

DODATNA ZNANJA IZ PALIATIVNE OSKRBE

“Korak za korakom”



Slovensko združenje
paliativne in hospic oskrbe

Paliativna oskrba v nefrologiji

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Splošna bolnišnica Slovenj Gradec

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Terminologija in vsebina

Paliativna obravnava v nefrologiji se običajno nanaša na obdobje končne ledvične odpovedi (KOL) in odločitev o dializnem zdravljenju.

Terminologija ni dorečena in standardizirana:

- Simptomatsko zdravljenje
- Podporno zdravljenje
- Paliativno zdravljenje
- Konzervativno zdravljenje

Zgodovina dializnega zdravljenja

- Konzervativno zdravljenje je najstarejša metoda zdravljenja končne odpovedi ledvic (KOL)
- Začetki dialize v 60. letih 20. stoletja – dializa uspešna, a draga metoda
- 1962 je Seattle Artificial Kidney Center ustanovil komisijo za izbiro primernih bolnikov
- Prednost imeli bolniki na podlagi „socialne vrednosti“ (patient’s social worth): pričakovan prispevek družbi

Odločitve – zbor bogov



Medical miracle and a moral burden of a small committee They Decide Who Lives, Who Dies

by SHANA
ALEXANDER

John Myers has known about his kidney trouble ever since a routine physical examination at the time of his Army discharge in 1945. But until two years ago he felt fine. Then the headaches began and his blood pressure began to rise. By last summer there were days when

he would barely drag himself out of bed to get to his office. He was 57 years old. Neither he nor his wife Kari had any idea that he had come, irrevocably, to the terminal stage of his disease. But a glance at his case history was enough to tell any physician that John Myers' death would be ugly and soon.

Last Christmas morning, when Myers awoke at his home in

Brumley, Wash., his heart was pounding violently. He could not stop coughing. Blood was seeping from his nose. He had an insupportable headache, a terrible taste in his mouth, dizziness, nausea. His feet and hands were grossly swollen. He was rushed to a hospital where it seemed certain he would be dead within a matter of hours. But today, 11 months later, Myers

is still alive. He is no longer even as troubled by the usual sense of the word. He is back at his old desk with an old company, and he is dining cheerfully as before with Kari and their three young children. To the casual observer, John Myers looks and acts just like everybody else. But he is different, in a very special way. There is now a small, U-shaped plastic tube attached into

the blood vessels of his left forearm, and it leads into bed. A compact bank of medical plumbing which looks like a mirrorless and washing machine is hooked to Myers' bedside. From its stands a translucent plastic tube a pair of clear plastic test-tubes six feet long. A nurse connects these to the little tube in Myers' forearm, and makes a few circuits. Suddenly, in one bright spot, one of the test-tubes becomes

milky as John Myers' blood rushes out to fill the bedside machine. The machine is an artificial kidney. Because it can be swapped out with the U-shaped tube in Myers' forearm, it has become the first true artificial organ in medical history. For the rest of his life Myers will spend two nights a week joined by a plastic artificial cord to this machine which keeps him alive.

At present the minuscule machine requires 90 to 12 hours to cleanse Myers' blood of accumulating poisons which otherwise would kill him. The procedure is quite painful, and Myers has now become an accustomed to the whole idea of introducing his life's blood to a medical instrument once a week during the cleaning he just goes to sleep. A

Search committee members, who are kept anonymous, meet periodically to determine which patients may receive treatment at the kidney center.

Dializa omogočena vsem

- Leta 1967 ustanovljen Komite za kronične ledvične bolezni
- Priporočilo za zvezno financiranje zdravljenja za vse bolnike s KOL
- Primerni:
 - Pod 54 letom z redkimi ali brez komorbidnosti
 - Ocena, da bo le 1 od 5 bolnikov s KOL primeren za dializo.
- 1972 v ZDA sprejet zakon , ki zagotavlja vsem plačano dializno zdravljenje (Medicare)
- Z leti so se kriteriji spreminjali
- Naraščala populacija starostnikov > 75 let



KOL, Končna odpoved ledvic

Ocena ledvične funkcije

- Za oceno ledvične funkcije največkrat uporabljamo formule – ocenjena GFR
- Normalni upad ledvične funkcije (staranje): 1ml/min/leto

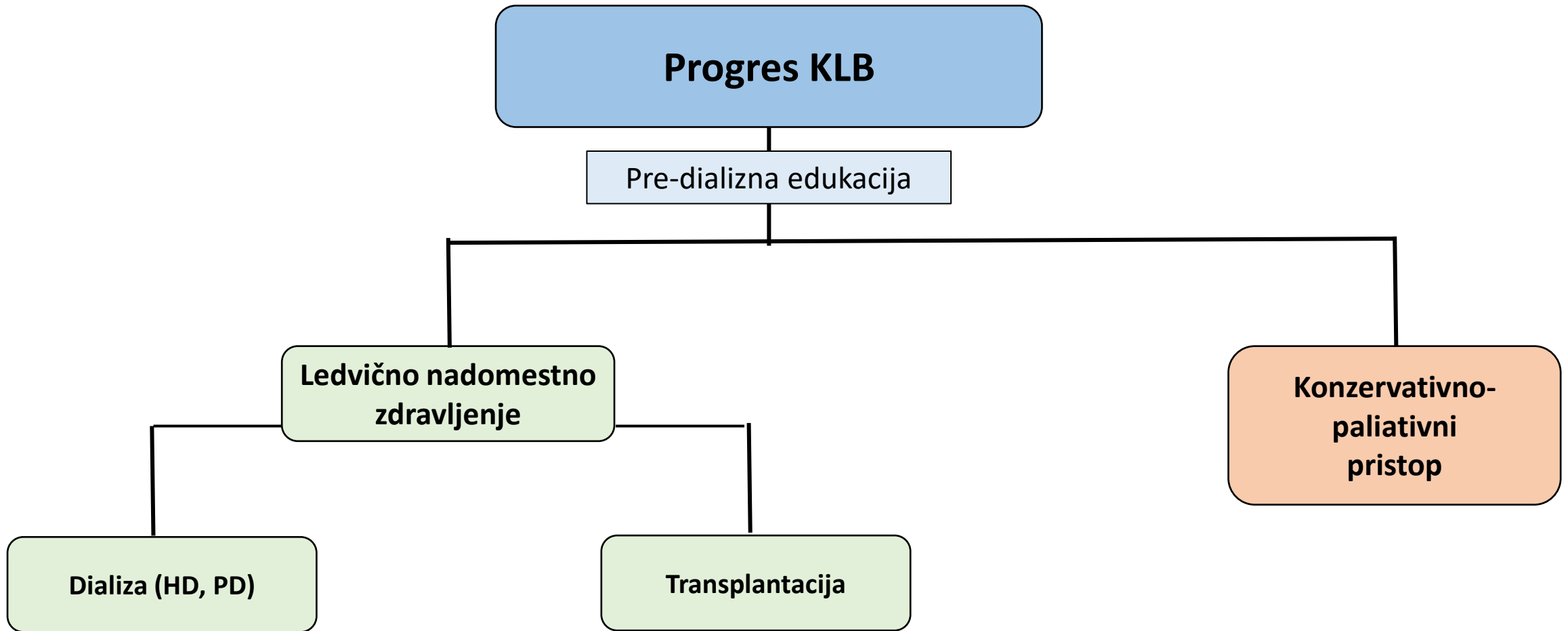
STOPNJA LEDVIČNE OKVARE	oGFR (ml/min/1,73m ²)
Stopnja 1	> 90
Stopnja 2	60 – 89
Stopnja 3a	45 – 59
Stopnja 3b	30 – 44
Stopnja 4	15 - 29
Stopnja 5	< 15

