5. SLOVENSKI KONGRES PALIATIVNE OSKRBE

z mednarodno udeležbo

»Živeti brez strahu«

13. – 14. oktober 2023

Domus medica, Dunajska 162, 1000 Ljubljana
Hibridni dogodek

ZBORNIK

Slovensko združenje
paliativne in hospic oskrbe

ONKOLOŠKI INŠTITUT
INSTITUTE OF ONCOLOGY
LJUBLJANA

Univerza v Mariboru
Medicinska fakulteta
Inštitut za paliativno medicino in oskrbo

Naslov:
5. SLOVENSKI KONGRES PALIATIVNE OSKRBE
z mednarodno udeležbo

Glavni urednici:
Ines Sever, Maja Ebert Moltara

Predsednica Slovenskega kongresa paliativne oskrbe:
Maja Ebert Moltara

Organizacijski odbor:
Marjana Bernot, Tadeja Gajšek, Nena Golob, Petra Gornik,
Maja Ivanetič Pantar, Jure Levart, Ana Jurčić, Maja Kolšek Šušteršič,
Barbara Kosmina Štefančič, Katja Kusek, Stanislav Malačič,
Srđan Mančić, Anamarija Meglič, Majda Oštir, Vesna Papuga,
Mateja Pišljar Mehle, Anita Riđič, Meta Rus, Ines Sever,
Andreja Cirila Škufca Smrdel, Irena Švab Kavčič, Maja Šeruga,
Ana Lina Vodušek, Erika Zelko, Andrej Žist

Strokovni odbor:
Blaž Koritnik, Nevenka Krčevski Škvarč, Maja Ebert Moltara

Založnik in izdajatelj:
Slovensko združenje paliativne in hospic oskrbe, SZD

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PROGRAM

Petek *(Friday)* 13. 10. 2023 Dan 1 *(Day 1)*

7:30	REGISTRACIJA	
08:30 - 9:00	OTVORITEV *Opening ceremony*	**Maja Ebert Moltara** predsednica Slovenskega združenja paliativne in hospic oskrbe **Marjan Pintar** Državni sekretar Ministrstvo za zdravje **Bojana Beović** predsednica Zdravniške zbornice Slovenije **Irena Oblak** strokovna direktorica Onkološkega inštituta Ljubljana **Nevenka Krčevski Škvarč** Inštitut za paliativno medicino in oskrbo Medicinska fakulteta Univerze v Mariboru
09:00 - 9:15	"Živeti brez strahu."	**Andrej Žist** podpredsednik Slovenskega združenja paliativne in hospic oskrbe

PLENARNA PREDAVANJA ***Plenary lectures***		
Moderatorja: Maja Ebert Moltara, Barbara Kosmina Štefančič		
09:15 - 10:00	Psiho-socialne in duhovne potrebe v paliativni oskrbi *Psycho-social and spiritual needs in palliative care*	**Andrew Goodhead** *St. Christophers, UK*
10:00 - 10:45	Anticipatorno žalovanje *Anticipatory grief*	**Maja Furlan de Brito** Faculty of Medicine, University of Coimbra, Portugal
10:45 - 11.00	RAZPRAVA – *Discussion*	
11:00 - 11:30	ODMOR – *Break*	
OBRAVNAVA SIMPTOMOV ***Symptom management***		
Moderatorja: Maja Šeruga, Vesna Papuga		
11:30 - 11:50	Kompleksna bolečina *Complex pain*	**Nevenka Krčevski Škvarč** Faculty of Medicine, University of Maribor, Slovenia
11:50 - 12:10	Zdravljenje kompleksne bolečine *Management of difficult pain in palliative care*	**Sebastiano Mercadante** La Maddalena Cancer center Palermo, Italy
12:10 - 12:30	Obravnava kostne bolečine v paliativni oskrbi *Management of bone pain in palliative care*	**Jasna But Hadžić** Institute of Oncology Ljubljana, Slovenia

12:30 - 12:50	Obravnava delirija v paliativni oskrbi *Management of delirium in palliative care*	**Helena Jagodič Korošec** General hospital Celje, Slovenia
12:50 - 13:10	Nevropsihiatrični simptomi v paliativni oskrbi - pogled psihiatra *Neuropsychiatric symptoms in palliative care – The view of a psychiatrist*	**Jana Knific** Institute of Oncology Ljubljana, Slovenia
13:10 - 13:25	RAZPRAVA – *Discussion*	
13:25 - 14:30	KOSILO – *Lunch*	
13:30 - 14:00	Satelitski simpozij *(Satellite symposium)* MSD: »Paliativna oskrba onkološkega bolnika zdravljenega z imunoterapijo.« **Marina Čakš,** Univerzitetni klinični center Maribor	
PSIHOLOŠKA OBRAVNAVA V PALIATIVNI OSKRBI ***Psychological treatment in palliative care***		
Moderatorja: Anamarija Meglič, Marjana Bernot		
14:30 - 15:00	Žalovanje pri zdravstvenih delavcih *Bereavement in healthcare workers*	**Andreja Cirila Škufca Smrdel** Institute of Oncology Ljubljana, Slovenia
15:00 - 15:20	Žalovanje pri odraslih *Grieving in adults*	**Maja Furlan de Brito** Faculty of Medicine, University of Coimbra, Portugal
15:20 - 15:40	Žalovanje pri otrocih *Grieving in children*	**Martina Bürger Lazar** Center for Mental Health of Children and Adolescents Brezovica, Slovenia
15:40 - 16:00	RAZPRAVA – *Discussion*	
16:00 - 16:30	ODMOR – *Break*	
ETIČNA VPRAŠANJA V PALIATIVNI OSKRBI ***Ethical issues in palliative care***		
Moderatorja: Nevenka Krčevski Škvarč, Andrej Žist		
16:30 - 16:50	Etična in pravna vprašanja pri odločitvah o predčasni prekinitvi življenja in pomoči pri samomoru *Issues in Ethics and Law regarding wishes to die and assisted suicide*	**Stefan Dinges** Department for Ethics and Law in Medicine, Austria
16:50 - 17:10	Pogosta etična vprašanja s področja paliativne oskrbe *Common ethical questions in the field of palliative care*	**Peter Golob** Committee for Legal and Ethical Issues, Medical Chamber of Slovenia, General hospital Izola
17:10 - 17:30	Etične dileme v paliativni oskrbi *Ethical dilemmas in palliative care*	**Roman Globokar** Faculty of Theology, University of Ljubljana, Slovenia
17:30 - 17:45	RAZPRAVA – *Discussion*	
17:45 - 18:00	ZAKLJUČEK dan 1 – *End of day 1*	

Sobota *(Saturday)* 14. 10. 2023 Dan 2 *(Day 2)*

8:00 – 9:00	**DELAVNICE – *Workshops***	
	Parenteralni pristopi *Parenteral approaches*	**Suzana Crljenica, Laura Petrica, Nizra Palamar, Kristina Durić** Institute of Oncology Ljubljana, Slovenia
	Žalovanje otrok po smrti bližnjega *Children's mourning after the death of a loved one*	**Manja Rančigaj Gajšek, Mateja Šušteršič** Pediatric clinic, University medical centre Ljubljana
	Prehranska podpora bolnika z rakom *Nutritional support of a cancer patient*	**Karla Berlec** Institute of Oncology Ljubljana, Slovenia
	Delo v mobilni paliativni enoti *Working in a mobile palliative care unit*	**Predstavniki različnih mobilnih paliativnih enot**
PODPORA BOLNIKU IN NJIHOVIM BLIŽNJIM ***Support for patients and their loved ones***		
Moderatorja: Petra Gornik, Majda Oštir		
09:00 - 09:20	Skrb za bolnikove bližnje *Caring for the patient's loved ones*	**Marjana Bernot** Institute of Oncology Ljubljana, Slovenia
09:20 - 09:40	Kadar je bolnikov bližnji zdravstveni delavec... *When the relative is a healthcare professional...*	**Maja Ebert Moltara** Institute of Oncology Ljubljana, Slovenia
09:40 - 10:00	Potrebe bolnika in njegovih bližnjih v domačem okolju *The needs of patients and the relatives in home eviroment*	**Jana Mali** Faculty of Social work, University of Ljubljana, Slovenia
10:00 - 10:20	Skupnostna psihiatrična obravnava *Community psychiatric treatment*	**Katja Sraka Recek** Le skupaj d.o.o., Slovenia
10:20 - 10:30	RAZPRAVA – *Discussion*	
10:30 - 11:00	ODMOR – *Break*	
ORGANIZACIJA PALIATIVNE OSKRBE V SLOVENIJI IN V TUJINI ***Organization of palliative care in Slovenia and abroad***		
Moderatorja: Erika Zelko, Maja Kolšek Šušteršič		
11:00 - 11:20	Predstavitev mreže paliativne oskrbe v Sloveniji *Presentation of the palliative care network in Slovenia*	**Mirjam Končan** Institute of Oncology Ljubljana, Slovenia
11:20 - 11:40	Izzivi paliativne oskrbe v Italiji *Challenges of palliative care in Italy*	**Raffaella Antonione** Trieste, Italy

11:40 - 12:00	Izzivi paliativne oskrbe v Avstriji *Challenges of palliative care in Austria*	**Matthias Huemer** Graz, Austria
12:00 - 12:20	Razvoj in trenutno stanje paliativne oskrbe v Istri in na Hrvaškem *Development and current state of PC in Istria County and Croatia*	**Julijana Franinović Marković** Croatia
12:20 - 12:40	Mobilne paliativne enote na Hrvaškem *Mobile palliative care units in Croatia*	**Julijana Franinović Marković** Croatia
12:40 - 13:00	Izkušnje v paliativni oskrbi v BIH in na Hrvaškem *Experience in palliative care in BiH and Croatia*	**Samir Husić** Bosnia and Herzegovina
13:00 - 13:15	RAZPRAVA - *Discussion*	
13:15 - 14:15	KOSILO – *Lunch*	
PALIATIVNA OSKRBA V NAŠI DRUŽBI ***Palliative care in our society***		
Moderatorja: Stanislav Malačič, Irena Švab Kavčič		
14:15 - 15:45	Predstavitev nevladnih organizacij, ki se vključujejo v paliativno oskrbo: *Presentation of non-governmental organizations involved in palliative care* • LjubHospic • Slovensko društvo Hospic • Karitas • Društvo onkoloških bolnikov Slovenije • Ko-rak • Društvo Spominčica • Europa Donna • Europacolon	
15:45 - 16:30	Predstavitev nagrajenih prispevkov *Presentation of awarded abstracts*	
16:30 - 17:30	**OKROGLA MIZA – ROUND TABLE DISCUSSION:** **»Kako naprej? / What`s next?«**	
Moderator: Ana Lina Vodušek		
	• **Maja Ebert Moltara,** Institute of Oncology Ljubljana, Slovenia • **Marjana Bernot,** Institute of Oncology Ljubljana, Slovenia • **Anamarija Meglič,** Pediatric clinic, University medical centre Ljubljana • **Manja Rančigaj Gajšek,** Pediatric clinic, University medical centre Ljubljana • **Julijana Franinović Marković,** Croatia	
17:30	**ZAKLJUČEK KONGRESA** ***Closing ceremony***	

Vzporedna srečanja (Rantova soba)

Posebna znanja – predstavitev ZZS (Galuf Zajc) Sestanek za zaprto skupino: Vabljeni člani UO in NO SZPHO	**Petek, 13. 10. 2023** 13:30 – 14:30
Srečanje specializiranih paliativnih enot Sestanek za zaprto skupino: Vabljena po dva predstavnika Specializiranih enot paliativne oskrbe (zdravnik, medicinska sestra)	**Petek, 13. 10. 2023** 17:30 - 18:30
Srečanje predstavnikov regionalnih timov paliativne oskrbe ***Meeting of representatives of regional palliative care teams*** **Kako podpreti mednarodno in regionalno sodelovanje?** ***How to support international and regional cooperation?*** Vabljeni člani regionalnih timov (invited guests)	**Sobota, 14. 10. 2023** 13:15 – 14:15

KAZALO

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POVZETKI PREDAVANJ

DELAVNICE

PRISPEVKI UDELEŽENCEV

PREDSTAVITEV PREDAVATELJEV

Raffaella Antonione

Director of SC Rete Cure Palliative e Hospice, Area Giuliana,
Azienda Sanitaria Universitaria Giuliano-Isontina (ASUGI),
Trieste, Professor in palliative care university of Trieste,
Coordinator on north eastern area Italian Society of Palliative Care (SICP)
rantonione@units.it

CURRENT POSITIONS

- Director of Palliative Care Network, Trieste
- Professor of Palliative Care, Trieste University
- Coordinator of Macro-area Nord-Est SICP (Italian Society Palliative Care)

EDUCATION AND DEGREES

- 2019 Master in Sanitary and Health Management
- 2013-2015 High qualification and specialization Master in Palliative Care
- 2009-2010 Master in Palliative Care
- 1995-2000 Internal Medicine Specialization, University of Trieste
- 1994 Medical degree, University of Trieste

MAIN TEACHING AND UNIVERSITY EXPERIENCES in Palliative Care

- Professor in Palliative Medicine in Medical and Nursing Schools, Specialization in Palliative Medicine University of Trieste (from 2013)
- Coordinator and Professor of “Master in Palliative Care” University of Trieste
- Professor in Palliative Care Master, University of Milan (from 2016)

MAIN ACTIVITIES AND COMPETENCES in Palliative Care

- Component of national board of SICP from 2020
- Coordinator of Italian north eastern Macroarea from 2020
- Regional coordinator for SICP in Friuli Venezia Giulia; from 2017 to 2021
- Coordinator of many inter-society study groups
- Speaker to national and international events
- Author and co-author of posters and articles

Karla Berlec, MD

Institute of Oncology Ljubljana
kberlec@onko-i.si

6th year Medical oncology resident, who started her career as part of the nutrition team at the Institute of Oncology Ljubljana. In the framework of the European Association for Clinical Nutrition and Metabolism, in addition to Slovenia, she was educated in Greece, Cyprus, Spain and Poland. She is in the final phase of obtaining the ESPEN diploma in Clinical nutrition and metabolism. In september 2022 she has passed ESMO Examination for Medical Oncologists. She is very interested in combining the knowledge of oncology and nutrition and she is looking forward to further scientific research in both fields.

Marjana Bernot, dipl. m. s., univ. dipl. org.

Onkološki inštitut Ljubljana
mbernot@onko-i.si

Sprva je bila vključena v zdravstveno nego in zdravljenje pacientov z rakom po različnih področjih, nato v vodenje in management zaposlenih. Zadnja leta opravlja delo koordinatorja paliativne oskrbe. Pridobljena znanje redno dograjuje, v letu 2019 je uspešno zaključila Evropsko akademijo za paliativno oskrbo (EUPCA).

Je habilitirana predavateljica za področje zdravstvene nege in redna predavateljica na Fakulteti za zdravstvo Angele Boškin. Dejavna je na številnih srečanjih, delavnicah in šolah. Je članica Sekcije medicinskih sester in zdravstvenih tehnikov v onkologiji, Mednarodne zveze onkoloških medicinskih sester (ISNCC), Evropske zveze onkoloških medicinski sester (EONS), Evropskega združenja za paliativno oskrbo (EAPC) in aktivna članica izobraževalne dejavnosti v Slovenskem združenju paliativne in hospic oskrbe (SZPHO). Svoj prosti čas posveča hribolazništvu in someljerstvu.

Doc. dr. **Jasna But Hadžić**, dr. med.

Onkološki inštitut Ljubljana

Doc. dr. Jasna But Hadžić, dr. med. je specialistka onkologije z radioterapijo. Od l. 2006 je zaposlena v sektorju radioterapije na Onkološkem inštitutu Ljubljana, od l. 2017 na Medicinski fakulteti Univerze v Ljubljani, kjer je zadnji dve leti predstojnica Katedre za onkologijo. Njeno strokovno, znanstveno in raziskovalno področje zanimanja so sodobne obsevalne tehnike, njihovo uvajanje v klinično prakso in zagotavljanje kakovosti v obsevalnem postopku. Sprva je delovala na področju rakov prebavil. V okviru doktorske disertacije, pod vodstvom izr. prof. dr. Vaneje Velenik, je uvedla hipofrakcionirano intenzitetno modulirano tehniko obsevanja v predoperativno zdravljenje raka danke. Od 2017 je članica tima za zdravljenje tumorjev torakalnih organov. Ob zdravljenju pljučnega raka se v zadnjih letih ukvarja z uvajanjem novih tehnik in raziskavami s področja stereotaktičnega obsevanja, slikovno vodene radioterapije in imunomodulatornega učinka obsevanja. Je so-avtorica številnih obsevalnih protokolov, nacionalnih priporočil zdravljenja in znanstvenih prispevkov. Sodelovala je v mednarodnih EORTC raziskavah RAPIDO in TOP GEAR, ter je članica EORTC/ESTRO OligoCare. Poučuje onkologijo na Medicinski fakulteti v Ljubljani ter vadbo pri onkoloških bolnikih na Fakulteti za šport v Ljubljani. Je sourednica revije Onkologija.

Asist. dr. **Martina Bürger Lazar**, univ. dipl. psih., spec. klin. psih.

Center for Mental Health of Children and Adolescents Brezovica, Slovenia

As a clinical psychologist, I spend most of my professional time working with children and adolescents facing mental health problems, along with their parents or caregivers. My professional journey began 28 years ago as a young researcher at the Paediatric Clinic, Clinical Department for Haematology and Oncology. The desire for specialization and research led me to specialize in Clinical psychology, obtaining a Master of Science, and a doctoral dissertation.

For more than two decades, I have laid the professional foundations for the field of paediatric psycho-oncology and palliative care. I also co-developed a comprehensive program aimed at treating children and adolescents with tumours of the central nervous system. Throughout the years, I have actively participated in international congresses as well as professional conferences on a domestic level.

Seeking new horizons, I spent five years working at the University Rehabilitation Institute of the Republic of Slovenia – Soča. This period allowed me to diversify my skill set and deepen my understanding while working with both younger and older adults navigating the challenges of chronic pain.

At the commencement of this year, I returned to my initial roots and resumed my vocation at the Centre for Mental Health of Children and Adolescents.

Dr. Stefan Dinges, PM.ME.

Department for Ethics and Law in Medicine · University of Vienna
Spitalgasse 2-4, Hof 2.8 · A- 1090 Vienna, Austria
stefan.dinges@univie.ac.at

Current Post

Member of the scientific staff at the Department for Ethics and Law in Medicine (IERM), University of Vienna; Head of the centre for ethical counselling and patient safety at the IERM (2010 – till now)

Recent Posts Held

- Member of the scientific staff at the Department of Palliative Care and Organisational Ethics (Vienna), Faculty of Interdisciplinary Research and Education, Klagenfurt University, 2000 - 2007
- Scientific assistant at the Institute of Pastoral Theology, University of Vienna, 1994-1999

Teaching

- Lecturer at University and Medical University of Vienna
- Teaching positions and guest lecturer at University of Graz, (Masterstudiengang Angewandte Ethik)

Research areas

- Organisational development and counselling in Health-Care-Organisations
- Clinical Ethics and Ethical consultation in hospitals and in the care for elder people Ethica counselling and organisational ethics
- Implementation of ‘shared decision making processes’ in hospitals and elderly people’s homes

Consultancies

- Member of the workgroup ‘Ethikberatung’ (Health Care Ethics Consultation), German Academy for Ethics in Medicine (AEM), 2003 – till now
- Member of the German Academy for Ethics in Medicine (AEM)

asist. dr. **Maja Ebert Moltara**, dr. med.

Institute of Oncology Ljubljana
mebert@onko-i.si

Maja Ebert Moltara is currently employed at the Institute of Oncology Ljubljana as a medical oncology specialist. She performs the clinical work of a medical oncologist and a physician with additional specialized knowledge in palliative care. From 2013 she is a head of the Department for Acute Palliative Care, which annually treats over 1,000 patients with complex symptoms annually. As head of the department, they oversee the clinical, educational and research work of the department. She is the editor of Palliative care for adult cancer patients in Slovenia: basic concepts and recommendations and Palliative Care Manual and many other (full list in COBISS, researcher no. 34638).

She has been the president of the Slovenian Association for Palliative and Hospice Care since 2014 and is committed to the development of a palliative network adopted to palliative care patient needs regardless of their place of residence and the type of incurable disease.

She is also active as a lecturer in the field of oncology and palliative care. She teaches palliative care as part of oncology at the Faculty of Medicine at the University of Ljubljana and Palliative Care at the Faculty of Medicine at the University of Maribor.

Since 2012 she is a lecturer at the 60-hour postgraduate course on palliative care – “Step by step”, the only program for obtaining a Diploma in palliative care by the Slovenian medical society. Together with co-workers she established also the 40-hour palliative care training for all clinical residents. For several years, she participates as a lecturer also in the Module „Dying Patient“ for family physician residents.

One of her fundamental projects is “Project Butterfly“ - www.paliativnaoskrba.si, which was designed to support patients and their relatives during palliative care.

