

„SRETNI SMO POSLIJE SVAKOG TOG ZOOMA“: ISKUSTVO VIRTUALNE KOMUNIKACIJE ČLANOVA OBITELJI OSOBA S TEŠKOM OZLJEDOM MOZGA NA BOLNIČKOJ REHABILITACIJI TIJEKOM PANDEMIJE BOLESTI COVID-19

“EACH ZOOM MEETING MAKES US HAPPY”: VIDEO CONFERENCING EXPERIENCES OF FAMILY MEMBERS OF INDIVIDUALS WITH SEVERE BRAIN INJURY UNDERGOING INPATIENT REHABILITATION DURING THE COVID-19 PANDEMIC

IVANA KLEPO¹, ANDREJA BARTOLAC², DUBRAVKO TRŠINSKI¹, KLARA DILBER¹, DAMIRKA LEVANIĆ¹, VALENTINA BLAŽINČIĆ¹, IVAN DUBROJA¹, IVICA ŠČURIĆ¹

¹ Special Hospital for Medical Rehabilitation Krapinske Toplice, Gajeva 2, Krapinske Toplice, Croatia, contact: ivana.klepo@sbkt.hr

² University of Applied Health Sciences, Mlinarska 38, Zagreb, Croatia

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Sažetak: Uključenost obitelji u proces rehabilitacije osoba s ozljedom mozga iznimno je važna, no zbog prevencije širenja zaraze virusom SarsCov19 onemogućeni su posjeti i boravak uz bližnju oboljelu osobu u zdravstvenim ustanovama. Cilj je ovog istraživanja steći uvid u iskustvo članova obitelji kojima je bližnji boravio na bolničkoj rehabilitaciji zbog posljedica ozljede mozga u vrijeme pandemije, a kojima je omogućena komunikacija putem virtualne platforme Zoom. Namjeran uzorak sudionika uključuje 11 članova obitelji koji su imali kontinuiranu interakciju sa svojim bližnjim putem videoveze, koja je bila dio radnoterapijske intervencije. U ovom kvalitativnom istraživačkom nacrtu prikupljanje podataka provedeno je putem polustrukturiranog intervjua, a dva su neovisna istraživača provela tematsku analizu kojom su izdvojene tri glavne teme: (1) Suočavanje s traumatskom

Abstract: Family involvement is recognised as an important part of the rehabilitation process for individuals suffering from brain injuries. However, in an attempt to prevent the spread of COVID-19, healthcare institutions were obligated to implement visitor restrictions. The aim of this study was to understand the experiences of family members with respect to communication based on video calls with their close relatives who were suffering from brain injuries and undergoing inpatient rehabilitation during the pandemic. We included a purposive sample of 11 participants/family members who communicated consistently with their loved ones via video conferencing as part of the occupational therapy intervention. Qualitative data was collected using a semi-structured interview. Two independent researchers performed a thematic analysis based on the data inquiry method and highlighted

ozljedom člana obitelji, (2) Iskustvo omogućenog videopoziva tijekom rehabilitacije i (3) Čimbenici obiteljske otpornosti. Rezultati istraživanja upućuju na snažne emocionalne reakcije sudionika i promjene u njihovu svakodnevnom životu uslijed traumatskog događaja i nemogućnosti boravka uz ozlijeđenog člana u bolnici. Iskustvo interakcije putem video veze pokazalo se posebno značajnim za sudionike jer im je omogućilo uvid u zdravstveno stanje bližnjeg, uključenost u rehabilitacijski proces, kao i praćenje oporavka bližnjeg. Sve su to čimbenici koji su pridonijeli otpornosti članova obitelji. Istraživanje ukazuje i na perspektivu primjene virtualnih metoda komunikacije i uključivanja članova obitelji u proces skrbi i rehabilitacije i izvan pandemijskog konteksta, u drugim okolnostima u kojima članovi obitelji ne mogu fizički boraviti uz svojeg bližnjeg u bolnici.

Cljučne riječi: ozljeda mozga, rehabilitacija, obiteljska otpornost, COVID-19, videopoziv

UVOD

Traumatska ozljeda mozga

Traumatska ozljeda mozga (TOM) označava promjenu stanja svijesti ili drugu vrstu oštećenja mozga koje nastaje zbog utjecaja vanjske sile u području glave (Menon, Schwab, Wright i Maas, 2010). Težina ozljede najčešće se klasificira Glasgowskom ljestvicom kome (GCS; *Glasgow coma scale*; Teasdale i Jennett, 1974) kao blaga, umjerna ili teška, a posljedice mogu varirati od kratkotrajnog gubitka svijesti pa sve do kome ili smrtnog ishoda traumatskog događaja (Faul i Coronado, 2015). Mnoga istraživanja potvrđuju da uslijed oštećenja kognitivnih, motoričkih, emocionalnih ili bihevioralnih funkcija posljedice TOM-a dugoročno utječu na samostalnost i sudjelovanje u brojnim područjima svakodnevnog života (Beadle, Ownsworth, Fleming i Shum, 2016.; Douglas, 2020; Giles et al. 2019; Klepo, Sangster Jokić i Tršinski, 2020; Milders, 2019; Ponsford i sur., 2014; Rapport, Hanks i Bryer, 2006; Tršinski, Tadinac, Bakran i Klepo, 2019; Watkin, Phillips i Radford, 2020).

TOM se vrlo često naziva i „tiha epidemija“ jer posljedice ozljede na prvi pogled nisu uočljive i društvo ih uglavnom nije dovoljno svjesno (Peeters i sur. 2015). Krajnji ishod TOM-a je teško predvidjeti (Duff, 2002), a liječenje i rehabilitacija najčešće su dugotrajan proces koji čine akutna

three main themes: (1) coping with a traumatic brain injury of a family member; (2) video conferencing experiences with a family member during rehabilitation, and (3) family resilience factors. Our study highlighted that there were changes in the daily lives of the family, as well as that family members had a strong emotional response due to the traumatic event and the inability to stay with the affected individuals in the hospital. Interactions via video conferencing proved to be significant for the participants since it provided them with an insight into the health condition of their family members, enabled their involvement in the rehabilitation process, and allowed them to monitor the recovery process. The above-mentioned factors also contributed to the resilience of participants. Our findings indicate the benefits of virtual communication and involving family members in the rehabilitation process, especially in situations where hospital visitation is impossible.

Keywords: brain injury, inpatient rehabilitation, family resilience, COVID-19, video conferencing

INTRODUCTION

Traumatic brain injury

Traumatic brain injury (TBI) denotes a change in the state of consciousness, or other types of brain damage caused by the influence of an external force on the head (Menon, Schwab, Wright & Maas, 2010). Brain injuries are typically classified as mild, moderate, and severe based on the Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974), while the consequences of such injury can range from short-term loss of consciousness to coma or even death as a result of a traumatic event (Faul & Coronado, 2015). Several studies have confirmed that TBI can cause the impairment of cognitive, motor, emotional, and behavioural functions, subsequently affecting long-term independence and participation in many areas of daily life (Beadle, Ownsworth, Fleming & Shum, 2016; Douglas, 2020; Giles et al. 2019; Klepo, Sangster Jokić & Tršinski, 2020; Milders, 2019; Ponsford et al., 2014; Rapport, Hanks & Bryer, 2006; Tršinski, Tadinac, Bakran & Klepo, 2019; Watkin, Phillips & Radford, 2020).

Since the consequences of brain injuries are not immediately apparent, TBI is also known as a “silent epidemic”, and public awareness of TBI remains insufficient (Peeters et al., 2015). The outcome of TBI is difficult to predict (Duff, 2002) and rehabilitation is usually a long-term process that involves acute care, acute inpatient rehabilitation, and finally, communi-

faza, nakon koje slijedi akutna bolnička rehabilitacija te na kraju rehabilitacija u zajednici (Sandhaug, Andelic, Vatne, Seiler i Myglandet, 2010). Akutna bolnička rehabilitacija provodi se nakon akutnog zbrinjavanja koje uključuje neurološke i/ili neurokirurške intervencije i stabilizaciju stanja osobe s TOM-om (Dubroja, 2019). Bakran i suradnici (2015) navode da akutna rehabilitacija osoba koje su doživjele težak i srednje težak TOM u Republici Hrvatskoj obično traje od, minimalno, tri tjedna do šest mjeseci, ali može trajati i duže. Složenost posljedica ozljede zahtjeva cijeli tim stručnjaka: od liječnika različitih specijalnosti, medicinske sestre, fizioterapeuta, radnog terapeuta, psihologa pa do logopeda, a u središtu procesa nalazi se osoba koja je doživjela TOM i njezina obitelj (Bakran i sur., 2015).

Značenje obitelji u procesu rehabilitacije osoba s TOM-om

Uloga obitelji u rehabilitacijskom procesu osoba s umjerenim do teškim TOM-om u literaturi je prepoznata kao iznimno važna, a najčešće je i primarni izvor potpore (Vangel i sur., 2011). Potvrđuje to i istraživanje Bogner i suradnika (2019) u kojem su sudionici s TOM-om čiji su članovi obitelji najmanje 10% vremena bili uključeni u terapijski proces tijekom bolničke rehabilitacije, nakon otpusta kući pokazali veću integriranost u svoje zajednice. U istom se istraživanju pokazuje da prisutnost i potpora obitelji mogu voditi i do boljeg kognitivnog funkcioniranja u odnosu na ozlijeđene osobe čiji su članovi obitelji bili uključeni manje od 10% vremena. Kao moguće razloge uspješnijeg funkcionalnog statusa tri i devet mjeseci nakon otpusta autori navode bolju pripremljenost na fazu tranzicije koja slijedi nakon otpusta iz bolnice i educiranost obitelji u potpori daljnjeg oporavka (Bogner i sur., 2019). Mogućnost boravka uz svoje bližnje u bolničkom okruženju pomaže i u procesu suočavanja s posljedicama i žalovanja obitelji, daje mogućnost zagovaranja potreba bližnjeg koji to nije u stanju, ali i daje osjećaj sigurnosti da se članovi tima adekvatno brinu za pacijenta (Creutzfeldt i sur., 2021; Montauk i Kuhl, 2020). Značajnom se pokazuje i emocionalna potpora zdravstvenog osoblja kao i drugih obite-

ty-based rehabilitation (Sandhaug, Andelic, Vatne Seiler & Myglandet, 2010). Acute inpatient rehabilitation is followed by acute care, which includes neurological or neurosurgical interventions, as well as the stabilisation of health conditions (Dubroja, 2019). Bakran et al. (2015) highlighted that, in the Republic of Croatia, acute inpatient rehabilitation of individuals who have sustained severe and moderate TBI typically extends between three weeks to six months, but can take even longer. The complexities associated with brain injuries often requires a whole team of health-care professionals, including physicians specialising in different fields, nurses, physiotherapists, occupational therapists, psychologists, and speech and language pathologists, in addition to the individual who experienced TBI and his/her family members, who are at the heart of this process (Bakran et al., 2015).

Importance of family members in the rehabilitation process

The role of the family in the rehabilitation process of individuals with moderate to severe TBI has been recognised as particularly relevant, since family members are the primary source of support (Vangel et al., 2011). Furthermore, Bogner et al. (2019) showed that individuals with TBI whose family members were involved in the therapeutic process for at least 10% of the time during inpatient rehabilitation showed greater community integration after discharge. The authors went on to demonstrate that family presence and support could also lead to better cognitive functioning when compared to individuals whose family members were involved in less than 10% of the rehabilitation process. Bogner et al. (2019) pointed out that the reasons for improved functional status at 3- and 9-months post discharge might be due to improved readiness for the transition phase following hospital discharge, as well as the fact that families were educated to provide support during further recovery (Bogner et al., 2019). Being able to stay with family members in the hospital supports the process of coping, and grieving as a family provides an opportunity to advocate for a family member who is not able to do it by him/herself. It also provides a sense of security that the team members care for the patient adequately (Creutzfeldt et al., 2021; Montauk & Kuhl, 2020). The emotional

lji koje prolaze kroz slično iskustvo (Creutzfeldt i sur., 2021). Iz perspektive samih osoba koje su na rehabilitaciji zbog stečene ozljede mozga posjeti obitelji i prijatelja pozitivno utječu na njihovo iskustvo rehabilitacije jer osiguravaju povezanost s događanjima izvan bolnice, oni poznaju njihove osobnosti, pokazuju razumijevanje i pružaju emocionalnu potporu (Fleming i sur., 2012). Kad je riječ o hrvatskom kontekstu, već dulji niz godina članovi obitelji predstavljaju sastavni dio rehabilitacijskog tima na stacionarnoj rehabilitaciji osoba nakon TOM-a u Krapinskim Toplicama (Dubroja, Valent, Miklić i Kesak, 1995), pri čemu su prije pandemije imali mogućnost cjelodnevnog boravka uz krevet svojeg bližnjeg.