< 45 Nefrolog

< 20 Pre-dializna edukacija

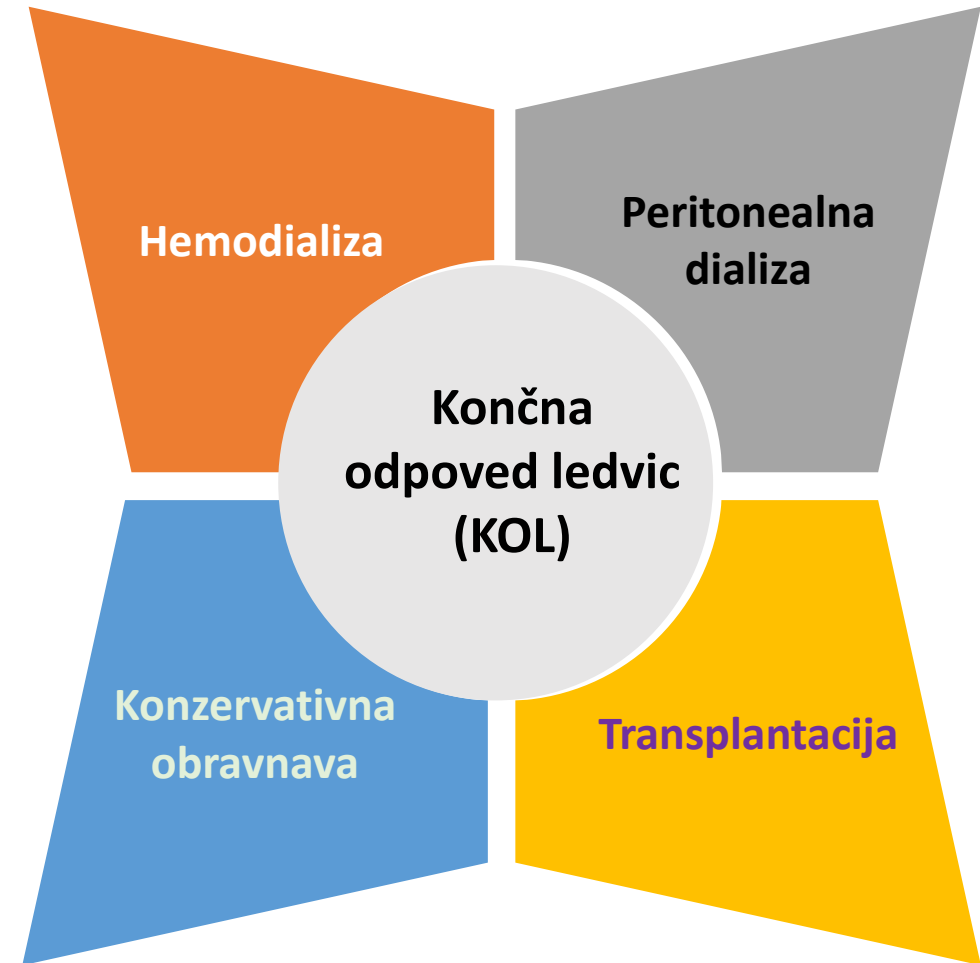
5 - 8 Dializa

Od kronične ledvične bolezni (KLB) do končne odpovedi ledvic (KOL)



Ena sama terapevtska možnost za celo življenje?

- Nobena metoda ni superiorna nad drugo
- Bolnikova individualna odločitev na osnovi:
 - Ustreznih informacij (edukacija)
 - Zdravstveni status
 - Možnost posameznih v lokalnem okolju
 - Zdravnikovo znanje in praksa
- V praksi bolniki redko zamenjajo metodo
- Zamenjava ali prehod na drugo metodo bi moral biti odvisen od bolnikovega zdravstvenega stanja in psihosocialnih potreb



Izhod zdravljenja s HD je odvisen od bolnikove starosti in komorbidnosti¹⁻³

- > 80% bolnikov prične s hemodializo kot prvo nadomestno metodo^{1,2}
- Običajna „receptura“ 3x/tedensko po 4-5h

Mlajši bolniki:

- Brez komorbidnosti in/ali zapletov
- Izhod zdravljenja:
 - Dobro preživetje
 - Dobra kvaliteta življenja

Starejši bolniki:

- Številne komorbidnosti in zapleti
- Izhod zdravljenja:
 - Za zagotavljanje preživetja
 - Visoka kardiovaskularna morbiditeta in mortaliteta
 - Slaba kvaliteta življenja (visoko dializno breme, pogoste hospitalizacije)

1. Wetmore J et al. Jan;71(1):123-132 Am J Kidney Dis. 2018.; 2. US-DOPPS Practice Monitor, April 2018; <http://www.dopps.org>;

3. Kalantar-Zadeh K et al. Ensuring Choice for People with Kidney Failure - Dialysis, Supportive Care, and Hope. N Engl J Med. 2020 Jul 9;383(2):99.

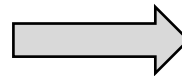
Dializa pri starejših bolnikih¹⁻⁴

- Starostniki > 75 let najhitreje rastoča populacija na HD
- Narašča tudi delež starostnikov, ki so opustili HD
- Kljub stalnemu tehnološkemu razvoju na področju dializnega zdravljenja:
 - Bolniki stari **> 65 let 3-letno preživetje** :
 - 54% pri HD pacientih in 65% pri PD pacientih
 - Bolniki stari **> 75 let 1-letno preživetje**:
 - na HD 46 – 58%

Visoko dializno breme pri starejših bolnikih

Breme “geriatričnih sindromov”¹:

- Krhkost
- Motnje gibljivosti
- Padci
- Kognitivni upad



Starostniki na hemodializi²:

- Visoka stopnja hospitalizacij
- Številni zapleti zdravljenja
- Kratko pričakovano preživetje

Dializno zdravljenje pri starostnikih je precejšnje fizično in psihološko breme za posameznika, preživetje pa se pomembno ne podaljša

Dializa da ali ne – pri starejših bolnikih

Nephrol Dial Transplant (2007) 22: 1955–1962
doi:10.1093/ndt/gfm153
Advance Access publication 4 April 2007

Original Article

NDT
Nephrology Dialysis Transplantation

Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5

Fliss E. M. Murtagh¹, James E. Marsh², Paul Donohoe³, Nasirul J. Ekbal⁴, Neil S. Sheerin⁵ and Fiona E. Harris²

