, 2) zahtjevni aspekti liječenja i 3) percipirani negativni i pozitivni ishodi oboljenja. Rezultati izvješćuju o reakcijama na dobivanje dijagnoze i o razumijevanju prirode bolesti. Upućuju na to da je za mlade tijekom liječenja bila zahtjevna socijalna izolacija, odvojenost od članova socijalne mreže, određeni medicinski postupci i nerazumijevanje od strane okoline. Bolest je utjecala na njihov tjelesni izgled i uzrokovala gubitak samopouzdanja i bezbrižnog djetinjstva, smanjenu mogućnost obrazovanja, smanjeni izbor aktivnosti slobodnog vremena te slabljenje društvenih kontakata. Unatoč nepovoljnim posljedicama bolesti prisutne su i one*

Abstract: *The aim of this study was to gain a better understanding of the experience of surviving a malignant disease from the perspective of young people who have been cured. The study involved 20 young patients who had previously undergone treatment for a malignant disease (acute lymphoblastic leukaemia, medulloblastoma, osteosarcoma, Ewing’s sarcoma, Non-Hodgkin’s lymphoma, and aplastic anaemia). Data was collected using a questionnaire and results were analysed using the thematic analysis method. The three main themes of the study are: 1) realization of being seriously ill, 2) the demanding aspects of treatment, and 3) perceived negative and positive outcomes of the illness. The results describe the reactions of the children when they found out about the diagnosis and their understanding of the nature of the disease. The results indicate that the young people did not respond well to social isolation, separation from members of their social network, certain medical procedures, and the lack of understanding shown by their social circle. The disease had an impact on their physical appearance, self-confidence, and carefree childhood, as well as reduced their possibility of further education, choice of activities in free time, and weakened social contacts. In spite of the damaging consequences of the illness, these young* *pozitivne koje mladi prepoznaju kroz povećanu zrelost i osobnu snagu te angažman u organizacijama civilnog društva koje se bave vršnjačkom podrškom oboljelima. Dobivene empirijske spoznaje sugeriraju potrebu za sveobuhvatnom psihosocijalnom podrškom oboljelima, tijekom i nakon aktivnog tretmana liječenja u područjima informacijske podrške, tjelesnog i mentalnog zdravlja, obrazovnih postignuća i vršnjačke edukacije.*

Ključne riječi: *maligna bolest, psihosocijalne posljedice, mladi, preživljenje*

UVOD

U posljednjim desetljećima postignuti su značajni pomaci u liječenju oboljelih od maligne bolesti u dječjoj dobi. Primjena suvremenih dijagnostičkih i tretmanskih protokola rezultirala je smanjenjem sveukupnog mortaliteta u pedijatrijskoj populaciji (Janić, 2018). U skladu s time izgledno je petogodišnje preživljenje djece i mladih (u dobi od 0 do 19 godina) od 84,1% za leukemije i 74,8% za tumore središnjeg živčanog sustava (National Cancer Institute, 2020). Unatoč poboljšanim ishodima liječenja i karakteristikama bolesti koja sve više nalikuje drugim kroničnim stanjima oboljenje od maligne bolesti i dalje je prototip stresne situacije s potencijalno razarajućim učincima za dijete i njegovu obitelj (Mört, 2012; Orbuch, Parry, Chesler, Fritz i Repetto, 2005). Liječenje uključuje zahtjevan medicinski tretman tijekom kojeg su i djeca i roditelji izloženi višestrukom i sveprisutnom stresu (Pai i sur., 2007), a po završetku aktivnog liječenja suočavaju se s kompleksnim rehabilitacijskim zadacima (Elad, Yagil, Cohen i Meller, 2003). Zbog specifične razvojne dobi u kojoj se nalaze, prisutan je povećan empirijski interes za iskustvo oboljenja od maligne bolesti iz perspektive preživjelih mladih (Hølge-Hazelton, 2011). Istraživačka pitanja oblikuju se oko teme identiteta (Jones, Parker-Raley i Barczyk, 2011; Madan-Swain i sur., 2000), psihosocijalnih potreba (Keegan i sur., 2012; Beerbower, 2018), psihosocijalnih posljedica oboljenja (Bellizzi i sur., 2012; Mattsson, Lindgren i Von Essen, 2008), kvalitete života (Castellano i sur., 2013; Klassen, Anthony, Khan, Sung i Klaassen, 2011), zdravstvenog statusa (Tai i sur., 2012; Oeffinger i sur., 2004), posttraumatskog rasta (Tobin i sur., 2018;

people observed many positive impacts, including increased maturity, personal strength, and engagement in civil society organisations dealing with peer-to-peer support. These empirical findings suggest the need for comprehensive psychosocial support programmes for young people suffering from malignant diseases, both during and after active medical treatment. These programmes should focus on improving information technology, physical and mental health, educational achievements and peer education.

Keywords: *malignant diseases, young people, psychosocial consequences, survival*

INTRODUCTION

Over the last decades, significant progress has been achieved in the treatment of children with malignant diseases. The implementation of modern diagnostic and treatment protocols has resulted in an overall reduction in mortality in paediatric populations (Janić, 2018). Accordingly, the 5-year survival rate of children and young adults (ages 0-19 years) with leukaemia was 84.1% and that of those with tumours in the central neural system was 74.8% (National Cancer Institute, 2020). In spite of the enhanced outcomes of currently available treatments and the fact that such diseases are increasingly similar to chronic illnesses, being diagnosed with a malignant disease continues to be the prototype of a stressful situation with potentially devastating effects on the children and their families (Orbuch, Parry, Chesler, Fritz and Repetto, 2005; Mört, 2012). The treatment typically includes demanding medical procedures during which the children and their parents are exposed to several stressful situations (Pai et al., 2007); they also face complex rehabilitation tasks at the end of an active treatment (Elad, Yagil, Cohen and Meller, 2003).

Given the specific developmental phase during which the disease has occurred, there is an increased interest in examining empirical data in order to understand the experience of children suffering from a malignant disease, especially from the perspective of those who have been cured (Hølge-Hazelton, 2011). Previous studies have addressed the theme of identity (Jones, Parker-Raley and Barczyk, 2011; Madan-Swain et al., 2000), psychosocial needs (Keegan et al., 2012; Beerbower, 2018), psychosocial consequences of falling ill (Mattsson, Lindgren and Von Essen, 2008; Bellizzi et al., 2012), quality of life (Klassen, Anthony, Khan, Sung and Klaassen, 2011; Castellano et al., 2013), health status (Oeffinger et al., 2004; Tai et al., 2012), post-traumatic growth (Turner-

Turner-Sack, Menna i Setchell, 2012), zdravstvene skrbi tijekom i nakon aktivnog tretmana liječenja (Berg, Stratton, Esiashvili i Mertens, 2016; Earle, Davies, Greenfield, Ross i Eiser, 2005) i sl. Preživljenje se određuje kao proces koji započinje postavljanjem dijagnoze, nastavlja se tijekom tretmana liječenja i traje do kraja života (Zebrack, 2015; Doyle, 2008. prema Mört, 2012), a orijentiran je na tjelesne, mentalne, emocionalne, socijalne i financijske učinke maligne bolesti u svim navedenim vremenskim točkama (National Cancer Institute, 2020).