PhD Julijana Franinović Marković, neurologist

jfraninovic@gmail.com

Education:

2006/7	Postgraduate certificate of supportive and palliative care. University of Kent/ University of Zagreb.
2008	Multi-Professional week in palliative care. St Christopher’s hospice, London.
2009	PRISMA project (Package 3.): Clinical research priorities in end-of-life care. Trondheim.
2011	Palliative care outcome scale training. King׳s College London.
2013	Clinical education in Graz

Work experience in the field of palliative care

2005	Volunteer palliative care team in the League Against Cancer Pula.
2011	clinical coordinator of the regional team for implementatio of palliative care in the primary health care system in Istria County.
2011	member of the mobile palliative care team
2015	Clinical project manager -Hospice of the Diocese Poreč-Pula

Teaching experience

2010	Postgraduate course: The Basics of palliative medicine. Medical School Zagreb
2015	Nursing school, Pula
2017	Faculty of Pharmacy and Biochemistry, Zagreb
2020	Palliative care with clinical praxis, University of Pula

Association

Croatian Society for Palliative Medicine (CrSPM)- vice president
Ligue against cancer Pula- president
Committee of Palliative Care of Ministry of health- member

Maja Furlan de Brito MSc, Clin & Health Psych Spec

Faculty of Medicine, University of Coimbra, Portugal

Maja Furlan de Brito did her first degree in Psychology at the University of Ljubljana (2009), including internship in the Palliative Care Unit of the University Clinic of Respiratory and Allergic Diseases Golnik. She got a MSc in Palliative Care from King's College London (KCL), UK, with distinction (2017) and is now a PhD candidate at the Faculty of Medicine at the University of Coimbra (UC), Portugal. She is a member of Palliative, End of Life and Bereavement Research Group at UC and a visiting research associate at Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation at KCL. Her additional clinical training is in CBT and Grief Therapy, having experience in private practice settings working with people who have experienced different types of losses. Maja's research focus is on epidemiological needs assessment triangle in bereavement and psychosocial oncological care, combining research on prevalence of needs for support, effectiveness of interventions, and issues related to access to services. Her PhD thesis is on variations in quality of bereavement support. She is currently co-coordinating a work package of the EU NAVIGATE project (funded by European Commission), leading a randomized controlled trial that will test a navigation intervention with older cancer patients. Her work is published in Jrl of Pain and Symptom Management, Palliative Medicine, The Lancet Public Health, and The Lancet. She is a co-author of three books published by Elsevier, The Oxford University Press and PACTOR.

izr. prof. dr. Roman Globokar

Faculty of Theology, University of Ljubljana, Slovenia

Roman Globokar is an associate professor of theological ethics at the Faculty of Theology, University of Ljubljana. He completed his doctoral studies at the Pontifical Gregorian University in Rome in 2001 on the topic of responsibility towards all living beings. He teaches subjects of moral theology, bioethics, social ethics and human rights. Since 2005, he has been a member of the National Medical Ethics Committee. His main research areas are environmental ethics, medical ethics, religion and ethics in the digital age, and ethical education. He was a visiting fellow at Boston College, USA (2015) and at Trinity College, Dublin (2018). He is a member of the board of the Association of Bioethicists in Central Europe (Vienna). He has participated in various international projects in the field of ethics and education. Currently, he is leading a European project to develop bioethics education in high schools.

Peter Golob, MD

General hospital Izola, Slovenia

President of the Commission for Law and Ethics of the Medical Chamber of Slovenia. Member of the Executive Committee of the Medical Chamber. General surgeon and traumatologist.

As a medical professional he specializes in upper extremity trauma and surgery. He currently holds the positions of Head of Emergency Department and Chief of General Surgery Division at Department of Surgery of Izola General Hospital. Being also a lawyer, he takes keen interest in medical law and bioethics and serves as a Chair of Law and Ethics Committee of Medical Chamber of Slovenia. He is also a member of Medical Chamber's Executive Committee.

Rev Dr Andrew Goodhead, Lead Chaplain

St. Christopher's, UK
a.goodhead@stchristophers.org.uk

Andrew Goodhead joined St Christopher's as Chaplain in January 2005, completing his doctoral research in 2007. He is a Methodist Minister with 14 years Church based experience gained in across the UK, both urban and rural. In his role at St Christopher's Andrew is concerned to ensure that all End of Life Care professionals have the skills and confidence to offer spiritual assessment and ongoing support to all patients and their families. He has a particular interest in the concept of spiritual pain as a way of understanding spiritual need.

Andrew has studied how bereaved people memorialise those who have died and has published on this theme. He has also researched clergy attitudes to religious and spiritual care for dying people

In 2018, Andrew co-edited with Nigel Hartley *Spirituality on Hospice Care: How staff and volunteers can support the dying and their families, (JKP).*

He has also published his PhD thesis under the title *A Crown and a Cross; the Origins, Development and Decline of the Methodist Class Meeting in Eighteenth Century England.*

Assist. Prof. Samir Husić, MD, PhD

- Date and place of birth: Nov. 06 1963, Tuzla BiH
- Medical School Tuzla; 1982 – 1990; MD

- **POSTGRADUATE STUDIES DATA:**
- Master work title: " Life quality of patients after mastectomy due to breast cancer". Date: Sep. 11 2008.
- Doctorate dissertation title: "Treatment of breakthrough pain in terminal cancer stage" Date: Apr. 08 2011.

- **PROFESSIONAL EDUCATION:**
- F.E.E.A. /permanent education in anaesthesiology and reanimation
- Education on palliative care; England: 2008; 2009; 2010.
- EFIC Pain therapy School; AKH - Austria/Wienna: Mar 01 2015 - Apr. 04 2015
- EFIC Erasmus + Project: Strengthening Capacities for Higher Education of Pain Medicine in Western Balkan Countries (HEPMP). Florence; Ljubljana; Rijeka; Belgrade; Banja Luka; Tuzla; Podgorica; 2017 – 2020.

- **PROFESSIONAL CAREER**
- Anaesthesiology specialist: Clinic for anaesthesia, reanimation and intensive treatment: 1995 -2006;
- Head of Palliative Care Unit (2006-2009); Director of Palliative Care Centre (hospice): 2009-2012; Head of Palliative Care and Pain Therapy Centre: 2012 – 2021.

- **PROFESSIONAL AND SCIENTIFIC AWARDS:**
- Senior assistant in the subject Urgent Medicine, Medical School, University of Tuzla
- Docent in the subject ''Anaesthesiology, Reanimation, Intensive Treatment, Medical School, UN Tuzla
- Docent in the subject ''Palliative Health Care'', 'Pain Therapy'' Medical School, ''Kallos University Tuzla'' and ''Oncology and Palliative Care'', Faculty of Health Studies, ''Kallos University Tuzla''

- **MENTORING:**
- Master work under the title: ''Health and Social Importance of Palliative Care in Bosnia and Herzegovina'' graduate nurse Olivera Sadiković; Tuzla University, Medical School; Faculty of Health Studies. Study programme - Nursery. Graduated in 2019.
- Master work under the title: ''Pharmacological Treatment of Pain in Palliative Medicine''. graduate nurse Amra Stuhli; European University ''Kallos '' Tuzla, Faculty of Health Studies, Nursery. Graduated in 2020.
- Graduation thesis: ''Pain at Head and Neck Carcinoma'', nurse Amila Đulović; European University ''Kallos '' Tuzla, Faculty of Health Studies, Nursery. Graduated in 2021.
- Graduation thesis: ''Treatment of the Symptoms at the Patients with Brain Cancer'', nurse Jolanda Mujagić; European University ''Kallos '' Tuzla, Faculty of Health Studies, Nursery. Graduated on Apr. 16 2022.

Dr. med. univ. **Matthias Huemer**

Internal Medicine, Assistant doctor at the University clinic for internal medicine, Division of Oncology, Palliative Care Unit, Graz, Austria. University lecturer at the Medical University of Graz for palliative care.

Asist. **Jana Knific**

Institute of Oncology Ljubljana

Assist. Jana Knific works at the Institute of Oncology Ljubljana as a specialist in psychiatry, and is the head of the Department of Psycho-Oncology. After completing her medical studies at the Faculty of Medicine in Ljubljana and completing her specialization in psychiatry, she got a job at the Begunje Psychiatric Hospital. She worked in various hospital wards, in the outpatient clinic, for seven years she was the head of day-hospital programs for patients with psychotic and mood disorders.

Her specific interest and work focused on women‘s mental health, mood disorders and the quality of life of people with mental disorders. She is the main tutor for specializations in psychiatry. She acquired additional knowledge in psychotherapeutic approaches and palliative care.

Mirjam Končan

Faculty of Medicine Ljubljana

I was born in 1999 in Celje. I am currently 6th year medical student at Faculty of Medicine in Ljubljana. During my studies I also applied to various part-time jobs within medicine, which helped me to get to know different areas of medicine, form Internal medicine to surgery. I also came upon Oncology Institute, specifically the ward for acute palliative care, where I help collect patient data. I also participate in a study about the burden of care for oncologic patients on their family members and caretakers.

Dr. Helena Korošec Jagodič

General hospital Celje, Slovenia

- Date of Birth: September 29, 1973
- Place of Birth: Postojna

Education:

- Graduation: Faculty of Medicine, University of Ljubljana, June 1999
- Field: Medicine
- Master‘s Degree: Faculty of Medicine, University of Ljubljana, May 2006
- Field: Biomedicine
- Specialization: Psychiatry, October 2011
- Specialization: Anesthesiology, Reanimatology, and Perioperative Intensive Medicine, January 2016
- Doctor‘s Degree: Faculty of Medicine, University of Ljubljana, January 2017
- Field: Biomedicine

Work Experience:

- Employment: General Hospital Celje, Department of Anesthesiology and Perioperative Intensive Medicine
- Position: Specialist in Anesthesiology, Reanimatology, and Perioperative Intensive Medicine and specialist in Psychiatry
- Management of psychiatric outpatient clinic
- Consultative psychiatric activity

Professional Publications:

- Publications in Slovenian and foreign professional journals in the fields of psychiatry and anesthesiology

Additional Skills:

- Profound professional knowledge in the field of anesthesiology, reanimatology, and perioperative intensive medicine
- Specialized knowledge and experience in psychiatry
- Excellent communication skills, adaptability, and teamwork
- Ability to lead and organize clinics and activities
- Successful integration of professional knowledge between psychiatry and anesthesiology

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With deep experience in anesthesiology, reanimatology, perioperative intensive medicine, and psychiatry, I am dedicated to providing high-quality healthcare to patients. By combining skills from different fields, I strive for comprehensive patient care and improving their health and comfort. Through my professional publications and active work in the hospital and clinic, I aim to contribute to the development of medical science and the improvement of the healthcare system.

Assist. Prof. Nevenka Krčevski Škvarč, MD, MS, PhD

Faculty of Medicine, University of Maribor, Slovenia

Currently active as consultant in pain management and palliative care in Palliative Care Unit, Dept. of Oncology, University Clinical Center Maribor, Slovenia and teacher at Faculty of Medicine and Faculty of Health Sciences University of Maribor, and College of Nursing in Celje.

Education background

- MD: Medical Faculty, University Zagreb, Croatia 1974
- Master of Science, University Zagreb, Croatia 1988
- PhD, University Maribor, Slovenia, 2011
- Assist. prof. in Anesthesiology and perioperative medicine 2011

Specialty:

- Anesthesiology and Reanimation 1981
- Diploma in Palliative Care 2013

Diploma in Pain Medicine 2017

Work experience

- Work in anesthesiology and intensive care, University Clinical Center Maribor, Slovenia 1975 – 2017
- Primarius, 2001
- Head of Pain Unit, University Clinical Center Maribor, 1984 – 2016

- Head of Palliative Care Unit, University Clinical Center Maribor, 2013 – 2017ead of Palliative Care Unit H
- Head of Institute for Palliative Medicine and Care from 2013

Research interest
- During professional career involved in clinical researches on domestic and European level. In bibliography (COBISS) is noted more than 360 marks.

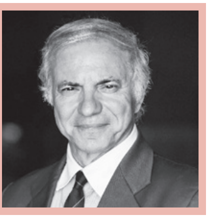
Membership and awards
- IASP, EFIC, SZZB, SZAIM, SZD, SZUM; SZPHO
- Honorary Member of Croatian Pain Association, 2000
- Honorary Member of Croatian Medical Chamber, 2013
- Honorary member of Slovenian Pain Association, 2017
- Past President of SZZB
- Past Honorary Secretary European Pain Federation - EFIC
- Ethic Committee, EFIC
- Co-chair Survivorship and Quality of life, ECO
- Member of supervisory Board SZZB
- Member of supervisory Board SZPHO
- Silver Award, University Maribor 2007
- Award of Merit, Medical Faculty Maribor, 2016
- Pain Champion, EFIC 2017
- Golden Award, SZZB, 2017
- Award for Lifetime Work, SZAIM, 2017
- Award of Merit, Hospic Maribor, 2021

prof. dr. Jana Mali

Faculty of Social work, University of Ljubljana, Slovenia

Jana Mali is Associate Professor of Social Work at the Faculty of Social Work, University of Ljubljana and works as an associate professor in the field of social work. Her research and teaching interests include social work with older people, social work with people with dementia, supervision in social work, social work methods, long-term care and palliative care. Her bibliography includes over 300 academic and professional publications. From the rich corpus of written material, six scientific monographs are worth mentioning, in which she deals with institutional care for the elderly, long-term care, social work with people with dementia and personal planning with service delivery. Her original scientific articles deal with deinstitutionalisation in the field of care for the elderly, intergenerational coexistence, care for people with dementia, social work methods, research in social work and the study of social work with older people.

In the last ten years she has worked for the integration of social work theory and practise, as the coordinator of the Centre for Professional Development, as a member of the Gerontological Society and the Activity of Social Workers of the Community of Social Institutions of Slovenia. Her international involvement is evident in the area of international projects, membership in the international network of European Schools of Social Work and as director of the international training programme Social Work with Old Age at the School for Social Work Theory and Practise at the Inter-University Centre in Dubrovnik, Croatia.



Prof. Sebastiano Mercadante

La Maddalena Cancer center Palermo, Italy

Born on 3rd December 1955

- Doctor's degree (Medicine & Surgery), 1973-1979 with full marks, 110/110 cum laude, University of Palermo. Specialization in Anesthesiology (1980-1983), and Science of Nutrition (1984-1987), University of Palermo.
- National abilitation for Professor of Anesthesiology, Intensive Care, and Pain Therapy
- Director of Anesthesia & Intensive Care Unit, Main regional center for Pain Relief & Palliative/Supportive Care Unit, La Maddalena, Palermo, Italy
- Scientific Director, Regional home care program SAMOT, Regione Sicily.
- More than 600 lectures at national and international congresses.
- Associated Editor, editorial Board and/or referee of more than 40 international peer-reviewed journals in the field of pain and symptom management, and anesthesiology
- More than 500 papers published in peer-reviewed international journals (H-index = 81).
- Author of more than 40 chapters and books.
- Award Umberto Veronesi 2003
- Award of excellence in scientific research, American Academy of Hospice and palliative medicine, Boston 2010
- John Mendelson MD Award, University of Texas MD Anderson cancer center "for extraordinary contribution in palliative care" Houston, 11-12 October 2013.
- Patent for "new delivery system for analgesics". N.21596IT/EL/FG/EM
- Since 1st December 2016, Adjunct professor of palliative medicine, MD Anderson, University of Texas, Houston, TX, USA
- 2018-2021. Member of the national ministerial commission for pain and palliative care.
- 2022-2021. First expert around the world on "cancer pain" and breakthrough pain" (expert.com)
- Clinical Impact Award. EAPC Rotterdam June 2023

Laura Petrica, Nizra Palamar

Obe sta diplomirani medicinski sestri, zaposleni na Oddelku za klinično prehrano OI Ljubljana. Njuno področje dela je edukacija in spremljanje bolnikov s parenteralno prehrano na domu.

Dr. Manja Rančigaj Gajšek, univ. dipl. psih., spec. klin. psih.

Pediatrična klinika UKC Ljubljana

Dr. Manja Rančigaj Gajšek je klinična psihologinja, zaposlena na Kliničnem oddelku za intenzivno terapijo otrok Pediatrične klinike na UKC Ljubljana. Osrednji del njenega dela predstavlja podpora otrokom in staršem ter sorojencem ob velikih izgubah – hudih boleznih, poškodbah ali celo smrti otroka. Je članica Tima za paliativno oskrbo otrok Pediatrične klinike v Ljubljani. Je certificirana kognitivno vedenjska terapevtka in se pri svojem delu opira na metode, ki izhajajo iz omenjene terapevtske usmeritve. Redno se udeležuje znanstvenih in strokovnih kongresov ter izobraževanj in usposabljanj, predvsem s področja psihološke podpore staršev in otrok ob hujših in kroničnih boleznih ter travmatskih dogodkih in s področja paliatvne oskrbe. Sama predava in pripravlja učne delavnice na različnih srečanjih in izobraževanjih, predvsem o psiholoških vsebinah, pomembnih za delo zdravstvenega osebja.

Katja Sraka Recek, MD, psychiatry specialist

Le skupaj d.o.o., Slovenia

I graduated from Medical Faculty of Ljubljana, Slovenia in 2008 and started my internship the same year. In 2011 I started Psychiatry Residency, which I completed in 2017. First 5 years as a psychiatry specialist, I was working partly in an outpatient setting and partly as a community mental health psychiatrist and as a team leader of Adult community mental health. Since 2019 I was an active participant of Interdisciplinary group at National institute for public health, which was covering the practical and clinical implementation of Mental Health Centres throughout the country. Currently I work as an ambulatory psychiatrist outside Mental Health Centre and still remain active at the National institute for public health in the field of coordination and implementation of Community Mental Health Centres.

mag. Andreja Cirila Škufca Smrdel, MSc

Institute of Oncology Ljubljana

Andreja Škufca Smrdel is a Master of Science in Psychology and a specialist in clinical psychology at the Department of Psycho-Oncology of the Institute of Oncology Ljubljana. As part of her work, she meets cancer patients with different localisations and at different stages of treatment, and collaborates in particular with the Department of Acute Palliative Care. She is an accredited psychotherapist for cognitive behavioural therapy and a qualified lecturer at the Faculty of Health at the University of Ljubljana. In her educational work she participates in the training of clinical psychologists and other health professionals and is also the author of numerous professional articles for patients and other lay people.

POVZETKI PREDAVANJ

PSYCHOLOGICAL AND SPIRITUAL NEEDS IN PALLIATIVE CARE

Andrew Goodhead

For patients approaching the end of life, there should always be opportunities to review life and, face death without fear. However, facing death openly often requires the supportive accompaniment of others, derived through honest and trusting relationships. These 'others' working in psychological and spiritual roles have a key part to play in enabling patients, and, when appropriate, their family members and friends to describe their psychological, emotional or spiritual distress and, through support, regain a sense of religious or spiritual purpose, personhood, meaning and autonomy.

This address will seek to pick up the title of the congress, 'To Live Without Fear', and set this into the context of how social workers, psychologists, art and music therapists, chaplains and spiritual care workers, as well as all health professionals, can address need in the palliative stage of illness, so that the individual will matter for being themselves. I will speak from the perspective of a hospice chaplain.

Dame Cicely Saunders, who founded the first modern hospice; St Christopher's in London, famously stated 'you matter because you are you, and you matter to the last moment of your life'. For over 55 years, palliative care organisations have also picked this phrase up and turned it into something of a mantra; a byword for the delivery of holistic care. What though, does this mean today? In a changed healthcare landscape, as people survive longer with terminal diagnoses, how can a person 'matter' while living longer with degenerative disease?

The address will explore the early theme of Total Pain described by Dame Cicely Saunders and set this into her model of care, including the theme of having value as a human being at the end of life. Included within this will be the idea of a 'good death'. Additionally, recent models which approach psychological and spiritual support from a non-religious perspective will be considered. The question here is, 'how do we ensure that all who face the end of life receive not just acceptable support but life enhancing support?'

Quality of life and its value to the individual and those around them is a significant marker for psychological and spiritual interventions. Clinically, the International Palliative Outcome Scale with its physical and psychological domains is being utilised by more palliative services to assess need. During this address we will consider how the psychological domains can help practitioners in the assessment of need.

In conclusion, psychological and spiritual needs remain central to the delivery of holistic care for patients who enter palliative care services. Enabling the expression of psychological, emotional and spiritual concerns enables professionals to help in meeting need and these can improve outcomes and the quality of life of patients and, by extension, those close to them.

ANTICIPATORY GRIEF

Maja Furlan de Brito

How do you usually go about when supporting a person with cancer experiencing preparatory grief or their family member struggling with managing anticipatory grief? While commonly observed in palliative care, the topic of preparatory and anticipatory grief is less discussed and researched in comparison to post-death grief. In this session we will look at the prevalence of both and issues related to assessment of needs for support. Current evidence on interventions will be discussed. This will be done based on two three-tiered models of bereavement support that differentiates the type of support depending on the complexity of person's needs. Author will outline the major scientific findings to date and will briefly present Portuguese experience with development of anticipatory grief model and support.

COMPLEX PAIN IN PATIENTS WITH CANCER

Nevenka Krčevski Škvarč

Pain is distressing symptom that affects about 66% of patients with advanced cancer and among these 51,9% have moderate to severe pain. Despite evidence -based practice guidelines and multiple position paper on the management of cancer pain, there are barriers to optimal pain management. Respecting World Health Organisation guide for pain relief it is possible to achieve pain control in 75 – 90% of patients. This means that 10 – 20% of patients with cancer suffer from pain that is complex and not easily relieved. Complex cancer pain is defined as a pain that does not improve with conventional pharmacological and non -pharmacological strategies.