¹Department of Palliative Care and Policy, King's College Hospital, London, ²Department of Renal Medicine, Epsom and St Helier University Hospitals, Surrey, ³Department of Renal Medicine, King's College Hospital London, ⁴Division of Renal Medicine, St George's Hospital, London and ⁵Department of Renal Medicine, Guy's and St Thomas' Hospital, London, UK

Abstract

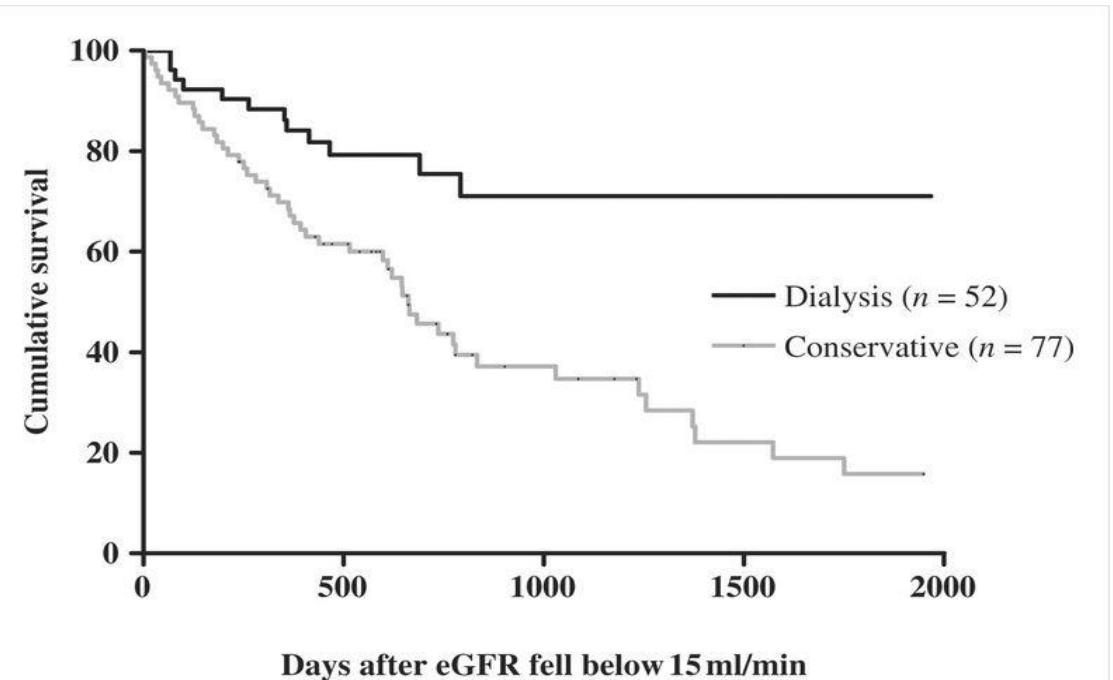
Background. The number of elderly patients with chronic kidney disease (CKD) stage 5 is steadily increasing. Evidence is needed to inform decision-making for or against dialysis, especially in those patients with multiple comorbid conditions for whom dialysis may not increase survival. We therefore compared survival of elderly patients with CKD stage 5, managed either with dialysis or conservatively (without dialysis), after the management decision had been made, and explored which of several key variables were independently associated with survival.

Comorbidity should be a major consideration when advising elderly patients for or against dialysis.

Keywords: chronic kidney disease stage 5; comorbidity; conservative management; elderly; survival

Introduction

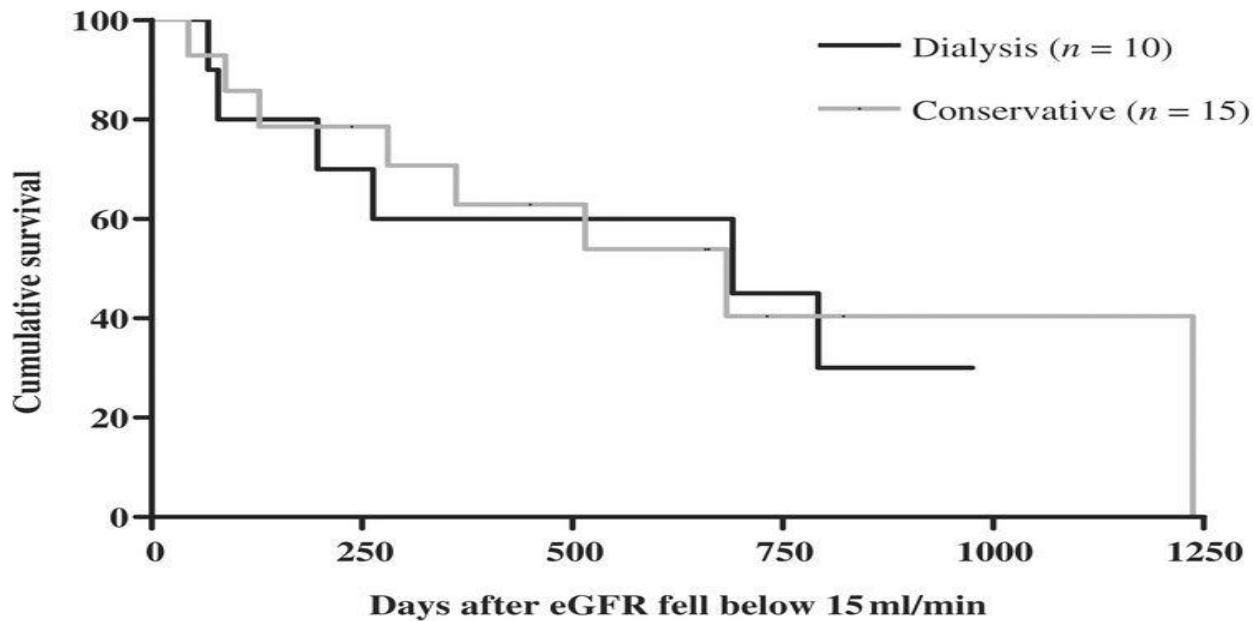
The annual acceptance rate for renal replacement therapy (RRT) in the UK is rising steadily, from



Kaplan-Meier survival curves comparing the dialysis and conservative groups (log rank statistic = 13.63, $P < 0.001$).