Oboljenje od maligne bolesti mladima donosi iskustvo koje je nedostupno njihovim vršnjacima, povećava njihovu ovisnost o roditeljima i komplicira im proces uspostave novih odnosa (Lewis, Jordens, Mooney-Somers, Smith i Kerridge, 2013). Donosi im prekid dotadašnjeg života i daje novi doživljaj vremena: i život i vrijeme dijele se na periode “prije” i “poslije” bolesti (Rasmussen i Elverdam, 2007). Oni imaju “identitet oboljelog” i “identitet preživjelog”. Identitet povezan s oboljenjem odnosi se na tjelesna, kognitivna i društvena ograničenja, dok identitet preživjelog uključuje nova iskustva, fokus je na sadašnjosti i planiranju budućnosti te educiranju drugih o iskustvu bolesti (Jones i sur., 2011). Kada sagledavaju utjecaj koji bolest ima na njihovo svakodnevno funkcioniranje, navode da je taj utjecaj istovremeno i negativan i pozitivan (Doyle, 2008. prema Mört, 2012). Negativne posljedice bolesti s jedne strane prepoznaju u promijenjenom mentalnom (Robison i Hudson, 2014; Zebrack, Kent, Keegan, Ikuko i Wilder Smith, 2014; Klassen i sur., 2011) i tjelesnom zdravlju, slici o vlastitom tijelu (Doukkali i sur., 2013; Zebrack i Isaacson, 2012), školskom uspjehu (Foster i sur., 2014; Robison i Hudson, 2014; Zebrack i Isaacson, 2012; Jones i sur., 2011), promjenama u socijalnoj mreži i vršnjačkim odnosima (Lewis i sur., 2014; Lewis i sur., 2013; Jones i sur., 2011). S druge strane zaključuju o fragilnosti budućnosti koju su “uzimali zdravo za gotovo” (Rasmussen i Elverdam, 2007), imaju promijenjene životne prioritete (Duran, 2013; Doukkali i sur., 2013), privrženiji su obitelji (Duran, 2013; Yallop, McDowell, Koziol-McLain i Reed, 2013) i spremniji su pružati podršku trenutno oboljelima (Jones i sur., 2011).

Sack, Menna and Setchell, 2012; Tobin et al., 2018), as well as health care during and after an active treatment (Earle, Davies, Greenfield, Ross and Eiser, 2005; Berg, Stratton, Esiashvili and Mertens, 2016). Survival is determined as a process starting with establishing a diagnosis, continuing during the medical treatment, and going on till the end of life (Doyle, 2008. as cited in Mört, 2012; Zebrack, 2015). This process is oriented to the physical, mental, emotional, social, and financial effects of a malignant disease at all the above-mentioned timepoints (National Cancer Institute, 2020).

The experience of suffering from a malignant disease at a young age is not comparable to any other experience of similarly aged children: the diagnosis typically increases parental dependence and makes the process of establishing new relationships more complicated (Lewis, Jordens, Mooney-Somers, Smith and Kerridge, 2013). It also brings their previous life to an end and gives them a new perception of time: life and time are divided into ‘”before” and ‘’after” the disease (Rasmussen and Elverdam, 2007). Children suffering from such diseases assume the identity of “those who are ill” and ‘’those who survived”. The identity connected to being ill is related to physical, cognitive, and social limitations, while the identity of those who survived includes new experiences with a focus on the present and plans for the future, as well as educating others about their experience of having had a malignant disease (Jones et al., 2011). They report that the impact that this illness has had on everyday functioning is both positive and negative at the same time (Doyle, 2008, as cited in Mört, 2012). On the one hand, they recognise the negative effects of the illness with respect to changes in mental (Klassen et al., 2011; Robison and Hudson, 2014; Zebrack, Kent, Keegan, Ikuko and Wilder Smith, 2014) and physical health, body image (Zebrack and Isaacson, 2012; Doukkali et al., 2013), success at school (Jones et al., 2011; Zebrack and Isaacson, 2012; Foster et al., 2014; Robison and Hudson, 2014), as well as social networking and relationships with similarly aged children (Lewis et al., 2014; Lewis et al., 2013; Jones et al., 2011). On the other hand, they are aware of the fragility of their future, which they had been taking for granted before the diagnosis (Rasmussen and Elverdam, 2007), they have changed their life priorities (Duran, 2013; Doukkali et al., 2013), are more attached and devoted to their families (Duran, 2013; Yallop, McDowell, Koziol-McLain and Reed, 2013), and more ready to offer support to others who are currently ill (Jones et al., 2011).

Istraživanja s mladima koji su se izliječili od maligne bolesti empirijski su zanemarena u zemljama na Balkanu. Pod tim vidom istraživanje o iskustvima preživljenja maligne bolesti iz perspektive mladih (rane i srednje adolescentne dobi) predstavlja pionirski iskorak. Uvid u njihove osobne perspektive od osobitog je značaja za bolje razumijevanje poteškoća s kojima se susreću tijekom i po završetku tretmana liječenja, ali i radi kreiranja novih i unapređenja postojećih psihosocijalnih programa podrške koji će odgovoriti na njihove specifične potrebe.

CILJ ISTRAŽIVANJA

Cilj je istraživanja steći potpunije razumijevanje iskustva preživljenja maligne bolesti iz perspektive izliječenih mladih. Postavljena su sljedeća istraživačka pitanja:

1. Na koji način opisuju iskustvo oboljenja?
2. Koje promjene prepoznaju u svom životu nakon bolesti?

METODA

Sudionici istraživanja

U istraživanju je sudjelovala skupina mladih osoba koje su preživjele neki oblik maligne bolesti (akutnu limfoblastičnu leukemiju (ALL), meduloblastom, osteosarkom, Ewingov sarkom, Non-Hodgkinov limfom i aplastičnu anemiju). Ukupno je sudjelovalo 20 mladih osoba (šest sudionika i četrnaest sudionica) prosječne dobi 17,05 godina. Njihova dob u vrijeme liječenja bila je od tri do 17 godina. U vrijeme prikupljanja podataka od završetka liječenja protekle su u prosjeku 6,4 godine. Liječenje je trajalo od jedne (za većinu mladih) do četiri godine. Dvoje je sudionika odbilo sudjelovati u istraživanju. U periodu od prikupljanja podataka do objave rada jedna je sudionica preminula od recidiva. Svi su se sudionici liječili u nekoliko bolničkih centara u Republici Srbiji.

Metoda prikupljanja podataka

Primijenjena metoda prikupljanja podataka bila je anketni upitnik koji se sastojao od otvorenih pitanja. Pitanja u upitniku odnosila su se na opis

There are very few empirical studies dealing with young patients who have survived a malignant disease, especially in the Balkan countries. Therefore, examining the experience of surviving a malignant disease from the perspective of children and young adults represents a pioneering breakthrough. Collecting and analysing data on their personal perspective is very important in order to gain a better understanding of the difficulties faced during and after treatment. It is also important to create new treatments and improve the existing psychosocial programmes of support in order to respond to the specific needs of children suffering from malignant diseases.

RESEARCH AIM

The aim of this study was to gain a better understanding of the experiences of surviving a malignant disease from the perspective of young people who have been cured. The following research questions were addressed:

1. How do they describe their experience of suffering from a malignant disease?
2. What changes have they observed in their life after surviving the disease?

METHODS

Participants

Our study involved 20 young people (14 girls and 6 boys; average age, 17.05 years) who have survived a malignant disease (acute lymphoblastic leukaemia, medulloblastoma, osteosarcoma, Ewing's sarcoma, Non-Hodgkin's lymphoma, and aplastic anaemia). During the time of treatment, they were between 3 and 17 years old. At the time of collecting data, an average of 6.4 years had passed after completing their treatment. The duration of the treatment was between 1 (for a majority of the participants) and 4 years. Two respondents refused to take part in the study. In the period between data collection and publication, one girl died due to relapse of her illness. All respondents were treated in several medical centres in the Republic of Serbia.