Socijalne i psihološke posljedice zabrane bolničkih posjeta tijekom pandemije bolesti COVID-19

Održavanje fizičke distance, uz nošenje maske na licu, diljem je svijeta u vrijeme pandemije bolesti COVID-19 uključeno u osnovne epidemiološke mjere zaštite zdravlja i prevencije širenja bolesti. Za osobe koje se iz različitih razloga nalaze u bolnici i za članove njihovih obitelji to je značilo zabranu posjećivanja i boravka uz bližnje kad im je potpora vjerojatno najviše potrebna. U istraživačkoj literaturi tek se sporadično pronalaze informacije o posljedicama takvih odluka na sve dionike u zdravstvenom i socijalnom sustavu. Integrirani pregled literature koji su proveli Hugelius, Haranda i Marutani (2021) upravo je imao za cilj istražiti posljedice ograničavanja posjeta tijekom pandemije bolesti COVID-19, a 17 uključenih istraživanja obuhvatila su različita područja, od domova za starije osobe, intenzivne i palijativne skrbi, pedijatrije do drugih vrsta bolničke skrbi. Pregledni rad otkriva da su, iz perspektive samih pacijenata, restrikcije u posjećivanju utjecale na njihovo fizičko i mentalno zdravlje. Smanjeno uzimanje nutrijenata, povećana fizička bol i smanjenje sposobnosti brige o sebi neke su od fizičkih posljedica, dok su simptomi depresije, povišena razina percipirane usamljenosti, agitacija, agresija, smanjena kognitivna sposobnost i općenito nezadovoljstvo neke od posljedica na mentalno stanje pacijenata uslijed nemogućnosti kontakta

support of healthcare professionals and other families going through a similar experience was recently highlighted as a significant factor of hospital presence among individuals with TBI (Creutzfeldt et al., 2021). From the perspective of individuals suffering from an acquired brain injury, visits from family and friends have a positive effect on their rehabilitation experience as they provide a connection with events outside the hospital, help them engage with someone who understands and knows them well, and provides them emotional support (Fleming et al., 2012). In the Croatian context, family members have been an integral part of the rehabilitation team during the inpatient rehabilitation of individuals with TBI at the Special Hospital for Medical Rehabilitation Krapinske Toplice in Croatia (Dubroja, Valent, Miklić & Kesak, 1995). Before the pandemic, family members and visitors had the opportunity to be present at the patients' bedside for the entire day.

Social and psychological consequences of visitor restriction policies during the COVID-19 pandemic

Maintaining physical distance and wearing a face mask were introduced as basic epidemiological measures aimed to protect public health and prevent the spread of COVID-19 worldwide. For patients in hospitals and their family members, other restrictions included a ban on visitation and the inability to be with their loved ones in situations where they probably needed a lot of support. There is a lack of research on the consequences of such decisions on stakeholders in the health and social system. An integrated literature review (Hugelius, Haranda, & Marutani, 2021) investigated the consequences of visitors restrictions during the COVID-19 pandemic and included 17 studies covering various areas of health and social care: from nursing homes, intensive and palliative care, and paediatrics, to other types of hospital care. The review revealed that visitor restrictions impacted the physical and mental health of patients. Some of the physical consequences included increased physical pain, decreased nutrient intake, and decreased self-care abilities. In addition, patients experienced depressive symptoms, increased levels of perceived loneliness, agitation, aggression, reduced cognitive ability, and general

uživo s bližnjima (Hugelius i sur., 2021). Kod članova obitelji takva je situacija također uzrokovala niz neugodnih emocija, od brige, tuge, anksioznosti do ljutnje, a sve skupa utjecalo je i na socijalne odnose među članovima obitelji. Kako se nadalje navodi u istraživanju i osiguravatelji usluga suočavali su se s etičkim dilemama radi potrebe balansiranja zaštite javnosti i dobrobiti pacijenta te članova njihovih obitelji (Hugelius i sur., 2021).

Kada je riječ o osobama s ozljedom mozga, dostupno je istraživanje koje je provela Creutzfeldt sa suradnicima (2020), uključujući članove obitelji 19 osoba u akutnoj skrbi zbog posljedica TOM-a, moždanog udara i iznenadnog srčanog zastoja. Njihovo je istraživanje pokazalo da su uvođenjem zabrana posjećivanja članovi obitelji ostali zakinuti za potrebu bivanja uz svoje bližnje, kako bi ih zaštitili i kako bi bili njihov glas tijekom dana. Osjetili su i dodatnu nesigurnost i stres koji je povezan s nepostojanjem protokola komunikacije i dobivanja informacija o ozlijeđenom članu. Sutter-Leve, Passint, Ness i Rindfleisch (2021) također su proveli istraživanje koje je imalo za cilj ispitati razinu i prirodu stresa koji su iskusili članovi obitelji osoba koje su doživjele moždani udar i nalazile su se na rehabilitaciji u vrijeme pandemije bolesti COVID-19 te restriktivnih mjera kojima su zabranjeni posjeti. Rezultati su ukazali na postojanje zabrinutosti oko razine skrbi koja je pružena njihovim članovima obitelji, ali i da nemogućnost svjedočenja terapijskim postupcima dovodi do nepoznavanja funkcionalnih sposobnosti i razine pomoći koja će bližnjem biti potrebna kad se vrati kući. Jednako tako postojali su izazovi u komunikaciji, kako sa zdravstvenim osobljem zbog nepostojanja plana telefonskih kontakata tako i sa samim osobama koje su doživjele moždani udar i posljedično se susreću s komunikacijskim i kognitivnim teškoćama (Sutter-Leve i sur., 2021).

Pandemija bolesti COVID-19 potaknula je razvoj alternativnih metoda rada i komunikacije (Boulton i sur., 2021), a telemedicina je nedugo zatim postala središnji medij (Clement i sur., 2021) u zdravstvenom sustavu. Videopozivi i videokonferencije posebno su se pokazali značajnima u ublažavanju stresne situacije i omo-

dissatisfaction due to the inability to be close to their family members. The authors went on to show that, for family members, such a situation provoked unpleasant emotions, including worry, sadness, anxiety, and anger. The experience of separation affected social relationships among family members. Furthermore, service providers also faced ethical dilemmas with respect to balancing public health protection and the well-being of their patients and family members (Hugelius et al., 2021).

Creutzfeldt et al. (2020) conducted a study involving family members of 19 individuals in acute care as a consequence of TBI, stroke, and sudden cardiac arrest: they demonstrated that visitation restrictions left family members deprived of the need to be with their loved ones, to protect them, and to be their voice during the day. The participants in this study also reported additional insecurity and stress associated with the lack of communication protocol and reduced information about the patient. Another qualitative study (Sutter-Leve, Passint, Ness & Rindfleisch, 2021) investigated the level and nature of stress experienced by family members of individuals who had suffered a stroke and were admitted to rehabilitation centres at the time of the COVID-19 pandemic: they indicated concerns about the level of care provided to their family members and the inability to witness therapeutic procedures, which lead to unfamiliarity with functional abilities and the level of assistance that a loved one would require once discharged. Participants in this study also perceived challenges in communication, both with healthcare professionals due to the lack of a telephone contact plan, as well as with the patients who was suffering from communication and cognitive difficulties as a result of the stroke (Sutter-Leve et al., 2021).

The COVID-19 pandemic forced the need for alternative methods of work and communication (Boulton et al., 2021), and telemedicine became a central medium of service provision (Clement et al., 2021) in the healthcare system. Video calls and videoconferencing were found to be significant in reducing stressful situations and enabling family members to communicate with their loved ones, especially since they were not allowed to visit them and be with them in the hospital (Creutzfeldt et al. 2020; Feder et al. 2021; Sutter-Leve, 2021; Hugelius

gućavanju komunikacije članova obitelji uslijed nemogućnosti posjećivanja svojih bližnjih (Cretzfeldt i sur., 2020; Feder i sur., 2021, Sutter-Leve, 2021; Hugelius i sur., 2021). Prema dostupnim istraživanjima u neurorehabilitaciji za vrijeme pandemije iskustva članova obitelji osoba koje su doživjele tešku ozljedu mozga i koje se nalaze na dugotrajnoj akutnoj rehabilitaciji nisu dovoljno i detaljno istražena, a u Republici Hrvatskoj uopće nema dostupnih istraživanja kojima je to bio predmet interesa. Komunikacija putem tehnologije jedan je od načina kojima se interakcija među članovima obitelji može ostvariti. Za vrijeme pandemije provode je i radni terapeuti u Specijalnoj bolnici za medicinsku rehabilitaciju Krapinske Toplice koji omogućuju ovaj vid komunikacije s obitelji upravo onim osobama koje zbog teških posljedica ozljede mozga to nisu u mogućnosti činiti samostalno. Dostupna su istraživanja također nedovoljno istražila iskustva interakcije putem virtualnih platformi za vrijeme pandemije i dugotrajne bolničke rehabilitacije, stoga se pojavljuje potreba dobivanja detaljnog uvida u značenje komunikacije putem videoveze u vrijeme kada je fizička posjeta onemogućena, a boravak na neurološkoj rehabilitaciji dugotrajan i izazovan.

Cilj istraživanja

Imajući u vidu da je ozljeda mozga sama po sebi traumatski događaj za obitelj, koji ostavlja trajnije psihosocijalne posljedice (Warren i sur., 2016) te da obitelj ima značajnu ulogu u procesu rehabilitacije, cilj je ovog istraživanja steći uvid u iskustva članova obitelji tijekom pandemije bolesti COVID-19 koji nisu bili u mogućnosti ostvariti kontakt uživo i boraviti sa svojim bližnjim članom zbog ograničenja ili zabrane ulaska u bolnicu. U skladu s tim definirana su sljedeća istraživačka pitanja: (1) Kako članovi obitelji osobe s TOM-om opisuju svoje iskustvo suočavanja s posljedicama traumatskog događaja, kao i posljedične promjene u svakodnevnom životu obitelji? (2) Kako su članovi obitelji doživjeli nemogućnost posjećivanja bližnjeg za vrijeme bolničke rehabilitacije? (3) Kakvo značenje za članove obitelji ima kontinuirana interakcija putem videopoziva? (4) Koje

et al., 2021). According to recent research on neurorehabilitation conducted during the pandemic, the experiences of family members of individuals who had experienced a severe brain injury and were admitted to acute inpatient rehabilitation has not been sufficiently and thoroughly documented. So far, there is no research on this topic in the Republic of Croatia. Digital technology can provide an opportunity for family members to be in contact with their loved ones who are being treated in rehabilitation facilities. During the pandemic, occupational therapists at the Special Hospital for Medical Rehabilitation Krapinske Toplice enabled this form of communication with families and patients who could not use mobile devices by themselves due to the severity of the brain injury that they had undergone. Additionally, communication experiences via virtual platforms during pandemics and long-term rehabilitation have not been sufficiently explored, and there is a need to gain deeper insights into the effects of using video conferencing to communicate in times of visitation restrictions and long and challenging neurological rehabilitation periods.

Aim of study

Since a brain injury is a traumatic event for the entire family, leaving lasting physical and psychosocial consequences (Warren et al., 2016), and considering that one's family plays a significant role in the rehabilitation process, the present study aimed to further understand the experiences of family members during the COVID-19 pandemic. Family members could not visit and be in the hospital with their loved ones who had sustained a brain injury because of the visitation restrictions imposed during the COVID-19 pandemic. Therefore, we addressed the following research questions: (1) How do family members of an individual with TBI describe their experience of coping with the consequences of a traumatic event and subsequent changes to the family's daily life?; (2) How do family members describe their experience of the visitor restrictions imposed during the pandemic when their loved one was undergoing inpatient rehabilitation?; (3) How do family members describe their experience of communicating via video conferencing during the pandemic?; and (4) What are the recommenda-

su preporuke za poboljšanje komunikacije članova obitelji putem videopoziva?

METODOLOGIJA

Kako su postavljeni ciljevi ovog istraživanja usmjereni na dobivanje uvida u subjektivno iskustvo i perspektivu članova obitelji, primijenjen je kvalitativan metodološki nacrt (Ritchie i Lewis, 2003). Podaci su prikupljeni metodom polustrukturiranog intervjua putem virtualne platforme Zoom, dok je jedan razgovor proveden uživo u Specijalnoj bolnici za medicinsku rehabilitaciju Krapinske Toplice. Prije primjene intervjua pripremljena je matrica s otvorenim i poticajnim pitanjima kako bi se standardizirala struktura i tematski unificirao sadržaj intervjua u skladu s istraživačkim pitanjima. Intervjui su trajali prosječno 30 minuta, a uključivali su pitanja otvorenog tipa koja su vezana za promjene u svakodnevnom životu nakon ozljede mozga člana obitelji, iskustvo manjka komunikacije zbog epidemioloških mjera, značenje i zadovoljstvo komunikacijom putem videoveze u sklopu radne terapije, načelne pretpostavke o dobrobiti posjećivanja te na kraju prijedlozima za poboljšanje komunikacije. Intervjue je provodio treći autor, klinički psiholog, koji nije neposredno bio uključen u terapijski proces sa sudionicima, u razdoblju od početka veljače do kraja svibnja 2021. godine. Uz privolu sudionika intervjui su zabilježeni snimačem glasa te zatim doslovno transkribirani. Transkripti su poslani većini sudionika na provjeru čime je potvrđena autentičnost prijepisa i vjerodostojnost podataka (Nowell, Norris, White i Moules, 2017). Podaci prikupljeni ovim istraživanjem obrađeni su tematskom analizom prema autorima Braun i Clarke (2006) koja uključuje šest koraka: (1) upoznavanje s podacima, (2) inicijalno kodiranje, (3) generiranje tema, (4) revidiranje tema, (5) definiranje i imenovanje tema i (6) pisanje izvješća. Analiza podataka provedena je računalnim programom za obradu kvalitativnih podataka Quirkos v2.1 te programima Microsoft Word i Microsoft Excel. Triangulacija istraživača omogućena je neovisnim kodiranjem i imenovanjem tema prvog i drugog autora što dodatno pridonosi vjerodostojnosti istraživanja. Inicijalna međusobna pouzdanost

tions for improving video conferencing with family members undergoing inpatient rehabilitation?