- Primerjalna raziskava preživetja 129 bolnikov starejših od 75 let s KLB 5.stopnje
- Pomembno boljše preživetje tistih na dializi

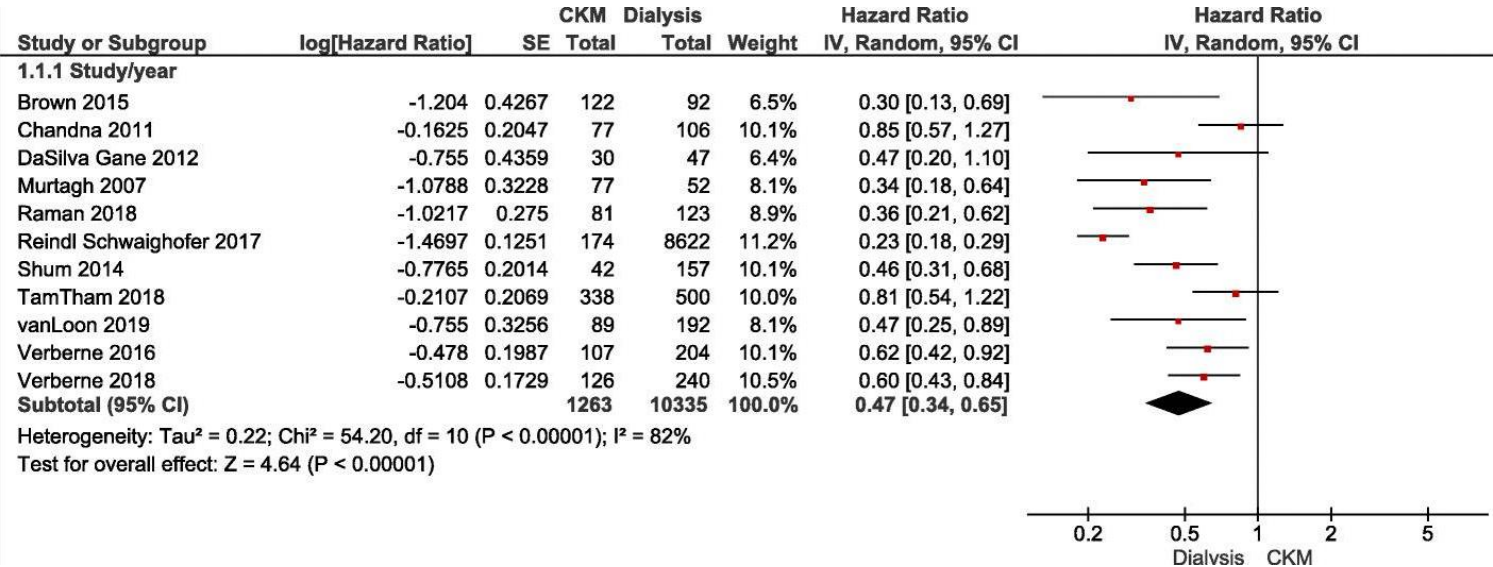
Preživetje in komorbidnosti



Kaplan-Meier survival curves for those with high comorbidity (score = 2), comparing dialysis and conservative groups (log rank statistic <0.001 , df 1, $P = 0.98$).

- **Nobene razlike v preživetju**, ko so obe populaciji bolnikov izenačili glede na starost in komorbidnosti
- Večinoma so bile prisotne srčno-žilne bolezni

Ali se je z leti kaj spremenilo?



- Meta-analiza 18 raziskav pri starostnikih
- Pri večini je preživetje boljše pri pacientih na dializi
- Z višjo starostjo (>80 let) in s komorbidnostmi pa se razlika izniči.

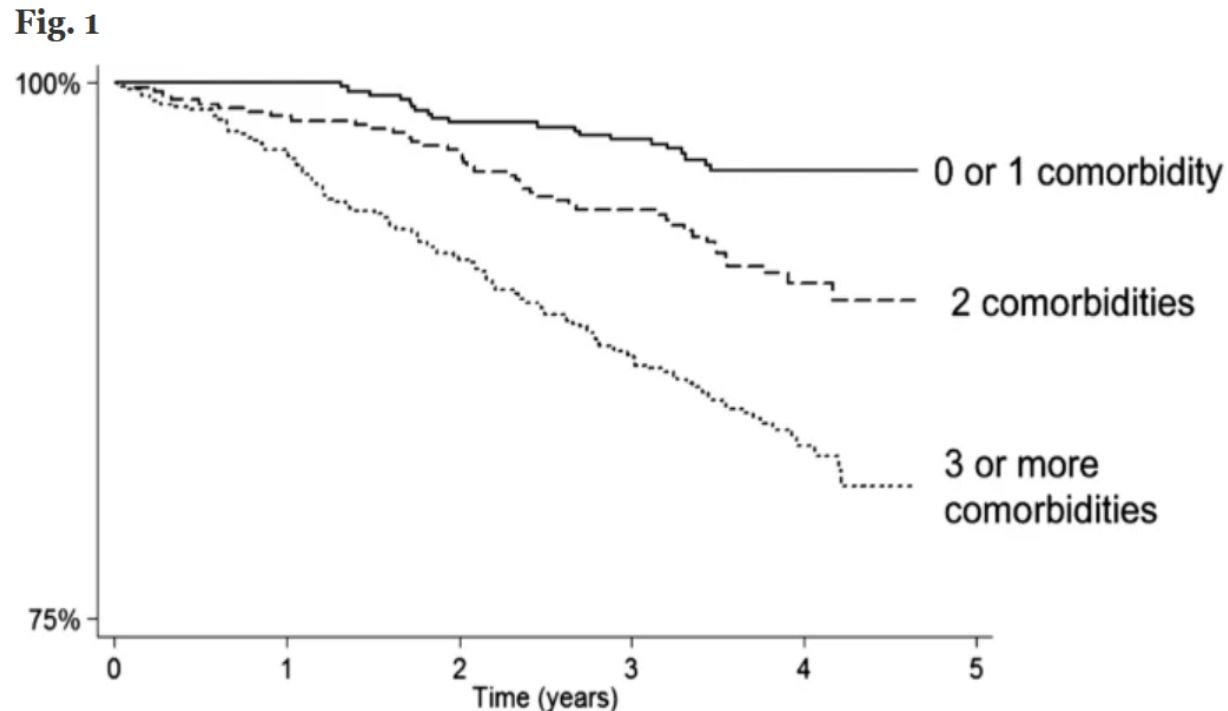
- Konzervativni pristop – boljši rezultati glede kvalitete življenja, hospitalizacij, bremena simptomov in mesta smrti
- Rezultati zelo nekonzistentni (izbira pacientov) – potreben individualni pristop

Komorbidnosti so pogoste pri KLB

- EU multicentrična raziskava pri 2.252 starejših bolnikih (75 – 96 let)
- Samo KLB, brez prisotnih drugih bolezni **pri samo 0.9%**
- KLB je pogosto prisotna skupaj z (usklajena glede na leta, spol in ostale bolezni):
 - Art. hipertenzija
 - Anemija
 - Kronično srčno popuščanje
 - Atrijska fibrilacija
 - AMI
 - Zlom kolka
 - Motnje sluha
 - Diabetes
 - Rakavo obolenja

Co-occurring pairs		Cases n	Observed %	Expected %
CKD	Hypertension	1224	54.4	50.7
CKD	Vision impairment	880	39.1	38.1
CKD	Hearing impairment	822	36.5	34.2
CKD	Osteoporosis	449	19.9	20.1
CKD	Diabetes	420	18.7	16.6
Anemia	CKD	388	17.2	13.9
CHF	CKD	305	13.5	10.9
Cancer	CKD	282	12.5	11.4
Atrial fibrillation	CKD	276	12.3	10.1
CKD	Depression	212	9.4	9.3
CKD	COPD	202	9.0	7.8
CKD	Myocardial infarction	182	8.1	6.4
CKD	TIA	136	6.0	5.7

Komorbidnosti pomembno vplivajo na preživetje



Kaplan Meier plot showing cumulative survival (all-cause mortality) by comorbidity status.