Data collection

The data collecting method applied was a questionnaire that consisted of open-ended questions. The questions referred to describing the experience of being diagnosed with cancer and subsequent treatment, as well

Tablica 1. *Sociodemografska obilježja sudinika (n = 20) /* **Table 1.** *Socio-demographic characteristics of participants (n = 20)*

Characteristic	Number
Gender:	
• Male	6
• Female	14
Age (years):	
• 12-18	14
• 19-21	4
• 22-29	2
Age at the time of diagnosis (years):	
• 0-7	7
• 8-14	12
• 15-18	1
Time after completion of treatment (years):	
• 0-3	3
• 4-6	12
• 7-9	4
• 10+	1
Duration of treatment (years):	
• 1	16
• 2	2
• 3	1
• 4	1
Diagnosis of malignant disease:	
• acute lymphoblastic leukaemia	9
• medulloblastoma	4
• Non-Hodgkin’s lymphoma	3
• osteosarcoma	2
• Ewing’s sarcoma	1
• aplastic anaemia	1

doživljaja bolesti i liječenja, percipirane gubitke i pozitivne ishode povezane s malignim oboljenjem. Podaci su prikupljeni tijekom ljetnog rehabilitacijskog kampa za djecu i mlade liječene od maligne bolesti u Republici Srbiji. Sadržaj upitnika preveden je na srpski jezik, uz mogućnost ispunjavanja na ćirilici ili latinici. Sudionici su izdvojili od 30 do 60 minuta za pisanje svojih odgovora. Podatke je samostalno prikupljala autorica rada, po zanimanju socijalna radnica, s iskustvom provedbe kvalitativnih istraživanja u području psihoonkologije i sudjelovanja na rehabilitacijskim kampovima. Odaziv sudionika bio je vrlo visok, odnosno od ukupno 22 mladih sudjelovalo ih je 20. Razlozi ovakvog odaziva prepoznaju se u spremnosti dijeljenja iskustva liječenja, ali i u sigurnom okruženju rehabilitacijskog kampa. U svojim radovima tako zaključuju i autori Zebrack i sur. (2006) i Crom (2009). Osim što je imala istraživačku ulogu, autorica je sudjelovala (samostalno ili u suvoditeljstvu)

as the perceived negative and positive outcomes related to the illness. Data was collected in the summer of 2015 during a nine-day rehabilitation camp for children and young adults who had been undergoing medical treatment for a malignant disease in the Republic of Serbia. The content of the questionnaire was translated into Serbian language, with the possibility to fill in the details using the Cyrillic or the Latin alphabet. It took between 30 and 60 minutes for the respondents to write down their answers.

The data was independently collected by the author of the present study, as well as a social worker with experience in carrying out qualitative research in the field of psycho-oncology and taking part in rehabilitation camps. The response of the respondents was very high: of the 22 young people considered, 20 agreed to take part in the study. The reason for such a high response may be due to the readiness of the participants to share their experience of treatment in a safe environment of the rehabilitation camp. Similar conclusions were reported by Zebrack i u izvedbi drugih programskih, neistraživačkih aktivnosti kampa.

Postupak istraživanja

Istraživanje je predstavljeno Udruženju roditelja, staratelja i prijatelja dece obolele od malignih bolesti "Čika Boca" iz Beograda, koje je odobrilo i podržalo njegovu provedbu. Tijekom pripremnih aktivnosti organizatori rehabilitacijskog kampa najavili su roditeljima i (punoljetnim) sudionicima provedbu istraživanja. Detaljne informacije o istraživanju bile su sastavni dio prijave za sudjelovanje na kampu.

Etički aspekti istraživanja

Tijekom svih etapa istraživačkog procesa poštovana su načela etične i dobre istraživačke prakse. S ciljem usklađene primjene i uvažavanja etičkih procedura koje vrijede u istraživanju s djecom u Republici Srbiji, konzultirana je literatura u tom području (Đurić, 2012). Utvrđeno je da su važeće odredbe srodne Etičkom kodeksu u istraživanju s djecom (Vijeće za djecu Vlade Republike Hrvatske, 2003) i isti je dosljedno primjenjivan u svim istraživačkim fazama. Informiranu odluku o participaciji u istraživanju roditelji i punoljetni sudionici donijeli su nakon primjerenog (pismenog i usmenog) upoznavanja s planiranim istraživanjem. Sudionici mlađi od 18 godina koji su pristali sudjelovati u istraživanju dali su usmeni pristanak, dok su njihovi roditelji odnosno skrbnici dali i pismeni i usmeni pristanak. Iako su svi roditelji i skrbnici pristali da njihovo dijete odnosno štićenik sudjeluje u istraživanju, krajnja je odluka bila na samom sudioniku. Pod vidom vulnerabilnosti populacije i njihovih iskustava sudionicima je osigurana psihološka podrška. Jedna je sudionica nakon ispunjavanja upitnika zatražila razgovor s psihologinjom, dok je troje sudionika dodatno s provoditeljicom istraživanja željelo prokomentirati sadržaj napisanog.

Obrada podataka

Dobiveni podaci analizirani su metodom tematske analize. Obrada podataka uključivala je sljedeće etape: (1) upoznavanje s cjelokupnim korpusom prikupljenih podataka kroz sveobuhvatna i ponov-

et al. (2006) and Crom (2009). Apart from her role as a researcher, the author of this study also participated (independently or as a co-leader) in carrying out other programme and non-research activities in the camp.

Research procedure

This study was presented to the Association of parents, guardians and friends of the children with malignant diseases ''Čika Boca'' from Belgrade, who approved and supported its realization. During preparations, the organisers of the rehabilitation camp announced the research study to the parents and participants of legal age. Detailed information on the study was an integral part of the application for attending the camp.

Ethical aspects of the study

During all phases of the research process, the principles of ethical and good research practice were followed. In order to abide by the ethical procedures valid in the Republic of Serbia with respect to research on children, relevant literature was consulted (Đurić, 2012) and the existing terms were found to be in correlation with the Ethical Codex for research involving children (Ajduković & Kolesarić, 2003), and therefore, consistently applied in all phases of the study.

After being fully informed about the research (both verbally and in writing), the parents and the young participants of legal age made a decision to take part in the study. Children younger than 18 years old agreed verbally, and their parents/ guardians provided written and verbal consent. Although all the parents and guardians agreed that their child/foster child could participate in the study, the final decision was left up to the child. Taking into consideration the vulnerability of the participants and their experience, they were granted psychological support. After having filled in the questionnaire, one girl requested a consultation with a psychologist, while three other participants wanted to discuss the written content further with the author of this study.

Data processing

All data were analysed using the thematic analysis method. Data processing included the following stages: 1) examining the whole corpus of the collected data ljena čitanja; (2) generiranje inicijalnih kodova temeljem kraćih opisa manjih dijelova podataka; (3) razvoj i identificiranje tema; (4) pregled i usklađivanje postojećih tema; (5) definiranje i imenovanje tema i njihovih podtema; (6) interpretacija dobivenih rezultata (Braun i Clark, 2006). Podaci su analizirani grupno i zbirno bez uporabe računalnog programa za obradu. Dobivene rezultate kritički su sagledala i komentirala dva neovisna istraživača koji su u etapi izrade nacrta istraživanja imali konzultativnu ulogu. U prikazu kodne strukture rezultata postojalo je visoko slaganje uključenih, dok se razlikama u imenovanju kodova pristupilo po modelu konsenzusa.

REZULTATI

O iskustvu oboljenja i promjenama koje su uslijedile po preživljenju bolesti mladi progovaraju kroz tri glavne teme:

1. Saznanje bolesti
2. Zahtjevni aspekti liječenja
3. Percipirani negativni i pozitivni ishodi oboljenja

Saznanje bolesti

Odgovori mladih upućuju na to da je saznanje dijagnoze bolesti kod nekih bilo popraćeno stanjem šoka i nevjerice te intenzivnim osjećajem straha: "Bila sam jako uplašena, pogotovo kad sam vidjela svu tu djecu bez kose, pitala sam se gdje sam ja, Bože? (11)." Kod nekoliko mladih osoba domini-

through comprehensive and repeated readings; 2) generating initial codes on the basis of shorter descriptions of smaller parts of the data; 3) developing and identifying the themes; 4) surveying and coordination of existing themes; 5) defining and naming subordinated and superior themes; and 6) interpreting the results (Braun and Clark, 2006). Group-wise and totality analysis of the data was conducted without using data processing software. Results were critically reviewed and analysed by two independent researchers who had a consulting role in the drafting/outlining stage of the study. There was a high degree of agreement across everyone involved in the study regarding designing code structure, and differences regarding code naming were resolved using a model of consensus.