Pain assessment and classification are the foundation to optimal pain management. Pain assessment must be comprehensive with inclusion of all aspects of pain experience. New ICD-11 classification of cancer pain is great help for its assessment.

The most frequent complex pain syndromes are bone pain, spinal cord compression, chest wall pain, brachial plexopathy, pancreatic pain, lumbosacral plexopathy and pelvic pain.

Neuropathic pain and breakthrough pain are common among patients with cancer and present types of pain difficult to treat.

“Total pain” is the interplay of physical, psychological, social, and spiritual component and presents the situation of complex cancer pain.

Responsiveness to opioids can be changed due to the type of pain, individual variability in analgesic response to opioids and to occurrence of their side effects, or personal preference. Inter individual variability could be connected with human genetic variation in genes related to opioid metabolism, opioid receptors or opioid transporters. As well analgesics’ therapy can be compromised due to patients’ condition.

It is also possible to have problems with pain alleviation in special populations such as older adults, patients with substance use disorders, culturally diverse populations, patients and who are nonverbal or cognitively impaired.

Patients with complex pain require more time to achieve stable pain control and may require different interventions. Patients with complex cancer pain must have systematic screening and proper assessment of pain, personalization of cancer pain therapy, proper choice of pharmacological management and novel non- pharmacological interventions for pain management.

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MANAGEMENT OF DIFFICULT PAIN IN PALLIATIVE CARE

Sebastiano Mercadante

Most patients with cancer pain can be managed with relatively simple methods using oral analgesics at relatively low doses, even for prolonged periods of time. However, in some clinical conditions pain may be more difficult to manage. Various factors can interfere with a desirable and favorable analgesic response. Data from several studies assessing factors of negative pain prognosis have indicated that neuropathic pain, incident pain, psychological distress, opioid addiction and baseline pain intensity were associated with more difficult pain control.

OBRAVNAVA KOSTNE BOLEČINE V PALIATIVNI OSKRBI

Jasna But Hadžić

Bolečina je zelo pogost simptom maligne bolezni z visoko prevalenco in hudo morbiditeto. Po nekaterih ocenah z bolečino živi tretjina bolnikov po kurativnem zdravljenju, več kot polovica aktivno zdravljenih bolnikov in kar dve tretjini bolnikov na simptomatski in podporni terapiji.

Najpogostejši vzrok bolečine zaradi raka je maligna kostna bolečina. Kostni zasevki povzročajo tudi utrujenost, hiperkalcemijo, patološke frakture in maligno utesnitev hrbtenjače - stanja, ki potrebujejo urgentno ukrepanje. Ti skeletni dogodki zmanjšujejo stanje zmogljivosti bolnika in pomembno zmanjšujejo kakovost življenja.

Za kostno bolečino je značilna triada tope trajne bolečine, bolečine pri premikanju in izbruhov močnejše bolečine. Za diagnostiko je v večini primerov dovolj rentgensko slikanje in dodatno CT/MRI pri sumu na patološko frakturo ali utesnitev hrbtenjače.

Primarno zdravljenje kostne bolečine je farmakološko, z NSAID, paracetamolom in opioidi. Osnovno dopolnilno zdravljenje je obsevanje, kar bi morali prejeti vsi bolniki z nezadostnim učinkom analgetikov ali prekomernimi stranskimi učinki zdravil. Zdravljenje z obsevanjem je enostavno, hitro, poceni in varno. Že z enkratnim obsevanjem z 8 Gy dosežemo protibolečinski učinek pri 80% bolnikov, s srednjim trajanjem 18-21 mesecev. Randomizirane klinične raziskave niso pokazale razlik v protibolečinskem učinku in preživetju med enkratnim paliativnim obsevanjem (1 x 8Gy) in frakcioniranim obsevanjem (5 x 4 Gy in 10 x 3 Gy) z višjim deležem ponovno obsevanih bolnikov po enkratnem obsevanju (20% proti 8%). Tudi visoke ablativne doze, s katerimi stereotaktično obsevamo kostne zasevke oligometastatskih bolnikov nimajo dokazano boljšega protibolečinskega učinka. Zato po najnovejših smernicah še vedno velja, da je standardno protibolečinsko obsevanje kosti enkratno, z dozo 8 Gy. Enkratno obsevanje je učinkovito tudi z namenom re-mineralizacije in pri maligni utesnitvi hrbtenjače. V primeru patološke frakture, grozeče frakture ali maligne utesnitve hrbtenjače je pred obsevanjem potrebna kirurška intervencija, s stabilizacijo in/ali dekompresijo. Za zagotovitev dobre lokalne kontrole sledi pooperativno frakcionirano obsevanje.

Radioterapija pri preprečevanju kostnih dogodkov še nima mesta izven kliničnih raziskav. Kot dopolnilno zdravljenje se v ta namen predpisujejo bifosfonati in denosumab, ki z inhibicijo osteoklastov ustavijo resorbcijo kostnine.

Kljub osupljivo hitremu napredku znanja v onkologiji se žal delež bolnikov, ki trpijo za bolečino ne spreminja in je bolečina pogosto nezadostno zdravljena. Zato je pomembno, da je obravnava bolečine multidisciplinarna.

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OBRAVNAVA DELIRIJA V PALIATIVNI OSKRBI

MANAGEMENT OF DELIRIUM IN PALLIATIVE CARE

Helena Korošec Jagodič, Vesna Papuga

Povzetek

Delirij pomembno zvišuje obolevnost in umrljivost različnih skupin bolnikov, še posebej bolnikov v paliativni oskrbi, kjer je trdovraten delirij pogost v zaključni fazi umiranja. Tako pogosto zaplete zadnje ure ali dni življenja pri večini paliativnih bolnikov. Po drugi strani pa je delirij klinična diagnoza, ki je pogosto spregledana ali napačno diagnosticirana.

Delirij je stanje skaljene zavesti in izrazitih motenj pozornosti ter spoznavnih sposobnosti. Poznani so dejavniki ranljivosti pri bolnikih (na primer že obstoječa kognitivna okvara) in sprožilni dejavniki delirija (na primer okužba sečil). Ker pa je v razvoj delirija vpletenih več dejavnikov, obstaja verjetno tudi več nevrobioloških procesov, ki prispevajo v patogenezo delirija, vključno z nevrovnetjem, motnjo v delovanju možganskih žil, spremenjen metabolizem v možganih, porušeno ravnovesje živčnih prenašalcev in okvarjena povezava nevronskih omrežij.

Zdravljenje delirija je kompleksno, saj vključuje obravnavo več različnih področij. Multikomponenten pristop lahko povzamemo takole: obravnava sprožilnih dejavnikov delirija, poprava fizioloških motenj, zdravljenje simptomov delirija, vključno z obravnavo stiske bolnikov in komunikacija z bolniki in svojci. Raziskave kažejo, da je pri paliativnih bolnikih kar 50% delirijev reverzibilnih, še posebej tistih, ki jih sprožijo zdravila, okužba (antibiotiki), dehidracija in neravnovesje elektrolitov (zdravljenje z bisfosfonati pri hiperkalcemiji). Zdravila so pogosti sprožilci delirija in drugih nevropsihiatričnih neželenih učinkov, še posebej pri starejših in hudo bolnih bolnikih s spremenjeno farmakokinetiko in farmakodinamiko. Pomembno se je izogibati prekomernih odmerkov zdravil, ki vplivajo na delovanje možganov (npr. benzodiazepini, antidepresivi, antipsihotiki, antikonvulzivi, kortikosteroidi in kinoloni). Pri bolnikih v paliativni obravnavi je tudi pomembna obravnava oziroma lajšanje bolečine, za kar pogosto uporabljamo opioide, ki pa lahko povzročajo nevropsihiatrične neželene učinke, pogosto skupno imenovane kot opioid-induced neurotoxicity (OIN) ali nevrotoksičnost, povezana z opioidi.

Za simptomatsko zdravljenje delirija uporabljamo tudi zdravila, zlasti antipsihotike, kljub omejenim dokazom iz raziskav. Treba je opozoriti, da trenutno nobeno zdravilo nima uradne indikacije za zdravljenje delirija. Tako so se klasični (npr. haloperidol) kot atipični antipsihotiki (npr. olanzapin, risperidon, kvetiapin, aripiprazol) izkazali za enako učinkovite, le da im-

ajo atipični manj ekstrapiramidnih neželenih učinkov. Benzodiazepini so zdravila prve izbire pri obvladovanju odtegnitvenega delirija (od alkohola in zdravil s sedativno-hipnotičnimi učinki). Druga zdravila, ki so jih raziskovali kot potencialne pri zdravljenju delirija, vključujejo metilfenidat, modafinil, valprojsko kislino, gabapentin, ondansetron in melatonin. Zaradi omejenih dokazov trenutno niso priporočljiva za rutinsko klinično prakso. Obstaja tudi nekaj sporadičnih primerov uspešne uporabe dexmedetomidina v paliativni obravnavi.

Abstract

Delirium is associated with significant patient morbidity and increased mortality in many patient populations, especially palliative care where refractory delirium is common in the dying phase. So, delirium commonly complicates the last hours or days of life for most patients in palliative care settings. However, delirium is a clinical diagnosis that is frequently overlooked or misdiagnosed by the healthcare team.

Delirium is a syndrome characterized by an acute change in attention, awareness and cognition. Multiple predisposing factors (for example, pre-existing cognitive impairment) and precipitating factors (for example, urinary tract infection) for delirium have been described. Because multiple factors are implicated in the aetiology of delirium, there are likely several neurobiological processes that contribute to delirium pathogenesis, including neuroinflammation, brain vascular dysfunction, altered brain metabolism, neurotransmitter imbalance and impaired neuronal network connectivity.

Delirium treatment is complex, as it involves addressing multiple domains. This multidomain approach can be summarized as follows: addressing the often multiple delirium triggers, correcting physiological disturbances, treating the symptoms of delirium including distress, communicating with patients and carers, and addressing the current and future risks linked with delirium. In palliative care, evidence suggests that approximately 50% of delirium episodes can be reversed, especially those precipitated by medications, infection (antibiotics), dehydration and electrolyte abnormalities (bisphosphonates for hypercalcemia). Medications are an increasingly common precipitant of delirium and other neuropsychiatric adverse effects, especially in the elderly and other patients with altered pharmacokinetics and pharmacodynamics. Important, active de-prescribing of deliriogenic medications (e.g., benzodiazepines, antidepressants, antipsychotics, anticonvulsants, corticosteroids, and quinolones) is the most important component of delirium management. Opioids are commonly used in palliative care, and their neuropsychiatric side effects, often collectively referred to as opioid-induced neurotoxicity (OIN), commonly occur in patients with advanced disease.

Medications, in particular antipsychotics, have been utilized in the routine symptomatic treatment of delirium in palliative care despite limited research evidence. It should be noted that no medication is currently licensed for use in the management of delirium, so the use of medications for the indication of delirium is 'off-label'. Both conventional (e.g., haloperidol) and atypical antipsychotics (e.g., olanzapine, risperidone, quetiapine, aripiprazole) were shown to be equally effective in the treatment of delirium, the later are associated with fewer extrapyramidal side effects. Benzodiazepines are used as first-line agents in the management of alcohol or sedative–hypnotic withdrawal. Other medica-

tions that have been examined for a potential role in delirium treatment include methylphenidate, modafinil, valproic acid, gabapentin, ondansetron, and melatonin. They are not currently recommended for routine clinical practice due to limited evidence. There have been sporadic case reports about the successful use of dexmedetomidine in palliative care.

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NEVROPSIHIATRIČNI SIMPTOMI V PALIATIVNI OSKRBI – POGLED PSIHIATRA

NEUROPSYCHIATRIC SYMPTOMS IN PALIATIVE CARE – THE VIEW OF A PSYCHIATRIST

Jana Knific

Vsaj 25-30 % vseh bolnikov z rakom in še večji odstotek bolnikov v paliativni oskrbi dosegajo kriterije za različne duševne motnje - depresivne, anksiozne, prilagoditvene motnje z demoralizacijo in delirij. Pomoč bolnikom pri soočanju z boleznijo in zahtevnim zdravljenjem, spoprijemanje s stresom, ki je spremljevalka bolezni in lajšanje stisk in/ali simptomov ob tem ter izboljšanje kvalitete življenja so glavne komponente psihoonkološke obravnave.

Komunikacija z bolnikom o zadnjem obdobju življenja je pomembna in zahtevna, neizogibno s seboj prinaša čustvene odzive in zahtevo po nagovarjanju biomedicinskih in psihosocialnih aspektov tega obdobja življenja. V tem obdobju se v obravnavo vse bolj vključujejo tudi družinski člani bolnika, tako se bolnik in njegova družina vse bolj sooča in prilagaja na nove vidike bolezni in nove vloge tega obdobja. Več kot 50 % bolnikov z rakom poroča o anksioznih simptomih, čeprav je metaanaliza 94 študij pokazala bistveno nižjo prevalenco anksioznih motenj (10.3%). 38.2% bolnikov poroča o razpoloženjski motnji, od tega jih je 19.4% ocenjenjenih kot prilagoditvene motnje. Svojci bolnikov, ki so napoteni v paliativno oskrbo poročajo o izdatni anksioznosti v 47%. Anksiozne in depresivne motnje se pogosto sopojavljajo in sovplivajo druga na drugo. Prevalenca depresivnih motenj variira od 7-49 % pri paliativnih bolnikih, sistematični pregled 59 študij, ki so jih izvajali v raznolikih okoljih paliativne oskrbe (bolnišnični/onkološki oddelki, dnevnobolnišnični odd., paliativni odd, hospic) je pokazal 2-56% prevalenco depresije. Tii podatki kažejo, da je prevalenca 2 do tri krat večja kot v splošni populaciji in podobna kot pri bolnikih z drugimi telesnimi boleznimi.

V prispevku bodo obravnavana teoretična izhodišča posameznih sklopov psihiatričnih simptomov, njihov način izražanja pri paliativnih bolnikih in njihovih svojcih, ocenjevanje in diferencialno diagnostične dileme, ki se ob tem pojavljajo ter njihova specifična klinična obravnava v paliativni oskrbi.

At least 25-30% of all cancer patients and an even larger percentage of patients in palliative care meet the criteria for various mental disorders - depression, anxiety, adjustment disorders with demoralization and delirium. Helping patients cope with the disease and demanding treatment, dealing with the stress that accompanies the disease and alleviating the suffering and/or accompanying symptoms and improving the quality of life are the main components of psycho-oncology treatment.

Communication with the patient about the last period of life is important and demanding, it inevitably brings with it emotional responses and the requirement to address the biomedical and psychosocial aspects of this period of life. During this period, the patient's family members are increasingly involved in the treatment, so the patient and his family face and adapt to new aspects of the disease and new roles of this period. More than 50% of cancer patients report anxiety symptoms, although a meta-analysis of 94 studies showed a significantly lower prevalence of anxiety disorders (10.3%). 38.2% of patients report a mood disorder, of which 19.4% are assessed as adjustment disorders. Relatives of patients referred to palliative care report extensive anxiety in 47%. Anxiety and depressive disorders often co-occur and influence each other. The prevalence of depressive disorders varies from 7-49% in palliative patients, a systematic review of 59 studies conducted in diverse palliative care settings (hospital/oncology departments, palliative/hospic unit, outpatient service) showed a 2-56% prevalence of depression. These figures are 2 to 3 times higher than those of the general population and similar to that of patients with other physical diseases.

The paper will discuss the theoretical starting points of individual sets of psychiatric symptoms, their way of expression in palliative patients and their relatives, assessment and differential diagnostic dilemmas that arise and their specific clinical treatment in palliative care.

BEREAVEMENT IN HEALTHCARE WORKERS

Andreja C. Škufca Smrdel

Caring for seriously ill patients can elicit grief responses in health professionals - „professional grief“ Research shows that it can manifest in different ways at emotional, cognitive, physical, and behavioral levels. The intensity of grief following the death of a patient is described as moderate to high, but it is less intense than grief following the loss of a loved one, but still a source of distress. Grief affects the well-being of medical staff, relationships with patients and their families, and patient care. Few authors have explored this area, nor is it a completely clear concept that overlaps with both distress and burnout. On the other hand, it raises the question of whether the research disinterest follows the „unwritten request“ - ignore, suppress, hide, because working in healthcare with many losses, one is often expected to turn away from one‘s internal experiences in order to rapidly move on to the next patient. In addition, it is important for grieving health care professionals to attend to their well-being, as this is important both to themselves and to the patients and family members they will continue to care for.

GRIEVING IN ADULTS

Maja Furlan de Brito

What has introduction of DSM and ICD-11 diagnosis of Prolonged grief disorder done for the bereaved, for health care professionals working in bereavement support and what is the role of community in all of this? What are the implications of COVID pandemics for people who suffered a loss due to COVID or during the restrictions imposed by governmental measures at the time of pandemics. In this session we will look at clinical and research aspects of these questions.

GRIEVING IN CHILDREN

Martina Bürger Lazar

Children often ask questions about life and death. Conversations about death are supposed to be a part of everyday life, as children sooner or later confront that all beings, animals, plants, humans, and even parents, eventually die. Usually, this happens when we grow old or are very ill. However, discussing dying, death, and grieving among adults is still taboo, and even more so when the conversation involves a grieving child.

Grief is a complex emotional process that affects children and adolescents in unique ways and is usually a normal reaction to loss. It can include affective, cognitive, behavioural, and physiological reactions. As children navigate the experience of loss, understanding their psychological responses becomes essential in providing adequate support. Younger children are not yet developmentally capable of understanding the concept of death cognitively and emotionally, making their grief expression distinct from that of adults. Their understanding of death might be literal, causing confusion or fear. Encouraging open conversations and utilizing age-appropriate language can help them grasp the situation while promoting emotional expression. Younger children might display grief through changes in behaviour, such as regression, clinging behaviour, or even separation anxiety. Adolescents, on the other hand, grapple with grief within the context of identity development. The loss can disrupt their sense of self and trigger existential questions. They might alternate between expressing their emotions and withdrawing, as they navigate between seeking support and establishing independence. Peer relationships often play a crucial role during this phase, impacting their grieving process.

It‘s essential to recognize that grieving is not a linear process; children and adolescents may revisit their emotions as they reach new developmental milestones or significant life events. Providing a safe space for expression, where their feelings are validated, can facilitate healthy grieving. Some children manage to cope with their loss with resilience, whereas others do not. Children with prolonged grief reactions and adjustment difficulties need professional treatment by a child psychologist or support groups, who can offer coping strategies tailored to their age and developmental stage. Additionally, involving parents and caregivers is vital. They serve as role models for healthy grieving and can create an environment that encourages emotional openness. In conclusion, the grieving process for children and adolescents is multifaceted, and influenced by their cognitive and emotional development. Tailoring support to their specific needs, fostering open communication, and incorporating creative ways can help them healthily cope with their grief. By understanding the unique dynamics of grief at different developmental stages, we can provide meaningful assistance during their healing journey.

In my presentation, I will share, with great gratitude to all families, insights and experiences gained from their intimate narratives that unveil the experiences of grieving children, adolescents, and parents. Through their stories, both children and parents have become my most important teachers, which shaped me both as a professional and as a person.

ISSUES IN ETHICS AND LAW REGARDING WISHES TO DIE AND ASSISTED SUICIDE

Stefan Dinges

In my comment I will reflect on several issues in the Austrian society and Austrian law regarding assisted suicide (with a reflection on other European countries and maybe shared values and questions) and the involvement and the experiences in the Austrian Palliative Movement.

We know that ignored wishes to die (often linked with symptoms without sufficient treatment, social death and feelings of loss in meaning and dignity) in health care organizations can lead to a stronger wish for assisted suicide – which observations were made (in health care organizations, in palliative care teams) since the start of the new law for an advanced directive in dying (2022)? And we can look on the first research results of two different registers (one run by government, one by the Austrian palliative society) regarding a wish to die, the consultation by physician and the fulfilling of assisted suicide – in short we can also report, that a wider, open minded consultation by a specialized palliative care physician and the offer for an appropriate symptomatic treatment can influence the strong wish for assisted Suicide.

On the second level we should reflect some aspects about assisted suicide – an individual right, but does it lead to an obligation of health care organizations? And in general, whom has the Austrian law to protect – the patient, the health care workers and/or the health care organizations?!

By the way – some of these aspects – ignored wishes to die, pain and other symptoms without sufficient treatment and loss in meaning and dignity – causes moral distress to health care workers as a second victim. The last question that should be discussed: Is Assisted Suicide – with all understanding for the individual free will, autonomy and the right to make their own decision – an offer or a duty made by the Health Care-System and it's organizations? In Switzerland assisted suicide is organized in a private sector, regulated by law.

COMMON ETHICAL DILEMMAS IN PALLIATIVE CARE

Peter Golob

Numerous ethical dilemmas persist surrounding the integration of palliative care into modern healthcare systems, yet the fundamental challenge of ensuring appropriate and equitable access remains unresolved. In Slovenian legal context, the notion of palliative care finds a solitary mention within Article 39 of the Patient's Rights Act[1]. This specific provision extends the right to palliative care to patients who are in the terminal stages of an ailment or those afflicted by an incurable disease causing them severe distress. The Patient's Rights Act, however, does not regulate the financial reimbursement of health-related expenses[2], nor does it address the organizational intricacies of health services[3]. Consequently, the procedural pathway for patients to assert this right remains obscure. The inception of the National Program on Palliative Care (Državni program paliativne oskrbe[4]) in 2010 set a foundational course for the evolution of palliative care in Slovenia. Over the course of the ensuing 13 years, progress has been made; however, the core objectives of ensuring appropriate and equitable access to palliative care still elude realization. Presently, only an unknown fraction of those necessitating palliative care can access it.