METHODOLOGY

Since this study aims to gain insights into the subjective experiences and perspectives of family members of individuals undergoing rehabilitation after TBI, a qualitative methodological design was applied (Ritchie & Lewis, 2003). Data were collected using semi-structured interviews conducted via the virtual platform Zoom, while one participant was interviewed in live at Special Hospital for Medical Rehabilitation Krapinske Toplice in Croatia. Before the interviews, an interview guide was prepared with open and prompting questions based on the aims of the study in order to standardise the structure of the interview. Each interview lasted 30 minutes (on average). It included open-ended questions related to changes in daily life after a family member experienced brain injury, the experience of lack of communication due to epidemiological measures setup to combat the pandemic, the significance and satisfaction of video conferencing as part of the occupational therapy service, basic assumptions about the benefits of visits, and finally, suggestions for improving this form of virtual communication. The interviews were conducted by an independent author, a clinical psychologist, who was not directly involved in the therapeutic process with the participants. Data were collected from the beginning of February 2021 to the end of May 2021. With the consent of the participants, the interviews were recorded using a voice recorder and transcribed verbatim. Transcripts were sent to most participants for review in order to confirm the authenticity and trustworthiness of the data (Nowell, Norris, White, & Moules, 2017). According to Braun and Clarke (2006), data were organised for further thematic analysis based on the following six steps: (1) familiarising with the data, (2) initial coding, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) writing the report. Data analysis was performed using a software for processing qualitative data, Quirkos 2.1 and MS Office. The first and the second authors achieved triangulation by coding and naming the themes independently, which further contributed

istraživača (ICR) iznosila je 82,5% (O'Connor i Joffe, 2020), nakon čega je postignut konsenzus oko svih neslaganja.

Ovo istraživanje odobrilo je Etičko povjerenstvo Specijalne bolnice za medicinsku rehabilitaciju Krapinske Toplice. Sudionici istraživanja dobrovoljno su pristali sudjelovati nakon što su bili detaljno upoznati s ciljem istraživanja, metodama prikupljanja podataka i etičkim načelima. Povjerljivost podataka poštovana je tijekom cijelog procesa istraživanja i prikaza podataka na način da su identificirajući podaci koji uključuju ime, na osoba, mjesta i ustanova poznati samo prvom i trećem autoru. Sudionici su u ovom radu označeni slovom S i rednim brojem sudjelovanja, od 1 do 11 (npr. prvi je sudionik S1).

Sudionici

Sudionici su ovog istraživanja 11 članova obitelji pacijenata s teškom ozljedom mozga koji su boravili na akutnoj bolničkoj rehabilitaciji u Specijalnoj bolnici za medicinsku rehabilitaciju Krapinske Toplice i koji su ostvarivali interakciju sa svojim ozlijeđenim članom putem videoveze zbog zabrane/ograničenja bolničkih posjeta uslijed pandemije bolesti COVID-19. Broj sudionika određen je sadržajnom saturacijom kodova kao posljedice kontinuirane transkripcije i analize podataka (Fusch i Ness, 2015; Guest i sur., 2020). Saturacija se prvi put pojavila u 6. intervjuu, uz pojavu dvaju novih kodova u 8. intervjuu te bez novih kodova u 9. intervjuu, čime je prikupljanje podataka okončano. Intervjui su provedeni na namjernom uzorku koji čini sedam žena i četiri muškarca, a u svojstvu su supruge, partnera, majke, oca, brata i sestre. Raspon je dobi sudionika od 28 do 58 godina. Jedan od uvjeta za uključivanje u ovo istraživanje bio je kontinuitet sudjelovanja u videopozivima najmanje mjesec dana. Tako je ukupno pozvano 11 obitelji, devet ih je pristalo sudjelovati u istraživanju, s tim da su iz dvije obitelji sudjelovala po dva člana, što onda čini ukupno 11 sudionika istraživanja. Ako je u obitelji sudjelovalo više članova u komunikaciji videopozivom, zamoljeni su da se dogovore tko će biti sudionik istraživanja. Demografski podaci sudionika istraživanja prikazani su u Tablici 1.

to the credibility of the research. Initial inter-coder reliability was 82.5% (O'Connor and Joffe, 2020), following which a consensus was reached on all disagreements through further discussion.

This study was approved by the Ethics Committee of the Special Hospital for Medical Rehabilitation Krapinske Toplice, Croatia. Participants were provided with detailed information about the research objectives, data collection methods, and ethical principles involved in the study. All participants agreed to participate voluntarily. Confidentiality and participant anonymity was maintained throughout the study, and data were presented in a way that identifying information related to the names of persons, places, and institutions were known only to the first and third author. Participants in this study were denoted with the letter S and the ordinal number of participation, ranging from 1 to 11 (e.g., the first participant is S1).

Participants

This study included a total of 11 family members of patients with severe brain injury who were undergoing inpatient acute hospital rehabilitation at the Special Hospital for Medical Rehabilitation Krapinske Toplice in Croatia. They interacted with their injured family members via video conferencing due to the ban/restriction of hospital visitations due to the COVID-19 pandemic. The ideal number of participants required for such a study was determined based on data saturation, continuous transcription, and subsequent coding during content analysis (Fusch & Ness, 2015; Guest et al., 2020). Data saturation was initially observed in the 6th interview and two new codes were recorded in the 8th interview. There were no new codes in the 9th interview, and we considered that the data collection process was complete. The purposive sample included interviews of seven women and four men who were related to a patient with TBI as a spouse/partner, a parent, or a sibling. The participants ranged in age from 28 to 58 years. One key inclusion criterion in this study was continuous participation in video calls for at least a month. Thus, 11 families were invited and nine of them agreed to participate in the study. Since two members participated from two families, our analysis is based on data collected from a total

Tablica 1. Demografski podaci sudionika istraživanja ($N = 11$) / **Table 1.** Demographic characteristics of research participants ($N = 11$)

Characteristic		N	Mean	Range
Sex	Female	7		
	Male	4		
Age			40	28-58
Relationship to patient	Spouse	4		
	Parent	4		
	Sister	1		
	Brother	1		
	Partner	1		
Time since last physical contact (days)	0-30	5	70	5-186
	31-90	1		
	91-186	3		

Karakteristike pacijenata na neurološkoj rehabilitaciji uključenih u komunikaciju putem videopoziva

U komunikaciju putem videopoziva bilo je uključeno devet pacijenata na rehabilitaciji, od kojih je osam zadobilo traumatsku ozljedu mozga, a kod jedne se osobe radilo o arteriovenskoj malformaciji (AVM). Prometna nesreća i pad u ovom su uzorku podjednako zastupljeni kao uzrok TOM-a. Prosječno je vrijeme proteklo od ozljede 165 dana. Od ukupno devet pacijenata osam je muškaraca, jedna je žena, a prosječna je dob ozlijeđenih 38 godina. Prema Glazgovskoj ljestvici kome svi su pacijenti inicijalno zadobili težak TOM; medijan na GCS-skali iznosio je 3, s rasponom od 3 do 7. Mjereno Galvestonskom ljestvicom orijentacije i amnezije (GOAT; *Galveston orientation and amnesia test*, Levin, O'Donnelli i Grossman, 1979), duljina posttraumatske amnezije kod svih pacijenata s TOM-om prelazila je 70 dana, što prema literaturi predstavlja ekstremno tešku traumatsku ozljedu mozga (Nakase-Richardson i sur., 2009). U razdoblju kad je započela komunikacija videopozivom s članovima obitelji, četiri su pacijenta bila u vegetativnom stanju, četiri u minimalnom stanju svjesnosti, prema CRS-R-ljestvici (Giacino, Kalmar i Whyte, 2004), a jedan u posttraumatskom konfuznom stanju i verbalnom kontaktu.

of 11 participants. If more than one family member participated in the video call communication, they were asked to delegate the research participant. The demographic characteristics of the participants are listed in Table 1.

Characteristics of patients involved in video call communication

Of the nine patients (eight men and one women) involved in video call communication, eight had suffered from TBI and one had an arteriovenous malformation. Traffic accidents and falls were equally represented in this sample as the cause of TBI. The average time since the injury was 165 days, and the average age of patients with TBI was 38 years. According to the Glasgow Coma Scale, all patients initially sustained a severe brain injury: the median of the GCS scale was 3 (range 3-7). Based on the Galveston Orientation and Amnesia Test (Levin, O'Donnell and Grossman, 1979), the length of posttraumatic amnesia for all patients with TBI exceeded 70 days, which represents an extremely severe traumatic brain injury (Nakase-Richardson et al., 2009). At the very beginning of the study when the video calls were arranged, four patients were in a vegetative state, four in a minimally conscious state based on the Coma Recovery Scale - Revised (Giacino, Kalmar and Whyte, 2004), and one was in a posttraumatic confusional state, but was able to communicate verbally.

Opis načina provođenja komunikacije putem videopoziva

Interakcija članova obitelji i pacijenata odvijala se u sklopu radne terapije, i to onih osoba koje zbog kvalitativnih promjena svijesti i/ili kognitivnih smetnji nisu samostalno mogli komunicirati s članovima obitelji putem mobitela ili videopoziva. Zbog pristupa videovezi putem stolnog računala bila je potrebna adaptiranost na invalidska kolica. Vrijeme od zadnjeg susreta članova obitelji uživo do prvog susreta videovezom variralo je od svega pet do 186 dana. Videosusreti su se odvijali dva do tri puta tjedno, u trajanju od najviše pola sata, najčešće putem platforme Zoom ili komunikacijske aplikacije WhatsApp. Oba medija omogućuju vizualnu i glasovnu komponentu komunikacije, a WhatsApp je korišten s pacijentom koji je imao vlastiti mobitel koji je koristio uz pomoć radnog terapeuta. Prije provođenja intervjua sa sudionicima prosječno je održano 12 videosusreta pojedinačno.

Recentna istraživanja ukazuju na to da senzorna stimulacija, koja podrazumijeva kontroliranu izloženost okolinskim ili specifičnim senzoričkim podražajima, povećava budnost i svjesnost kod osoba s poremećajem stanja svijesti nakon TOM-a (Li, Cheng, Liu, Huang i Feng, 2020). Upravo senzorni trening koji uključuje poznate glasove pri tome ima značajnu ulogu (Pape i sur., 2015). Stoga osim mogućnosti susretanja članova obitelji virtualnim putem, izloženost poznatim glasovima članova obitelji mogla je imati i terapijski učinak za osobe na rehabilitaciji. Programe senzorne stimulacije provode i radni terapeuti imajući u vidu sklonosti osobe prije ozljede (Padilla i Domina, 2016). S druge strane osiguravanje mirnog i konzistentnog okruženja, povećavanje funkcionalne samostalnosti te praćenje utjecaja aktivnosti na umor i agitiranost neke su od smjernica za rad s osobama u posttraumatskoj amneziji (Ponsford, 2014). Radni je terapeut prema potrebi poticao i usmjeravao pacijenta, modificirao zahtjevnost interakcije i okruženja kako bi se omogućilo što uspješnije sudjelovanje i komunikacija članova obitelji.

Procedure description of communication via video conferencing

In this study the interaction of family members and patients via virtual platforms has been a part of occupational therapy interventions. It has been utilised in the case of patients with qualitative disorders of consciousness or cognitive impairments who cannot communicate on their own with family members via mobile phones or video calls. Furthermore, in order to approach the desktop computer, adaptation to sitting position in a wheelchair was required. The time between the last live physical meeting of the participants and their family members and the first meeting by video conference ranged from 5 to 186 days. Video conferences were held two to three times a week, lasting a maximum of half an hour, most often via the Zoom platform or the WhatsApp communication application. Both media provided access to audio-visual interaction. WhatsApp was used with a patient who had his own mobile phone and could use it with the support of an occupational therapist. Before conducting interviews with participants, an average of 12 video meetings were held.

Recent studies suggest that sensory stimulation, which involves controlled exposure to environmental or specific sensory stimuli, increases alertness and awareness in people with disorder of consciousness (Li, Cheng, Liu, Huang, & Feng, 2020). Furthermore, sensory training that includes familiar voices has proven to be particularly effective (Pape et al., 2015). Therefore, virtual communication could be beneficial both for meeting family members and providing therapeutic effects because of the exposure to familiar voices. Sensory stimulation programs have been conducted by occupational therapists, emphasising the patient's premorbid preferences (Padilla & Domina, 2016). On the other hand, ensuring a calm and consistent environment, increasing functional independence, and monitoring the impact of activities on fatigue and agitation are some of the clinical recommendations for people with posttraumatic amnesia (Ponsford I sur., 2014). In the present study, the occupational therapist encouraged and guided the patient as needed, modifying the demands of the interaction and the environment to enable successful participation and communication between family members.

Tablica 2. Prikaz glavnih tema i podtema istraživanja iskustava obitelji osoba s TOM-om / **Table 2.** Overview of the main themes and subordinate themes in the research of family experiences of people with TBI

Main (superordinate) theme	Subordinate theme
Theme 1: Coping with the traumatic injury of a family member - <i>“Everything has changed because there is no him”</i>	Emotional reactions to injury/hospitalisation of a loved one (family member)
	Changes in daily life after hospitalisation of a family member
	Impaired health status of caregivers
Theme 2: Experience of video conferencing during rehabilitation - <i>“When you live to see your child”</i>	Inability to have physical contact with a family member during the pandemic
	Communication with loved ones via video call as a form of support
	Experience in communication with healthcare professionals during hospitalisation
	Reflections on post-rehabilitation care
Theme 3: Factors of family resilience - <i>“We thought our voices would wake him up”</i>	Family factors: Family cohesion
	Personal factors: Personal resilience of caregivers
	Participatory factors: A sense of contributing to patient recovery through involvement in the rehabilitation process

REZULTATI I RASPRAVA

Tematskom analizom podataka izdvojene su tri glavne (nadređene) teme i deset podtema koje su prikazane u Tablici 2. Prva je tema sažela iskustva u suočavanju s ozljedom i promjenama koje se događaju u životu članova obitelji u svjetlu pandemije. Značenje koje komunikaciji video-pozivima pripisuje obitelj prikazano je u drugoj temi, dok treća tema opisuje čimbenike obiteljske otpornosti koji su pomogli sudionicima u suočavanju s posljedicama traumatskog događaja. U prikazu rezultata svaka pojedinačna tema bit će potkrijepljena izjavama sudionika.