RESULTS

The young people participating in this study described their experience of suffering from a malignant disease through three main themes:

1. Realizing that they have cancer
2. Demanding aspects of treatment
3. Perceived negative and positive outcomes of being ill

Realizing that they have cancer

The responses of the young participants indicated that some of them experienced a state of shock, disbelief, and intense fear after being diagnosed with a malignant disease: ''I was very frightened, especially

Tablica 2. *Teme i podteme povezane s preživljenjem maligne bolesti iz perspektive izliječenih mladih /* **Table 2.** *Themes and subthemes associated with surviving malignant diseases from the perspective of young people who have been cured*

THEMES	SUBTHEMES
Realizing that they have cancer	• Reactions to finding out the diagnosis • Understanding the nature of the disease
Demanding aspects of treatment	• Social isolation • Separation from the members of their social network • Medical procedures • Lack of understanding shown by their social circle
Perceived negative outcomes of being ill	• Changes in physical appearance • Lack of self-confidence • Reduced possibility of education • Loss of carefree childhood • Weakening of social contacts • Reduced possibility to choose activities in free time
Perceived positive outcomes of being ill	• Personal growth • Engagement in supporting similarly aged children and other who are ill

ralo je propitivanje zašto su upravo oni ti koji su oboljeli, ali i zabrinutost za zdravlje i tijek liječenja općenito: “Kada sam saznala da sam bolesna, bila sam razočarana i tužna što se baš meni to dogodilo? (8)”, “Sjećam se trenutka kada sam kroz prozor bolničke sobe gledala djecu na ulici kako su bezbrižna i vesela i pitala se: ‘Bože, zašto baš ja? (9)’.” U pogledu razumijevanja prirode same bolesti pokazala se heterogenost njihovih iskustava. Pojedine mlade osobe bile su u određenoj mjeri upoznate s ozbiljnosti bolesti, percipirajući je kao “ozbiljnu i opaku bolest”, “ozbiljnu situaciju u kojoj su se našli”. O bolesti su najčešće bili informirani kroz razgovor s roditeljima ili temeljem prethodnih iskustava s malignim oboljenjima u obitelji. Sudionici koji nisu imali saznanja o bolesti o njoj su saznavali od svojih vršnjaka ili prema prepoznatljivim nuspojavama liječenja: “Na početku samog liječenja nisam ni bila svjesna od čega bolujem i koliko je ta bolest ustvari opasna. Počela je kemoterapija, ali ja i dalje nisam znala da imam rak. Tek kada mi je kosa počela otpadati i kada je mama rekla da će mi morati obrijati glavu, shvatila sam da je to ustvari borba za život, a ne neki običan virus (9)”; “Kada su mi dijagnosticirali bolest imala sam 11 godina i nisam imala nikakvu predstavu o tome što je rak. Do tada sam znala samo da se od toga umire. Iz razgovora s drugom djecom sam zaključila sama o kakvoj bolesti je riječ (18).”

Zahtjevni aspekti liječenja

U opisu iskustva oboljenja mladi su istaknuli neke aspekte liječenja koji su im bili posebno teški i zahtjevni. Nekima je od njih početak liječenja i saznanje dijagnoze ujedno bio i najteži period tijekom cjelokupnog liječenja: “Doktor je majci odgovorio: ‘Vaše dijete ima tumor’. Tada se zamalo nisam srušila sa stolice. Bilo je kao metak u srce. Cijeli taj dan sam sjedila kući i plakala. Tako sam saznala, a to mi je ujedno bio i najteži period (10)”; “Početak mi je bio najteži, zbog neznanja i gubitka nekih stvari. Nisam se toliko bojao smrti koliko sam se bojao za svoju obitelj. (20)”, “Početak mi je bio strašan. Bila sam uplašena, svega sam se bojala. Najviše igala (7).”

Mladi ističu i socijalnu izoliranost i odvojenost od važnih članova svoje socijalne mreže: “Najteže mi je u tom periodu palo što sam bio

when I saw all these children without hair, I asked myself, ‘Oh God, where am I?’ (11)”. The most prevalent question that some of them asked was ‘’why it happened to me?”, along with a serious concern for their health and treatment in general: ‘’When I found out that I was ill, I was disappointed and sad, why it had to happen to me? (8)”; ‘’I remember the moment when I was watching through the window of my hospital room the children in the street who were unworried and happy, and I asked myself, ‘’Oh God, why me?’ (9)”.

With respect to understanding the nature of their disease, their experiences were heterogeneous. Some children were previously acquainted to a certain degree with the seriousness of their disease, and were looking at it as ‘’a serious and sinister illness” and/or ‘’a serious situation they were in”. Most often they were informed about the disease during discussions with their parents or through previous experiences of their family members. The respondents who did not know anything about cancer were informed by other similarly aged children or through recognizable side-effects of the treatment: ‘’At the beginning of the treatment, I was not aware of what kind of a disease I had and how it is really dangerous. Then chemotherapy started and I still didn’t know that I had cancer. Only when my hair started to fall off and when my mom said that she would have to shave my head, only then have I realized that it was, as a matter of fact, struggle for life, and not some plain virus. (9)”; ‘’When I was diagnosed with cancer, I was 11 and didn’t have any notion what kind of a disease it was. Until then, I only knew that you die of it. After talking to other children, I came to conclusion what kind of disease it was. (18)”.

Demanding aspects of treatment

When they described their experience of the illness, the young participants pointed out some aspects of treatment that had been especially hard and demanding. To some of them the beginning of treatment and finding out about the diagnosis at the same time was the most difficult period of the entire treatment: ‘’Doctor said to my mother, ‘’Your child has a tumour”. I almost fell from the chair. It was as ‘’a bullet to the heart”. That whole day I was sitting at home crying. This is the way that I found out and it was at the same time the most difficult period. (10)”; ‘’The beginning was the most difficult, due to ignorance and losing some zatvoren u bolnici, nisam se mogao družiti s prijateljima iz razreda, nisam mogao piti i jesti što hoću tj. kad hoću, itd. (3)"; "Zatvoren u sobi, razna testiranja, svakodnevno vađenje krvi, bilo mi je muka svega. Dobio sam osjećaj da sam u zatvoru, smiješ samo do vrata, obrok dobiješ u isto vrijeme kad i ostali, svjetla se gase u isto vrijeme… (20)." Jedna je osamnaestogodišnja djevojka socijalnu izolaciju opisala na sljedeći način: "Teško mi je palo odvajanje od obitelji, društva i škole. Nedostajao mi je moj dom. U jednom trenutku mi je toliko bilo dosta svega, jer već preko mjesec i po dana nisam puštena kući. Tada sam odbijala i jesti, i piti lijekove, i razgovarati sa bilo kim (18)."