Footnote to Fig. 1: Please note that the x axis does not cross the y axis at 0 %

- **Izolirana KLB je redka** in prisotnost **komorbidnosti** je običajna.
- **Polifarmacija** je pogosta in je dobro merilo za **breme zdravljenja** – povezana s:
 - stopnjo komorbidnosti
 - starostjo
 - nizko stopnjo izobrazbe
- **Preživetje** je neodvisno obratno sorazmerno povezano z večjim številom komorbidnosti.

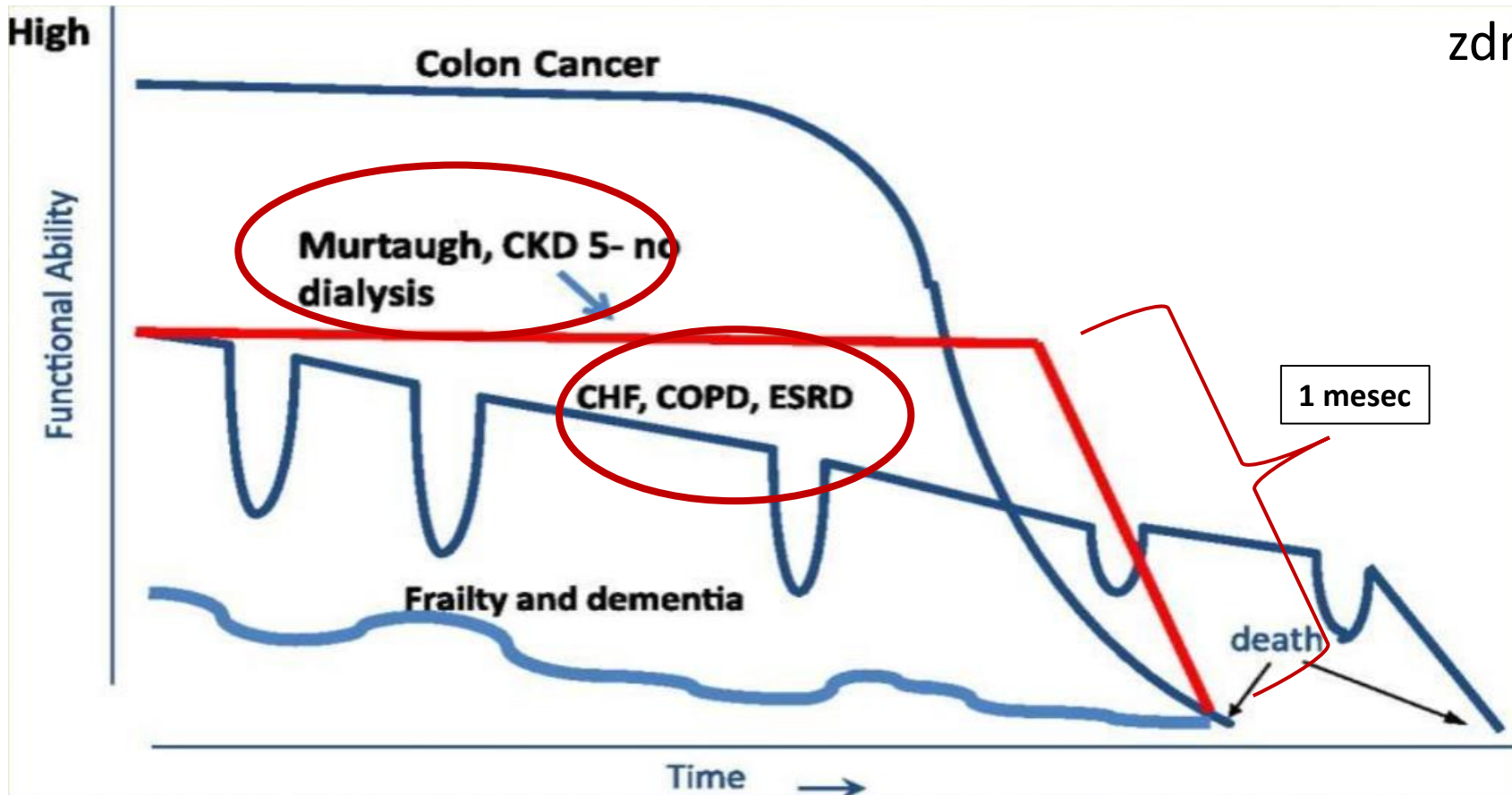
Dializni bolniki so ob koncu življenja zdravljeni bolj agresivno kot ostali

Table. Intensity of Care During the Final Month of Life

Intensity of Care	Medicare Beneficiaries		
	Dialysis (Present Study)	Cancer ⁷	Heart Failure ^{8,9}
Hospitalization, %	76.0	61.3	64.2
Days hospitalized, mean	9.8	5.1	NA
Intensive care unit admission, %	48.9	24.0	19.0
Days in an intensive care unit, mean	3.5	1.3	NA
Any intensive procedure, %	29.0	9.0	NA
Hospice use, %	20.0	55.0	39.1
Death in a hospital, %	44.8	29.0	35.2

Bolj intenzivno zdravljenje
ob koncu življenja
=
Nižja kvaliteta življenja (QoL)

„Naravni potek“ KLB z ali brez dialize



Primerjava HD/konzervativno zdravljenje³:

- Podobno preživetje
- Višja stopnja hospitalizacij na HD (20% vseh dni)
- Bolniki na konz. zdravljenju umrejo doma 4x pogosteje
- Boljša kvaliteta življenja pri konzervativnem zdravljenju
- Bolniki s končno ledvično odpovedjo lahko preživijo precej časa brez dialize, pri počasnem upadu oGFR).
- Nasprotno pa lahko hemodializa pospeši izgubo preostale ledvične funkcije.

Kateri so kandidati za konzervativno paliativno (KP) zdravljenje?

- KP je možnost za tiste, pri katerih breme dialize presega pričakovane koristi

Idealni kandidati za KP zdravljenje so bolniki:

- Pri katerih je malo verjetno, da bodo imeli dolgo preživetje
- Z eno ali več spremljajočih boleznimi, ki pomembno vplivajo na preživetje (npr. končno srčno popuščanje ali končno jetrno popuščanje).
- Krhki bolniki, s pomembno predhodno funkcionalno ali kognitivno okvaro (po začetku dialize se pogosto pojavi pospešeno funkcionalno in kognitivno nazadovanje)
- S hudimi, trajnimi in nepopravljivimi telesnimi ali psihološkimi simptomi (dializa podaljša trpljenje)
- Z nepopravljivo duševno nezmožnostjo, ki ovira varno izvajanje dialize

Jassal SV, Chiu E, Hladunewich M. Loss of independence in patients starting dialysis at 80 years of age or older. N Engl J Med 2009; 361:1612.