Tema 1: Suočavanje s traumatskom ozljedom člana obitelji: *Sve se promijenilo jer nema njega*

Ozljeda mozga člana obitelji neočekivan je traumatski događaj koji pogađa sve članove obitelji. Posljedice iznenadne ozljede člana obitelji sa sobom su donijele niz emocionalnih reakcija i promjena u svakodnevici koje su ih zatekle nespremne: *Mi smo se vidjeli u četvrtak, slao sam joj poruke, vidim nema odgovora. I onda saznaš (...), osam sati da je u komi, da je imala operaciju (S4).* Neposredno nakon traumatskog događaja većina je sudionika opisala doživljaj šoka i nevjericice: *Iskreno, nekako imam osjećaj kao da nekad to nije ni istina, kao da se to ne dešava (S4); Baš svi smo bili iznenađeni, utučeni, nismo mogli vjerovati da nam se to događa (S9).* Posebno stresno razdoblje za obitelj jest vrijeme kad je ozlijeđe-

RESULTS AND DISCUSSION

The thematic analysis of the data highlighted three main (superordinate) themes and ten sub-themes, presented in Table 2. The first theme summarised the experiences of participants related to dealing with injury and revealed the changes in the lives of family members in light of the pandemic. The second theme represents the significance associated with being able to use video conferencing to communicate with family members, while the third theme describes family resilience factors that helped participants cope with the new situation. As part of the results, each theme will be illustrated by the quotes from the participants.

Theme 1: Coping with the traumatic injury of a family member - *“Everything has changed because there is no him”*

When a family member experiences a brain injury, it is an unexpected traumatic event that affects the whole family. The participants reported that the consequences of the sudden trauma of a loved one was accompanied by emotional responses and changes in everyday life that left them feeling unprepared: *“We saw each other on Thursday, I’ve sent her messages, and there was no response. Then I found out that she had been eight hours in a coma, that she had surgery (S4)”*. Immediately after the traumatic event, most participants described the experience of shock and disbelief: *“Honestly, I somehow feel as if sometimes this is not true, as if it’s not happening (S4)”*; *“We were all surprised,*

ni član obitelji zbrinjavan na intenzivnoj skrbi, životno ugrožen i s poremećajem stanja svijesti, u stanju kome. Zbog strepnje i straha hoće li se uopće probuditi i hoće li će se više vidjeti, cijela je obitelj bila u strahu i neizvjesnosti: *Ne možete spavati iz tih nekih strahova da se možda neće ni probuditi, da će sutra javiti... a vi ga niste vidjeli (S9)*. Jedan sudionik istraživanja opisao je primjer situacije u kojoj cijela obitelj strepi kad zazvoni telefon pribojavajući se najgorih mogućih vijesti: *Kad telefon zazvoni, svi se okupe, svi iz svojih soba, svi se strče (...) Ako vide da ja razgovaram normalno s nekim drugim, onda se svi raziđu kao da ništa nije bilo. Ali uglavnom, svi strepe hoće li netko nešto loše javiti (S8)*.

Slična su iskustva potvrđena u sustavnom pregledu literature (Oyesanya, 2017) koji je uključio 11 kvalitativnih istraživanja čiji je cilj bio sažeti iskustva tijekom bolničke rehabilitacije članova obitelji i njihovih bližnjih koji su zadobili ozljedu mozga, uključujući i onu traumatske etiologije. Navedeno istraživanje navodi dominantnost različitih emocionalnih reakcija kod članova obitelji kao što su šok, nevjerica, stres. Sudionici su također bili izloženi neizvjesnosti koja je posljedica nesigurnosti hoće li njihov član obitelji uopće preživjeti, probuditi se, prisutna je strepnja oko prognoze vezane uz oporavak i promjenu načina života koja čeka cijelu obitelj (Oyesanya, 2017). U svjetlu pandemije, bez mogućnosti fizičkog kontakta i boravka uz krevet svojih bližnjih, pomiriti se s činjenicom da oni sami ne mogu učiniti ništa kako bi na bilo koji način pomogli svojem bližnjem bilo je posebno teško zbog čega je kod nekih sudionika dominirao osjećaj bespomoćnosti: *Osjećaj bespomoćnosti... Ne dam se radi njege, ali da je teško, teško je (S7); Jer što god da napraviš nekako misliš da nije dovoljno (S4)*.

Članovi obitelji koji su najčešće i skrbnici osobama koje su doživjele TOM prolaze kroz značajne promjene u svom svakodnevnom životu i ulogama koje imaju, često preuzimajući na sebe dodatne dnevne obaveze (Blake, 2008). Pokazuje to i kvalitativno istraživanje (Checklin, Fernon, Soumilas i Stephens, 2020) kojim je istraženo iskustvo devet skrbnika osoba sa stečenim ozljedama mozga, gdje se kao značaj-

depressed. We couldn't believe it was happening to us (S9)". Some family members reported about a particularly stressful period when their loved one with a brain injury was admitted to the intensive care unit in a life-threatening condition, along with impaired consciousness and in a comatose state. The entire family was facing a situation filled with anxiety and uncertainty, and they were in fear about whether he would wake up at all, or if they were ever going to see each other again: *"And you can't sleep from those fears, that he might not wake up, that they will call tomorrow... and you have not seen him (S9)"*. One participant described a situation when the whole family trembled whenever the phone rang because they feared the worst possible news: *"When my phone rings, it means that everyone gathers, everyone comes from their rooms, everyone rushes (...) If they realize that I am talking with someone else, then everyone disperses as if nothing had happened. In general, everyone is worried if someone calls to report bad news (S8)"*.

Similar experiences were confirmed in a systematic review of the literature that included 11 qualitative studies summarising experiences during inpatient rehabilitation of family members and their loved ones who suffered a brain injury, including those with traumatic aetiology (Oyesanya, 2017). This review reported a dominance of various emotional reactions among family members, such as shock, disbelief, and stress-related symptoms. Participants were also exposed to the uncertainty resulting from insecurity about whether their family member would survive or wake up from a coma, and anxiety related to the prognosis, recovery, and life changes awaiting the entire family (Oyesanya, 2017). In the light of the pandemic, the participants in the present study could not be physically close to their loved ones (e.g., at their bedside), and some of them felt helpless since they could not do anything to assist them: *"Oh, the feeling of helplessness... I don't give up because of him, but it's hard, it's really hard (S7)"*; *"Whatever you do, you think, is not enough (S4)"*.

Family members are often the primary caregivers of loved ones who have sustained TBI and they experience significant changes in their daily lives and social roles, often having to take on additional daily responsibilities (Blake, 2008). Checklin, Fernon,

na tema nameću promjene koje su se dogodile, od obiteljskih uloga i odnosa, praktičnih stvari koje članovi obitelji mogu i ne mogu više obavljati, sve do promjena koje su se dogodile samom ozlijeđenom članu obitelji, od njegove osobnosti koja može biti drugačija uslijed ozljede, do nekih fizičkih osobina. Tako je traumatski događaj potpuno promijenio svakodnevne živote i rutinu sudionika ovog istraživanja. Dnevne obveze koje su supružnici prije dijelili, sad su morali u potpunosti preuzeti na sebe: *Većinu po kući, sve moram sam* (S3); *Sve je sad na meni (...) Tu imamo kuću, sve treba... okolo, uređivanje okućnice. On je isto račune plaćao, vodio brigu o tome, o autima, o svom i mom, sad ja moram, sve je na meni* (S11). Zbog velike preopterećenosti pojedinih članova obitelji pojavila se potreba za potporom šire obitelji, posebno kad je bila potrebna pomoć u brizi oko djece: *Što se tiče djece, preuzela je i baka dio obaveza na sebe. Moj brat mi dosta pomaže oko rada na kući. Svi zajedno sudjelujemo nekako u tome. Svaki dan radimo raspored, od jutra... kako tko stigne i može* (S9). Osim na sudjelovanje u aktivnostima u kućanstvu i brizi oko djece, TOM bližnjega utjecao je i na nužnost promjene radnog mjesta nekih sudionika jer su osjećali bojazan da bi stres i šok koje su doživjeli mogli utjecati na odgovoran posao koji su do sada obavljali: *Više ne vozim, bio sam vozač autobusa (...) ost' o bez D kategorije. Nisam mog' o preuzet' odgovornost da vozim pedeset ljudi u autobusu i da zbog moje nesreće nanese nesreću nekom drugom* (S8).

Narativom o promjenama u svojoj svakodnevici sudionici su se sa sjetom i žalom prisjetili člana obitelji koji je doživio ozljedu mozga, zajedničkog života prije nesreće, međusobne povezanosti, odnosa i uloga koje je imao njihov bližnji: *Nikad nismo bili duže od dva tjedna razdvojeni, nikad, otkad smo skupa* (S3); *Fali ona čvrsta ruka u obitelj. Malo više je sinova pa im fali onaj uzor, očinska...* (S2); *Sve se promijenilo, jer je sve drugačije, jer nema njega* (S5). *Sve se promijenilo, svi smo uzdrmani s tim i svi smo promijenili svoje živote* (S8). Ozljeda, gubitak i žaljenje za članom obitelji kakvim su ga poznavali prije ozljede dominantne su teme i u drugim istraživanjima (Townshend i

Soumilas & Stephens (2020) investigated the experiences of nine caregivers of individuals with acquired brain injuries and highlighted that an important topic was the changes that occurred to the family members. These changes include family roles and relationships, practical things they were able to or no longer able to do, but also changes that occurred to the injured family member, including personality changes and changes to certain physical features (Checklin, Fernon, Soumilas & Stephens, 2020). Similarly, the traumatic event completely changed the daily lives and routines of the participants in the present study. Daily responsibilities that were previously shared by spouses were now taken on entirely by individuals: *Most of the housework I have to do now, by myself* (S3); *It's all up to me now (...) We have a house there ... everything needs to be done ... around landscaping. He used to pay bills, took care of it, of the cars, his and mine, now I have to do it, it's all up to me* (S11)". Since some caregivers were feeling overloaded, other family members had to assist in managing everyday occupations, especially in childcare: *Regarding children, their grandmother also took on some duties. My brother helps me a lot with these tasks around the house. We all participate together, somehow. Every day we make a schedule, from the morning... it depends on what someone can do* (S9)". Apart from the impact on housework overload and caring for children, TBI in loved ones also caused changes at the workplace for some participants since they felt that the stress and shock they experienced could affect their actual job performance: *I'm not driving anymore. I was a bus driver... I lost D category (licence). I couldn't take responsibility to drive fifty people in a bus and cause a tragedy to others because of my situation* (S8)".

Reflecting on changes in their lives, participants recalled that when a family member had sustained a brain injury, they felt grief and sadness reminiscing about their life before the accident, their relationships, and the roles of their loved one: *We have never been separated for more than two weeks since we've been together.* (S3); *The firm hand is missing in the family. We have a few sons, so they lack the role model, paternal...* (S2); *Everything has changed, everything is different because there is no him* (S5); *Everything has changed, we are*

Norman, 2018), s tim da su ona provedena u većem razmaku nakon ozljede, kad su članovi obitelji otpušteni kući, dok su u ovom istraživanju još uvijek u fazi oporavka nakon ozljede i prisutna je nada u daljnji napredak.

Emocionalni i okupacijski disbalans, promjene u ulogama i odgovornostima kao i briga za člana obitelji koji je doživio TOM dugoročno utječu na zdravstveno stanje članova obitelji koji najčešće imaju ulogu skrbnika (Kratz, Sander, Brickell, Lange i Carlozzeti, 2017; Kreutzer i sur., 2009). Sam događaj u kojem je član obitelji doživio TOM i činjenica da ne mogu biti uz njega u bolničkom okruženju zbog restriktivnih epidemioloških mjera ostavili su traga na osjećaj dobrobiti i zdravstveno stanje svih članova obitelji u ovom istraživanju; suprurnika, partnera, njihove djece, roditelja, braće i sestara: *Osjećaji? Pa zbog tih osjećaja, nažalost, dobila sam visok tlak (S4); Kad sam se vratila kući, šećer mi je bio deset i po', baš se povisio, stresni taj šećer (S11).*

Ozljeda člana obitelji utjecala je posebno i na braću i sestre: *Normalno, to su osjećaji, ja i moj brat imamo kao neku telepatiju, kad mu se nešto desi, ja to osjećam (S1).* Jedan roditelj je opisao na koji je način bratov TOM utjecao na ostalu djecu i kakve su promjene ponašanja kod njih posljedično uslijedile: *Prvo vrijeme nisu bili zainteresirani, ni za društvo, nisu išli u školu, premda se to i preklapalo s online nastavom. Na neki svoj način doživljavaju ovu situaciju i proživljavaju to sve, pogotovo najmlađi sin. On trenira nogomet, pa jedno duže vrijeme nije ni šutnuo loptu, nije išao na treninge (...) Svi su jako pogođeni s tim (S8).*

Upravo je perspektiva braće i sestara, kada jedno od njih doživi TOM, u literaturi prepoznata kao područje kojem je potrebno posvetiti više pažnje. Sustavni pregled literature (Ownsworth i Karlsson, 2020) kojim su prikazani rezultati 11 istraživanja poprečnog presjeka ukazuje na to da njihovo raspoloženje i uznemirenost više varira u odnosu na kontrolnu skupinu te da im je psihosocijalno funkcioniranje slično onom drugih članova obitelji, bez obzira na to što oni najčešće nisu primarni skrbnici. Kao zaključak navodi se potreba usmjeravanja podrške braći i sestrama,

all shaken by it, and we have all changed our lives (S8)". The injury, loss, and grief felt for a family member as they remember him/her before the injury are dominant themes reported in other studies as well (Townshend & Norman, 2018). However, those studies were conducted a long time after the injury and when the family member with the brain injury had already been discharged. In the present study, the patients were still in the recovery process and their families were hoping for further progress.