Dijelu mladih bili su zahtjevni određeni medicinski postupci, u najvećoj mjeri nuspojave kemoterapije, operacije i drugi medicinski postupci: "Najteže što mi je bilo tijekom liječenja nije bio rak kao rak, već ono što on nosi uz sebe. Najgore mi je bilo podnijeti nuspojave kemoterapije, često mi je bilo muka, bila sam izmorena i neraspoložena (18)"; "Ono što mi je teško palo je bio moj gubitak kose od lijekova (16)"; "Kada bi mi radili lumbalne, toliko sam bila nemirna da je moralo petero njih da me drži, jer ja sam to shvaćala kao neko mučenje, pa kada bi prozvali moje ime i prezime, sakrivala bih se po bolnici od liječnika (15)." Mladi su istaknuli i nerazumijevanje okoline u pogledu nuspojava i prijenosa bolesti. Jedna osamnaestogodišnja djevojka, opisuje to ovako: "Kada sam se vratila u školu, bilo mi je teško pored mojih vršnjaka. Imali su gomilu glupih pitanja. Nisu razumjeli zašto mi je kosa opala, zašto moram paziti na sebe više nego ranije. Pogotovo kada živiš u maloj sredini, onda se priče šire brzinom svjetlosti. Uglavnom su to izmišljene priče. Dolazilo je do toga da su mislili da je rak zarazan, da se prenosi (18)", dok devetnaestogodišnji sudionik navodi: "Teško mi je bilo i to što su me djeca zapitkivala zašto nemam kosu i zašto me nema često kući (4)."

Percipirani negativni i pozitivni ishodi oboljenja

Izliječeni mladi prepoznaju različite promjene u svom fizičkom i psihičkom zdravlju kao posljedice oboljenja. Navode promjene u tjele-

things. I was not so afraid of dying as much as I worried about my family. (20)"; ''The beginning was terrible. I was scared, I was afraid of everything. Needles the most. (7)".

They also pointed out that social isolation and separation from important members of their social network was difficult: ''The most difficult for me at that period was that I was closed in a hospital, I could not hang around with my classmates, I could not eat and drink what and when I wanted, etc. (3)"; ''Closed in a room, numerous tests, daily taking out blood, I was sick of it all. I had a feeling that I was in prison, you are allowed to go only to the door, you get the meal at the same time as everybody else, the lights are turned off at the same time…(20)". One 18-year-old girl described social isolation in the following way: ''It was hard for me to be separated from my family, friends and school. I missed my home. At one moment, I was so sick of it all because over a month and a half I couldn't go home. Then I refused to eat, drink and talk to anybody. (18)".

Certain medical procedures had been difficult to take part in, especially after observing the full extent of the side effects of chemotherapy, operations, and other medical procedures. ''It was not cancer as cancer that was the most difficult for me during the treatment, but all other things that go along with it. The worst thing for me was to bear side effects of chemotherapy, I was often feeling sick, I was tired and in a bad mood. (18)"; "Really tough for me was the loss of hair due to drugs. (16)"; ''When they performed lumbar punctures on me, I was so restless that it took five people to hold me because I understood it as a torture, so when they would call my name and surname, I used to hide from doctors somewhere in the hospital. (15)".

The participants also pointed out lack of understanding of shown by their social circle in relation to the side effects and transmission of the disease. An 18-year-old girl describes it as follows: ''When I came back to school, I felt bad in the company of my classmates. They had bunch of stupid questions. They didn't understand why my hair had fallen off, why I had to take care of myself more than before. Especially when you live in a small town milieu, then the stories spread at light speed. These are mostly fake stories - such as that cancer is infectious, that it can be transferred. (18)", while a 19-year-old responded: ''It was hard for me that children used to ask me why I didn't have hair and why I was often away from home. (4)".

snom izgledu uslijed amputacije udova, oštećenja sluha i vida, gubitka ravnoteže i grafomotoričkih smetnji: “Najvažnije što mi je bolest oduzela jeste moju nogu naravno, a oduzela mi je i neku slobodu, da se slobodno osjećam u društvu (4)”; “Izgubila sam i brzinu. Izgubila sam ravnotežu, prije sam bila prva u trčanju, sada se sapletem kad potrčim, ne igram tjelesni, ne znam igrati igre jer ne hvatam dobro loptu. Ne vidim dobro, ne kao ostala djeca (6)”. Gubici se iz njihove perspektive odnose i na smanjeno samopouzdanje i samokontrolu: “Samopouzdanje i sve što ide uz to. Mislim da ne bi bila takva da nisam bila bolesna. Izgubila sam samokontrolu zbog štitnjače, lako planem (6)”. Mladi ističu i smanjenu mogućnost obrazovanja: “Bolest mi je oduzela dva razreda (treći i četvrti). I zato se ne mogu uklopiti u društvo (2)”; “Propustila sam dio školovanja i to mi ponekad stvara problem u vidu praznina u znanju, dijelova nekih školskih predmeta (18)”, ali i gubitak bezbrižnog djetinjstva: “Bolest mi je oduzela bezbrižno djetinjstvo na koje svako dijete ima pravo, a prvenstveno izgubili smo zdravlje pa poslije i školovanje (8).” Percipirani negativni ishodi oboljenja kod mladih uključuju i slabljenje društvenih kontakata: “Bolest mi je isto oduzela par prijatelja koji su me zaboravili tijekom liječenja (16)”; “Pa propustila sam druženje s djecom zato danas nemam puno prijatelja (6)”, kao i smanjene mogućnosti u izboru aktivnosti slobodnog vremena, npr. odlazak na grupna putovanja s vršnjacima, bavljenje plesom i sportom.

Mladi su u ovom istraživanju istaknuli i neke pozitivne ishode koji su uslijedili kao posljedice oboljenja. Oni se uglavnom odnose na različite aspekte osobnog rasta i razvoja: “Postala sam zrelija, hrabra, odlučna i ustrajna osoba što mi i sada koristi (13)”; “Mislim da djeca kojoj se rak dogodio u životu sazrijevaju brže od svojih vršnjaka (18).” Dio mladih posebno je istaknuo motivaciju za pomaganjem drugima i angažiranost u organizacijama civilnog društva koje se bave vršnjačkom podrškom oboljelima od maligne bolesti: “Pripadam grupi vršnjaka koji me razumiju, koji su liječeni od iste bolesti i ne moram im objašnjavati ništa vezano uz rak. Jednostavno osjećam da pripadamo jedni s drugima, zato naglašavam

Perceived negative and positive outcomes of being ill

The young participants who were cured from a malignant disease recognized different changes in their physical and mental health as a consequence of having been ill. They reported changes in their physical appearance due to the amputation of limbs, impairment of vision and hearing, loss of balance, and graphomotor problems: ‘’The most important is, of course, that cancer took my leg, but it took a certain freedom to make me feel free among people. (4); ‘’I lost speed. I lost balance, I used to get first in running races, now when I start running, I stumble, I don’t take part in physical education, I can’t play because I don’t catch the ball well. I can’t see well, not like other children. (6)”. From their perspective, the negative impacts also included decreased levels of self-confidence and self-control: ‘’Self-confidence and all related to it. I think I wouldn’t have been like that if I wasn’t ill. I lost self-control because of my thyroid gland, I am short-tempered. (6)”.

The participants also pointed out a reduction in the possibility of learning ‘’The disease took away from me two grades (third and fourth). That’s why I can’t fit in society (2)”; “I missed a part of my education and this is sometimes causing problems of having gaps in knowledge, in the parts of some school subjects. (18)”, as well as the loss of a carefree childhood: ‘’The disease took an unworried childhood away from me which every child is entitled to, but first and foremost we lost our health and after that education (8)”. Other perceived negative outcomes of the disease included the weakening of social contacts: ‘’The disease also took a couple of friends away from me who forgot me during my treatment (16)”; ‘’And I missed out hanging around with the children so today I don’t have many friends. (6)”, as well as a decrease in the possibility of choosing free time activities (e.g.,) going on trips with their classmates, dancing, and participating in sports.