Kurella Tamura M, Covinsky KE, Chertow GM, et al. Functional status of elderly adults before and after initiation of dialysis. N Engl J Med 2009; 361:1539.

Moss AH. Revised dialysis clinical practice guideline promotes more informed decision-making. Clin J Am Soc Nephrol 2010; 5:2380.

UpToDate – dostop januar 2024

Ključni sestavni deli konzervativne obravnave KLB



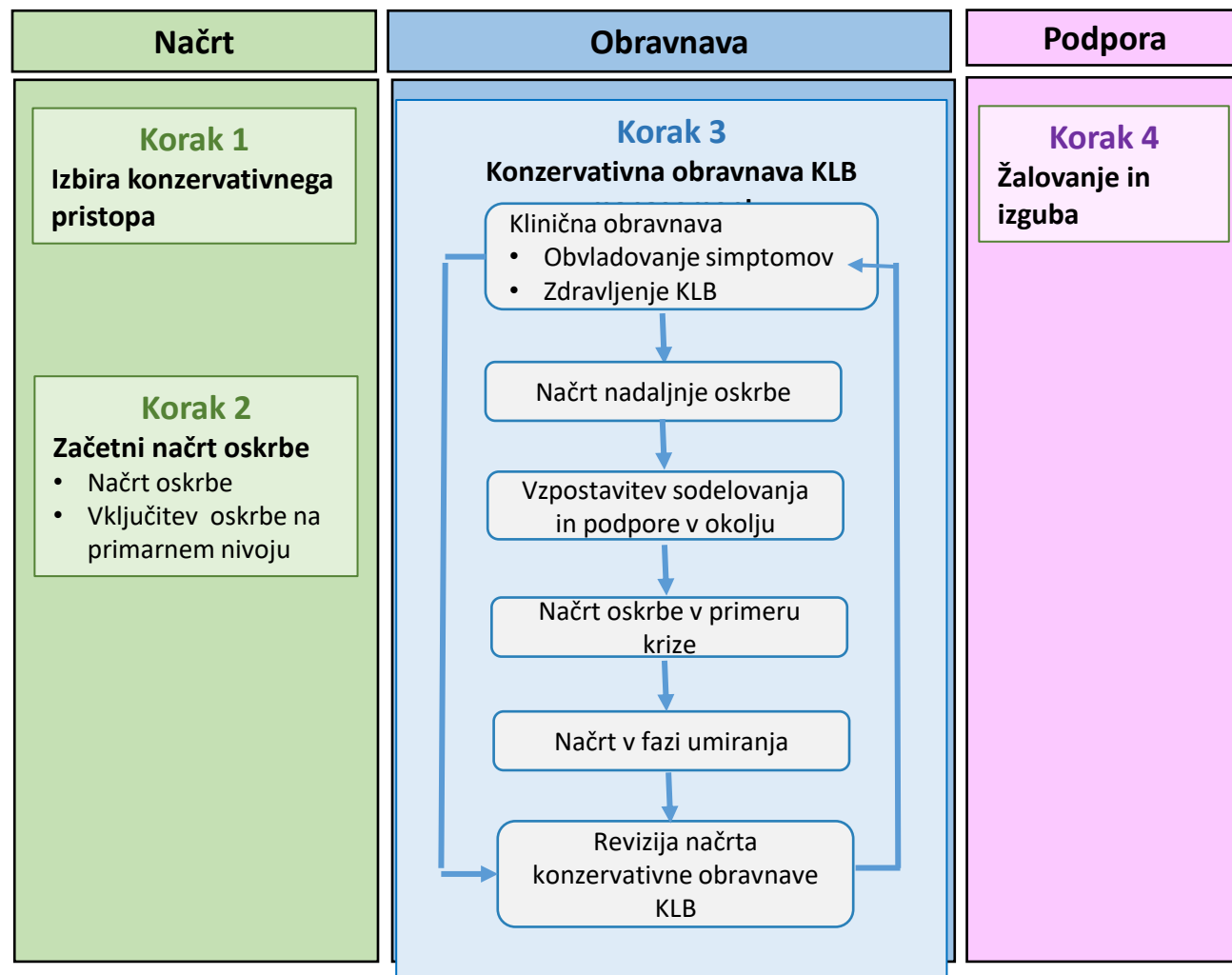
Recommendations for the Care of Patients Receiving Conservative Kidney Management Focus on Management of Chronic Kidney Disease and Symptoms

Sara N. Davison,¹ Beth Tupala,² Betty Ann Wasyluk,³ Valerie Siu,⁴ Aynharan Sinnarajah,⁵ and Jean Triscott⁶

Abstract

Conservative kidney management is increasingly accepted as an appropriate treatment option for patients with eGFR category 5 CKD who are unlikely to benefit from dialysis and/or who choose a nondialysis care option. However, there remains great variation in the delivery of their care. As part of the development of a conservative

¹Division of Nephrology and Immunology, Department of



Proces skupnega dogovarjanja (Share decision making process – SDM)

- Ključni del zdravstvene oskrbe, ker je **bolnik v središču**. Proces pri katerem se **nefrolog, bolnik in družinski člani** dogovarjajo in **sprejemajo odločitve**.



- Bolnik prejme informacije o:
 - bolezni,
 - prognozi,
 - možnostih zdravljenja
- Odločitev v skladu z bolnikovimi pričakovanji, željami in vrednotami (**avtonomija bolnika**)
- Skupna odločitev in načrt oskrbe
- Redno preverjanje odločitve in načrta

Prilagodljivost je pomemben del v procesu skupnega odločanja

- Zagotavlja, da je oskrba v skladu z bolnikovimi preferencami in vrednotami.
- **Preference** se lahko **spreminjajo** v teku razvoja bolezni – bolnik si lahko premisli in želi na dializo, možno pa je tudi **obratno**.
- To ne predstavlja odpovedi konz. zdravljenja kot metode.
- Konzervativni pristop – predvsem se želi **izogniti dializi ali akutnemu začetku** kot posledice slabo obvladanih simptomov v krizi, če se pri tem niso spremenile bolnikove preference in vrednote.

Konzervativna obravnava – načrt oskrbe

- Konzervativno obravnavani bolniki so **aktivno obravnavani**, usmerimo pa se na **kontrola in zdravljenje** zapletov bolezni
- Pri tem upoštevamo bolnikovo splošno zdravstveno stanje in prognozo – **lajšanje**
- **Zgodnje faze bolezni** – fokus na **QoL** in zmanjšanju simptomov in progressa KLB
- **Zadnji meseci življenja** – paliativna oskrba v fazi umiranja = aktivna kontrola specifičnih simptomov, ne laboratorijskih izvidov
- Primeri:
 - Manj striktna kontrola RR – boljše kognitivne in fizične funkcije, ker zmanjšamo tveganje za padce,
 - Ukinemo ali zmanjšamo nekatera zdravila (npr. statini)
 - Manj dietnih omejitev (fokus na zagotavljanju zadostne prehranjenosti)
 - Zmanjšamo število kontrol (vmes kontrole pri svojem zdravniku) ali povečamo njihov interval
 - Nasveti po telefonu

Obravnavna specifičnih simptomov

Številni in pogosti simptomi pri bolnikih v napredovali fazi KOL

Ti simptomi in njihova obravnava se lahko spreminjajo s časom in z razvojem bolezni.