The question arises: In the absence of a robust legal framework, why is palliative care provided within the Slovenian healthcare landscape? This inquiry leads to the postulation that the central reason for the provision of palliative care—despite the absence of a comprehensive legal framework—lies in its alignment with medical ethics and adherence to the established standards of practice (lex artis). The act of providing palliative care without a legal framework, while concurrently adhering to ethical principles and established standards, inadvertently diminishes the impetus for the establishment of a comprehensive legal structure. Consequently, an ethical approach to palliative care, while indispensable, is insufficient. What is imperative is the dual commitment to ethical conduct and the advocacy for a comprehensive legal framework that will ensure appropriate and equitable access to palliative care. This endeavor acknowledges the potential dichotomy wherein the very ethics driving current practices might paradoxically impede the attainment of the two objectives in focus.

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ETIČNE DILEME V PALIATIVNI OSKRBI

ETHICAL DILEMMAS IN PALLIATIVE CARE

Roman Globokar

Etika ni matematika. Kontekst vsake odločitve je enkraten in specifičen, kar pride še posebej do izraza v najbolj ranljivih trenutkih, kot je paliativna oskrba. Etika predstavlja sistematično razmišljanje o tem, kaj je dobro za človeka kot posameznika, za človeško družbo in za celotno naravno okolje. Etično odločanje je vedno odločanje za dobro življenje, vprašanje pa se postavlja, kako opredeliti, kaj je to dobro življenje in kakšna je pot do uresničitve le-tega. Vsaka oseba ima svoje vrednostne nazore in življenjske izkušnje, na podlagi katerih vrednoti, kaj je zanjo dobro. Na različnih področjih življenja se velikokrat znajdemo v situacijah, ko ni povsem jasno, kaj je dobro za nas in za druge, in v nas pride do konflikta vrednot. Odločamo se za tisto, za kar smo prepričani, da je v določenem trenutku najboljše. Postavi pa se vprašanje, na podlagi česa izbiramo? Kako opredelimo, kaj je dobro v določenem trenutku? Kako odločitev tudi uresničimo?

Skozi zgodovino so se oblikovali različni etični sistemi. Nekateri bolj poudarjajo absolutno dolžnost upoštevanja določenih načel in zapovedi (deontološka etika), drugi postavljajo kot glavni kriterij največje možno dobro za največ ljudi (utilitaristična etika), zopet drugi vidijo pravo pot v oblikovanju temeljnih etičnih drž, s pomočjo katerih bo posameznik v določenem trenutku sprejel odgovorno odločitev (etika kreposti oz. vrline). Vsem etičnim pristopom je skupna osebna odgovornost posameznika, ki izhaja iz njegovega avtonomnega delovanja. Etičnih odločitev ne moremo prelagati na ramena drugih: dobro je, da jim prisluhnemo in se z njimi posvetujemo, vendar moramo na koncu sprejeti osebno odgovornost za sprejeto odločitev. Del etične odgovornosti je tudi poznavanje situacije, zato sta strokovnost in etika med seboj neločljivo povezani. Za področje medicinske etike je to ključnega pomena. Če neka odločitev ni strokovno podprta, ne more biti etična, tj. dobra za pacienta. Prav tako pa tudi neetične odločitve ne moremo imeti za strokovne.

Na področju paliativne oskrbe se odpirajo številne dodatne etične dileme, ko imamo dve (ali več) izbiri in ni povsem enoznačno, katera je prava. Prva dilema je strokovna: kar je dobro za bolnika v procesu zdravljenja, zanj ni nujno dobro tudi v procesu umiranja. V terapevtski medicini se kot osnovno dobro zdi ozdravljenje. Pri neozdravljivo bolnih se zato dozdeva, da je osnovni cilj medicine ni dosežen. Pojavijo se nova vprašanja: kako spoštovati človekovo dostojanstvo v procesu umiranja? Kaj sploh pomeni spoštovanje dostojanstva človeka? Do kdaj vzdrževati njegove biološke funkcije? Kakšno obliko nege nuditi umirajočemu? Kako upoštevati njegove želje in spoštovati njegovo avtonomijo? Kako sploh razumemo avtonomijo? Smo dolžni povedati resnico pacientu (in njegovim svojcem) glede zdravstvenega stanja? Kaj narediti, kadar pride do različnih pogledov med pacientom in njegovimi svojci? Kdo naj odloča namesto pacienta v primerih, ko ta ni več sposoben odločanja o sebi? Kaj narediti, ko so želje pacienta (ali svojcev) v nasprotju z načeli kodeksa zdravniške etike?

Eden od uveljavljenih etičnih modelov je paradigma štirih etičnih načel (avtonomija, neškodovanje, dobrodelnost in pravičnost), ki veljajo kot načela *prima facie*. Nobeno od načel ni absolutno, pri vsaki odločitvi je treba pretehtati vsa štiri načela in na koncu narediti individualno odločitev. Po našem prepričanju sama paradigma načel ni zadostna, ampak jo je nujno dopolniti z etiko kreposti. Poleg jasnih pravil in etičnih načel je ključnega pomena etičen značaj zdravstvenih delavcev.

Ethics is not mathematics. The context of each decision is unique and specific, and this is especially true in the most vulnerable moments, such as palliative care. Ethics is a systematic reflection on what is good for human beings as individuals, for human society and for the natural environment as a whole. Ethical decision-making is always a decision for a good life, but the question is how to define what that good life is and what is the path to achieving it. Each person has his or her own values and life experiences on the basis of which he or she evaluates what is good for him or her. In different areas of life, we often find ourselves in situations where it is not clear what is good for us and for others, and a conflict of values arises within us. We choose what we are convinced is best at a given moment in time. But the question is, on what basis do we choose? How do we define what is good at a given moment? How do we implement the decision?

Throughout history, different ethical systems have developed. Some emphasise the absolute duty to follow certain principles and precepts (deontological ethics), others make the greatest possible good for the greatest number of people the main criterion (utilitarian ethics), while others see the right way forward in the development of fundamental ethical attitudes that will help individuals to make responsible choices at a given moment in time (virtue ethics). All ethical approaches have in common personal responsibility, which derives from his or her autonomous action. Ethical decisions cannot be placed on the shoulders of others: it is good to listen to them and consult them, but in the end, we must take personal responsibility for the decision we make. Part of ethical responsibility is situational awareness, so professionalism and ethics are inextricably linked. For the field of medical ethics, this is crucial. If a decision is not professionally based, it cannot be ethical, i.e. good for the patient. Similarly, an unethical decision cannot be considered professional.

Palliative care raises many additional ethical dilemmas when there are two (or more) choices and it is not clear which is the right one. The first dilemma is a professional one: what is good for the patient in the healing process is not necessarily good for the patient in the dying process. In therapeutic medicine, the basic good seems to be healing. In the case of the terminally ill, therefore, it seems that the basic aim of medicine has not been achieved. New questions arise: how to respect human dignity in the dying process? What does it mean to respect human dignity? How long should his biological functions be maintained? What form of care should be given to the dying person? How to respect *the dying person's wishes and autonomy? How do we understand autonomy? Do we have a duty to tell the truth to the patient (and his/her relatives) about the state of his/her health? What to do when there is a difference of opinion between the patient and his/her relatives? Who should make decisions for the patient when the patient is no longer able to make decisions for him/herself? What to do when the patient's (or relatives') wishes conflict with the principles of the Code of Medical Ethics?*

One of the established ethical models is the paradigm of the four ethical principles (autonomy, non-maleficence, beneficence and justice), which are considered prima facie principles. None of the principles is absolute; each decision must weigh all four principles and ultimately be made on an individual basis. In our view, a paradigm of principles (principlism) alone is not sufficient but must be complemented by virtue ethics. In addition to clear rules and ethical principles, the ethical character of health professionals is crucial.

SKRB ZA BOLNIKOVE BLIŽNJE

Marjana Bernot

Izhodišče: Napredovali rak vpliva na kompleksnost izvajanja paliativne oskrbe in na nadaljnji načrt obravnave. Posamezni simptomi napredovale bolezni obremenijo bolnika in prav tako bolnikove bližnje, vendar ti velikokrat niso deležni ustrezne podpore. Bolnikove bližnje se oskrba bolnega lahko dotika na različne načine in pušča posledice na telesnem, čustvenem, socialnem in finančnem področju. Pomembno je vedeti, kako bolnikovi bližnji sodelujejo pri oskrbi in kako jih pri tem lahko opolnomočimo. Cilj prispevka je preučiti potrebe bolnikov z rakom v paliativni oskrbi, upoštevajoč bolnikove bližnje kot pomemben dejavnik načrtovanja paliativne oskrbe. Prikazati želimo katere potrebe so prepoznane pri bolnikih in njegovih bližnjih v akutni paliativni oskrbi.

Metode: Retrospektivna kohortna študija je analizirala rutinske podatke pridobljene preko telefonskih beležk pacientov v akutni paliativni oskrbi med decembrom 2021 in julijem 2023. Primerjali smo vrsto potreb glede na diagnozo pacienta, potrebe bolnikovih bližnjih in planirane aktivnosti.

Rezultati: Najpogostejše izpostavljeni težavi sta bili vezani na obvladovanje simptomov in prejemanje zdravil. Bolnikovi bližnji prav tako iščejo dodatne informacije v zvezi s procesom umiranja in oskrbo bolnika v zadnjih dneh življenja ter socialno podporo - predvsem vezano na zagotavljanje pomoči pri osnovni negi bolnika in koordinaciji oskrbe. Podporo pa potrebujejo tudi v času žalovanja.

Razprava: Podatki bodo prispevali k razumevanju dejavnikov, ki prispevajo k kompleksnosti oskrbe bolnika z rakom v specializirani paliativni oskrbi. Pomembno je prepoznati potrebe tako bolnika kot njegovih bližnjih, da lahko zagotovimo ustrezno podporo in izvajanje paliativne obravnave bolnikov z rakom.

KADAR JE ZDRAVSTVENI DELAVEC BOLNIK ALI BOLNIKOV BLIŽNJI

WHEN A HEALTHCARE PROFESSIONAL IS A PATIENT OR PATIENT RELATIVE

Maja Ebert Moltara

Bolnikovi bližnji, to so sorodniki, družina, prijatelji, znanci, sosedje oziroma osebe, ki so pomembni zaradi odnosa z bolnikom ali nudenja pomoči in sodelovanja v oskrbi lahko živijo z bolnikom, v bližini ali so oddaljeni. Ne glede na to, kje se nahajajo, imajo vpliv na njegovo oskrbo, ki ga določa predvsem oseben odnos. Njihove vloge v obravnavi so lahko številne: spremljevalec, negovalec, administrator, voznik, varuh bolnikovih pravic, trener, zagovornik, koordinator, organizator lahko pa delujejo tudi kot zdravstveni delavec, če imajo tako izobrazbo.

V družinah, kjer se oskrbuje hudo bolnega, se pojavijo spremenjene vloge v družini, motnje v načinu življenja, delovanju družine, spremembi odnosov in občutkov, pomislekov glede lastne poklicne obremenjenosti in odgovornosti. Iz raziskav vemo, da je kar 72 % bolnikovih bližnjih vključenih v zdravstveno negovalno oskrbo bolnikov z rakom in 43 % od njih ni bilo o tem nikoli poučenih. Kadar gre za bolnikove bližnje, ki so zdravstveni delavci, pa se lahko celo zmotno pričakuje, da to znanje in veščine imajo, a to ni vedno res. In tudi če to znanje imajo, je to znanje lahko zaradi čustvenih povezav in izkušenj včasih lahko okrnjeno. Skupina bolnikov, ki so sami zdravstveni delavci ali svojci hudo obolelih, ki so zdravstveni delavci imajo zato specifične potrebe.

V predavanju bomo prikazali pregled literature, ki jo je zelo malo, in analizo naših podatkov med leti 2021 do 2023. Iz vsakodnevne prakse namreč vemo, da imajo družine zdravstvenih delavcev nekoliko drugačne potrebe, ki pa jih je temu primerno potrebno nasloviti in ubesediti.

The patient‘s loved ones, i.e. relatives, family, friends, acquaintances, neighbors, or persons who are important because of the relationship with the patient or offering help and participation in care, can live with the patient, be nearby or be far away. Regardless of where they are located, they have an impact on his care, which is primarily determined by personal relationships. Their roles in the treatment can be many: companion, carer, administrator, driver, guardian of the patient‘s rights, trainer, advocate, coordinator, organizer, but they can also act as a health worker if they have such an education.

In families where a seriously ill person is cared for, changed roles in the family, disturbances in the way of life, family functioning, changes in attitudes and feelings, concerns about one‘s own professional workload and responsibility appear. We know from research that as much as 72% of the patient‘s relatives are involved in the nursing care of cancer patients and 43% of them have never been taught about it. When it comes to the patient‘s relatives, who are medical professionals, it can even be erroneously expected that they have this knowledge and skills, but this is not always true. And even if they have that knowledge, that knowledge can sometimes be tainted by emotional connections and experiences. A group of patients who are themselves health workers or relatives of seriously ill people who are health workers therefore have specific needs.

In the lecture, we will present an overview of the literature, which is very scarce on this topic, and a small analysis of our data and our experiences from 2021 to 2023. We know from everyday practice that the families of healthcare workers have somewhat different needs, that need to be addressed appropriately.

POTREBE BOLNIKA IN NJEGOVIH BLIŽNJIH V DOMAČEM OKOLJU

THE NEEDS OF PATIENTS AND THE RELATIVES LIVING IN HOME ENVIRONMENT

Jana Mali

Povzetek
Pomoč bolnikom in njihovim sorodnikom postaja v socialnem delu vedno bolj prepoznano področje. V mednarodnem okolju je kvalitativno raziskovanje specifičnih vidikov pomoči bolnikom in njihovim sorodnikom veliko bolj prisotno kot pri nas. Zasledimo raziskave, ki proučujejo stališča žalujočih sorodnikov o primernosti oskrbe bolnikov v domačem okolju, raziskave, o prepoznavanju specifik pri oskrbi, ki jo sorodniki zagotavljajo družinskim članom v zadnjem obdobju življenja in raziskave o pomenu komunikacije strokovnjakov in neformalnih oskrbovalcev z bolniki.

V Sloveniji nimamo nacionalnih raziskav na tem področju, zato smo se na Fakulteti za socialno delo odločili, da samoiniciativno izvedemo poizvedbo o teh temah. Prvo raziskovanje smo izvedli leta 2019 in od takrat z raziskovanjem nadaljujemo vsako študijsko leto. Cilj raziskovanja je spoznati, katere teme so najbolj pereče pri zagotavljanju oskrbe bolnikom, kakšne so potrebe bolnikov in sorodnikov, kako so njihove potrebe zadovoljene in kakšno pomoč bi v zadnjem obdobju življenja potrebovali. Za namen tega prispevka predstavljamo rezultate raziskovalnega vprašanja, ki se nanaša na potrebe bolnikov in njihovih sorodnikov v domačem okolju.

Bolniki menijo, da je njihova oskrba doma, v domačem okolju edina sprejemljiva, da ni bilo potrebnih večjih prilagoditev prostora, ki bi imele tudi finančne posledice. Navajajo manjše spremembe pri ureditvi bivalnega in spalnega prostora, uporabo bolniške postelje, preselitev iz nadstropja v pritličje, uporabo dvigala, prilagoditev kopalnice in stranišča. Na drugi strani pa sorodniki menijo, da je bolj primerna oskrba v domovih, ker se izognejo preveliki emocionalni vpletenosti v oskrbo, ki jo povzročajo: šok, nesprejemanje bolezni, bolečina, obremenitve.

Finančni vidik oskrbe ni več v domeni bolnikov, skrb zanj prevzamejo sorodniki v celoti. Stroške oskrbe zakonci pokrivajo z obema pokojninama, tudi prihranki, zmanjka jim sredstev za vzdrževanje nepremičnine. Partner/ka opravi večino vsakodnevne pomoči,

kar bolniki tudi pričakujejo. Partnerji pa tožijo o tem, da imajo premalo pomoči, da bi se razbremenili. Razbremenitev predstavljajo različni socialni stiki, tudi pomoč strokovnjakov palitivnega tima. Obiski prijateljev, sorodnikov, znancev potekajo na domu bolnika. Dnevne rutine so prilagojene bolniku in spremembam zdravstvenega stanja. Sorodniki nimajo časa za zadovoljevanje svojih potreb. Več se zadržujejo doma in manj časa namenjajo vzdrževanju socialnih stikov, ki so jih vzpostavili pred boleznijo partnerja.

Bolniki izražajo zavist zdravim ljudem, svoje življenje pa razumejo kot čas brez upanja na ozdravitve. V zadrego jih spravi vsiljevanje pozitivizma, upanja, pogovori o smrti. Imajo občutek, da so domačim v breme. Sorodniki podobno kot bolniki doživljajo to obdobje življenje kot brezupno, dodajajo še občutke nerazumevanja bolnika in širše družine, travm iz otroštva. Ponekod so se družinske vezi okrepile, prav tako samozavest oskrbovalca/ke. Skrbi jih čas po smrti.

Raziskovanje potreb se tako kot v dolgotrajni oskrbi tudi v paliativni oskrbi kaže kot pomembno področje za razvoj socialnega dela. Slišati, spoštovati in upoštevati uporabniško perspektivo so koncepti, ki predstavljajo stičišče med socialnim delom in paliativno oskrbo.

Abstract

Supporting patients and their families is an increasingly recognised area of social work. Qualitative research on specific aspects of supporting patients and their relatives is much more widespread internationally than in Slovenia. We can follow research that explores bereaved relatives‘ views on the appropriateness of caring for patients in the home environment, research that highlights the specifics of caring for relatives for family members in the last phase of life, and research on the importance of communication between professionals and informal carers and patients.

In Slovenia, there is no national research in this area, so the Faculty of Social Work decided to conduct an initiative survey on these issues. The first survey was conducted in 2019 and we have continued it every academic year since then. The aim of the survey is to find out what issues are most pressing in patient care, what patients‘ and relatives‘ needs are, how their needs are met, and what kind of help they would need in the last phase of life. In this paper we present the results of a research question on the needs of patients and their relatives in the home environment.

Patients consider that their care at home, in their home environment, is the only acceptable one and that no major spatial adaptations are required, which would also have a financial impact. They mention minor changes in the living and sleeping arrangements, the use of a hospital bed, moving from the first floor to the ground floor, using a lift, adapting the bathroom and toilet. On the other hand, relatives believe that institutional care is more appropriate because it avoids too much emotional involvement in care caused by shock, non-acceptance of the illness, pain and strain.

The financial aspect of care is no longer the responsibility of the patient, but is taken over entirely by the relatives. The costs of care are covered by the pensions of both spous-

es, including savings, and they run out of funds to maintain the property. The spouse provides most of the daily help, which is expected of the patients. But the partners complain that they do not have enough help to relieve themselves. Relief is provided by various social contacts, including help from palliative care team professionals. Visits from friends, relatives and acquaintances take place in the patient's home. The daily routine is adapted to the patient and to the changes in his or her state of health. Relatives do not have time to meet their needs. They stay at home more and spend less time maintaining the social contacts they had established before their partner's illness.

Patients are envious of healthy people and see their lives as a time without hope of recovery. They are ashamed of the imposition of positivism, hope and talk of death. They feel they are a burden to their families. Relatives experience this stage of life as hopelessness, as do patients, adding childhood trauma to the feeling of being misunderstood by the patient and the wider family. In some places, family ties have strengthened, as has the self-esteem of the carers. They worry about the time after death.

As in long-term care, exploring needs in palliative care is proving to be an important area for social work development. Listening to, respecting and considering the user's perspective are concepts that represent the interface between social work and palliative care.

COMMUNITY MENTAL HEALTH OUTREACH TEAM

Katja Sraka Recek

In 2018 the National mental health plan - MIRA, was adopted. Slovenia is currently in the process of a mental health reform. During the lecture some outlines and achievements of the National mental health program so far will be presented, an important part of it is also a development of services that respond to the needs of individuals and communities.

Focus is on improved access, multidisciplinary care model, and emphasis on integration of newly established services into already existing network with good cooperation of all available service providers.

25 Community mental health centers (CMHC) are to be established on a regional level, each covering an area of 50 000 to 70 000 adults.

Teams in CMHC consists of ambulatory or outpatient team (AMB) and of mobile or outreach team (SPO). Both consist of different profiles which are represented in different numbers in each of the teams.

The level of mental health comorbidity in patients with serious chronic diseases is high and is often not detected and/or not (sufficiently) treated. That has an important impact on overall wellbeing and can increase the level of distress and suffering.

In CMHC we observed, that in patients, which are treated by mobile or outreach team, one of the frequently represented diagnoses are different types of dementia.

There is no doubt, that collaboration between mental health and palliative care is needed.

Potential for crossroads between mobile palliative and community mental health team care is still to be discovered as both services are still in development on a national level. Cases of collaborative or shared care between Mobile palliative team in General hospital M. Sobota and Community mental health team in Community health center M. Sobota will be presented.