The young participants in this study also pointed out some positive effects of experiencing a malignant disease. These positive impacts are mainly related to various aspects of their personal growth and development: ‘’I have become more mature, brave, determined, and tenacious person, which now proves advantageous too. (13)”; ‘’I think that children who have had cancer mature (grow up) more quickly than their peers. (18)”. A proportion of the participants particularly mentioned pripadnost toj grupi. Ušla sam u grupu mladih koji su prošli isto i zajedničkim radom smo se usmjerili na to da pomognemo onima koji se sada liječe. Radom naše grupe stekla sam vještine komunikacije u odnosu s drugim ljudima. Sudjelovanje na kampovima i konvencijama, međunarodnim okupljanjima survivora. Dobro zezanje s mladima koji su kao i ja (18)." Iskustvo oboljenja je donijelo i prepoznavanje pravih i stjecanje novih prijateljstava. Četrnaestogodišnja sudionica ističe: "Bolest me je naučila da tek kada upadnemo u nevolju, saznamo tko nam je pravi prijatelj i ma kolike šanse bile, ako vjerujemo, izborit ćemo se s bilo čime (10)."

RASPRAVA

Rezultati istraživanja upućuju na heterogenost iskustava preživljenja maligne bolesti iz perspektive izliječenih mladih. Sukcesivno po fazama liječenja mladi opisuju saznanje bolesti, tretman liječenja i posljedice oboljenja koje prepoznaju u svakodnevnom funkcioniranju. Iako postoje ograničene empirijske spoznaje o načinima reagiranja djece na dijagnozu bolesti (Eiser, 2004), utvrđeno je da ona reagiraju sukladno razvojnoj dobi, temperamentu, dostupnim strategijama suočavanja i stanju u kojem se nalaze (Wong i sur., 2006. prema Mört, 2012). Mladi koji su evocirali sjećanja vezana uz saznanje bolesti naveli su da su bili u stanju šoka, nevjerice, zabrinuti i preplavljeni strahom. Radi se o reakcijama koje su normalne, imaju adaptivnu funkciju u prijetećoj situaciji i mogu poslužiti kao zaštitni činitelj na početku liječenja (Eiser, 2004). Ista autorica navodi i pojavu regresivnih oblika ponašanja, povećanu ovisnost o roditeljima i povlačenje u sebe kao moguće odgovore na saznanje dijagnoze. Neki su se sudionici pitali zašto su baš oni oboljeli, što u većoj mjeri valja razumjeti kao odraz tjeskobe i zabrinutosti, a manje kao specifično propitivanje uzroka nastanka bolesti (Yi, Kim, Parsons i Wu, 2018). Oni sudionici koji s dijagnozom i prirodom bolesti nisu bili upoznati od strane roditelja i medicinskog tima, do informacija su dolazili alternativnim izvorima. U situacijama uskrate informacija o bolesti djeca i mladi skloni su ih samostalno potražiti, u razgovoru s drugom oboljelom djecom, pretražujući mrežne strani-

their motivation to help others and their engagement in civil society organizations that deal with providing support to cancer patients in the same age groups: ''I belong to a group of age-mates who understand me, who had been treated from the same disease and I don't have to explain to them anything related to cancer. I simply feel that we belong to each other, that's why I'm emphasizing belonging to this group. I entered the group of young people who had gone through the same thing and working together, we have focused to help those who are under treatment now. Working in the group I acquired communication skills. Taking part in the camps, conventions, international gatherings of the survivors. Good fooling around with the young who are the same as me. (18)''. Experiencing the illness resulted in a number of participants recognising true friendships and acquiring new ones. A 14-year-old girl emphasized: ''The disease has taught me that when we are in big trouble, only then do we find out who the real friend is, and whatever the odds, if we believe, we shall overcome no matter what. (10)''.

DISCUSSION

The results of this study indicate heterogeneity in the experiences of young people who survived a malignant disease. From one phase to next, these young patients successively described how they felt when they found out about their diagnosis, the subsequent treatment, and the consequences of the disease on everyday functioning. Although there are very few empirical studies about the ways in which children react to the diagnosis of diseases (Eiser, 2004), it has been ascertained that they react according to their age, stage of development, temperament, strategies available to face such situations, and their actual condition (Wong et al.; 2006. as cited in Mört, 2012).

When the participants in the present study recollected their memories of finding out about their diagnosis, they pointed out that they had been in a state of shock and disbelief, and they were worried and overwhelmed by fear. These are normal reactions that play an adaptive role in a threatening situation and may serve as a protective factor at the beginning of treatment (Eiser, 2004). Other responses to being diagnosed with malignant diseases include manifestation of regressive forms of behaviour, increased dependence on parents, and withdrawal into themselves (Eiser, 2004). Some respondents asked themselves ''why me?'': to a large extent, this can ce, tisak i slično (Yi i sur., 2018; Eiser, 2004). Tako su neki mladi o točnoj dijagnozi saznali po vremenskom odmaku, po uobičajenom simptomu bolesti i od druge oboljele djece. O raku su znali samo da se od njega umire. Ovakav način saznavanja dijagnoze otvara prostor za različite interpretacije uzroka i (pesimistične) prognoze bolesti, što može dodatno otežati suočavanje i nošenje sa zahtjevnim liječničkim tretmanom. Raniji empirijski nalazi ističu važnost dobno primjerenog informiranja na početku liječenja, koje se temelji na pretpostavci da bolje informirano dijete ostvaruje bolju kooperaciju tijekom aktivnog tretmana, ali ogleda se i u kasnijoj fazi posttretmana kroz posvećeniju skrb i praćenje zdravstvenog stanja (Eiser, 2004; Kadan-Lottick i sur., 2002).

Među osobito zahtjevne trenutke liječenja, osim saznanja da su oboljeli od potencijalno životno ugrožavajuće bolesti, mlade su osobe navele početak liječničkog tretmana. Kao i u ranijim istraživanjima mladima je bila zahtjevna socijalna izolacija, odnosno duži boravak u bolnici bez mogućnosti odlaska kući (Gomes, Abreu Lima, Vicente Rodrigues, Garcia de Lima i Collet, 2013). Uslijed odvojenosti od članova svoje obitelji i prijatelja neki od njih bili su skloni protestnom ponašanju. Stresni aspekti liječenja uključivali su i određene medicinske postupke. Slično rezultatima istraživanja Ander, Thorsell Cederberg, von Essen i Hovén (2018), Gomes i sur. (2013) mladi su navodili strah i nelagodu zbog liječničkih zahvata (npr. lumbalne punkcije), gubitka kose i boli zbog nuspojava kemoterapije. Pri povratku u školsku sredinu suočili su se s vršnjačkim nepoznavanjem nuspojava liječenja i prirode bolesti. Vršnjaci su, kao i u istraživanju Lehmann i sur. (2014), imali pogrešna uvjerenja o malignoj bolesti kao zaraznoj. Lewis i sur. (2014) apostrofiraju da u svim situacijama i u svim odnosima iskustvo oboljenja mlade čini drugačijima i zahtijeva reciprocitet, fleksibilnost, prilagodljivost ne samo u izliječenom nego i u odnosima koje ima. Neke se prijateljske veze prekidaju i često se stvaraju nove koje, uslijed povećane zrelosti, u većoj mjeri zadovoljavaju izliječene mlade (Zebrack i Isaacson, 2014).

be understood as a sign of anxiety and worry, and, to a smaller extent, as a specific investigation of the cause of the occurrence of the disease (Yi, Kim, Parsons and Wu, 2018). Respondents who had not been informed about the diagnosis and the nature of the disease by their parents and medical team found out through alternative sources. In situations where information about the disease was being withheld, children and young adults found out more by looking it up themselves, in conversations with other sick children, by browsing web pages and newspapers etc. (Eiser, 2004; Yi et al., 2018).

Some young participants learned about their diagnosis later after noticing typical symptoms of the disease and talking to other children with cancer. The only thing that they knew about cancer is that you die from it. Such a way of learning the diagnosis gives room for various interpretations of its cause and (pessimistic) prognoses of the disease, which can cause additional distress while facing and coping with demanding medical treatments. Previous empirical findings highlight the importance of providing age-appropriate information to young patients at the beginning of treatment. This is based on the presumption that a better-informed child may cooperate better during active treatment, as well as in the later phases of post-treatment through more dedicated care and observing one's state of health (Kadan-Lottick et al., 2002; Eiser, 2004).