Emotional and occupational imbalances, changes in roles and responsibilities, as well as caring for a loved one who has experienced TBI, can have long-term impacts on the health conditions of family members who typically take on the role of a caregiver (Kratz, Sander, Brickell, Lange & Carlozzeti, 2017; Kreutzer et al., 2009). The well-being of all participants in the present study, including spouses, partners, their children, parents, and siblings, was impacted by the TBI of their loved ones, as well as by the restrictive visitation policies that prevented them from staying within the hospital setting: *"Emotions? Well, because of those emotions, unfortunately, I got high blood pressure (S4)"; "When I got home, my sugar level was ten and a half, it just went up, sugar caused by stress (S11)".*

The injury of a family member particularly affected siblings: *"Normally, those are feelings. My brother and I have a sort of telepathy. When something happens to him, I just feel it. (S1)".* One participant described how the brother's TBI affected other children in the family and their behaviour: *"At first, they were not interested in school, although it overlapped with online classes. They perceive this situation in their way, especially the youngest son. He is 14 years, plays football, so for a long time he didn't even kick the ball, he didn't go to training (...). Everyone is affected by it (S8)".*

The perspective of siblings, when one experiences TBI, is recognised in the literature as an area that requires more attention. A systematic review of the literature (Ownsworth & Karlsson, 2020) summarised the results of 11 cross-sectional studies and concluded that their mood and anxiety levels varied more than the control group. Furthermore, the

posebno ako su kod ozlijeđene osobe primjetne smetnje u ponašanju i ukoliko nema osiguranu adekvatnu društvenu potporu (Ownsworth i Karlsson, 2020).

Tema 2: Iskustvo omogućavanja videopoziva tijekom rehabilitacije: Kad živite za to da vidite svoje dijete

Neki su sudionici imali priliku vidjeti svoje bližnje i za vrijeme bolničke rehabilitacije, prije nego što su uvedene potpune zabrane bolničkih posjeta: *Bio sam dva puta, svega po 15 minuta od devetog mjeseca kod njega (S6); U to doba kad sam ja bila još prvi put kod njega, on je bio još dezorijentiran, nije baš znao tko sam (S9); Bila sam u drugom mjesecu, pustili su me na pola sata. Vidjela sam ga, nisam ga smjela dodirnuti (...) Samo sam onako gledala (S11).*

Sudionici su osobito neugodnim (*teškim*) doživjeli razdoblje u kojem su donesene mjere kojima se u potpunosti zabranjuju posjeti u bolnici zbog čega uopće nisu imali mogućnosti vidjeti svoje bližnje uživo: *Preteška je situacija što se ne može doći (S5); Ja zovem (...) onda prenosiš drugima informacije. Znaš sve, a ne znaš, ne vidiš je (S3). Jer šest, sedam mjeseci nemaš praktički pojma što se njoj dešava, imaš informacije, ali nisi to vidio, nisi doživio (...) To je najgora stvar; mislim (S4).* Kod nekih sudionika je to posebno došlo do izražaja kad su u bolnicu donosili potrebne stvari članu obitelji i primopredaju obavljali sa zdravstvenim osobljem ispred ustanove, a nisu mogli ući u bolnicu i vidjeti bližnjeg: *Svakih deset dana sam čisti veš nosila i stvari, šta je trebalo, a nisam mogla do njega, tak da mi je jako teško padalo (S2); Najteže je bilo kad bi došli dolje donijeti joj stvari u Krapinske Toplice, i onda kad si blizu, a ne možeš je vidjeti (S4).* Oni sudionici koji nisu imali mogućnost vidjeti gdje se njihov bližnji nalazi, posebno su teško doživjeli to što nemaju spoznaju u kakvom se okruženju uopće nalazi: *Nisan ni znala di san ga poslala (...) Nisan ga mogla vidjet (S5).* Jedan sudionik je naveo zabrinutost za svog člana obitelji jer zbog narušene orijentiranosti i stanja konfuzije uslijed ozljede mozga nije znao gdje se nalazi i što se zapravo oko njega zbiva, a oprema

psychosocial functioning of siblings was similar to other family members, although they were not the primary caregivers. In conclusion, Ownsworth & Karlsson (2020) emphasised the need to support siblings, especially if the family member with TBI experienced behavioural changes and there was no appropriate social support.

Theme 2: Experience of video conferencing during rehabilitation – “When you live to see your child”

Before the implementation of total visitation bans, some participants had the opportunity to see their loved ones during inpatient rehabilitation: *“I stayed with him twice, only 15 minutes since September (S6)”*; *“When I saw him for the first time, he was still disoriented, he didn’t know who I was (S9)”*; *“I visited him in February, so they let me stay for half an hour. I just saw him. I was not allowed to touch him, anything. I was just looking at him (S11)”*.

Participants found the implementation of complete hospital visit bans particularly unpleasant, leaving them without the opportunity to see their loved ones: *“This situation is too difficult as we cannot come to visit him (S5)”*; *“I call (the hospital) (...) then you share information with others. You know everything, and at the same time, you don’t know anything, you don’t see her (S3)”*. *“Six, seven months you have no idea what’s happening to her, I mean, you have information, but you haven’t seen that, you haven’t experienced it (...) It’s the worst thing, I think (S4)”*. For some of them, this was especially apparent when they brought necessary items to a family member and met the medical staff in front of the institution, but could not enter the hospital to see their loved one: *“I brought clean clothes and all other things, every ten days, what was needed, and I couldn’t visit him. So, it was tough for me (S2)”*; *“The most challenging part was when you come down to bring her things to Krapinske Toplice, and you are so close, but can’t see her (S4)”*. Those participants who did not have the opportunity to see the setting where their loved ones were admitted found it quite challenging. One of them shared his concern for his loved one because the brain injury had caused disorientation and confusion, so the patient did not know where

koju zdravstveno osoblje obavezno mora nositi ne pridonosi poboljšanju njegova kognitivnog stanja: *On isto nije znao gdje se nalazi, šta je bilo s njim, zašto ne dolaze njegovi, njegova sestra, zašto ne dolazi njegova mama. On je okružen, sa svim uniformiranim osobama, nepoznatim, i plus maske, plus sve ostalo (S1).*

Istraživanje Creutzfeldt i suradnika (2021) ukazuje na važnost omogućavanja videokontakta članovima obitelji čija je bližnja osoba doživjela ozljedu mozga i nalazi se u bolnici u vrijeme pandemije jer im ublažava stres zbog nemogućnosti bivanja uz krevet svojeg bližnjeg. Nakon što je sudionicima u ovom istraživanju dana mogućnost komunikacije s bližnjima putem videoveze, mnogi su od njih izrazili oduševljenje tom idejom, a ujedno su doživjeli olakšanje jer napokon mogu vidjeti svojeg bližnjeg i ostvariti interakciju: *Sad je malo lakše jer se možemo vidit' na taj videopoziv (S5); I onda kad smo vidili, to je ona ista, naša sestra, cura (...) Sve isto, samo trenutno s tim stanjem. Meni je to olakšalo (S4); Ovo je sada super, s obzirom da ne možemo k njemu (...) Dvije, tri riječi s njim popričam, kao da sam bila kod njega (S10); Olakšao mi je puno, jako puno. Svaki put kad se trebam vidjeti s njima na radnoj terapiji, od radosti ne mogu spavati (S11).*

Istraživanje o iskustvu članova obitelji osoba koje su doživjele moždani udar i nalaze se na rehabilitaciji u vrijeme pandemije (Sutter-Leve i sur., 2021) ukazuje na to da nemogućnost uvida u funkcionalno stanje bližnjeg i praćenje njegova napretka pridonosi povećanoj anksioznosti i narušenom mentalnom zdravlju te da su upravo videopozivi jedan od načina kako olakšati stanje članova obitelji. Iskustvo s videopozivima sudionicima je bilo jako značajno jer su mogli vidjeti svojeg člana obitelji i sami se uvjeriti u njegovo stanje, bez obzira na to što im zdravstveno osoblje daje informacije o tome: *Svakim danom kad se vidimo, od utorka do četvrtka, vidimo nekakve pluseve kod nje, vidimo nekakva poboljšanja u njenom stanju, bistrije nas gleda, i to nam puno znači (...) Za mamu, mislim da je njoj nekako, otkad smo ostvarili taj kontakt preko videopoziva, da je ona polako počela dolaziti k sebi (S4).* To što su mogli vidjeti da postoji neka vrste in-

he was and what was happening around him. At the same time, the uniforms worn by the medical staff contributed to his confusion: *“He did not know where he was, what had happened to him, why his family was not coming to see him, his sister, why his mother was not coming. He was surrounded by all the uniformed persons, strangers, and masks, plus everything else (S1)”.*

Creutzfeldt et al. (2021) highlighted the importance of providing video contact to family members whose loved ones had experienced a brain injury and were admitted to the hospital during the pandemic, especially because it relieves stress from not being able to be there at their bedside. This is consistent with the findings of our study: here participants expressed enthusiasm about an opportunity to communicate with their loved ones via video conferencing and felt relief when they were able to finally see their loved one: *“Yes, it is a little easier because we can see each other during the video call. (S5)”*; *“And then, when we saw her, she was the same, our sister, girl (...) All the same, at this moment, only in that condition. I felt a relief(S4)”*; *“Now, this is great, since we can't go to visit him (...) Two or three words I tell him, it's just like I was with him (S10)”*; *“It made it much, much easier for me. Every time I need to see him at occupational therapy, I can't sleep because of some joy (S11)”.*

Research on the experience of family members of individuals who had suffered a stroke and were being treated in rehabilitation during a pandemic (Sutter-Leve et al., 2021) showed that the inability to see the functional status of a loved one and monitor his/her progress can contribute to increased anxiety and impaired mental health of family members. Video calls are just one solution to ease that experience. Our results confirm these findings: participants indicated that video calls were significant for them because they could see their family member and witness changes in his/her health condition: *“Each day when we see each other, from Tuesday to Thursday, we notice some progress, we see some improvements in her condition, her eyes are more clear, and it means a lot to us (...) To Mom, I think to her, since we made that contact via video call, she had been slowly coming to her senses (S4)”.* Interaction between family members, specific responses of loved

terakcije među njima, da bližnji na njih reagira, da razumije što mu oni govore, isto se tako pokazalo značajnim: *Znači, vidjeli smo ga, vidjeli smo da je on u nekom kontaktu s nama, da nas razumije.* (S2). To iskustvo smatraju značajnim i za same bližnje koji su na rehabilitaciji. Vjeruju da su na njih pozitivno djelovali tako što ih oni vide i čuju: *Mislim, puno mi to znači, a vjerujem i njemu isto da čuje poznati glas* (S7); *Ali to je za pacijenta kao mog brata, pošto on nije mogao razgovarati, nije mogao hodati, nije mogao ništa. Dovoljno mu je bilo da vidi slike* (S1). Jedna sudionica je podijelila iskustvo uključivanja supruge preko videoveze u obiteljsku svakodnevicu pri čemu je posebno došla do izražaja njegova uloga oca, a što je bio dragocjen poticaj za cijelu obitelj: *Pokazani mu dijete kako puže, kako se hrani, jučer tijekom videopoziva. Davala sam mu kašicu, maleni je otvorila usta, on „Bravo”, pohvali ga, to je neprocjenjivo. Ne mogu Van to opisati, stvarno* (S5).

Sa svim dobrobitima za obitelj i njihova bližnjeg koji je u bolnici ili trajnom smještaju, videosusreti mogu izazvati i određeni osjećaj nelagode zbog straha i neizvjesnosti hoće li stanje bližnjeg biti gore od očekivanog kad ga vide putem virtualnog medija. To se posebno potvrdilo u istraživanjima koja su se provodila s osobama u palijativnoj skrbi (Feder i suradnici, 2021), a nekoliko sudionika je ostalo šokirano vidjevši bližnje te nisu imali daljnju želju nastaviti susrete putem videopoziva (Dhahri, 2021). Iskustvo susreta s bližnjima putem videopoziva i u ovom je istraživanju na neki način djelovalo stresno na sudionike. S jedne je strane stres utjecao na to da oni sami nešto zaborave pitati: *Malo stresno. Kaj god sam ga mislila pitati, kaj sam mu mislila reći, ja sam pol toga zaboravila, jednostavno sam zablokirala* (S7). Jedan sudionik je morao čak popiti lijek za smirenje prije videopoziva: *I svaki put kad pričam tu, popijem Normabel, i sve to izdržim* (S11). Neki su sudionici bili zabrinuti i pitali su se kako član obitelji izgleda nakon što je doživio ozljedu mozga. Postojala je i bojazan hoće li prepoznati svoju obitelj i strah da oni sami nekim svojim riječima ne izazovu neželjene emocionalne reakcije: *Moja mama čak je i pitala, što*

ones with brain injury, and the feeling that they understood what they were telling them also proved to be significant for the participants: *“So, we saw him, we noticed that he was in some kind of contact with us, that he understands us.* (S2)”. At the same time, video conferencing was perceived as helpful for the person with brain injury as well. Participants believe that seeing and hearing them had a positive effect on their loved one: *“I mean, it means a lot to me, and I think it is helpful for him too, listening to a familiar voice* (S7)”; *“It’s for a patient like my brother, since he couldn’t talk, he couldn’t walk, he couldn’t do anything. It was enough for him to see (our) pictures.* (S1)”. One participant shared the experience of involving her husband during the video call into family life, emphasising his role as a father and how valuable it was for the whole family: *“I have shown him a child crawling, eating, during the video call yesterday. I was feeding our son a porridge, the little one opened his mouth, and he said: “Bravo”, he praised him. That is invaluable! I can’t describe it to you, really* (S5)”.