PREDSTAVITEV MREŽE PALIATIVNE OSKRBE V SLOVENIJI

PRESENTATION OF THE PALLIATIVE CARE NETWORK IN SLOVENIA

Mirjam Končan

Palliative care is needed by the patients with incurable disease which presents itself with symptoms that affect the quality of life. These patients should be recognised early with the assessment of all their needs (physical, psychological, social, spiritual). In accordance to all the collected data the plan for palliative care is made. This plan is dynamic and can be modified based on patient`s general state, their wishes and values. The needs of the close ones are also considered in the plan.

The need for palliative treatment approach is best assessed by the specialist who treats the chronic incurable disease or by the general practician of the patient. In countries with modern organization of medical practice an estimated 80% of patients need basic palliative care, while only 20% need specialised palliative care. Basic palliative care is provided on all levels of healthcare system and social securty – at patients` homes, healthcare centres, in hospitals, rehabilitation centres, nonprofit organisations – hospics to name a few.

Specialised palliative care is provided by expert teams which specialise in palliative care. They operate in hospitals (units dedicated to providing palliative care) as well as outside of hospitals as mobile palliative teams. THey also offer expert support an opinion to the providers of basic care.

The needs for palliative care differ in the span of life of incurable patients. The assessment is best carried out by the physician that knows the patient the best and which provided care for a longer period of time. The majority of patients has moderate ailments, therefore they need help with basic palliative care on primary healthcare level (GP, home care nurses) or from specialists from hospital wards without expert organisation of palliative care.

However, some more complex cases require more through care, which can only be sufficient with the help of specialised palliative teams.

In the year 2023 we have those palliative teams in 6 regions of Slovenia. For central part of the country the telephone number available to adult pacients is 030 662 139. For adult pacients with ALS the support number is 01 522 15 24 and for children 01 522 71 94.

In Gorenjska region the number is 031 379 861, in southeast region 031 259 430, in Podravska region 041 442 494, in Pomurska region 041 329 561 and last but not least in Koroška region the telephone number is 031 604 366.

To aquire the access to the specialised palliative care the patient needs refferal from GP/ family medicine or some other specialist.

For more information on organisation and work of palliative care, which is updated regularly, you can visit these websites: www.projektmetulj.si, www.szpho.si.

CHALLENGES OF PALLIATIVE CARE IN ITALY

Raffaella Antonione

In Italy, sanitary costs in the last year of life are mainly linked to acute hospital care and admissions many of which are inappropriate and are attributable to only 1% of population that dies within 1 year. Furthermore, 43% of deaths in Italy are in hospital settings, which poses further burden on the Health System.

In Italy, PC is organized as a network, providing advanced home care, inpatient care (e.g., hospice) and consulting services in acute settings. In Italy, PC need in adults is estimated approximately in 1-1.4% of total population. The majority of these people (60%) have chronic progressive diseases other than cancer. Of the total patients in need of PC, only 35-40% have Specialistic PC (SPC) needs. These numbers clearly indicate that no Specialistic PC service will be able, alone, to cover population care needs. To guarantee the appropriateness of intervention of specialist services and their economic sustainability, it is essential to reflect on organizational models that can cope with current demographic and epidemiological changes, reserving the intervention of SPC services only to the most "complex" clinical and assistance conditions. One of the main challenges that Italy is facing now, is the re-organization of Heath System in order to give adequate and appropriate responses to population-based needs, including PC. The Ministry Deliberation 77/2022, strongly supports PC in order to achieve within 2028, 90% of coverage of population in need of PC. Criticities at the moment are deficiency in health care professionals, no clear definition of standard rates for reimbursement of PC activities and different regional organization.

PC is still delivered too late in the course of the disease (last weeks or days) and mainly to cancer patients. The extension of PC services to non-cancer advanced chronic conditions, is still inadequate in Italy.

Investing of education is one of the possible solutions and a new challenge for Italian PC network.

Increase in undergraduate PC teaching in medical and nursing schools, could be a first step to implement PC knowledge. At the moment, PC teaching in medical school is not compulsory. In 2022, PC Specialization has been instituted. Unfortunately, only 12 cities were able to open to PC specialization. Tightly connected to education, is lack in research in PC in Italy. Implementation of research, best clinical practices, monitorization of data and activities, could not only lead to better care of patients, but also to better development of measurable outcome/process indicators to ensure accurate organization of services.

As probably in other countries, cultural challenge is one of the biggest problems in Italy. Death is still a taboo and physicians are not at ease in talking with patients of EoL issues.

Communication of diagnosis and prognosis is still too often delayed by other specialists and patients are not prepared adequately on PC benefits. Furthermore, if cancer is in some ways linked to the concept of "death", dying of heart disease or of chronic organ insufficiency is not accepted and this delays referral to PCS, leads to inappropriate treatments, increase in costs of care with low quality of life and death.

Finally, increasing knowledge in advanced care planning should be a challenge for PC professionals. In 2017, Italian Ministry approved a law on "Informed Consent and Anticipated Treatment Directives", which clearly indicates that each patient has the right to accept or refuse treatments, including life-support, and that physicians have to respect their will. Unfortunately, "paternalism" and ignorance of the law are still important in Italy.

CHALLENGES OF PALLIATIVE CARE IN AUSTRIA

Matthias Huemer

The Austrian constitutional court declared the restriction of assisted suicide unconstitutional in 2020. Consequently, legal measurements were implemented by the Austrian government to regulate an assisted suicide, which became effective in 2022. Since then, people with incurable diseases may choose a voluntary assisted death. The new legislative challenges palliative care in its fundamental principles and requires a reorientation and expansion of palliative care in Austria. However, currently only about 50% of people in Austria who need specialized palliative care have access to it. In this talk, first experiences with assisted death and subsequent challenges in the care of incurable ill people are presented.

DEVELOPMENT AND CURRENT STATE OF OUTPATIENT PALLIATIVE CARE IN THE COUNTY OF ISTRIA- CROATIA

Julijana Franinović Marković (IDZ), Ante Ivančić

Since the adoption of the National program for the development of palliative care in Croatia (year 2014), specialized palliative care has been systematically developed (1). This includes outpatient care (mobile palliative care teams (MPCT) with coordinators) and inpatient palliative care (palliative care beds in hospitals and 2 hospices). Although much has been achieved, we face numerous challenges in education, organization, provision, and monitoring of the implementation of palliative care.

Palliative Care in Istria County

The Istria County has 205,000 residents over 2,800 km2. About 2,500 people die annually, out of which 1,875 need palliative care. Most die in hospitals (50%), followed by homes (28%), and nursing homes (18%) (2). Two MPCTs are providing palliative care to patients at their homes and in nursing homes (46%).

The development of palliative care in Istria County had a bottom-up approach (from volunteers to professionals). During the volunteer work (2005-2011), the needs of patients and caregivers were identified, care providers were educated, and the public was sensitized. Home visits of a volunteer team and equipment lending service were organized (3). In 2011, palliative care became a regional priority and a program for developing palliative care in the county was defined.

Specialized palliative care is organized at the Istria Health Centre (*cro*. Istarski domovi zdravlja - IDZ). MPCT consists of a doctor and a nurse with a palliative care coordinator. Other specialists, social workers, psychologists, pharmacists, priests, dentists, and volunteers are included on request. Since 2014, two MPCTs have been active for the entire county. The implementation of MPCT in primary health care took about 3 months. Family doctors, district nurses, and social workers were presented with the possibilities of MPCT work and tools to recognize the needs of palliative patients. Six workshops were held for about 170 participants.

MPCT teams work in 2 shifts with phone availability 24/7. The family doctor activates the inclusion of MPCT. On average, about 900 patients are in palliative care annually. About 55% of patients die within 12 months of care. Palliative care is most often needed by cancer patients, followed by neurological patients, heart disease patients, dementia, and geriatric fragile patients. The desired place of care is the patient’s home, which was possible for half of the patients. For nearly 60% of patients in care, the family doctor did not visit the patients at home. This indicates the need to raise the awareness and knowledge of family (and hospital) doctors about providing general palliative care. To support the work of MPCT, there are 16 palliative beds available in Pazin, Labin, and Umag hospitals. A hospice in Pula with 14 beds is set to be operational soon.

In addition, there is a hospital palliative team and a volunteer team (10 members) operating in the patient's home. Basic education (72 hours) in palliative care is provided at the University.

Conclusion: In Istria County, a sustainable system of specialized outpatient palliative care is organized. The new challenges are the development of general palliative care, education, and digitalization.

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THE BEGINNING, PRESENT AND FUTURE OF PALLIATIVE CARE IN BOSNIA AND HERZEGOVINA (BIH) AND CURRENT STATE OF PALLIATIVE CARE IN CROATIA

Samir Husić

Palliative care in BiH. During the seventies and eighties of the last century, there was no idea for the development of palliative care in Bosnia and Herzegovina. Earlier model of health care and the communist system of government had no place in their „thoughts“ for „those who will die“, nor for spiritual support and faith in God. The idea of palliative treatment, given the closedness of the information system and the subordinate position of Bosnia and Herzegovina as a „dark province“ of the former state, was completely unknown in these parts. The aggression against Bosnia and Herzegovina, murders, hunger and bombing of cities (from 1992 to 1995) influenced that during those four years there was a „struggle for survival“, and „acute death“ was a daily part of our lives. Palliative patients could hardly have been given anything better than relief from physical ailments and a helping hand.

The cooperation of UCC Tuzla and the NGO „Sister of the Cross and Passion“ (UK) led to the opening of the Hospice Department in Tuzla (November 11, 2003) as part of the Clinic for Pulmonary Diseases, with 13 beds for patients. In the following years, partnership cooperation will continue and the following will be opened:

1. Day hospice (2005) – for psychosocial support of patients during and after oncological treatment by a multidisciplinary team,
2. Amphitheater with a library (2006) for training staff, students, nurses and doctors, congresses, symposiums,
3. Children‘s hospice (2009) with six patient beds for children suffering from malignant and incurable neuromuscular diseases,
4. Parents‘ house (2011) for accommodation of parents of children staying in the Children‘s Hospice.

With the opening of the Children‘s Department, a separate organizational unit is created within the JZU UKC Tuzla, called the Center for Palliative Care (hospice) (Table).

Table.
Number of treated patients in the Palliative Care Center (hospice) of the UKC Tuzla

Year	Department for adults	Daily hospice	Department for children	Department of pain therapy
2004	247	-	-	-
2009	577	373	5	188
2010	604	351	30	571
2018	441	294	32	1839
2019	438	313	28	1974

Education. Continuous education of the staff of Hospice Tuzla, in cooperation with the NGO „Sisters of the Cross and Passion", is carried out at St Gemma's Hospice Leeds or by visits of educators from England. The most important educational gatherings, in which the employees of Hospice Tuzla participated, are: - The first conference „Palliative and hospice care" (2003) in Tuzla with lecturers from Leeds; - Conferences on palliative care in February 2007 in Zagreb and Rijeka in November 2007, - First Balkan conference on pediatric palliative care in Romania, May 2007. - V Research Congress of the European Association of Palliative Care, Trondheim, Norway (2007). - Three Conferences organized by the Palliative Care Center (hospice) Tuzla, Hospice in Leeds (UK) and Francis House in Manchester (UK).

On May 9, 2011, the Association „Initiative for the introduction of palliative treatment in BiH" was formed in Tuzla, which helped publish the first book in the field of palliative care in BiH „Palliative medicine in the terminal stage of cancer in women".

A key role in the long-term quality development of palliative treatment would be played by education along with plans and programs during secondary medical education and at undergraduate and postgraduate studies.

Conclusion. Institutions for palliative treatment in poor and countries in transition (such as Bosnia and Herzegovina) are best organized as part of larger medical centers as special organizational units, with financing of the services of these institutions from the Health Care Fund. In this way, patients receive free and high-quality palliative care.

Palliativer care in Croatia. After explanation of terms of palliative medicine and palliative care, the development of hospice movement in Croatia is presented as well as the establishment of The Croatian Society for Hospice and Palliative Medicine within the Croatian Medical Association. The framework for the organization of palliative care is introduced according to the Health Care Act, by which The Institution for Palliative Care is defined. The Institution encompasses the clinic for pain and palliative care, day care and palliative interdisciplinary team for home visits consisting of a doctor, nurse, pharmacist, physical therapist, social worker specially trained to approach the dying and spiritual guide (chaplain). Although it is not included in the system of compulsory health insurance, there is still interest of health care policy in palliative care. The addressees are presented as well as the forms of palliative care (home hospice care; day hospice care; clinics/counselling centres for palliative care, and for pain; bereavement services). In the final part the first hospice in Croatia, “Marija Krucifiksa Kozulić” in Rijeka, is presented, established by the Archdiocese of Rijeka.

Rijeka, September. 2023.

DELAVNICE

PARENTERALNI PRISTOPI

PARENTERAL APPROACHES

Suzana Crljenica, Laura Petrica, Nizra Palamar,
Kristina Durić

Na delavnicah parenteralnih dostopov v paliativni oskrbi bodo predstavljene najpogostejše možnosti vnosa zdravil in infuzijskih tekočin pri paliativnih bolnikih.

Aplikacije preko subkutane kanile, PICC katetra ali venske valvule se uporabi, ko bolnik zaradi kakršnihkoli razlogov ne zmore zaužiti zdravil ali ko s per oralno terapijo ni možno obvladati različnih simptomov napredovale bolezni.

Na delavnicah bo predstavljena oskrba dostopov in najpogostejši zapleti ob uporabi.

ŽALOVANJE OTROK PO SMRTI BLIŽNJEGA

CHILDREN´S MOURNING AFTER THE DEATH OF A LOVED ONE

Manja Rančigaj Gajšek, Mateja Šušteršič

Znano je že, da je žalovanje po smrti bližnjega zelo individualna izkušnja, ki jo je težko umestiti v okvire pričakovanih odzivov. Če to velja za odrasle, je pri različno starih otrocih toliko bolj jasno, da so možni odzivi otrok po smrti bližnjega zelo raznoliki in obstaja zelo širok spekter običajnega vedenja, saj se otrokovo zaznavanje, vedenje in čustvovanje zelo spreminjajo skozi razvojna obdobja. Ljudje imamo ob stiku z žalujočimi otroki lahko sami stisko in dvome o tem, kako naj bi do otroka, ki žaluje, pristopili. Poleg tega nas lahko pri tem dodatno obremenijo lastna pričakovanja do sebe glede tega, kaj lahko otroku po smrti bližnjega nudimo in na kakšen način mu lahko pomagamo.

Na delavnici o žalovanju otrok po smrti bližnjega bomo spoznali značilnosti in pričakovane odzive otrok ob smrti bližnjega v različnih razvojnih obdobjih. Prek izkustvenega dela bomo spoznali nekatere možne pristope in načine podpore otroka, ki se sooča s pomembno izgubo, z namenom omogočanja varnega okolja za izražanje doživljanja, podpore prilagojenim načinom odzivov in pomoči ob morebitni povečani stiski.

PREHRANSKA PODPORA PRI BOLNIKIH Z RAKOM
NUTRITION SUPPORT IN CANCER PATIENTS AT THE END OF LIFE

Karla Berlec

Povzetek

S prehransko podporo onkoloških bolnikov preprečujemo podhranjenost bolnikov, ki močno pospeši procese kaheksije. Cilj prehranske podpore bolnika je, čim dlje ohranjati funkcionalno maso ter s tem bolnikovo zmogljivost in kvaliteto življenja, vendar pa se prioritete prehranske podpore spreminjajo glede na stanje bolezni.

Pri bolnikih v zgodnji fazi paliativne oskrbe, veljajo enaka priporočila kot pri ostalih kroničnih bolnikih. Prehranska podpora je individualno naravnana in osnovana na ugotovitvah procesa prehranske obravnave. Proces prehranske obravnave omogoča postavitev prehranske in/ali presnovne diagnoze. S prehransko podporo vzdržujemo oziroma izboljšamo prehranski status ter s tem tudi zvišamo možnost odziva na specifično onkološko zdravljenje.

V obdobju pozne paliativne oskrbe, ko je izčrpano sistemsko zdravljenje, za ohranjanje kakovosti življenja še naprej uporabljamo ostale ukrepe. V tem obdobju vnos hrane prilagodimo bolnikovemu počutju in presnovnim spremembam zaradi napredovale kaheksije. Prednost ima hrana, ki jo bolnik lahko prenaša in mu predstavlja minimalno breme.

Pri oskrbi umirajočega hranila niso koristna. Večina bolnikov ne potrebuje hrane in tekočine. Nudimo jo tistim, ki si je želijo. Pri vseh odločitvah, še posebno pri parenteralni prehranski podpori ter hidraciji, je, v izogib stiskam, nesoglasjem in dodatnim kliničnim zapletom, potrebna dobra, strokovno podprta in odkrita komunikacija med bolnikom, svojci in lečečimi zdravniki.

Abstract

With the nutritional support of oncology patients, we prevent malnutrition in patients, which greatly accelerates processes of cachexia. The goal of nutritional support for patients is to maintain functional weight as long as possible and with it the patient‘s capacity and quality of life, but the priorities of nutritional support change depending on the state of the disease.

For patients in the early phase of palliative care, the same recommendations apply as for other chronic patients. Nutritional support is individually oriented and based on the findings of the nutritional assesment. Nutritional assesment enables the establishment of a nutritional and/or metabolic diagnosis. With nutritional support we can maintain or improve nutritional status, thereby increasing the possibility of responding to specific oncological treatment.

In the period of late palliative care, when systemic treatment has been exhausted, we continue to use other measures to maintain the quality of life. During this period, we adjust food intake to the patient‘s well-being and metabolic changes due to advanced cachexia. Food that is easy for the patient to tolerate and represents a minimal burden is preferred.

When caring for a dying person nutrients are not benefitial. Most patients do not need food and liquids. We offer it to those who want it. In all decisions, especially parenteral nutritional support and hydration, good, professionally supported and open communication between the patient, relatives and treating doctors is necessary to avoid pressure, disagreement and additional clinical complications.

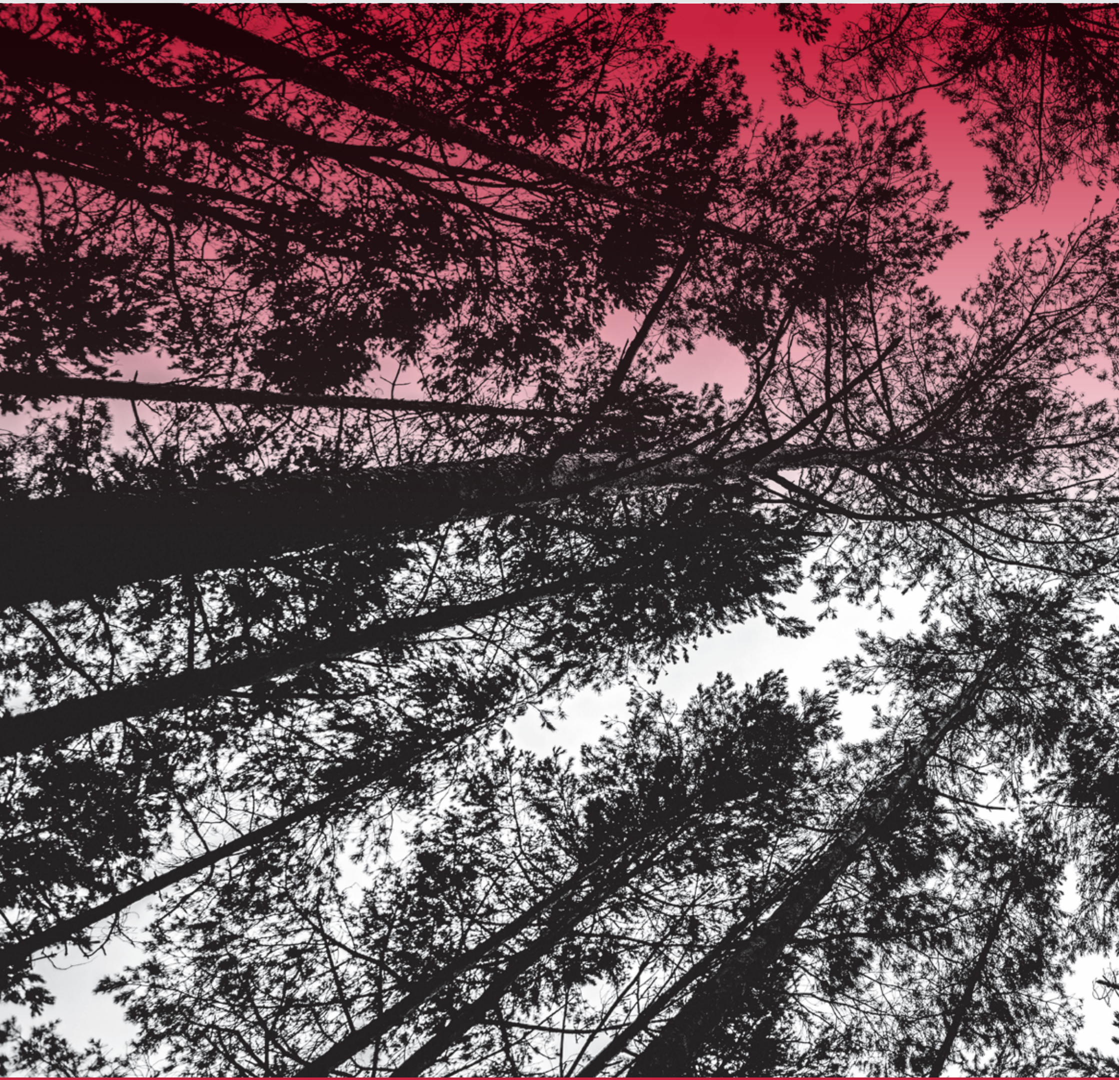
DELO V MOBILNI PALIATIVNI ENOTI *WORKING IN A MOBILE PALLIATIVE CARE UNIT*

Ines Sever

Mobilni paliativni tim je del specializirane paliativne obravnave, ki jo potrebuje 10-20 % bolnikov v paliativni oskrbi. Mobilna paliativna enota je specializirana enota z dodatnimi ali specialnimi znanji iz paliativne oskrbe, omogoča prehod bolnika iz bolnišnice v domače okolje ali koordinira obratno. Storitve naj bi izvajala 24 ur dnevno 7 dni v tednu preko obiskov na domu in telefonskih posvetov. Optimalno časovno obdobje za vključitev bolnika v mobilni palitivni tim so zadnji tedni bolnikovega življenja. Razlogi za vključitev mobilne paliativne enote so: kompleksne bolnikove težave, ki bi sicer potrebovale obravnavo v bolnišnici; specifične intervencije na domu (npr. punkcija ascitesa); aktivno umirajoči bolnik, kjer je potreben reden nadzor nad simptomi in podpora bližnjim. Bolnika v obravnavo vključi družinski ali katerikoli drug zdravnik preko e-napotnice z VZS-jem 2022P (Paliativna obravnava – prvi pregled). Na spletni strani paliativnaoskrba.si (Seznam izvajalcev) so zbrane vse informacije o delujočih mobilnih paliativnih timih v Sloveniji po regijah in njihovi kontaktni podatki. Trenutno delujoči mobilni paliativni timi so: v osrednje slovenski regiji izvaja Onkološki inštitut Ljubljana, v podravski regiji izvaja Univerzitetni klinični center Maribor, v gorenjski regiji izvaja Splošna bolnišnica Jesenice, v pomurski regiji izvaja Splošna bolnišnica Murska Sobota ter za Dolenjsko, Posavje in Belo krajino izvaja Splošna bolnišnica Novo mesto. Omenjeni mobilni paliativni timi oskrbujejo le odrasle bolnike. Paliativno oskrbo za otroke izvaja tim Pediatrične klinike Ljubljana.