- Anksioznost/depresija
- Edemi
- Nevropatska bolečina
- Sindrom nemirnih nog
- Občutek težke sape (zasoplost)
- Utrujenost in motnje spanja
- Bolečina na dotik
- Nemir/agitiranost
- Zaprtje (konstipacija)
- Nausea/bruhanje
- Respiratorna sekrecija
- Uremični pruritus

Hipervolemija/edemi

Nefarmakološki ukrepi

- Omejitev vnosa soli (2-4 g/dan)
- Omejitev vnosa tekočine (pazljivo!)
- Telesna aktivnost
- Položaj telesa (dvigovanje nog, sedenje v postelji)
- Povijanje nog

Farmakološki ukrepi

- Diuretiki – furosemid (Edemid, Lasix)
- Začnemo 20 mg 2x/d
- Postopoma do 120 mg 2x/d
- Re-evaluacija čez 2-5 dni

Dušenje

Nefarmakološki ukrepi

- Isti kot pri hipervolemiji
- Dihanje pri odprtem oknu
- Pihanje v obraz (stimulacija trigeminusa – centralna inhibicija dispnee)
- Ustrezna vlažnost prostora
- Kisik
- Relaksacijske tehnike, meditacija...

Farmakološki ukrepi

- Diuretiki – furosemid (Edemid, Lasix)
- Kombinacija z drugimi diuretiki (?)
- Opioidi (morfini preparati fentanil)

Nausea in bruhanje

Pomembno opredeliti vzrok: najpogosteje uremija in/ali zdravila

Nefarmakološki ukrepi

- Ustrezna oralna higiena
- Uživanje majhnih količin hrane in naj jedo počasi
- Ukinitev alkohola
- Tekočine naj se zaužije 30-60 min. pred ali po obroku
- Zmanjšati arome v okolici (od kuhanja, parfum, kajenje)
- Izogibanje mastni, papricirani ali zelo sladki hrani
- Akupunktura, določena hrana (ingver)

Farmakološki ukrepi

- Zofran tbl. a 4 mg
 - Titriranje do 8 mg 4x/d
- Reglan po. ali sc.
- Pri hudih primerih: Haldol ali Zyprexa

Pruritus

Nefarmakološki ukrepi

- Nega kože in vlaženje
- Redno kopanje (ne prhanje) v mlačni/hladni vodi 15 minut
- Izpostavljanje zmernemu soncu
- Izogibanje praskanju
- Udobna, zračne oblačila

Farmakološki ukrepi

- Antihistaminiki
- Mentolova mazila
- Dimetinden (Fenistil gel 2-4x/d)
- Pregabalin (Lyrica) ali Gabapentin (Neurontin)
- Konoplja
- Nalokson
- Akupunktura

Sindrom nemirnih nog

Nefarmakološki ukrepi

- Izogibanje alkoholu, nikotinu in kavi
- Ukrepi za dobro higieno spanja
- Telesna aktivnost pred spanjem (če možna)

Farmakološki ukrepi

- Pramipeksol (Mirapexin)
 - Začnemo z 0,125 mg
- Benzodiazepini
 - Previdnost – pogosti padci
- Gabapentin (Neurontin)
 - Začnemo 50-100 mg 2-3 ure pred spanjem
- Pregabalin (Lyrica)
 - Začnemo s 25 mg pred spanjem

Hiperkaliemija

Ukrepanje odvisno od stanja in dogovora s pacientom

Nefarmakološki ukrepi

- Preveriti prehrano (kalij pride zmeraj skozi usta!)
- Preveriti zdravila
- Ukiniti ACEi in ARB*

Farmakološki ukrepi

- Lokelma (Na cirkonijev ciklosilikat) prašek
- Resincalcio (polistirensulfonat) prašek
- Kalcijev glukonat in inzulin
- Hemodializa

Kako je z dializnim zdravljenjem?

Pre-dializni bolniki

- **Ne pričnemo z dializo** pri bolniku, ki se je odločil za KP – razen v primeru, ko je kljub ustreznemu zdravljenju trpljenje bolnika preveliko (ne trpljenje zdravnika!)

Dializni bolniki

- **Prilagajanje in/ali zmanjševanje** pogostosti in časa dializnih postopkov
- **Prehod** na drugo dializno metodo (npr. iz HD na PD)
- **Prekinitev dializnega zdravljenja** – v kolikor ta le podaljšuje bolnikovo umiranje in trpljenje

1. Grubbs V et al. A Palliative Approach to Dialysis Care: A Patient-Centered Transition to the End of Life. Clin J Am Soc Nephrol 2014; 9(12): 2203–09.

2. Davison SN et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. Kidney Int 2015; 88: 447–59.

CKM care – orodje za konzervativno obravnavo

<https://www.ckmcare.com/>

Patient Decision Aid Patients Health Professionals Create Profile

CONSERVATIVE KIDNEY MANAGEMENT

CONSERVATIVE KIDNEY MANAGEMENT (CKM)

CKM is a treatment option for managing advanced chronic kidney disease. This pathway is a resource for patients and healthcare professionals with a focus on quality of life, symptom management, and living well without dialysis.

Patient Decision Aid Patient/Family Healthcare Professional

- Interaktivna spletna aplikacija
- **Pomoč pri odločitvi**- z upoštevanjem bolnikovih **specifičnih prognostičnih markerjev** (starost, funkcionalni status, kognitivne funkcije, domače okolje in komorbidnosti) in z njegovimi **vrednotami, preferencami**, in sprejetimi **cilji oskrbe**
- **Pomoč bolnikom, svojcem in zdravnikom** pri razumevanju bolnikovih tveganj in prednosti med dializo in konzervativno obravnavo.