Along with all the benefits for the family and their loved ones at the time of inpatient rehabilitation or permanent accommodation, video conferences can also provoke discomfort because of fear regarding the general condition of the loved one and whether it would be worse than expected. These findings have been observed in previous studies involving individuals in palliative care (Feder et al., 2021). Dhahri (2021) reported that several participants were shocked to see a loved one’s condition and had no further desire to continue video calls. In the present study, several participants reported that the experience of video calls was stressful. The excitement of seeing their loved ones in the hospital setting made some participants forget to ask certain questions or about certain aspects: *“A little stressful. Whatever I planned to ask him, what I wanted to tell him, mostly I forgot, I just blocked* (S7)”. One participant even had to take a sedative before the video call: *“Every time I talk like that, I must take Normabel (anxiolytic), to endure it all* (S11)”. Some were concerned and wondered how their loved on would look after sustaining a brain injury. There was also concern about whether they would recognise family members or provoke unwanted

ako nas ona ne prepoznaje? Toga sam se nekako najviše bojao; kako ona sad izgleda, dal' je dobro. Nemaš nikakvu sliku. Uvijek razmišljaš prije nego kažeš; dal' je pametno to reći, nije pametno. Isto tako, s druge strane gledam, koliko to nju pogađa, to ne znamo (S4).

Posebno se osjetljivim pokazala reakcija djece i pokušaj približavanja situacije njima, na način na koji ona to mogu razumjeti. Djeci je bilo teško razumjeti da njihov otac sada nije u verbalnom kontaktu i da fizički drukčije izgleda: *Onda sam joj ja objasnila da ne može još glavu dobro držati. I svaki put ona mene pita za tatu i ja joj objašnjavam da tata ne može govoriti, mama joj objašnjava. Ali sad, kak' ona to u njezinoj glavici, ne znam (S7).* Reakcija djece čijem je ocu uslijed kraniotomije nedostajala kost na glavi bila je emocionalno izraženija: *Malo su se prestrašili radi njegove glave. Ja sam im to pokušala objasniti da ih pripremim (...) Baš nisu dobili neku predodžbu kako to izgleda (S9).*

Premda su sudionici izrazili iznimno zadovoljstvo iskustvom komunikacije videopozivima i nisu navodili posebne nedostatke, ipak su izrazili svoje želje i iznijeli planove vezane uz mogućnost kontakta uživo: *Držala bi ga za ruku, možda bi i njemu bilo lakše, i malo bi ga zagrlila (S11); I djeca bi mogla doći, i iznajmili bi negdje nešto. Mogli bi biti što duže, mogli bi s njim prošetati po parku (S9).* Da je postojala mogućnost posjećivanja, sudionici nadalje smatraju da bi njihova prisutnost, podrška i angažman znatno utjecali na oporavak bližnjeg: *Sad stalno mislim da sam kraj njega i da mu stalno nekaj pričam (...) Da bi to bilo bolje, da bi bila bolja reakcija, da bi možda prije došiel k sebi (kroz suze, S7); Išlo bi u puno boljem smjeru, jer on danas na nas tako fino reagira i prati nas (S6).*

Kad je riječ o preporukama za poboljšanje komunikacije u vrijeme pandemije, istraživanje provedeno u jedinici intenzivnog liječenja neuroloških i kardioloških pacijenata tijekom pandemije bolesti COVID-19 pokazuje važnost vizualnog uvida u kontekst u kojem se bližnji nalazi (Kennedy i sur., 2021). Kao jedan od glavnih prijedloga članova obitelji u tom je radu istaknuto pozicioniranje kamere tako da obitelj može vidjeti pacijen-

emotional reactions: *“My mother even asked, what if she doesn't recognise us? I was most afraid of how she looks now, is she well, you don't have any clue. You always ask yourself before you say something, is it wise to say that or not. Because, honestly, on the other hand, I also wonder how much it affects her, we don't know (S4)”*.

The children's reaction to the situation and the attempt of adults to explain it to them proved to be particularly sensitive. It was difficult for the children to realise that their father could not communicate verbally and looked physically different: *“Then I explained to her that he can't hold his head well yet. And every time she asks me about Dad, I explained to her that Dad can't speak, her Mom is trying to explain it to her. But how she understands it, I don't know (S7)”*. The reaction of children whose father was missing a part of the skull bone due to a craniotomy was more pronounced: *“And they were a little bit frightened because of his head. I tried to explain to prepare them (...) They just didn't have an idea of what it looks like (S9)”*.

In general, participants expressed satisfaction with the experience of video conference communication. They did not mention any specific shortcomings. Yet, they expressed their wishes and plans to visit their loved ones in the hospital: *“I would hold his hand, maybe it would be easier for him too, and I would hug him (S11)”*; *“And the kids could come, and we would rent some flat. We could stay as long as we can, we could walk around the park with him (S9)”*. The participants believed that their presence, support, and engagement would significantly impact the recovery process of their loved ones: *“Now, I think all the time, if I was by his bedside, and if I were talking to him about something all the time (...) It would be better, he would respond better, his consciousness would be better (tears) (S7)”*; *“It would keep going in a much better direction, because he responded so nicely and eyes tracking now (S6)”*.

Research conducted during the COVID-19 pandemic involving neurological and cardiac patients in the intensive care unit demonstrated the importance of insights into the patient's hospital setting (Kennedy et al., 2021). The participants in the above-mentioned study highlighted the importance of positioning the

ta i njegovo okruženje, pri čemu imaju mogućnost pitati zdravstvene djelatnike što ih zanima, ali i ostvariti interakciju s članom obitelji bez prisutnosti kliničara. Jedan od prijedloga sudionika u ovom istraživanju također je mogućnost njihova uvida u terapijski proces putem videoveze ili pak snimanje terapijskog procesa i slanje članu obitelji: *Dobila sam ja već video kako on jede čokolino. Prezadovoljna sam, stvarno. Jedino to (...) ako on sad napravi korak, da ja to mogu vidit' i da me on vidi na videopozivu. Eto, to bi mi bilo super (S5)*. Jedna sudionica je kao prijedlog navela želju za komunikacijom i s odjelnom liječnicom putem videoveze, umjesto putem telefona: *Razgovarala bi s doktoricom, da o tome svemu porazgovaramo. Ovak', a ne prek' telefona (S7)*. Dio je sudionika težio tome da videopozivi budu učestaliji, pa i da se svaki dan odvijaju. To su ujedno bile i glavne zamjerke dijela sudionika ovom iskustvu komunikacije preko videosusreta: *Jedino kad bi moglo bit češće, onda bi to bi bilo bolje (S8)*; *Da se gledalo češće, bilo bi bolje (S6)*.

Ovo istraživanje nije uzelo u obzir perspektivu radnih terapeuta koji su organizirali i provodili videosusrete članova obitelji, ali druga istraživanja ukazuju na zahtjevnost provođenja te usluge iz pozicije zdravstvenih djelatnika u smislu preopterećenosti dodatnim poslom i mogućim tehničkim izazovima s kojima se mogu susresti (Kennedy, 2021). Stručnjaci koji su provodili videokonferencije s pacijentima koji su bili pozitivni na COVID i u palijativnoj skrbi nisu se ugodno osjećali vidjevši uznemirene članove obitelji (Dhahri et al., 2021). Značajnim se tako pokazalo i definiranje učestalosti susreta na samom početku kako obitelj ne bi imala osjećaj da vrši pritisak na zdravstvene djelatnike (Kennedy et al., 2021).

Potreba za dobivanjem informacijama od zdravstvenog osoblja jedna je od važnijih potreba tijekom rehabilitacijskog procesa osoba s TOM-om. Ako pogledamo iskustvo komunikacije sa zdravstvenim osobljem tijekom cijelog procesa rehabilitacije, većina je sudionika iznimno zadovoljna pristupom stručnjaka i davanjem informacija o zdravstvenom stanju i oporavku njihova člana obitelji: *A što se tiče zdravstvenog osoblja, svi su stvarno susretljivi, ljubazni, može se nazvati*

camera to see the patient and his environment, to talk to him/her and the healthcare professionals, and the need to interact with a family member without the presence of a clinician. The participants in our study also provided insights into the therapeutic procedure during the video conference, and suggested filming the performance of the patient and sending the video to a family caregiver: *"I already got a video where he was eating Čokolino (chocolate-based porridge). I am pleased, really. Only (...) I wish I saw him walking during a video call and that he could see me. I think, it would be great (S5)"*. One participant suggested communicating with the ward doctor via video conferencing, instead of by phone: *"I would like to talk to the doctor. Talk about all this, this way, not by phone (S7)." Some participants wished for video calls to be more frequent, even daily. This was reported as one of the setbacks of communication via video calls: "I wish it could be more frequent, then all would be better (S8); If video calls were more often, it would be better (S6)"*.

The present study did not consider the perspective of occupational therapists who organised and conducted the video meetings. Other similar studies have indicated the challenges faced by healthcare professionals with respect to providing video calls, such as work overload and possible technical challenges (Kennedy, 2021). Additionally, staff conducting videoconferencing with patients who were COVID positive and in palliative care did not feel comfortable seeing anxious family members (Dhahri et al., 2021). Defining the frequency of meetings at the beginning so that the family would not feel the need to exert pressure on health professionals (Kennedy et al., 2021) also proved noteworthy.

Obtaining information from healthcare professionals is one of the essential needs during the rehabilitation process of people with TBI. When we reviewed the experience of communication with healthcare professionals throughout the rehabilitation process, we noticed that most participants expressed satisfaction with staff behaviour and provision of information related to the health and recovery of their family members: *"The staff, everyone is friendly, kind, you can call anytime for some information or something else, and for an appointment, so, no objections (S2); They kept*

bilo kad za neke informacije, i za dogovor, tako da nema nikakvih primjedbi (S2); Stalno su nam se javljali, konstantno, i suosjećali, davali su nam, riječi podrške (S4). Jedan se sudionik požalio da mu je otežano dobiti liječnika: *Teško nam je dobit informacije u vrijeme informacija. Teško je dobit doktora u to vrijeme, neki put gotovo nemoguće (S7)*. To je ujedno bio i jedini prigovor na komunikaciju sa zdravstvenim osobljem tijekom bolničke rehabilitacije u ovom istraživanju. Međutim, dio sudionika izrazio je nezadovoljstvo dostupnošću informacija i zdravstvenog osoblja, posebno liječnika, tijekom akutne skrbi, prije same rehabilitacije: *Kad smo pitali, uvijek su rekli „sve u redu, sve u redu“. To što su govorili „sve u redu“ uopće nije bilo onako. On ustvari nije mog'o ni jest, on nije mogo ni hodati (S1); (...) jako su bili šturi na informacijama. Tek pred njegov odlazak, dobila sam razgovor sa liječnikom koji ga je operirao. Prije toga nismo ama baš ništa o tome znali (S9); Iskreno, oni meni nisu nikakve nade davali (S7)*.

Lefebvre i Levert (2012) navode da je davanje potpunih informacija članovima obitelji u akutnoj fazi vrlo teško uzevši u obzir činjenicu da je u tom razdoblju zdravstveno stanje ozlijeđene osobe nestabilno i sam ishod neizvjestan, a obitelj je zbog neizvjesnosti koja vlada često anksiozna i smetena. Duff (2002) drži da bi se u akutnoj fazi nakon TOM-a neizvjesnost koju osjećaju članovi obitelji možda mogla umanjiti tako da stručnjaci govore i prenose informacije o brizi i skrbi koju kane primijeniti, umjesto da prognoziraju sam ishod ozljede. U komunikaciji s članovima obitelji važnim se pokazuje i konzistentnost u davanju informacija, kao i to da jezik kojim stručnjaci govore bude jasan kako bi članovi obitelji mogli razumjeti informacije koje su im upućene (Wetzig i Mitchell, 2017). Stručna terminologija koju je koristilo zdravstveno osoblje za vrijeme akutne skrbi za jednog člana obitelji osobe koja je bila u kritičnom stanju dodatno je otežala situaciju: *Znate, te stručne riječi i izrazi nisu nama jednako k'o kad ste vi kraj osobe, primite je za ruku i vidite u kakvom je ona stanju. Mislim to, kako je? „Stabilno. Nije u kontaktu.“ S kim nije u kontaktu? Zašto nije? To su vrlo štute informacije (S9)*.

informing us, constantly, and empathising, giving us support (S4)". One participant complained that it was difficult for him to contact a physician: *"It is difficult for us to get information at a given time. It is challenging to get a doctor at that time, sometimes almost impossible (S7)"*. It was the only complaint related to communication with healthcare staff during inpatient rehabilitation reported in our study. However, several participants expressed their dissatisfaction regarding obtaining information and the availability of healthcare staff, especially physicians, during acute care: *"When we asked, they always said "everything was fine, everything was fine". When they were saying "it is all right", it was not like that at all. He actually couldn't eat at all, or even walk (S1)"; "They were very scanty with information. Before his transfer (to rehab hospital), I got a chance to talk with the physician who operated on him. Before that, we didn't know anything about it (S9)"; "Honestly, they gave me no hope (S7)"*.

Lefebvre and Levert (2012) stated that giving complete information to family members in the acute phase is very difficult since the health condition of individuals with TBI in that phase is unstable and their outcomes are uncertain, leaving family members anxious and confused due to this uncertainty. In order to reduce the uncertainty felt by family members, Duff (2002) suggested talking and conveying information about the care and interventions the professionals intend to implement, rather than talking about the potential outcomes of the injury itself. Consistency in providing information proved essential, while Wetzig & Mitchell (2017) advised that the experts use language that is clear and simple so that family members can understand. Unfortunately, this was not the case in the present study: during the acute care, participants reported that the professional terminology and communication of the medical staff further aggravated the situation: *"You know, this professional language and vocabulary. It is not the same for us as when we are next to the person, holding his hand and observing how he is. I mean, how is he? "Stable. Not in contact." He is not in contact with whom? Why not? That is very scanty information (S9)"*.