The mobile palliative team is part of the specialized palliative care that 10-20% of patients in palliative care need. The mobile palliative unit is a specialized unit with additional or special knowledge in palliative care, it enables the transition of the patient from the hospital to the home environment or coordinates vice versa. Services should be provided 24 hours a day, 7 days a week through home visits and telephone consultations. The optimal period of time to include the patient in the mobile palliative team is the last weeks of the patient's life. The reasons for including a mobile palliative unit are: complex patient problems that would otherwise require treatment in a hospital; specific interventions at home (e.g. ascites puncture); an actively dying patient who requires regular symptom control and support for close relatives and caregivers. The patient is included in the treatment by the family doctor or any other doctor with an e-referral with VZS 2022P (Palliative treatment - first examination). The website palliativnaoskrba.si (List of providers) contains all the information about mobile palliative care teams operating in Slovenia by

region and their contact information. Currently operating mobile palliative teams are: in the central Slovenian region implemented by the Institute of Oncology Ljubljana, in the Podravska region by the Maribor University Clinical Center, in the Gorenjska region by the Jesenice General Hospital, in the Pomurje region by the Murska Sobota General Hospital, and for Dolenjska, Posavje and Bela Krajina by Novo mesto General Hospital. The mentioned mobile palliative teams only serve adult patients. Palliative care for children is provided by the team of the Pediatric Clinic Ljubljana.



PRISPEVKI UDELEŽENCEV

OCENA POTREB PO PALIATIVNI OSKRBI PRI ODRASLIH BOLNIKIH Z RAKOM

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Ključne besede: *sistematični pregled, kohorta, Delfska študija*

Uvod: Potreba po paliativni oskrbi (PO) je bolnikova zmožnost, da pridobi korist od oskrbe. Namen je izvesti sistematični pregled literature in predstaviti raziskavo, s katero bomo ocenili potrebo po osnovni in specializirani PO pri odraslih bolnikih z rakom v Sloveniji.

Metode: Iskalni izrazi so bili ”palliative care”, ”cancer” in ”needs assessment”, vključitveni kriteriji pa primarne študije, bolniki z rakom, starost > 19 let, obdobje 2000-2021, analiza na rutinskih podatkih in angleščina. Iskanje smo izvedli v PubMed, Web-of-Science, Scopus in Google Scholar. Kakovost smo analizirali z NOS in podali rezultate po PRISMA 2020.

V letih 2022-2025 izvajamo kohortno študijo med odraslimi bolniki z rakom v 2017–2019 Sloveniji. Uporabili bomo uveljavljene ter razvili lastne metode za oceno potreb po PO; za določitev za naš prostor najbolj ustreznih metod in ocen bomo izvedli Delfsko študijo med strokovnjaki.

Rezultati: Od 1.155 člankov smo vključili 18 zmerno kakovostnih, večinoma (17) objavljenih v 2014–2021, večinoma s preučevanimi kohortami umrlih (5.441–56,8 mio) in znotraj Evrope (11). Metode največkrat vključujejo umrljivost, prevalenco bolezni in simptomov. Ocenjeno je, da bi od PO imelo korist 0,25-1,5 % populacije, 41-97 % bolnikov s kroničnimi boleznimi, med njimi 25-64 % bolnikov z rakom. V svoji raziskavi pričakujemo širši interval ocen in dosežen konsenz o najbolj veljavnih.

Diskusija: Ocene potreb po PO se razlikujejo znotraj držav in med državami glede na metodo, bolezen, podatke, raziskave in zdravstveni sistem. V raziskavi bomo razvili metodologijo in ocene potreb po PO za Slovenijo. Epidemiološka ocena potreb pomeni ključno izhodišče za določitev mreže.

Raziskava poteka v sklopu projekta ”Ocena potreb, prepoznava kriterijev in izdelava modela organizacije onkološke paliativne oskrbe na nacionalni ravni 2022–2025” (ARRS št. V3-2239).

ODNOS DIJAKOV SREDNJE ZDRAVSTVENE ŠOLE LJUBLJANA DO SMRTI IN UMIRANJA

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Ključne besede: *dijak, izobraževanje, odnos, religija, umiranje*

Uvod: Zdravstveno osebje se vsakodnevno sooča s smrtjo in umiranjem. Tudi šolajoči se lahko srečajo z umiranjem in smrtjo v času svojega izobraževanja, zato je potrebno proučevanje odnosa do smrti in umiranja v začetku njihovega izobraževanja. V prispevku raziskujemo povezanost med odnosom, spolom in religioznostjo dijakov do smrti in umiranja.

Metode: S pomočjo kvantitativnega pristopa in opisne statistike smo v raziskavo zajeli 102 dijaka 2. letnika Srednje zdravstvene šole Ljubljana. Analizirali smo odnos med starostjo in spolom do smrti in umiranja ter povezavo med religioznostjo in pozitivnim odnosom do smrti. Uporabili smo programsko orodje SPSS. Vrednost $p < 0,05$ je veljala za statistično značilno.

Rezultati: Analiza je pokazala statistično razliko med skupino z izkušnjami (N 26) in skupino brez izkušenj (N 74) glede smrti bližnje osebe, v primeru kako ravnati dobro, v korist pacienta ($p < 0,05$) in kako učinkovito lajšati bolečine pacientu ($p < 0,05$). Rezultati so pokazali, da moški bolj kot ženske pozitivno sprejemajo smrt in umiranje. Zanimivo je, da neverni (N 16) dijaki bolj kot verni (N 71) vidijo smrt kot del življenja ($p < 0,05$).

Diskusija: Naši rezultati se ujemajo z rezultati drugih raziskav. Raziskave drugih avtorjev so potrdile, da imajo izkušnje pozitiven učinek na delo z umirajočimi pacienti, kakor tudi višjo stopnjo izražanja strahu pred smrtjo pri ženskah, kot pri moških. Rezultati so potrdili, da starost in spol vplivata na občutek strahu pred smrtjo. Študije so tudi pokazale na povezanost med zagotavljanjem duhovne oskrbe pacienta in religioznostjo.

DELOVNOTERAPEVTSKA OBRAVNAVA UPORABNIKA V PALIATIVNI OSKRBI

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Ključne besede: *delovna terapija, paliativna oskrba, bivalno okolje*

Uvod: Cilj delovne terapije v paliativni oskrbi je optimizirati kakovost uporabnikovega življenja in dobrega počutja z vključitvijo v okupacije. Izvedba ali vključitev v okupacije ohranja tako samozavest kot identiteto uporabnika, nudi podporo, da živijo dostojno kljub nastali trenutni situaciji. Zaradi izgube uporabnikove neodvisnosti in vlog v povezavi z bolezenskim stanjem jim delovni terapevt pomagati pri iskanju primernih strategij za spopadanje s socialno izolacijo, za ohranjanje njihovih vlog in omogočanje vključevanja v izvajanje okupacij.

Vsebina: V prispevku je predstavljena delovnoterapevtska obravnava uporabnika storitev Slovenskega društva Hospic, ki je nastala v sklopu kliničnega usposabljanja. Obravnava je bila načrtovana in izvedena po Kanadski procesni metodi (CPPF) in z uporabo modela omogočanja izvedbe okupacije (CMCE) in modela vključenosti v izvedbo okupacije (CMOP-E). Terapevtski pristop je bil prilagojen uporabnikovim trenutnim potrebam, upoštevajoč njegove cilje ter želje. K sami obravnavi smo pristopili celostno, kar je vključevalo tudi delo s svojci.

Ugotovitve: Na podlagi izvedenih ocenjevanj kot je analiza aktivnosti po spretnostih, ocena bivalnega okolja, ocena utrudljivosti in ček lista interesov smo tekom delovnoterapevtske obravnave izvedli prilagoditve bivalnega okolja uporabnika, mu strukturirali dan z željenimi okupacijami, ki niso prenaporne ter prilagodili pripomočke za prehranjevanje.

Uporabnost za strokovno delo: Z delovnoterapevtsko obravnavo v paliativni oskrbi smo zagotovili celostno podporo uporabniku in njegovi družini pri doseganju zastavljenih ciljev. Interdisciplinarno medsebojno povezovanje in sodelovanje zdravstvenega osebja, svojcev in delovnega terapevta je omogočilo ohranjanje kakovosti življenja uporabnika in vključenje v vsakodnevne aktivnosti, ki so uporabniku pomembne v njegovem obdobju življenja in s katerimi ohranja svoje vloge ter dostojanstvo.

ZGODNJA VKLJUČITEV V PALIATIVNO OSKRBO LAHKO PREPREČI ETIČNE DILEME V KONČNEM OBDOBJU ŽIVLJENJA V ENOTI INTENZIVNE TERAPIJE OTROK

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Ključne besede: *največja korist, optimalna oskrba*

Izvleček

Eden izmed največjih izzivov v pediatriji je skrb za bolnike v končnem obdobju življenja. Primarna etična obveznost je vedno delovati v otrokovo največjo korist. Na to vpliva več dejavnikov: duševne in zdravstvene potrebe otroka, čustvene vezi in odnosi med otrokom in njegovo družino, zmožnost staršev, da otroku zagotovijo varen dom sprejemljive kakovosti življenja in mnogi drugi. Ugotavljanje otrokovih najboljših koristi pri odločanju o zdravljenju ob koncu življenja pri tistih z življenjsko omejujočim ali življenjsko ogrožujočim stanjem je pogosto zelo težka naloga in kot taka predstavlja poseben etični izziv.

Odtegnitev intenzivnega zdravljenja potem, ko smo tovrstno zdravljenje že uvedli, je običajno izjemno težka odločitev, tako za starše bolnega otroka kot za zdravstveni tim. V primerih neozdravljivo napredujoče bolnih otrok se temu lahko izognemo.

Pravočasna vključitev v paliativno oskrbo pomeni individualno prilagoditev zdravljenja otroka za doseganje ciljev, ki so družini pomembni. Multidisciplinarni tim skupaj z otrokovimi starši postopno oblikuje načrt, ki zajema tudi ukrepe ob poslabšanju stanja, prepoznavanje končnega obdobja življenja in optimalno oskrbo v tem času.

Reševanje etičnih dilem pri zdravljenju bolnikov v končnem obdobju življenja je zahtevno in čustveno izčrpno. Nujno je poglabljanje znanja in veščin paliativne oskrbe, spoštljive komunikacije in spoštovanja različnih mnenj, ki privedejo do izboljšanja oskrbe in za vsakega bolnika individualne presoje o zdravljenju, ki je v njegovo največjo korist.

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SINDROM SUHEGA OČESA PRI BOLNIKIH S PALIATIVNO OSKRBO

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Ključne besede: *paliativna oskrba, sindrom suhega očesa, umetne solze, higiena vek*

Sindrom suhega očesa je razširjena bolezen, za katero je značilno pomanjkanje zadostne količine solz ali prekomerno izhlapevanje solz. To povzroča nelagodje, draženje in morebitne poškodbe očesne površine. Obvladovanje suhega očesa v okoljih paliativne oskrbe predstavlja poseben izziv zaradi otežene komunikacije z nekaterimi bolniki s paliativno oskrbo. Obvladovanje suhega očesa pri paliativni oskrbi vključuje celovit pristop, ki upošteva posebne potrebe in omejitve bolnika. Redna uporaba umetnih solz brez konzervansov ali mazalnih kapljic za oči lahko pomaga ublažiti suhost in zagotovi olajšanje. Poleg tega lahko poučevanje bolnikov o pravilnih tehnikah higiene vek, kot je nežno čiščenje z blagimi čistili, spodbuja boljšo porazdelitev solznega filma in zmanjša simptome. Pomemben vidik obvladovanja suhega očesa v paliativni oskrbi je tudi prilagoditev bolnikovega okolja. Prilagajanje ravni vlažnosti, zmanjševanje pretoka zraka z ventilatorji ali klimatskimi napravami ter izogibanje izpostavljenosti dimu ali alergenom. Sodelovanje med izvajalci paliativne oskrbe in oftalmologi je bistvenega pomena za pripravo individualnega načrta oskrbe. Redna komunikacija in posodobitve glede bolnikovega stanja in odziva na zdravljenje omogočajo prilagoditve zdravljenja. Ključnega pomena je tudi obravnava čustvenih posledic suhega očesa pri bolnikih s paliativno oskrbo. Zagotavljanje čustvene podpore, izobraževanja in pomiritve bolnikom in njihovim družinam lahko pomaga ublažiti stisko, ki jo povzročajo simptomi suhega očesa, in izboljša splošno počutje. Za obvladovanje suhega očesa pri paliativni oskrbi je potreben celovit in prilagojen pristop. Z obravnavanjem edinstvenih potreb bolnikov lahko izvajalci zdravstvenega varstva učinkovito ublažijo simptome suhega očesa, izboljšajo zdravje oči ter izboljšajo splošno udobje in kakovost življenja bolnikov v paliativni oskrbi.

POVEZANI ZMOREMO VEČ!

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Ključne besede: *podpora, povezovanje, programi*

Paliativna oskrba je celostna oskrba, ki naslavlja poleg telesnih simptomov tudi vsa področja življenja posameznika, zato smo se odločili, da na območju Dolenjske in Bele krajine različne organizacije pristopimo k promociji kvalitetne paliativne oskrbe.

S tem namenom smo v splošni bolnišnici Novo mesto skupaj s partnerji, Univerza Novo mesto - Fakulteta za zdravstvene vede, Slovensko društvo HOSPIC območna enota Novo mesto, Rdeči križ Slovenije – območno združenje Novo mesto in Razvojni center Novo mesto, skupaj pristopili k projektu Integrirana mreža paliativne oskrbe in nevladnih organizacij 2022-2023.

Namen projekta je bil ozaveščanje strokovne in laične javnosti o paliativni oskrbi ter predstavitev novoustanovljenega mobilnega paliativnega tima. Izvedli smo posvete za primarno zdravstvo in predstavnike lokalnih skupnosti o pomenu paliativne oskrbe na domu in o vzpostavitvi mobilne paliativne enote znotraj regije. Vsi sodelujoči smo se zavezali, da bomo vsak na svojem področju in znotraj naših zmožnosti prispevali k razvoju paliativne oskrbe na domu. Oblikovan je bil izobraževalni program za neformalne oskrbovance z izdelanimi desetimi posnetki, ki so obravnavali pomembna področja paliativne oskrbe pacienta. Prepoznali smo tudi pomen žalovanja in velike potrebe v okolju za izvajanje celostnih obravnav in podpore za svojce, žalujoče in bolnike, zato smo opravili številna svetovanja in delavnice o žalovanju.

Paliativna oskrba v naši družbi je še vedno nepodprta iz več strani, bolniki in svojci večkrat ostajajo sami s svojimi strahovi, skrbmi in dilemami. Kako smo jim lahko v oporo pri soočanju z izzivom in strahom? Tako, da jih podpremo s potrebnimi informacijami ter vsebinami, ki so dostopne na enem mestu.

VIR:

https://www.sb-nm.si/gradivo-pal

Z ROKO V ROKI

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Ključne besede: *lokalna skupnost, izobraževanje, povezovanje, celostna oskrba, žalovanje*

Povzetek

Namen izvlečka je predstavitev projekta Z roko v roki, ki smo ga izvajali na področju Dolenjske in Bele Krajine in v letu 2022-2023. Nosilec projekta je bilo Slovensko društvo hospic v sodelovanju s Splošno bolnišnico Novo mesto. Namen projekta je bila predstavitve paliativne oskrbe splošni populaciji (16 predavanj), priprava promocijskega materiala in izvedba tabora za žalovanje mladostnikov.

V našem lokalnem okolju Dolenjske in Bele Krajine je pogovor o napredovanju bolezni, smrti in žalovanju še vedno tabu tema. Bolniki so pogosto soočeni z vprašanji, zakaj niso poskusili tega ali onega, žalujoči pa se morajo zagovarjati, če ne sledijo predsodkom, kako in kdaj še lahko žalujejo. Sodelavci SDH in SBNM smo se zato odločili, da naredimo korak naprej in v naših lokalnih skupnostih v 16 krajih izvedemo predavanja o paliativni oskrbi. Po predavanjih so lahko poslušalci tudi postavljali vprašanja in prestavili svoje izkušnje. V okviru projekta je bil izvedena vikend delavnica za žalujoče mlade od 18. – 26. leta (ki so prepogosto spregledana skupina žalujočih), na kateri smo mlade podprli v njihovem specifičnem načinu žalovanja.

Poslušalci predavanj so bili izjemno hvaležni za predavanja in odkrit pogovor. Potrdilo se je, da moramo aktivno vstopiti v lokalno skupnost in se približati ljudem, odpreti prostor za pogovor o bolezni, smrti in žalovanju. Prav tako pa se nam zdi pomembno, da prikažemo, kako pomembno je sodelovanje med različnimi poklicnimi skupinami in strukturami v lokalnem okolju (društvo, bolnišnica), ki lahko le enotni zagotavljajo celostno paliativno oskrbo. Povezani, z roko v roki, podpiramo neozdravljivo bolnega in njegove najbližje v naši lokalni skupnosti.

VIR:

https://www.sb-nm.si/las-dbk-z-roko-v-roki-2022-2023-

PREDSTAVITEV SLOVENSKEGA ZDRUŽENJA ZA PALIATIVNO IN HOSPIC OSKRBO

Slovensko združenje paliativne in hospic oskrbe (SZPHO) je bilo ustanovljeno 24. oktobra 2011 in deluje pod okriljem Slovenskega zdravniškega društva (ZSD). Od leta 2016 smo člani Evropskega združenja za paliativno oskrbo (EAPC).

Trenutno ima združenje preko 450 članov: zdravnikov, medicinskih sester ter drugih zdravstvenih delavcev in sodelavcev. Prednost članstva je redna obveščenost o dogodkih, ki jih organizira SZPHO, nižja kotizacija za kongresih EAPC in možnost aktivnega sodelovanja v različnih projektih združenja. Član postaneš tako, da izpolniš elektronsko prijavnico na **www.szpho.si**. Članarine ni.

Glavno poslanstvo združenja je povezovanje strokovnjakov s področja paliativne oskrbe in širjenje znanja na tem področju. S tem namenom redno izvajamo številne aktivnosti.

Za strokovno javnost

- 60-urna Dodatna znanja iz paliativne oskrbe *„Korak za korakom“*
- 40-urno Dodiplomsko izobraževanje za specializante kliničnih strok
- 15-urno izobraževanje Obravnava simptomov v praksi – *»Iz teorije v prakso.«*
- Slovenski kongres paliativne oskrbe (na dve leti)
- Aktualne teme s področja paliativne oskrbe – *»V znanju je moč«*
- Loko-regionalni posveti – *»Gradimo mostove k ljudem«*
- Tematski posveti – *»Na stičišču poti«*

Za laično javnost

- dogodki ob svetovnem dnevu paliativne oskrbe in hospica,
- programi za prepoznavanje paliativne oskrbe v javnosti.