Besides discovering that they had a potentially life-threatening disease, the young participants emphasized that the beginning of the medical treatment was especially demanding. Similar to previous studies, social isolation, more specifically long periods of time spent in the hospital without the possibility of going home, was challenging for the young participants in our study (Gomes, Abreu Lima, Vicente Rodrigues, Garcia de Lima and Collet, 2013). Due to the separation from their family and friends, some of them were inclined to act demonstratively.

Other stressful aspects of the treatment included certain medical procedures. Similar to previous results (Gomes et al., 2013; Ander, Thorsell Cederberg, von Essen and Hovén, 2018), the young patients in our study mentioned fear and uneasiness caused by certain medical procedures (e.g., lumbar puncture), as well as loss of hair and pain caused by chemotherapy. When they returned to school, they faced the ignorance of their classmates about the side effects of cancer treatments and the nature of the disease. Children from the same age groups tend-

Mladi u ovom istraživanju nalaze se u dobi u kojoj su glavni razvojni zadaci pripadnost grupi, stvaranje pozitivne slike o sebi i samopoštovanje (Stevens, Dunsmore, Bennett i Young, 2009). Oboljenje ove razvojne zadatke može dovesti u pitanje. Prethodni empirijski rezultati navode negativne posljedice bolesti u vidu promijenjene slike o tijelu i poteškoća tjelesnog zdravlja (Ander i sur., 2018; Abu Shosha, 2016; Zebrack i sur., 2014; Doukkali i sur., 2013; Lee i sur., 2012). U istraživanju Lehmann i sur. (2014) tjelesne poteškoće perzistirale su i nakon deset godina od dijagnoze. Mladi su, kao i neki sudionici ovog istraživanja, opisivali probleme pokretljivosti, poteškoće povezane s vidom, sluhom, ustima, trbuhom, ravnotežom, manjkom tjelesne kondicije i umorom. Takve promjene utjecale su na doživljaj slike o vlastitom tijelu koja se razlikovala od one njihovih vršnjaka i bila im je ponekad abnormalna ili čudna (Larouche i Chin-Peuckert, 2006. prema Lee i sur., 2012). Promijenjeno tjelesno zdravlje kod dijela mladih osoba utjecalo je i na smanjenu slobodu u izboru aktivnosti slobodnog vremena. U istraživanju Lehmann i sur. (2014) ograničenja su se odnosila na slobodno vrijeme, sport i prehranu. Uslijed čestih boravaka u bolnici nisu bili u mogućnosti redovito prisustvovati nastavi i, kao što je potvrđeno i u ranijim istraživanjima, neki od njih imaju iskustvo slabijeg obrazovnog uspjeha (Berg i sur., 2016; Doukkali i sur., 2013).

Unatoč nizu nepovoljnih posljedica bolesti prisutne su i one pozitivne koje sudionici prepoznaju u svakodnevnom funkcioniranju. Pozitivan utjecaj oboljenja, iz prethodnih istraživanja, ogleda se u području bliskih odnosa, budućih planova, promijenjenih prioriteta, povećane empatije i zdravstvene kompetencije (Duran, 2013; Doukkali i sur., 2013; Bellizzi i sur., 2012; Jones i sur., 2011). Iskustvo bolesti facilitira brže i zrelije odnose mladih s roditeljima dajući im mudrost, svijest o neizbježnoj smrtnosti i uvid nedostupan njihovim vršnjacima (Lewis i sur., 2013). U skladu s navedenim jesu i rezultati ovog istraživanja. Mladi ističu povećanu zrelost i angažman u organizacijama civilnog društva povezanim s vršnjačkom podrškom oboljelima. Navedeno može upućivati na posttraumatski rast sudionika koji se definira

ed to have incorrect assumptions about malignant diseases and thought that they were contagious (Lehman et al., 2014). Lewis et al. (2014) identified that, among all situations and all relationships, the experience of having a malignant disease makes young people different, and it demands reciprocity, flexibility, and adaptability, not only among those who have been cured, but also in the relationships that they are involved in. Some friendships are broken, but new ones emerge with greater maturity and substantially satisfy young people who have been cured (Zebrack and Isaacson, 2014).

In the present study, the young participants were of the age at which their main social developmental tasks involve forming group attachments, a positive self-image, and self-respect (Stevens, Dunsmore, Bennett and Young, 2009). Falling ill can jeopardize these developmental tasks. Previous empirical results have shown the negative effects of such illnesses such as a changed body image and issues with physical health (Lee et al., 2012; Doukkali et al., 2013; Zebrack et al., 2014; Abu Shosha, 2016; Ander et al., 2018). Lehman et al. (2014) showed that physical difficulties can persist for ten years after the diagnosis. Many young patients, including some of the respondents in the present study, described problems with mobility, sight, hearing, mouth, abdomen, balance, lack of physical fitness, and fatigue. Such changes have had an impact on body image, which differed from that of their fellow-mates, and sometimes was abnormal or awkward to them (Larouche and Chin-Peuckert, 2006. as cited in Lee et al., 2012). Some of the respondents also mentioned that changes in physical health resulted in a reduced choice of activities in their free time. Lehman et al. (2014) reported that these limitations were related to free time, sports, and diet. Frequent stays in the hospital reduced their ability to attend classes regularly. Similar to previous results, this resulted in some of them experiencing lower educational success (Doukkali et al., 2013; Berg et al., 2016).

Despite the numerous unfavourable consequences of the illness, there are also positive ones that can be recognized in everyday functioning. Based on previous studies, the positive influence of falling ill can be seen in the sphere of close relationships, future plans, changed priorities, increased empathy, and competence related to health issues (Jones et al., 2011; Bellizzi et al., 2012; Duran, 2013; Doukkali et al., 2013). The experience of being ill facilitates more mature relationships between young people kao iskustvo pozitivne promjene proizašle iz suočavanja s iznimno izazovnim životnim krizama, a uključuje više vrednovanje života općenito, smislenije interpersonalne odnose, jači osjećaj vlastite snage, promjenu prioriteta, bogatiji egzistencijalni i duhovni život (Tedeschi i Calhoun, 2014. prema Duran, 2013). Bolest je, metaforički rečeno, donijela veće zrcalo koje omogućava bolji pogled u unutarnji svijet izliječene osobe (Kluckhohn, 1949. prema Duran, 2013). O tome da posjeduju takvo zrcalo, izvješćuju i neki mladi u ovom istraživanju.

Ograničenja istraživanja

Ograničenje istraživanja primarno se odnosi na heterogenu strukturu sudionika po pitanju dobi oboljenja. Dob oboljenja za većinu sudionika bila je od osam do četrnaest godina, dok je za sedmero sudionika bila do sedme godine života. Oskudno je empirijsko znanje vezano uz način na koji djeca mlađa od osam godina razumiju bolest ili posljedice koje oboljenje ima na njihovo zdravlje u budućnosti (Eiser, 2008). Pod tim vidom moguće je kritički propitivati rezultate koji se odnose na saznanje bolesti i tretman aktivnog liječenja sudionika koji su tada bili mlađi od sedam godina, radi li se o autentičnim sjećanjima ili posredovanim saznanjima dobivenim od roditelja, drugih izliječenih i sl.