Tema 3: Čimbenici obiteljske otpornosti: *Mi smo mislili da će naši glasovi njega probuditi*

Verhaeghe i suradnici (2005) zaključili su da se suočavanje s TOM-om odvija u fazama te da se strategije suočavanja mogu svrstati u dvije kategorije: one strategije koje su usredotočene na problem (primjerice traženje savjeta) i one koje su vođene emocijama (negiranje, izbjegavanje, traženje distrakcije, konzumacija lijekova i sl.). Iz sljedećih se citata može zaključiti da je dio sudionika u ranoj fazi bio sklon strategijama koje su više bile vođene emocijama te da su zaokupljenost dnevnim obavezama, izbjegavanje određenih situacija i konzumacija medikamenata bili neki od načina suočavanja: *Imam dvije curice, manje (...) dosta sam s njima zaokupljena (S2); Meni je sreća što je baš u ovo vrijeme bilo toliko posla. Jednostavno, radiš, radiš, radiš. I da nije bilo posla, ne znam, stvarno (S3); Nekad imam vremena i niti ne dođem doma. Jer nekako je teško i pričati, osobito s mamom, i sa svim. Konstantno se ta tema vrti. (S4); Nekad mi dođe da ne znam kud bi i šta bi. Dođe mi da bi udarala glavom u zid, vjerujte mi (...) Zatim popijem Normabel i onda mi bude dobro (S11).*

Američko psihološko udruženje (APA, 2006) proces uspješne prilagodbe u svjetlu nepovoljnih okolnosti kao što su trauma, tragedija, zdravstveni, obiteljski ili bilo kakav drugi izazov definira kao *otpornost* (engl. *resilience*). To je višeslojan i dinamičan proces kojem pridonose različite kvalitete pojedinca kao što su osobne i društvene kompetencije, obiteljska kohezija, društveni resursi i struktura ličnosti (White, Driver i Warren, 2008). Nekoliko se čimbenika u ovom istraživanju pokazalo značajnim u stvaranju otpornosti članova obitelji u suočavanju s posljedicama ozljede mozga bližnjeg i nemogućnošću ostvarivanja bliskog kontakta u vrijeme kad im je podrška bila najpotrebnija. Optimističan stav i prethodna iskustva uspješnog svladavanja životnih izazova pridonijeli su boljoj otpornosti i boljem nošenju sa situacijom: *Inače sam pozitivna osoba i onda automatski pozitivno djelujem na njega (...) Prošla sam i rak, i sve pobijedila. Ne bojim se ničega (S1); Imam ja i sa sinom isto iskustva u bolnici, i morala sam biti i odvojena od njega (S9).*

Theme 3: Factors associated with family resilience – “*We thought our voices would wake him up*”

In a literature review, Verhaeghe et al. (2005) concluded that coping with TBI takes place in stages, and coping strategies include two categories: those that focus on the problem (e.g., seeking advice), and those that are driven by emotions (e.g., avoidance, seeking distraction, taking medicaments). In the present study, at the early stage of coping, some participants used strategies based on emotions to distract them from daily obligations and avoid certain situations, or chose to take medications as a coping method: *“I have two young daughters (...) I’m pretty occupied with them (S2)”*; *“I was lucky there was so much work at that time. Simply, you work, work, work. And if there was no work, I don’t know, really (S3)”*; *“Sometimes I have time, but I don’t go home because it is hard to talk, especially with my Mom, and with everyone. This topic is quite dominant (S4)”*; *“Sometimes I have a feeling that I don’t know where to go and what to do. It comes to me to hit my head against the wall, just like that, believe me (...) Then I take Normabel, and I feel better (S11)”*.

The American Psychological Association (APA, 2006) defines ‘resilience’ as the process of successful adaptation to adverse circumstances such as trauma, tragedy, or other health or family challenges. It is a multi-layered, dynamic process that depends on individual characteristics, including personal and social competencies, family cohesion, social resources, and personality structure (White, Driver & Warren, 2008). In our study, numerous factors proved significant in improving the resilience of participants to be able to cope with the fact that their family members suffered brain injuries, as well as the fact that they were unable to be present in the hospital when support was most needed. A positive attitude and previous experiences of successfully overcoming life challenges contributed to better resilience and being able to cope with this situation: *“Otherwise, I am a positive person and then I automatically positively influence him (...) I had cancer, and I beat everything, I am not afraid of anything (S1)”*; *“I had the same experience in the hospital with my son, and I had to be separated from him (S9)”*.

Sljedeći način suočavanja koji su primjenjivali sudionici jest racionalizacija okolnosti, podržavajući fizičku distancu kako ne bi bili odgovorni za unos zaraze u bolnicu: *Teško ti je i sve, ali opet razumiješ situaciju u kojoj se nalazi, trenutno s tim virusom* (S4); *Mislim, razumijemo tu situaciju kakva je i ne bi ni želio da i mi donesemo kakvu bakteriju u bolnicu* (S6). Osim prihvaćanja zabrane posjećivanja bližnjega u bolnici, prihvaćanje i mirenje sa svim ostalim okolnostima i posljedicama ozljede, zahvalnost što im je član obitelji preživio tešku ozljedu, informiranost i planiranje budućnosti nekim su sudionicima pomogli u lakšem nošenju sa svim izazovima: *Prihvatili smo to kak' je i sad krećemo dalje. Mislim da nas to drži, da idemo dalje u nekom smjeru. Kako bude. Bitno nam je da je ostao živ. Eto, to nam je najbitnije* (S9); *Iskreno, ja nisam puno više zabrinut, u početku da. U najgorem slučaju kako... u kući nešto promijenit da njoj bude lakše. Meni su, i mama fizioterapeut, sestra mi je logopedica. Malo sam više upućen u neke stvari* (S3).

Istraživanja potvrđuju važnost prihvaćanja trenutnih okolnosti koje nastaju u obitelji nakon što bližnji doživi ozljedu glave (Townshend i Norman, 2018; Las Hayas, López de Arroyabe i Calvete, 2015). Las Hayas i suradnici (2015) u istraživanju s 237 skrbnika osoba s ozljedom mozga potvrđuju važnost čimbenika otpornosti u uspješnoj prilagodbi sa svim izazovima u jednom takvom životnom iskustvu, pri čemu se najveća povezanost pokazala upravo između čimbenika prihvaćanja trenutnih okolnosti i kvalitete života članova obitelji koji se brinu o ozlijeđenoj osobi.

Ozljeda člana obitelji kod pojedinih je sudionika potaknula veću povezanost, brižnost i bliskost ostalih članova premda je većina navela da su i prije obiteljski odnosi bili stabilni. Pokazala se značajnom i socijalna podrška šire obitelji i prijatelja. *Pa moglo bi se reći da smo se više zblížili, više pričamo o svemu. Prije je bilo više rutinski* (S3); *Svi stalno zovu i pomažu, nude prijevoze za sve. Ja nisam vozač, pa onda je to malo kompliciranije, oko škole. Ali evo, izađu nam ljudi u susret, što god treba* (S9).

Značaj podržavajućih odnosa u obitelji kao važnog resursa u nošenju s izazovima uslijed

Another participants' coping strategy included rationalisation of the circumstances. They expressed an understanding of the implementation of physical distancing in the hospital and did not want to take responsibility for the possible spread of the infection: *“It is difficult for you, but again, you understand the situation, currently with this virus* (S4)”; *“I mean, we know the problem, and I wouldn't even want to bring any bacteria to the hospital* (S6)”. Furthermore, the acceptance and reconciliation of the circumstances, gratitude that a family member survived a severe injury, as well as acquiring all the necessary information and plans helped some participants cope with the challenges: *“We accepted it as it is, and now we are moving on. I think that keeps us going, to go further in some direction. As it's going to be. What matters is that he is alive. That is the most important thing for us* (S9)”; *“Honestly, I'm not so concerned anymore. In the beginning, I was. In the worst case... thinking how to change something in the house to make it easier for her. My mother is a physiotherapist, and my sister is a speech and language pathologist. I am more familiar with some things* (S3)”.

Previous studies have confirmed the importance of accepting current circumstances in the family after a loved one has sustained a head injury (Townshend & Norman, 2018; Las Hayas, López de Arroyabe and Calvete, 2015). A study involving 237 caregivers of individuals with brain injury highlighted the significance of resilience factors in the successful adaptation of the caregivers to challenges occurring as a consequence of such life experiences (Las Hayas et al., 2015). At the same time, the dominant correlation appeared to be between the element of acceptance of current circumstances and the quality of life of family members caring for the injured person.

The brain injury of a family member induced some participants to become much closer with other family members and be more caring and supportive for each other. However, most of them reported positive family relationships even before the injury as well. The social support of extended family and friends also proved to be significant: *“Well, I can say that we get closer, we talk more about everything. It used to be more routine, I think.* (S3)”; *“Everyone is constantly calling and helping and*

ozljede mozga bliskog člana obitelji potvrđuje i kvalitativno istraživanje koje su proveli Segev, Levinger i Hochman (2018). Pokazalo se da uže, nuklearne obitelji koje su u dobrim odnosima sa širom obitelji, dijele sudbinu, podupiru jedni druge i nadopunjuju se sa svojim vrlinama u brizi za člana obitelji, krasi ih protok informacija o njemu i otvorena komunikacija, stoga osjećaju još veću međusobnu povezanost.

Istraživanja naglašavaju da je članovima obitelji iznimno važno da budu direktno uključeni u skrb o svojem bližnjem koji je doživio ozljedu mozga (Oyesanya, 2017; Fisher, Bellon, Lawn i Lennon, 2020). Fizička blizina uz krevet bližnjeg, pomoć u njezi i zagovaranje njegovih potreba naglašavaju osjećaj veće uključenosti u brigu o članu obitelji i daju skrbniku svrhu (Oyesanya, 2017). Premda nisu fizički mogli biti uz svoje bližnje i pružati izravnu skrb, sudionici ovog istraživanja pronašli su načine sudjelovanja u procesu rehabilitacije i davanja svojeg doprinosa oporavku. Osim redovitog slanja higijenskih potrepština i omiljene hrane te redovite komunikacije sa zdravstvenim osobljem, pružanja kontinuirane potpore i ohrabivanja tijekom videopoziva, članovi obitelji snimali su i slali obiteljske videomaterijale i audiomaterijale kako bi senzornim podražajima potaknuli reakcije i svjesnost svojih bližnjih s ozljedom mozga. Istraživanja potvrđuju da je senzorna stimulacija koja uključuje poznate i bliske glasove učinkovita kod osoba koje su bliže minimalnom stanju svjesnosti (Padilla i Domina, 2016). *A gospođa (ime-njuje radnu terapeutkinju) mi je rekla da kad njemu god pusti video (...) Curica mu snima video pa mi šaljemo, da on ne skreće pogled s toga videa dok to nije gotovo (S7); Još dok je bio na (imenuje ustanovu), onda smo mi njemu napravili... Htjeli smo da čuje naše glasove. Snimka je s njim otišla i ovamo u Toplice. Mi smo mislili da će ti naši glasovi njega probuditi (S10).*

Članovi obitelji u idealnoj su poziciji da budu aktivni članovi rehabilitacijskog tima jer daju svoj emocionalni ulog u oporavak, mogu osigurati spoznaje o potencijalima ozlijeđene osobe te dati značajnu potporu u optimizaciji oporavka (Fisher i sur., 2020). Kao jedna od važnih potreba članova obitelji u procesu rehabilitacije jest i postojanje

offering transportation. I'm not a driver, so it is more complicated, to go to school. Yes, people are offering their help, whatever we need (S9)".

The significance of supportive relationships in the family as an important resource in dealing with the challenges of brain injury of a close family member was also confirmed by another qualitative study (Segev, Levinger & Hochman, 2018). Elementary families who had good relationships with extended family shared their destiny, supported each other, and complemented their skills in caring for injured family members. They were also more interconnected as a result of the flow of information and open communication between family members (Segev, Levinger & Hochman, 2018).

Several studies have emphasised that family members have to be directly involved in caring for a loved one who has sustained a brain injury (Oyesanya, 2017; Fisher, Bellon, Lawn & Lennon, 2020). Their physical presence by the patients' bedside, as well as their assistance in caring and advocating for the needs of the patient can bring a sense of greater involvement and provide the caregiver with a purpose (Oyesanya, 2017). Although they could not physically be with their loved ones and provide direct care, participants in the present study found ways to participate in the rehabilitation process and contribute to the recovery. They regularly sent hygiene supplies and favourite foods, communicated with healthcare staff, as well as provided ongoing support and encouragement during video calls. In addition, they recorded and sent family videos and audio messages to stimulate the injured patients in order to help improve consciousness. Sensory stimulation involving familiar voices is effective especially for individuals closer to the minimum state of consciousness (Padilla & Domina, 2016): *"And the lady (an occupational therapist) told me that whenever a video plays (...) A daughter recorded a video for him and we sent it. He is staring at a video until the end (S7)"; "While he was still at (names the institution), we recorded... We wanted him to hear our voices. So, the recording came with him to the rehab hospital. We thought our voices would wake him up (S10)".*

nade u oporavak. Kuipers i suradnici (2014) u svojem kvalitativnom istraživanju o iskustvu uključenosti članova obitelji u rehabilitacijski proces kao jednu od ključnih dimenzija koja se proteže kroz cijeli kontinuitet rehabilitacije ističu postojanje jedne razine nade koja daje potrebno ohrabrenje članovima obitelji i pridonosi otpornosti. Kontinuitet u komunikaciji videopozivima omogućio je sudionicima da prate napredak svojih bližnjih, da primjećuju poboljšanja u njihovim reakcijama i vještinama izvedbe, što im je olakšalo situaciju, umanjilo strah i dalo nadu u oporavak: *(Sad) kad imamo taj susret sa Zoom-om (...) Svaki njegov treptaj oka i pomicanje ruke nama sad daje snagu za život (S8); Sad vidim hoda, govori, doduše tiho govori (...) Vidim sve ide naprijed. I sve razumije, sve zna, nikog nije zaboravio. Gospođa je tražila, pa smo joj neke slike poslali (...) Sve je znao, i tko je, ispričao joj je sve. Mislim, zadovoljna sam sada (S10); A za budućnost ne znam, nekako baš u dubini duše nadan se ili želin, mislin da će bit donekle u redu (S5).*