Projekt METULJ – informativne vsebine s področja paliativne oskrbe za bolnike in njihove svojce (v tiskani in spletni obliki: **www.paliativnaoskrba.si**)

Več o dogodkih in terminih izobraževanj najdete na koledarju dogodkov objavljenem na **www.szpho.si**.

Založništvo

Slovensko združenje paliativne in hospic oskrbe je aktivno tudi na področju založništva izobraževalnih vsebin s področja paliativne oskrbe. Konec leta 2021 smo izdali Priročnik PALIATIVNA OSKRBA, ki je osnovna literatura za izobraževanje specializnatov kliničnih strok, letos pa je izšel tudi priročnik Paliativna oskrba odraslih bolnikov z rakom v Sloveniji, Temeljni pojmi in priporočila. Vse publikacije v elektronski obliki so brezplačno na voljo na naši spletni strani, v tiskani obliki pa so na voljo proti plačilu (vse informacije na **www.szpho.si**)

SPONZORJI

25 LET | *kliničnih raziskav v Sloveniji*

V 25 letih smo sponzorirali ali podprli 57 intervencijskih kliničnih raziskav, ki so gonilo razvoja in napredka v medicini, in s tem je več kot 780 bolnikov dobilo možnost inovativnega zdravljenja.

M-SI-00000814 (V2.0)
Informacija pripravljena v marcu 2023.

Takeda | ONKOLOGIJA

Prizadevamo si zagotoviti nova zdravila bolnikom z rakom po vsem svetu z zavezanostjo znanosti, s prodornimi inovacijami in strastjo za izboljšanje življenja bolnikov.

Takeda Pharmaceuticals d.o.o.
Bleiweisova 30, 1000 Ljubljana, Slovenija
www.takeda.com

VV-MEDMAT-91710, DP: September 2023

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Sloveniji, Verovškova ulica 57, 1000 Ljubljana

Datum priprave informacije: september 2023 | SI-561672

Znanost zmaguje

V družbi Pfizer si nenehno prizadevamo za znanstvene dosežke in revolucionarna zdravila, ki pomenijo bolj zdrav svet za vse.[1] Ponosni smo na sodelovanje s tisoč raziskovalnimi mesti in deset tisoč udeleženci raziskav po vsem svetu, s čimer ustvarjamo zdravila, ki spreminjajo življenje.[2] Cilj vseh naših odločitev je ohranjanje zdravja in kakovosti življenja naših bolnikov. Pri uresničevanju tega se opiramo na vrhunsko svetovno znanost ter na sodelovanje z drugimi udeleženci v zdravstvenem sistemu, da bi izboljšali dostopnost naših zdravil. Navsezadnje je eden naših glavnih ciljev tudi skrb za okolje, ki omogoča razvoj prelomnih dosežkov.[3]

Literatura: **1.** Pfizer: One of the world's premier biopharmaceutical companies. Dostopno na: https://www.pfizer.com/. Dostopano: februar 2023. **2.** Our Science: Pharmaceutical Development. Dostopno na: https://www.pfizer.com/science. Dostopano: februar 2023. **3.** Breakthroughs That Change Patients' Lives. Dostopno na: https://www.pfizer.com.hk/en/our-purpose-en/breakthroughs-that-change-patients-lives. Dostopano: februar 2023.

Pfizer

Odkritja, ki spreminjajo življenja bolnikov

Pfizer Luxembourg SARL, GRAND DUCHY OF LUXEMBOURG, 51, Avenue J.F. Kennedy, L – 1855,
Pfizer, podružnica Ljubljana, Letališka cesta 29a, 1000 Ljubljana

PP-UNP-SVN-0074 Datum priprave: februar 2023

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Sestava: Ena filmsko obložena tableta vsebuje 58,24 mg tapentadolijevega klorida (kar ustreza 50 mg tapentadola). Ena tableta s podaljšanim sproščanjem vsebuje 58,24 mg, 116,8 mg ali 174,72 mg tapentadolijevega klorida (kar ustreza 50 mg, 100 mg ali 150 mg tapentadola). 1 ml peroralne raztopine vsebuje 20 mg tapentadola (v obliki klorida). **Pomožne snovi z znanim učinkom:** PALEXIA 50 mg filmsko obložene tablete in PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem vsebujejo laktozo. PALEXIA 20 mg/ml peroralna raztopina vsebuje propilenglikol, natrijev benzoat in natrij. **Terapevtske indikacije:** Zdravilo PALEXIA 50 mg filmsko obložene tablete je namenjeno odraslim bolnikom za zdravljenje srednje hude do hude akutne bolečine, ki jo je mogoče ustrezno obvladati samo z opioidnimi analgetiki. Zdravilo PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem je namenjeno odraslim bolnikom za zdravljenje hude kronične bolečine, ki jo je mogoče ustrezno obvladati samo z opioidnimi analgetiki. Zdravilo PALEXIA 20 mg/ml peroralna raztopina je namenjeno odraslim bolnikom in otrokom od 2. leta starosti dalje s telesno maso več kot 16 kg za zdravljenje srednje hude do hude akutne bolečine, ki jo je mogoče ustrezno obvladati samo z opioidnimi analgetiki. **Odmerjanje:** Odmerjanje je treba prilagoditi posamezniku glede na resnost zdravljene bolečine, predhodne izkušnje z njenim zdravljenjem in glede na možnost spremljanja bolnika. PALEXIA 50 mg filmsko obložene tablete: Zdravljenje je treba začeti z jemanjem enkratnega odmerka 50 mg tapentadola v filmsko obloženi tableti vsakih 4 do 6 ur. Bolnik sme prvega dne vzeti še dodatni odmerek že eno uro po začetnem odmerku, če bolečina ni bila obvladana. Odmerek je nato treba pod skrbnim nadzorom lečečega zdravnika individualno prilagoditi do ravni, ki bolniku zagotavlja ustrezno analgezijo in omeji neželene učinke na najmanjšo mero. Skupni dnevni odmerki, večji od 700 mg tapentadola prvi dan zdravljenja, in vzdrževalni dnevni odmerki, večji od 600 mg tapentadola, niso raziskani in zato niso priporočljivi. *Trajanje zdravljenja:* Filmsko obložene tablete so namenjene akutnim bolečinskim stanjem. Če je predvideno ali potrebno dolgotrajno zdravljenje in je bilo z zdravilom PALEXIA 50 mg filmsko obložene tablete doseženo uspešno olajšanje bolečine brez nevzdržnih neželenih učinkov, je treba razmisliti o prehodu na zdravilo PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem. Nadaljnjo uporabo tapentadola je treba redno ocenjevati. Zdravilo PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem je treba jemati dvakrat na dan, približno vsakih 12 ur. *Začetek zdravljenja*: Pri bolnikih, ki trenutno ne jemljejo opioidnih analgetikov, je zdravljenje treba začeti z jemanjem posameznih odmerkov po 50 mg tapentadola v tableti s podaljšanim sproščanjem dvakrat na dan. *Začetek zdravljenja pri bolnikih, ki trenutno jemljejo opioidne analgetike:* V primeru prehoda iz opioidov na zdravilo PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem in pri izbiri začetnega odmerka, je treba upoštevati naravo prej uporabljanega zdravila, način dajanja in povprečni dnevni odmerek. To lahko zahteva pri bolnikih, ki trenutno prejemajo opioide, uporabo večjih začetnih odmerkov zdravila PALEXIA SR 50 mg, 100 mg, 150 mg tablete kot pri bolnikih, ki pred začetkom zdravljenja z zdravilom PALEXIA SR 50 mg, 100 mg, 150 mg tablete niso prejemali opioidov. *Prilagoditev in vzdrževanje:* Po uvedbi zdravljenja je treba odmerek pod natančnim nadzorom lečečega zdravnika individualno prilagoditi do ravni, ki zagotavlja ustrezno analgezijo in omeji neželene učinke na najmanjšo mero. Izkušnje iz kliničnih preskušanj kažejo, da je shema prilagajanja v povečanjih po 50 mg tapentadola v tableti s podaljšanim sproščanjem dvakrat na dan vsake 3 dni pri večini bolnikov ustrezna za doseganje ustreznega obvladanja bolečine. Skupni dnevni odmerki zdravila PALEXIA SR 50 mg, 100 mg, 150 mg tablete, večji od 500 mg tapentadola, še niso raziskani in zato niso priporočljivi. PALEXIA 20 mg/ml peroralna raztopina: Uporaba pri otrocih je omejena na bolnišnice, kjer je na voljo primerna oprema za vzpostavitev podpore pri dihanju. Zdravljenje je treba začeti z jemanjem enkratnega odmerka 50 mg tapentadola v obliki peroralne raztopine vsakih 4 do 6 ur. Nekateri bolniki potrebujejo večje začetne odmerke, kar je odvisno od jakosti bolečine in podatka v anamnezi o potrebi po analgetiku. Bolnik sme prvega dne vzeti še dodatni odmerek že eno uro po začetnem odmerku, če bolečina ni bila obvladana. Odmerek je nato treba pod skrbnim nadzorom lečečega zdravnika individualno prilagoditi do ravni, ki bolniku zagotavlja ustrezno analgezijo in omeji neželene učinke na najmanjšo mero. Skupni dnevni odmerki, večji od 700 mg tapentadola prvi dan zdravljenja, in vzdrževalni dnevni odmerki, večji od 600 mg tapentadola, niso raziskani in zato niso priporočljivi. *Trajanje zdravljenja*: Peroralna raztopina je namenjena akutnim bolečinskim stanjem. Če je predvideno ali potrebno dolgotrajno zdravljenje pri odraslih in je bilo z zdravilom PALEXIA doseženo uspešno olajšanje bolečine brez nevzdržnih neželenih učinkov, je treba razmisliti o prehodu na obliko s podaljšanim sproščanjem. Nadaljnjo uporabo tapentadola je treba redno ocenjevati, tako kot velja za vsa simptomatska zdravljenja. *Prenehanje zdravljenja:* Zdravilo PALEXIA 50 mg filmsko obložene tablete, PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem in PALEXIA 20 mg/ml peroralna raztopina: Po nenadnem prenehanju zdravljenja s tapentadolom se lahko pojavijo odtegnitveni simptomi. Če bolnik zdravljenja s tapentadolom ne potrebuje več, je odmerek priporočljivo zmanjševati postopoma, da bi preprečili odtegnitvene simptome. Za odmerjanje pri posebnih populacijah (*okvara ledvic, okvara jeter, starejši bolniki (stari 65 let in več), pediatrični bolniki*) glejte celoten povzetek glavnih značilnosti zdravila. **Način uporabe:** Zdravili PALEXIA 50 mg filmsko obložene tablete in PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem je treba vzeti z dovolj tekočine; jemljeta se lahko s hrano ali brez nje. PALEXIA SR 50 mg, 100 mg, 150 mg tablete je treba zaužiti cele in se jih ne sme deliti ali zgristi. Zdravilo PALEXIA 20 mg/ml peroralna raztopina se uporablja peroralno, lahko se vzame s hrano ali brez nje. Lahko se vzame nerazredčeno ali razredčeno v vodi ali brezalkoholni pijači. V pakiranju je priložena odmerna pipeta z nameščenim nastavkom. To pipeto je priporočljivo uporabiti, da se iz plastenke vzame točno tolikšen volumen zdravila, kot ustreza predpisanemu enkratnemu odmerku tapentadola. Zdravilo PALEXIA 20 mg/ml peroralna raztopina je možno dajati preko nazogastričnih sond iz poliuretana, silikona ali polivinilklorida. **Kontraindikacije:** Preobčutljivost na tapentadol ali katerokoli pomožno snov; izražena depresija dihanja, akutna ali huda bronhialna astma ali hiperkapnija; paralitični ileus ali sum nanj; akutna zastrupitev z alkoholom, hipnotiki, centralno delujočimi analgetiki ali psihotropnimi učinkovinami. **Posebna opozorila in previdnostni ukrepi:** *Toleranca in motnje uporabe opioidov (zloraba in odvisnost):* Pri ponavljajočem se dajanju opioidov se lahko razvijejo toleranca, fizična in psihična odvisnost ter motnje uporabe opioidov (OUD – opioid use disorder). Zloraba ali namerna nepravilna uporaba opioidov lahko povzroči preveliko odmerjanje in/ali smrt. Tveganje za razvoj OUD je večje pri bolnikih z osebno ali družinsko (starši ali sorojenci) anamnezo motenj uporabe substanc (vključno z motnjo uporabe alkohola), pri trenutnih uporabnikih tobaka ali pri bolnikih z osebno anamnezo drugih motenj duševnega zdravja (npr. klinična depresija, anksioznost in osebnostne motnje). Bolnike bo treba spremljati glede znakov vedenja, ki kažejo na zlorabo zdravila (npr. prezgodnje zahteve za ponovno izdajo zdravila). To vključuje pregled sočasno uporabljanih opioidov in psihotropnih zdravil (kot so benzodiazepini). Pri bolnikih z znaki in simptomi OUD je treba razmisliti o posvetu s specialistom za zasvojenost. *Sočasna uporaba zdravila PALEXIA* in sedativnih zdravil, kot so benzodiazepini ali sorodne učinkovine, lahko povzroči sedacijo, respiratorno depresijo, komo in smrt. Zaradi teh tveganj je sočasno predpisovanje zdravila PALEXIA s sedativnimi zdravili dovoljeno le za bolnike, pri katerih alternativne možnosti zdravljenja niso možne. Če se odločite, da boste zdravilo PALEXIA predpisali sočasno s sedativnimi zdravili, je treba razmisliti o zmanjšanju odmerka enega ali obeh zdravil, trajanje sočasnega zdravljenja pa mora biti čim krajše. Pri visokih odmerkih ali pri bolnikih, občutljivih na agoniste mi-opioidnih receptorjev, lahko zdravilo PALEXIA povzroči z odmerkom povezano *depresijo dihanja*. Zato je treba zdravilo PALEXIA pri bolnikih z okvarjeno dihalno funkcijo uporabljati previdno. Razmisliti je treba o drugih analgetikih, ki niso agonisti mi-opioidnih receptorjev, zdravilo PALEXIA pa je treba pri takšnih bolnikih uporabljati le pod natančnim zdravniškim nadzorom in v najmanjšem učinkovitem odmerku. Če se pojavi depresija dihanja, jo je treba zdraviti kot vsako depresijo dihanja, ki jo povzročijo agonisti mi-opioidnih receptorjev. *Poškodba glave in zvišan intrakranialni tlak:* Zdravila PALEXIA se ne sme uporabljati pri bolnikih, ki so lahko posebej dovzetni za intrakranialne učinke povišanega ogljikovega dioksida. Analgetiki, ki delujejo kot agonisti mi-opioidnih receptorjev, lahko pri bolnikih s poškodbo glave prikrijejo klinični potek. Pri bolnikih s poškodbo glave ali tumorji možganov je treba zdravilo PALEXIA uporabljati previdno. *Konvulzije:* Zdravila PALEXIA niso sistematično ovrednotili pri bolnikih s konvulzivno motnjo; takšni bolniki niso bili vključeni v klinična preskušanja. Toda tako kot druge analgetike z mi-opioidnim agonističnim delovanjem, tudi zdravila PALEXIA ni priporočljivo uporabljati pri bolnikih, ki imajo v anamnezi konvulzivne motnje ali kakšno drugo stanje, ki bi povečevalo tveganje za pojav konvulzij. Poleg tega lahko tapentadol poveča tveganje za nastanek konvulzij pri bolnikih, ki jemljejo druga zdravila, ki znižajo prag za nastanek konvulzij. *Okvara ledvic:* Zdravilo PALEXIA ni raziskano v kontroliranih preskušanjih učinkovitosti pri bolnikih s hudo okvaro ledvic, zato ga v tej populaciji ni priporočljivo uporabljati. *Okvara jeter:* Pri preiskovancih z blago okvaro jeter je bila sistemska izpostavljenost 2-krat večja, pri tistih z zmerno okvaro jeter pa 4,5-krat večja kot pri preiskovancih z normalnim delovanjem jeter. Zdravilo PALEXIA je treba pri bolnikih z zmerno okvaro jeter uporabljati previdno, zlasti pri uvedbi zdravljenja. Zdravilo PALEXIA ni raziskano pri bolnikih s hudo okvaro jeter, zato ga v tej populaciji ni priporočljivo uporabljati. *Uporaba v primeru bolezni trebušne slinavke/žolčnika in žolčevodov:* Učinkovine, ki delujejo kot agonisti mi-opioidnih receptorjev, lahko povzročijo spazem Oddijevega sfinktra. Zdravilo PALEXIA je treba pri bolnikih z boleznijo žolčnika ali žolčevodov in tudi z akutnim pankreatitisom uporabljati previdno. Opioidi lahko povzročajo *s spanjem povezane motnje dihanja*, vključno s centralno apnejo v spanju (CSA - central sleep apnea) in s spanjem povezano hipoksemijo. Uporaba opioidov lahko poveča tveganje za CSA v odvisnosti od odmerka. Pri bolnikih, pri katerih so prisotni znaki CSA, razmislite o zmanjšanju skupnega odmerka opioidov. V primeru kombinirane uporabe zdravila PALEXIA z *mešanimi agonisti/antagonisti mi-opioidnih receptorjev ali delnimi agonisti mi-opioidnih receptorjev* je potrebna previdnost. Pri bolnikih, ki se zdravijo od odvisnosti od opioidov z buprenorfinom, je treba razmisliti o alternativnih možnostih zdravljenja, v primeru če je za zdravljenje akutnega bolečinskega stanja potrebna uporaba čistega mi-opioidnega agonista. V primeru kombinirane uporabe z buprenorfinom, so poročali o potrebnih višjih odmerkih čistega agonista mi-opioidnih receptorjev, zato je v takih primerih potrebno skrbno spremljanje neželenih učinkov. PALEXIA 50 mg filmsko obložene tablete in PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem *vsebujejo laktozo*. Bolniki z redko dedno intoleranco za galaktozo, laponsko obliko zmanjšane aktivnosti laktaze ali malabsorbcijo glukoze/galaktoze ne smejo jemati teh zdravil. Zdravilo PALEXIA 20 mg/ml peroralna raztopina v 5 ml raztopine (maksimalni enkratni odmerek) vsebuje 5,9 mg natrijevega benzoata, 10 mg propilenglikola in manj kot 1 mmol (23 mg) natrija, kar v bistvu pomeni 'brez natrija'. **Interakcije:** Sočasna uporaba zdravila PALEXIA z zdravili z delovanjem na osrednje živčevje/zaviralci centralnega živčnega sistema (CŽS), vključno z alkoholom in mamili, ki so zaviralci CŽS povečuje tveganje za sedacijo, respiratorno depresijo, komo in smrt zaradi dodatnega zaviralnega učinka na osrednji živčni sistem. Če je predvideno kombinirano zdravljenje z zdravilom PALEXIA in respiratornim zaviralcem ali zaviralcem CŽS, je treba razmisliti o zmanjšanju odmerka enega ali obeh zdravil in omejiti čas trajanja sočasne uporabe. Sočasna uporaba opioidov in gabapentinoidov (gabapentina in pregabalina) zvečuje tveganje za preveliko odmerjanje opioidov, respiratorno depresijo in smrt. V primeru kombinirane uporabe zdravila PALEXIA z mešanimi agonisti/antagonisti mi-opioidnih receptorjev ali delnimi agonisti mi-opioidnih receptorjev je potrebna previdnost. Zdravilo PALEXIA lahko povzroči nastanek konvulzij in poveča potencial selektivnih zaviralcev ponovnega privzema serotonina, zaviralcev ponovnega privzema noradrenalina, tricikličnih antidepresivov, antipsihotikov in drugih zdravil, ki znižajo prag za nastanek konvulzij. Poročali so o serotoninskem sindromu pri časovno povezani terapevtski uporabi tapentadola v kombinaciji s serotoninergičnimi zdravili, kot so SSRI, SNRI in triciklični antidepresivi. Glavna pot izločanja tapentadola je konjugacija z glukuronsko kislino, ki poteka z uridin-difosfattransferazo. Zato lahko sočasna uporaba z močnimi zaviralci teh izoencimov poveča sistemsko izpostavljenost tapentadolu. Pri bolnikih, zdravljenih s tapentadolom, je potrebna previdnost v primeru uvedbe ali prenehanja uporabe zdravil, ki so močni induktorji encimov; to namreč lahko zmanjša učinkovitost tapentadola (po uvedbi) ali poveča tveganje neželenih učinkov (po prenehanju). Zdravljenju z zdravilom PALEXIA se je treba izogniti pri bolnikih, ki prejemajo ali so v zadnjih 14 dneh prejemali zaviralce monoaminooksidaze. Obstaja namreč možnost aditivnih učinkov na sinaptično koncentracijo noradrenalina, kar lahko povzroči neželene srčnožilne učinke. **Neželeni učinki:** PALEXIA 50 mg filmsko obložene tablete: Zelo pogosti: omotica, zaspanost, glavobol, navzea in bruhanje. Pogosti: zmanjšan apetit, anksioznost, stanje zmedenosti, halucinacije, motnja spanja, nenormalne sanje, tremor, zardevanje, zaprtost, driska, dispepsija, suha usta, srbenje, hiperhidroza, izpuščaj, spazmi mišic, astenija, utrujenost in občutek spremenjene telesne temperature. PALEXIA SR 50 mg, 100 mg, 150 mg tablete s podaljšanim sproščanjem: Zelo pogosti: omotica, zaspanost, glavobol, navzea in zaprtje. Pogosti: zmanjšan apetit, anksioznost, depresivno razpoloženje, motnja spanja, živčnost, nemir, motnje pozornosti, tremor, nehotene kontrakcije mišic, zardevanje, dispneja, bruhanje, driska, dispepsija, srbenje, hiperhidroza, izpuščaj, astenija, utrujenost, občutek spremenjene telesne temperature, suhost sluznic ter edemi. PALEXIA 20 mg/ml peroralna raztopina: Zelo pogosti: omotica, somnolenca, glavobol, navzea, bruhanje. Pogosti: zmanjšan apetit, anksioznost, stanje zmedenosti, halucinacije, motnja spanja, nenormalne sanje, tremor, zardevanje, zaprtost, driska, dispepsija, suha usta, srbenje, hiperhidroza, izpuščaj, spazmi mišic, astenija, utrujenost in občutek spremenjene telesne temperature. Neželeni učinki, ki se pri zdravilih PALEXIA pojavljajo občasno, redko ali z neznano pogostnostjo, so našteti v celotnem povzetku glavnih značilnosti zdravila. **Način in režim predpisovanja ter izdaje zdravila:** Rp/Spec - Predpisovanje in izdaja zdravila je le na recept zdravnika specialista ustreznega področja medicine ali od njega pooblaščenega zdravnika**. Imetnik dovoljenja za promet z zdravilom:** Grünenthal GmbH, Zieglerstrasse 6, 52078 Aachen, Nemčija. **Lokalni predstavnik imetnika dovoljenja za promet z zdravilom:** Stada d.o.o., Dunajska cesta 156, 1000 Ljubljana. **Datum zadnje revizije besedila:** 03.02.2023.
Pred predpisovanjem preberite celoten povzetek glavnih značilnosti zdravila!