Implikacije za praksu

Dobivene spoznaje mogu koristiti medicinskom timu, djelatnicima pomažućih profesija, obitelji i drugim osobama uključenima u skrb o oboljeloj i izliječenoj djeci i mladima. Empirijski nalazi sugeriraju važnost dobno primjerenog informiranja o dijagnozi bolesti i protokolu liječenja od strane medicinskog tima i/ili roditelja. Navedeno može koristiti u prevenciji netočnih i nepotpunih interpretacija bolesti, ali i u uspostavi dobno transparentnog odnosa liječnika i roditelja s djetetom. S obzirom na to da je početak liječenja sudionicima bio posebno zahtjevan, predlaže se osiguranje sveobuhvatne psihosocijalne podrške koja će, prema rezultatima ovog istraživanja, primarno adresirati strahovanja oboljelih. Dobiveni rezultati ukazuju na to da je podrška mladima potrebna i u nošenju s različitim gubicima uslijed kojih im je promijenjen

and their parents, giving them wisdom, awareness of unavoidable mortality, and the insight inaccessible to their fellow-mates (Lewis et al., 2013). The results of this study are also similar. The young participants emphasized an increased maturity and engagement in the civil society organizations dealing with providing peer-to-peer support. These factors highlight the post-traumatic growth of the respondents, which is defined as an experience of positive change stemming from facing highly challenging life crises, including a greater appreciation of life in general, meaningful interpersonal relationships, enhanced feelings of personal strength, change in priorities, as well as a richer existential and spiritual life (Tedeschi and Calhoun, 2014. as cited in Duran, 2013). The illness has, metaphorically speaking, brought in a bigger mirror that can enable a better view to the inner world of those who have been cured (Kluckhohn, 1949. as cited in Duran, 2013). Some of the respondents in this study also mentioned feeling like they have such a mirror.

Research limitations

The primary limitation of this study is to the heterogeneous structure of the respondents with respect to age at the time of diagnosis. A majority of the respondents were between 8 and 14 years old when they were diagnosed, while seven of them were under 7 years old. There is insufficient empirical knowledge with reference to the way children < 8 years old understand the illness and its consequences on their health in the future (Eiser, 2008). Therefore, it is possible to have critical reservations about the results referring to finding out that they had cancer and the active medical treatment of the respondents who were under 7 years old at that time. It is possible that they do not have authentic memories of that time, or that their responses were mediated by their parents and those of other children who had been cured.

Implications for practical work

Our findings can be used to inform and support medical teams, workers who help/support medical professionals, the families of patients suffering from such diseases, and other personnel engaged in the care of children and young adults who are sick and who have been cured. Empirical results suggest the importance of age, as well as the need to acquire adequate tjelesni izgled, socijalna mreža, obrazovni uspjeh i djetinjstvo. Pružati podršku značilo bi pomoći im u integriranju gubitaka u njihovo neveliko životno iskustvo i u prilagodbi na "promijenjenog i drugačijeg" sebe. Istovremeno valja osnaživati sve aspekte osobnog rasta koji može predstavljati jedan od zaštitnih činitelja u daljnjem adolescentnom razvoju. Osim oboljelima podrška je potrebna i njihovim vršnjacima. Njihova nedovoljna poučenost o nuspojavama liječničkog tretmana upućuje na potrebu za edukacijom. Razvijene mrežne platforme podrške namijenjene mladima, obiteljima, prijateljima pružaju odgovore na najčešća pitanja o prirodi bolesti i načinima pomoći. Jedna od takvih je Canteen (https://www.canteen.org.au/), The National Children's Cancer Society (www.thenccs.org), a u regionalnom okruženju Udruženje Čika Boca (www.cikaboca.org), NURDOR (www.nurdor.org), Udruženje Zvončica (www.zvoncica.org.rs), Udruženje Srce za djecu oboljelu od raka (www.srcezadjecu.ba), Udruga Krijesnica (http://krijesnica.hr/) i dr. Navedene organizacije civilnog društva mogu biti izvor informacija vršnjacima i nastavnom osoblju. U njima djeluju i grupe izliječenih mladih s razvijenim programima peer-to-peer-edukacije.

ZAKLJUČAK

Rezultati istraživanja donose uvid i omogućavaju bolje razumijevanje iskustva preživljenja maligne bolesti iz perspektive izliječenih mladih. "Preživjeti" malignu bolest znači suočavanje i nošenje s nizom nepovoljnih stresora koji, privremeno ili trajno, mijenjaju poznati psihički, tjelesni i socijalni svijet mladih. Pristup pomažućih djelatnika tom promijenjenom svijetu valja biti holistički i multidisciplinarno usmjeren te prisutan u svim vremenskim točkama njihova izlječenja. Na primjer u trenucima zahtjevne socijalne izolacije navedeno bi značilo angažiranje vršnjačke mreže podrške i osiguravanje različitih načina njezine prisutnosti tijekom bolničkog liječenja. Po završetku aktivnog tretmana uključivalo bi podršku u ponovnom pronalasku mjesta u vršnjačkoj grupi radi prevencije socijalne izolacije i u izvanbolničkom okruženju. Dobiveni rezultati upućuju i na pozitivno usmjerene promjene u životu preživjelih. One se ogledaju u različitim aspektima osobne transformacije koje

information on the diagnosis and treatment procedures by the medical teams and/or the parents. This can serve in the prevention of incorrect and insufficient interpretations of the illness and establish age transparent relationships between the medics, the parents, and the child.

Since the beginning of the treatment was particularly challenging for the respondents, it is proposed that a comprehensive psychosocial support programme is made available to these patients; according to the results of this study, this programme may be able to address the fears of those who suffered such illnesses. Our results also indicate that sufficient support is necessary to help the young people cope with different losses that have caused a change in their physical appearance, social networks, educational achievements, and childhood. In this case, to provide support would mean to help them integrate their losses into their limited life experience and adjust to ''a changed and different'' self. At the same time, all the aspects of their personal growth that can be protective factors in further adolescent development should be given a boost.

Support is necessary not only for those who are sick, but also for other children in the same age groups. The fact that they were insufficiently informed about the side-effects of the medical treatment underlines the necessity for further awareness and education. A number of network platforms have been developed to support young patients, as well as their families and friends; these platforms offer answers to the most frequently asked questions about the nature of the illness and the ways in which one can help children suffering from such diseases. Some important platforms include Canteen (https://www.canteen.org.au/), the National Children's Cancer Society (www.thenccs.org), and at the regional level, the Association Čika Boca (www.cikaboca.org). NURDOR (www.nurdor.org), Association Zvončica (www.zvoncica.org.rs), Association Srce for children with cancer (www.srcezadjecu.ba), and Association Krijesnica (http://krijesnica.hr/) are civil society organisations that can be a source of information for classmates and teaching staff. Additionally, groups of young people who have been cured engage in such associations by developing educational programmes and ''peer-to-peer'' networks.

mogu koristiti mladima u navigiranju kroz Scile i Haribde daljnjeg odrastanja. Stoga je pozicija (i zadaća) pomažućeg tima, ali i drugih pripadnika socijalne mreže preživjelih, u kontinuiranom ublažavanju negativnih i facilitiranju pozitivnih ishoda bolesti.

Zahvale

Željela bih se zahvaliti Udruženju roditelja, staratelja i prijatelja dece obolele od malignih bolesti “Čika Boca” za neprocjenjiv doprinos istraživanju. Posebne zahvale mladim preživjelima koji su velikodušno podijelili svoje iskustvo.

CONCLUSION

The results of this study provide further insights and understanding of the experience of surviving a malignant disease from the perspective of young people who have been cured. Based on our results, ‘’to survive” a malignant disease means facing and coping with many damaging stressors that can temporarily or permanently change the known psychological, physical, and social world of children and young adults. The approach of the team helping the patients adjust to this changed world should be holistic, multidisciplinary, and consistent at all timepoints of their treatment. For example, in the case of social isolation, this would mean the engagement in a peer-to-peer network of support and enabling such engagement during the time spent in the hospital. At the end of active treatment, the team should find a way to help patients find a place among others who have been through the same situations in order to prevent social isolation outside the hospital. Our results also indicate positive and directed changes in the lives of the cured participants, reflecting the different aspects of personal transformation that can help young people navigate through the Scylla and Charybdis of growing up. Therefore, an important task of the team, as well as other members of the social network of survivors is to continuously alleviate the negative outcomes and facilitate the positive outcomes of the disease.

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