Nažalost, dio sudionika ovog istraživanja nije dobio primjerenu stručnu pomoć koja bi potaknula otpornost i uspješnije nošenje članova obitelji s ovom teškom situacijom. Jedan je sudionik naveo primjer uključivanja u grupnu psihoterapiju koja nije bila primjerena njegovim potrebama, već je služila kao pokriće za osiguravanje bolovanja jer zbog stresa koji je doživio, više nije mogao raditi dotadašnji posao: *Konkretno, stručne pomoći nema. I onda je bio jedini način da idem psihijatru. Onda sam išo' na dnevnu bolnicu, što je poslužilo samo tome da to vrijeme ne moram ić' (raditi) (...). Nije mi pomoglo ništa u tome. Moji osjećaji se nisu promijenili jer je to jedna grupa ljudi koji su sa nekim svojim problemima došli tamo, svako priča o svojim strahovima. Ne'ko je zbog briga na poslu, priča neke svoje priče u što ja nisam mogo' bit uključen. Znali su moju priču, ja sam eto bio tamo kao jedna figura, da mi prolazi to vrijeme (S8).*

Podržavajuća uloga obitelji u rehabilitacijskom procesu iznimno je važna i značajan je čimbenik otpornosti za osobu koja je doživjela TOM (Holland i Schmidt, 2015) stoga se pokazuje neophodnim osnaživanje obiteljske otpornosti

Family members are in an exceptional position to be active members of the rehabilitation team because they are emotionally dedicated to the recovery process, can provide insights into the potential of the injured person, and provide significant support in optimising recovery (Fisher et al., 2020). One of the critical needs of family members in the rehabilitation process is hope for recovery. Based on the qualitative research conducted by Kuipers et al. (2014), the experience of the involvement of family members in the rehabilitation process was highlighted as one of the critical dimensions that extend throughout the continuity of rehabilitation, emphasising the presence of one level of hope that can provide the necessary encouragement to family members and contribute to resilience. In the present study, ongoing video call communication allowed participants to monitor the recovery of their loved ones and notice progress in their reactions and performance skills. These insights brought them relief, reduced fear, and offered hope for recovery: *“(Now) when we have those Zoom meetings, every blink of his eye and the movement of his hand gives us strength to live (S8)”*; *“Now I see that he is walking, speaks, although quietly (...) I see everything is moving forward. And he understands everything, he knows everything, he has not forgotten anyone. The lady asked us, so we sent her some pictures (...) He knew everything, and who he was, he told her everything, that's right. I mean, I'm happy now (S10)”*; *“And future, I don't know what to say, somehow in the depths of my heart I hope or wish, I think it will be somehow good (S5)”*.

Unfortunately, some participants in the present study did not receive suitable professional help to encourage resilience and help the family cope more successfully in this challenging situation. One participant reported engagement in group psychotherapy that did not meet his needs. Instead, it served as a way to provide leave of absence from work, since he could no longer continue his current job due to the stress he was experiencing: *“And specifically, professional support, there is no professional help at all. The only way was to go to a psychiatrist. Then I was referred to a daily hospital, which served only for not going to work at that time (...) It didn't help me at all. My feelings, they have not changed because it is*

kako bi mogli pružiti potrebnu skrb i potporu ozlijeđenom članu. Mnoge su intervencije koje mogu ublažiti stres, a uključuju osiguravanje informacija, grupne potpore, savjetovanje i podršku obitelji, trening skrbnika, upoznavanje s izvorima samopomoći (Blake, 2008). Čimbenici otpornosti neophodni su u uspješnom nošenju s dubokim i često trajnim posljedicama ozljede, što zahtjeva njihov razvoj i osnaživanje (Godwin, Lukow i Lichiello, 2015). Pri tome svakako treba uzeti u obzir da su potrebe članova obitelji subjektivne prirode te da njihova dinamika ovisi i o fazi oporavka u akutnoj fazi rehabilitacije, o čemu bi osiguravatelji usluga svakako trebali voditi brigu (Kreutzer i sur., 2018).

Prednosti i ograničenja istraživanja

Važno je naglasiti da je ovo prvo istraživanje u Republici Hrvatskoj koje u kontekstu obitelji usmjerene prakse dočarava perspektivu članova obitelji osoba s teškom ozljedom mozga, osobito u vrijeme pandemije bolesti COVID-19. Ujedno ovo istraživanje ukazuje na važna područja u unapređenju procesa akutne skrbi i kasnije rehabilitacije, koja proizlaze iz osobnog iskustva skrbnika.

S obzirom na to da do sada nismo imali nikakav uvid u perspektivu članova obitelji osobe s TOM-om, primjereno je bilo primijeniti kvalitativan istraživački nacrt. U skladu s tim jedno od ograničenja ovog istraživanja svakako je nemogućnost otkrivanja univerzalnog iskustva, odnosno generalizacije za sve osobe koje su na bolničkoj rehabilitaciji u vrijeme pandemije, što ova metoda ni ne nudi. No rezultati svakako daju vrijedne spoznaje o iskustvima obitelji osoba s ozljedom mozga te potvrđuju važnost kontinuiranog kontakta i podrške te uključenosti skrbnika u rehabilitacijski proces. Ujedno svojevrsno ograničenje generalizacije iskustava članova obitelji osoba nakon TOM-a predstavlja i već opisana težina same ozljede. Pri tome valja naglasiti da se, ako gledamo duljinu posttraumatske amnezije kao pokazatelj težine ozljede (Nakase-Richardson i sur., 2009), u većini naših slučajeva radilo o ekstremno teškoj ozljedi mozga. U vrijeme provođenja intervjua većina ozlijeđenih osoba još je uvijek bila na bolničkoj rehabilitaciji što je moglo utjecati na

a group of people who came there with their own problems. Everyone talks about their fears. Someone is there because of work, everyone tells their stories that I couldn't be involved in. They knew my story, what it was about, I was there like, as a figure, passing my time (S8)".

The supportive role of the family in the rehabilitation process is vital and is considered as a significant resilience factor for an individual who has sustained TBI (Holland & Schmidt, 2015). Therefore, strengthening family resilience is necessary to provide the necessary care and support to injured individuals. Many interventions can alleviate stress, such as providing essential information, group support, family counselling, caregiver training, and learning about different sources of self-help (Blake, 2008). Resilience factors are critical in order to be able to effectively cope with the severe and often long-lasting consequences of injury, and these factors are associated with further growth and empowerment (Godwin, Lukow & Lichiello, 2015). However, family needs are often subjective and their dynamics depend on the patients' recovery during the acute phase of rehabilitation: this is an important consideration for service providers (Kreutzer et al., 2018).

Advantages and limitations of the present study

It is important to emphasise that, as far as we know, this is the first study conducted in the Republic of Croatia that, in the context of family-oriented practice, captures the perspectives of family members of individuals with severe brain injury, especially during the COVID-19 pandemic. Our findings also provide important insights into the need for improving the process of acute care and subsequent rehabilitation, based on the experiences of caregivers.

Since we had no previous insights regarding the perspectives of family members of individuals with TBI in the Croatian rehabilitation context, it was appropriate to apply a qualitative research design to this study. Therefore, one of the limitations of this study is undoubtedly the inability to describe the universal experience of caregivers or family members (i.e., the inability to generalise the results to include all individuals who are family members of patients undergoing inpatient rehabilitation at the

slobodno iznošenje iskustava sudionika radi brige za dobrobit ozlijeđenog člana obitelji. Iz tog je razloga intervju vodio neovisni stručnjak koji nije bio uključen u terapijski proces s tim pacijentima.

Buduća istraživanja svakako bi mogla uključiti veći uzorak i mješovit istraživački nacrt, uzeti u obzir iskustva drugih sudionika, korisnika zdravstvenih i socijalnih usluga, samih zdravstvenih djelatnika i suradnika, koji su dio skrbi. Svakako bi bilo korisno saznati na koji su način ograničenja u boravku uz bližnje na rehabilitaciji utjecala na njihov oporavak.

ZAKLJUČAK

Ovim je istraživanjem dobiven uvid u kompleksnost iskustva članova obitelji osoba koje su doživjele ozljedu mozga i koje se nalaze na akutnoj rehabilitaciji u vrijeme ograničenja fizičkog kontakta i mogućnosti boravka uz bližnje uslijed pandemije bolesti COVID-19. Rezultati istraživanja ukazuju na to da je sam traumatski događaj izazvao niz emocionalnih reakcija i promjena u svakodnevnom životu i ulogama svih članova obitelji. To se prije svega očitivalo kroz šok i nevjericu da se takva ozljeda uopće dogodila, zajedno s neizvjesnošću o samom ishodu ozljede i sa strepnjom hoće li bližnji preživjeti i hoće li doći do oporavka stanja svijesti. Dodatni stres i osjećaj bespomoćnosti pridruženi su ionako teškoj situaciji uslijed nemogućnosti posjećivanja u bolnici i boravka uz svoje bližnje.

Mogućnost interakcije videovezom tijekom bolničke rehabilitacije svim je sudionicima pružila olakšanje jer su napokon mogli vidjeti svojeg bližnjeg. Videopozivi su im nadalje omogućili da se uvjere u zdravstveno stanje svog bližnjeg, prate njegov oporavak i sami se aktivnije uključe u proces rehabilitacije što im je dalo dodatnu nadu i snagu u nošenju sa svim izazovima i jačanju vlastite otpornosti. Češća mogućnost interakcije putem videoveze i uključivanje članova obitelji u terapijski proces neki su od prijedloga za poboljšanja ovog vida komunikacije.

Općenito gledajući, članovi obitelji zadovoljni su iskustvom komunikacije sa zdravstvenim osobljem i dostupnošću informacija tijekom boravka

(time of the pandemic). Considering that this was not the intention of our research study, we believe that our results certainly provide valuable insights into the experiences of the families of individuals with brain injuries and confirm the importance of continued contact, support, and involvement of caregivers in the rehabilitation process. Another factor limiting the generalisability of the experiences of family members is related to the description of injury severity. If we consider the length of post-traumatic amnesia as an indicator of the severity of the injury (Nakase-Richardson et al., 2009), most of our patients had extremely severe brain injuries. Furthermore, most people with brain injury in this study were still in hospital, which might impact the participants' readiness to share their experiences honestly due to their concern for the well-being of the injured family member. Therefore, we made sure that the interviewer was an independent professional who was not directly involved in the therapeutic process with these patients.

Future research could include a larger sample and a mixed-method research design, as well as take into account the experiences of health and social services users and professionals who work in the care system. It would definitely be helpful to find out more about how visitation restrictions for family members impacted the recovery of people undergoing inpatient hospital rehabilitation.

CONCLUSION

This study provides further insights into the experiences of family members of individuals who had sustained a brain injury and were being treated in acute rehabilitation programs during the COVID-19 pandemic. We focused on the significance of video conference communication at a time when visitation restrictions banned the presence of family members in the hospital in order to avoid the spread of COVID-19. Our findings indicate that the traumatic event itself caused several emotional responses and resulted in changes in everyday life and the roles of all family members. Firstly, it was manifested as shock and disbelief that such an unexpected event had occurred, followed by uncertainty of the outcome of the injury and anxiety related to the survival and improve-

na akutnom smještaju i bolničkoj rehabilitaciji. Ipak, komunikacija, dostupnost i razumljivost informacija tijekom akutne skrbi pokazala se nedovoljnom za dio sudionika.

Zaključno se može reći da je komunikacija videovezom tijekom neurološke rehabilitacije i ograničavanja boravka uz bližnjeg višestruko pomogla svim sudionicima. No ovaj oblik komunikacije može biti dragocjen medij interakcije i izvan pandemijskog konteksta za osiguravanje kontinuirane komunikacije sa skrbnicima koji žive daleko od bolnice i nemaju mogućnost čestog putovanja ili zbog brige za druge članove obitelji ili posla zbog kojeg nisu u mogućnosti svakodnevno dolaziti u posjete. Kako se iz perspektive sudionika istraživanja malo toga može usporediti s kontaktom uživo, a uvažavajući znanstvene dokaze koji potvrđuju značaj obitelji za oporavak osoba koje su doživjele ozljedu mozga, nužno je pronaći rješenja kojima će se to i omogućiti.

Zahvala

Iskreno zahvaljujemo svim sudionicima ovog istraživanja koji su podijelili svoje iskustvo s nama i na taj način omogućili da ga bolje razumijemo te zagovaramo njihove potrebe, cijenimo njihovu ulogu i mijenjamo rehabilitacijsku praksu.

ments in the state of consciousness of loved ones. Additional stress and helplessness were also observed due to the inability of family members to enter the hospital and stay with their loved ones.

The opportunity to interact through video conferencing provided relief to all participants since they finally saw their loved ones, monitor their health condition and their recovery, and become more involved in the rehabilitation process. This gave them additional hope and strength to cope with all the challenges and strengthen their resilience. The participants suggested more frequent interactions via video conferencing and further involvement of family members in the therapeutic process in order to improve this type of communication.

In general, family members were satisfied with the experience of communicating with healthcare staff and the availability of information about their loved ones during their stay in acute care and hospital rehabilitation facilities. However, they reported insufficiencies related to communication, availability and the understandability of information during acute care.

In conclusion, video conferencing during inpatient neurological rehabilitation and visitation restrictions policies was helpful for all participants in many ways. In other circumstances, video calls can also be a valuable communication medium for providing ongoing contact to family members who live far away from the hospital and do not have an opportunity to travel frequently because of work or care related responsibilities. From the perspective of the participants included in the present study, nothing can compare to live physical contact. Thus, considering the fact that previous research findings confirm that family presence is important for the recovery of individuals who have sustained a brain injury, it seems crucial to find solutions to enable their involvement in the rehabilitation process.

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