GRÜNENTHAL

STADA

Stada d.o.o.
Dunajska cesta 156
1000 Ljubljana

Samo za strokovno javnost.
PAL-092023-22, september 2023

ODGOVORNA
UPORABA

KEYTRUDA je odobrena za zdravljenje 22 indikacij rakavih obolenj[1]

Referenca: 1. Keytruda EU SmPC

SKRAJŠAN POVZETEK GLAVNIH ZNAČILNOSTI ZDRAVILA Pred predpisovanjem, prosimo, preberite celoten Povzetek glavnih značilnosti zdravila! Ime zdravila: KEYTRUDA 25 mg/ml koncentrat za raztopino za infundiranje vsebuje pembrolizumab. • **Terapevtske indikacije:** Zdravilo KEYTRUDA je kot samostojno zdravljenje indicirano za zdravljenje: odraslih in mladostnikov, starih 12 let ali več, z napredovalim (neoperabilnim ali metastatskim) melanomom; za adjuvantno zdravljenje odraslih in mladostnikov, starih 12 let ali več, z melanomom v stadiju IIB, IIC ali III, in sicer po popolni kirurški odstranitvi; metastatskega nedrobnoceličnega pljučnega raka (NSCLC) v prvi liniji zdravljenja pri odraslih, ki imajo tumorje z ≥ 50 % izraženostjo PD-L1 (TPS) in brez pozitivnih tumorskih mutacij EGFR ali ALK; lokalno napredovalega ali metastatskega NSCLC pri odraslih, ki imajo tumorje z ≥ 1 % izraženostjo PD-L1 (TPS) in so bili predhodno zdravljeni z vsaj eno shemo kemoterapije, bolniki s pozitivnimi tumorskimi mutacijami EGFR ali ALK so pred prejemom zdravila KEYTRUDA morali prejeti tudi tarčno zdravljenje; odraslih in pediatričnih bolnikov, starih 3 leta ali več, s ponovljenim ali neodzivnim klasičnim Hodgkinovim limfomom (cHL), pri katerih avtologna presaditev matičnih celic (ASCT) ni bila uspešna, ali po najmanj dveh predhodnih zdravljenjih kadar ASCT ne pride v poštev kot možnost zdravljenja; lokalno napredovalega ali metastatskega urotelijskega raka pri odraslih, predhodno zdravljenih s kemoterapijo, ki je vključevala platino; lokalno napredovalega ali metastatskega urotelijskega raka pri odraslih, ki niso primerni za zdravljenje s kemoterapijo, ki vsebuje cisplatin in imajo tumorje z izraženostjo PD-L1 ≥ 10, ocenjeno s kombinirano pozitivno oceno (CPS); ponovljenega ali metastatskega ploščatoceličnega raka glave in vratu (HNSCC) pri odraslih, ki imajo tumorje z ≥ 50 % izraženostjo PD-L1 (TPS), in pri katerih je bolezen napredovala med zdravljenjem ali po zdravljenju s kemoterapijo, ki je vključevala platino; za adjuvantno zdravljenje odraslih z rakom ledvičnih celic s povišanim tveganjem za ponovitev bolezni po nefrektomiji, ali po nefrektomiji in kirurški odstranitvi metastatskih lezij, za zdravljenje odraslih z MSI-H (microsatellite instability- high) ali dMMR (mismatch repair deficient) kolorektalnim rakom v naslednjih terapevtskih okoliščinah: prva linija zdravljenja metastatskega kolorektalnega raka; zdravljenje neoperabilnega ali metastatskega kolorektalnega raka po predhodnem kombiniranem zdravljenju, ki je temeljilo na fluoropirimidinu; in za zdravljenje MSI-H ali dMMR tumorjev pri odraslih z: napredovalim ali ponovljenim rakom endometrija, pri katerih je bolezen napredovala med ali po predhodnem zdravljenju, ki je vključevalo platino, v katerih koli terapevtskih okoliščinah, in ki niso kandidati za kurativno operacijo ali obsevanje; neoperabilnim ali metastatskim rakom želodca, tankega črevesa ali žolčnika in žolčnih vodov, pri katerih je bolezen napredovala med ali po vsaj enem predhodnem zdravljenju. Zdravilo KEYTRUDA je kot samostojno zdravljenje ali v kombinaciji s kemoterapijo s platino in 5-fluorouracilom (5-FU) indicirano za prvo linijo zdravljenja metastatskega ali neoperabilnega ponovljenega ploščatoceličnega raka glave in vratu pri odraslih, ki imajo tumorje z izraženostjo PD-L1 s CPS ≥ 1. Zdravilo KEYTRUDA je v kombinaciji s pemetreksedom in kemoterapijo na osnovi platine indicirano za prvo linijo zdravljenja metastatskega neploščatoceličnega NSCLC pri odraslih, pri katerih tumorji nimajo pozitivnih mutacij EGFR ali ALK; v kombinaciji s karboplatinom in bodisi paklitakselom bodisi nab-paklitakselom je indicirano za prvo linijo zdravljenja metastatskega ploščatoceličnega NSCLC pri odraslih; v kombinaciji z aksitinibom ali v kombinaciji z lenvatinibom je indicirano za prvo linijo zdravljenja napredovalega raka ledvičnih celic (RCC) pri odraslih; v kombinaciji s kemoterapijo s platino in fluoropirimidinom je indicirano za prvo linijo zdravljenja lokalno napredovalega neoperabilnega ali metastatskega raka požiralnika ali HER2-negativnega adenokarcinoma gastroezofagealnega prehoda pri odraslih, ki imajo tumorje z izraženostjo PD-L1 s CPS ≥ 10; v kombinaciji s kemoterapijo za neoadjuvantno zdravljenje, in v nadaljevanju kot samostojno adjuvantno zdravljenje po kirurškem posegu, je indicirano za zdravljenje odraslih z lokalno napredovalim trojno negativnim rakom dojk ali trojno negativnim rakom dojk v zgodnjem stadiju z visokim tveganjem za ponovitev bolezni; v kombinaciji s kemoterapijo je indicirano za zdravljenje lokalno ponovljenega neoperabilnega ali metastatskega trojno negativnega raka dojk pri odraslih, ki imajo tumorje z izraženostjo PD-L1 s CPS ≥ 10 in predhodno niso prejeli kemoterapije za metastatsko bolezen; v kombinaciji z lenvatinibom je indicirano za zdravljenje napredovalega ali ponovljenega raka endometrija (EC) pri odraslih z napredovalo boleznijo med ali po predhodnem zdravljenju s kemoterapijo, ki je vključevala platino, v katerih koli terapevtskih okoliščinah, in ki niso kandidati za kurativno operacijo ali obsevanje; v kombinaciji s kemoterapijo, z bevacizumabom ali brez njega, je indicirano za zdravljenje persistentnega, ponovljenega ali metastatskega raka materničnega vratu pri odraslih bolnicah, ki imajo tumorje z izraženostjo PD-L1 s CPS ≥ 1; v kombinaciji s trastuzumabom, fluoropirimidinom in kemoterapijo, ki vključuje platino, je indicirano za prvo linijo zdravljenja lokalno napredovalega neoperabilnega ali metastatskega HER2-pozitivnega adenokarcinoma želodca ali gastroezofagealnega prehoda pri odraslih, ki imajo tumorje z izraženostjo PD-L1 s CPS ≥ 1. • **Odmerjanje in način uporabe:** Testiranje PD-L1: Če je navedeno v indikaciji, je treba izbiro bolnika za zdravljenje z zdravilom KEYTRUDA na podlagi izraženosti PD-L1 tumorja potrditi z validirano preiskavo. Testiranje MSI/MMR: Če je navedeno v indikaciji, je treba izbiro bolnika za zdravljenje z zdravilom KEYTRUDA na podlagi MSI-H/dMMR statusa tumorja potrditi z validirano preiskavo. Odmerjanje: Priporočeni odmerek zdravila KEYTRUDA pri odraslih je bodisi 200 mg na 3 tedne ali 400 mg na 6 tednov, apliciran z intravensko infuzijo v 30 minutah. Priporočeni odmerek zdravila KEYTRUDA za samostojno zdravljenje pri pediatričnih bolnikih s cHL, starih 3 leta ali več, ali bolnikih z melanomom, starih 12 let ali več, je 2 mg/kg telesne mase (do največ 200 mg) na 3 tedne, apliciran z intravensko infuzijo v 30 minutah. Za uporabo v kombinaciji glejte povzetke glavnih značilnosti zdravil sočasno uporabljenih zdravil. Če se uporablja kot del kombiniranega zdravljenja skupaj z intravensko kemoterapijo, je treba zdravilo KEYTRUDA aplicirati prvo. Bolnike je treba zdraviti do napredovanja bolezni ali nesprejemljivih toksičnih učinkov (in do maksimalnega trajanja zdravljenja, če je le to določeno za indikacijo). Pri adjuvantnem zdravljenju melanoma ali RCC je treba zdravilo uporabljati do ponovitve bolezni, pojava nesprejemljivih toksičnih učinkov oziroma mora zdravljenje trajati do enega leta. Za neoadjuvantno in adjuvantno zdravljenje TNBC morajo bolniki neoadjuvantno prejeti zdravilo KEYTRUDA v kombinaciji s kemoterapijo, in sicer 8 odmerkov po 200 mg na 3 tedne ali 4 odmerke po 400 mg na 6 tednov, ali do napredovanja bolezni, ki izključuje definitivni kirurški poseg, ali do pojava nesprejemljivih toksičnih učinkov, čemur sledi adjuvantno zdravljenje z zdravilom KEYTRUDA kot samostojnim zdravljenjem, in sicer 9 odmerkov po 200 mg na 3 tedne ali 5 odmerkov po 400 mg na 6 tednov ali do ponovitve bolezni ali pojava nesprejemljivih toksičnih učinkov. Bolniki, pri katerih pride do napredovanja bolezni, ki izključuje definitivni kirurški poseg, ali do nesprejemljivih toksičnih učinkov povezanih z zdravilom KEYTRUDA kot neoadjuvantnim zdravljenjem v kombinaciji s kemoterapijo, ne smejo prejeti zdravila KEYTRUDA kot samostojnega zdravljenja za adjuvantno zdravljenje. Če je aksitinib uporabljen v kombinaciji s pembrolizumabom, se lahko razmisli o povečanju odmerka aksitiniba nad začetnih 5 mg v presledkih šest tednov ali več. V primeru uporabe v kombinaciji z lenvatinibom je treba zdravljenje z enim ali obema zdraviloma prekiniti, kot je primerno. Uporabo lenvatiniba je treba zadržati, odmerek zmanjšati ali prenehati z uporabo, v skladu z navodili v povzetku glavnih značilnosti zdravila za lenvatinib, in sicer za kombinacijo s pembrolizumabom. Pri bolnikih starih ≥ 65 let, bolnikih z blago do zmerno okvaro ledvic, bolnikih z blago ali zmerno okvaro jeter prilagoditev odmerka ni potrebna. Odložitev odmerka ali ukinitev zdravljenja: Zmanjšanje odmerka zdravila KEYTRUDA ni priporočljivo. Za obvladovanje neželenih učinkov je treba uporabo zdravila KEYTRUDA zadržati ali ukiniti, prosimo, glejte celoten Povzetek glavnih značilnosti zdravila. • **Kontraindikacije:** Preobčutljivost na učinkovino ali katero koli pomožno snov. • **Povzetek posebnih opozoril, previdnostnih ukrepov, interakcij in neželenih učinkov:** Imunsko pogojeni neželeni učinki (pnevmonitis, kolitis, hepatitis, nefritis, endokrinopatije, neželeni učinki na kožo in drugi): Pri bolnikih, ki so prejemali pembrolizumab, so se pojavili imunsko pogojeni neželeni učinki, vključno s hudimi in smrtnimi primeri. Večina imunsko pogojenih neželenih učinkov, ki so se pojavili med zdravljenjem s pembrolizumabom, je bila reverzibilnih in so jih obvladali s prekinitvami uporabe pembrolizumaba, uporabo kortikosteroidov in/ali podporno oskrbo. Pojavijo se lahko tudi po zadnjem odmerku pembrolizumaba in hkrati prizadanejo več organskih sistemov. V primeru suma na imunsko pogojene neželene učinke je treba poskrbeti za ustrezno oceno za potrditev etiologije oziroma izključitev drugih vzrokov. Glede na izrazitost neželenega učinka je treba zadržati uporabo pembrolizumaba in uporabiti kortikosteroide – za natančna navodila, prosimo, glejte Povzetek glavnih značilnosti zdravila Keytruda. Zdravljenje s pembrolizumabom lahko poveča tveganje za zavrnitev pri prejemnikih presadkov čvrstih organov. Pri bolnikih, ki so prejemali pembrolizumab, so poročali o hudih z infuzijo povezanih reakcijah, vključno s preobčutljivostjo in anafilaksijo. Pembrolizumab se iz obtoka odstrani s katabolizmom, zato presnovnih medsebojnih delovanj zdravil ni pričakovati. Uporabi sistemskih kortikosteroidov ali imunosupresivov pred uvedbo pembrolizumaba se je treba izogibati, ker lahko vplivajo na farmakodinamično aktivnost in učinkovitost pembrolizumaba. Vendar pa je kortikosteroide ali druge imunosupresive mogoče uporabiti za zdravljenje imunsko pogojenih neželenih učinkov. Kortikosteroide je mogoče uporabiti tudi kot premedikacijo, če je pembrolizumab uporabljen v kombinaciji s kemoterapijo, kot antiemetično profilakso in/ali za ublažitev neželenih učinkov, povezanih s kemoterapijo. Ženske v rodni dobi morajo med zdravljenjem s pembrolizumabom in vsaj še 4 mesece po zadnjem odmerku pembrolizumaba uporabljati učinkovito kontracepcijo, med nosečnostjo in dojenjem se ga ne sme uporabljati. Varnost pembrolizumaba pri samostojnem zdravljenju so v kliničnih študijah ocenili pri 7.631 bolnikih, ki so imeli različne vrste raka, s štirimi odmerki (2 mg/kg telesne mase na 3 tedne, 200 mg na 3 tedne in 10 mg/kg telesne mase na 2 ali 3 tedne). V tej populaciji bolnikov je mediani čas opazovanja znašal 8,5 meseca (v razponu od 1 dneva do 39 mesecev), najpogostejši neželeni učinki zdravljenja s pembrolizumabom pa so bili utrujenost (31 %), diareja (22 %) in navzea (20 %). Večina poročanih neželenih učinkov pri samostojnem zdravljenju je bila po izrazitosti 1. ali 2. stopnje. Najresnejši neželeni učinki so bili imunsko pogojeni neželeni učinki in hude z infuzijo povezane reakcije. Pojavnost imunsko pogojenih neželenih učinkov pri uporabi pembrolizumaba samega za adjuvantno zdravljenje (n = 1.480) je znašala 36,1 % za vse stopnje in 8,9 % od 3. do 5. stopnje, pri metastatski bolezni (n = 5.375) pa 24,2 % za vse stopnje in 6,4 % od 3. do 5. stopnje. Pri adjuvantnem zdravljenju niso zaznali nobenih novih imunsko pogojenih neželenih učinkov. Varnost pembrolizumaba pri kombiniranem zdravljenju s kemoterapijo so ocenili pri 3.473 bolnikih z različnimi vrstami raka, ki so v kliničnih študijah prejemali pembrolizumab v odmerkih 200 mg, 2 mg/kg telesne mase ali 10 mg/kg telesne mase na vsake 3 tedne. V tej populaciji bolnikov so bili najpogostejši neželeni učinki naslednji: anemija (54 %), navzea (54 %), utrujenost (37 %), diareja (36 %), nevtropenija (34 %), zaprtost (34 %), alopecija (32 %), bruhanje (29 %) in zmanjšanje apetita (28 %). Pojavnost neželenih učinkov 3. do 5. stopnje je pri bolnikih z NSCLC pri kombiniranem zdravljenju s pembrolizumabom znašala 67 % in pri zdravljenju samo s kemoterapijo 66 %, pri bolnikih s HNSCC pri kombiniranem zdravljenju s pembrolizumabom 85 % in pri zdravljenju s kemoterapijo v kombinaciji s cetuksimabom 84 %, pri bolnikih z rakom požiralnika pri kombiniranem zdravljenju s pembrolizumabom 86 % in pri zdravljenju samo s kemoterapijo 83 %, pri bolnikih s TNBC pri kombiniranem zdravljenju s pembrolizumabom 80 % in pri zdravljenju samo s kemoterapijo 77 %, pri bolnicah z rakom materničnega vratu pri kombiniranem zdravljenju s pembrolizumabom 82 % in pri zdravljenju s kemoterapijo z ali brez bevacizumaba 75 %, in pri bolnikih z rakom želodca pri kombiniranem zdravljenju s pembrolizumabom (kemoterapija in trastuzumab) 71 % in pri kemoterapiji v kombinaciji s trastuzumabom 65 %. Varnost pembrolizumaba v kombinaciji z aksitinibom ali lenvatinibom pri napredovalem RCC in v kombinaciji z lenvatinibom pri napredovalem EC so ocenili pri skupno 1.456 bolnikih z napredovalim RCC ali napredovalim EC, ki so v kliničnih študijah prejemali 200 mg pembrolizumaba na 3 tedne skupaj s 5 mg aksitiniba dvakrat na dan ali z 20 mg lenvatiniba enkrat na dan, kot je bilo ustrezno. V teh populacijah bolnikov so bili najpogostejši neželeni učinki diareja (58 %), hipertenzija (54 %), hipotiroidizem (46 %), utrujenost (41 %), zmanjšan apetit (40 %), navzea (40 %), artralgija (30 %), bruhanje (28 %), zmanjšanje telesne mase (28 %), disfonija (28 %), bolečine v trebuhu (28 %), proteinurija (27 %), sindrom palmarno-plantarne eritrodizestezije (26 %), izpuščaj (26 %), stomatitis (25 %), zaprtost (25 %), mišično-skeletna bolečina (23 %), glavobol (23 %) in kašelj (21 %). Neželenih učinkov od 3. do 5. stopnje je bilo pri bolnikih z RCC med uporabo pembrolizumaba v kombinaciji z aksitinibom ali lenvatinibom 80 % in med uporabo sunitiniba samega 71 %. Pri bolnicah z EC je bilo neželenih učinkov od 3. do 5. stopnje med uporabo pembrolizumaba v kombinaciji z lenvatinibom 89 % in med uporabo kemoterapije same 73 %. Za celoten seznam neželenih učinkov, prosimo, glejte celoten Povzetek glavnih značilnosti zdravila. Za dodatne informacije o varnosti v primeru uporabe pembrolizumaba v kombinaciji glejte povzetke glavnih značilnosti zdravila za posamezne komponente kombiniranega zdravljenja. • **Način in režim izdaje zdravila:** H – Predpisovanje in izdaja zdravila je le na recept, zdravilo se uporablja samo v bolnišnicah. • **Imetnik dovoljenja za promet z zdravilom:** Merck Sharp & Dohme B.V. , Waarderweg 39, 2031 BN Haarlem, Nizozemska.

MSD

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Samo za strokovno javnost.

H - Predpisovanje in izdaja zdravila je le na recept, zdravilo pa se uporablja samo v bolnišnicah. Pred predpisovanjem, prosimo, preberite celoten Povzetek glavnih značilnosti zdravila Keytruda, ki je na voljo pri naših strokovnih sodelavcih ali na lokalnem sedežu družbe.

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