Praktično orodje za bolnike in zdravnike

Patients

Patient Decision Aid Patients Health Professionals Create Profile

CONSERVATIVE KIDNEY MANAGEMENT

Pathway Symptoms Resources Myths & Questions

My Health:	Stable	Deteriorating	Rapidly Declining
My Kidney Function:	15-10	10-5	5-0
Life expectancy:	Years	Years to Months	Months

Use Pathway

Healthcare professionals

Patient Decision Aid Patients Health Professionals Create Profile

CONSERVATIVE KIDNEY MANAGEMENT

Pathway Guidelines Resources Myths & Questions

Plan

Step 1
Choosing CKM
If your patient requires support, consider using the Patient Decision Aid

Step 2
Initiate Care Planning

- Care Plan
- Engage Primary Care

Manage

Step 3
CKM Care

- Clinical Assessments
 - Symptom Management
 - CKD Management
- Advance Care Plan
- Establish Community Support & Referrals
- Crisis Management Plan
- End of Life Plan
- Update CKM Care Plan


Support

Step 4
Grief & Loss

CONSERVATIVE KIDNEY PROFESSIONALS PATHWAY

Use Pathway

Primeri algoritmov za obravnavo simptomov

CKM Breathlessness Guideline for Healthcare Professionals	CKM Uremic Pruritus Guideline for Healthcare Professionals	CKM Restless Legs Guideline for Healthcare Professionals 
<p>Guiding Principle: Treat the patient's breathlessness by addressing the underlying cause.</p> <p>► Step 1: Assess for and address any other potential causes of breathlessness</p> <ul style="list-style-type: none"> Breathlessness is a subjective discomfort involving one of the most distressing symptoms of ESKD. <p>► Step 2: If the patient is intravascularly volume overloaded, start or increase diuretic therapy</p> <ul style="list-style-type: none"> The most common cause for breathlessness in the ESKD patient is volume overload. Start or increase dose of furosemide (Lasix) (loop diuretic). Watch for hypotension and dehydration with decreased intake. <p>► Step 3: If the patient is still volume overloaded (low-dose metolazone and high-dose oral furosemide may be considered)</p> <ul style="list-style-type: none"> Metolazone 2.5 - 5 mg PO daily, in addition to intravenous furosemide. <p>► Step 4: Consider non-pharmacological management</p> <ul style="list-style-type: none"> Explore with patient contributing and alleviating factors. Sit in an upright position (45°) Position by an open window Have a fan blow air gently across the face (stimulates breathing) Maintain humidity in room 	<p>Guiding Principle: Treat the patient's daily pruritus by addressing the underlying cause.</p> <p>► Step 1: Address possible contributing factors</p> <ul style="list-style-type: none"> Correct iron deficiency (See: Anemia Guideline). Other: xerosis, drug hypersensitivities, allergies, etc. <p>► Step 2: Consider non-pharmacological management</p> <ul style="list-style-type: none"> Good skin care and moisturizers are considered first-line therapy <ul style="list-style-type: none"> Baths are better than showers (daily inpatient). Avoid harsh soaps, body washes, bubble baths, etc. Post bath: pat dry and moisturize skin with hypoallergenic moisturizers with ceramides. Avoid moisturizers on areas of broken skin. Other skin care strategies include the following <ul style="list-style-type: none"> Keep skin cool by wearing light and cool clothing. Avoid scratching – keep fingernails short. Maintain a humid home environment, etc. See: Itch Patient Handout <p>► Step 3: If non-pharmacological interventions fail, consider topical therapies:</p> <ul style="list-style-type: none"> Pramoxine 	<p>Guiding Principle: Treat the patient's restless legs syndrome (RLS) if it is affecting their sleep or quality of life.</p> <p>► Step 1: Address contributing factors:</p> <ul style="list-style-type: none"> Correct anemia and iron deficiency (See: Anemia Guideline) Correct hyperphosphatemia (See: Calcium/Phosphorous Guideline) Remove drugs which may contribute to or cause RLS: <ul style="list-style-type: none"> Dopamine antagonists: <ul style="list-style-type: none"> antipsychotics: pimozide, haloperidol (Haldol), olanzapine (Zyrex), risperidone, quetiapine (Seroquel), methotrimeprazine (Nozinan) other: metoclopramide (Metonia), promethazine Antidepressants <ul style="list-style-type: none"> Mirtazapine (Remeron) SSRIs: e.g. citalopram, escitalopram, fluoxetine (Prozac), paroxetine (Paxil), sertraline (Zoloft) SNRIs: e.g. duloxetine (Cymbalta), venlafaxine (Effexor) Others: TCA's, carbamazepine (Tegretol), lithium, calcium channel blockers; opioids may also exacerbate RLS in this population <p>► Step 2: Consider non-pharmacological management:</p> <ul style="list-style-type: none"> A trial of abstinence from stimulants such as alcohol, caffeine and nicotine. A trial of mental alerting activities, such as video games or crossword puzzles, to reduce symptoms at times of boredom. The promotion of good sleep hygiene: <ul style="list-style-type: none"> Wake up at the same time every morning. Do not go to bed until you feel sleepy. Do not "try" to fall asleep. Avoid napping during the day. Avoid caffeine in the evening. Save your bedroom for sleep (and sex) only. Leave your day's dilemmas at the door. Incorporate relaxation techniques. If realistic for the patient, encourage aerobic exercise, walking, and/or stretching. See: Fatigue and Sleep Disturbances Guideline See: Restless Legs Patient Handout <p>► Step 3: If the patient continues to report restless legs syndrome, consider pharmacological options:</p> <p>Many of the following medications have been dose-adjusted for the ESKD patient and some are being used off-label for RLS. Medications such as gabapentin and pregabalin should be tapered down as kidney function deteriorates. *Note that gabapentin is not commercially available in 50 mg capsules, but can be compounded for patients if the lower starting dose is desired.</p>

Ovire in pomanjkljivosti v dnevni praksi

Izbira metode nadomestnega zdravljenja v vsakdanji praksi

- Odločitev je večinoma sprejeta v bolnišnici v fazi akutnega poslabšanja
- Ni bilo dovolj časa za razumevanje vseh informacij

Odločitev bolnika za HD je bila sprejeta na predlog:

- Zdravnika (52%)
- Svojcev (14%)
- 61% bolnikov je kasneje obžalovalo svojo odločitev

Pomisleki in dileme iz prakse

- Ali koristimo tudi način „cherry picking“ ?
 - Odklanjanje pacientov, ki zamujajo, so konfliktni
 - Pacienti, ki niso kompliantni pri zdravljenju, dieti
- Prehitro sprejemanje pacientovih odločitev „ne na dializo“
 - Manj jih je v KLB ambulantni – pacient mora razumeti o čem se odloča
- Občasne dialize (npr. 1x na 7 ali 10 dni)
 - Lajšanje simptomov
 - Socialna vloga
 - Nasprotovanje osebja – tak pristop ruši rutino
- Neopredeljena oblika in način izvajanja KP (razlike v praksi v izvajanju KP med posamezniki, oddelki in ustanovami)

Glavne ovire in pomanjkljivosti

- Pomembne razlike med teorijo in prakso
- Celoten proces KP je zelo **kompleksen** in zato potreba po:
 - sprememba v **dojemanju** KP (bolniki, svojci, izvajalci, družba)
 - povečati **osveščanje** o potrebi KP
 - sistematična **edukacija** (bolnikov in izvajalcev)
 - KP bi moral biti sestavni del **redne obravnave bolnikov** z napredovalo KLB
 - organizacija **multidisciplinarnega pristopa**
 - **povezanost** različnih služb in servisov
 -

Ovire na različnih nivojih:

- Individualne
- Sistemske in/ali institucionalne

Individualne ovire za KP

Bolnik (in svojci)

- **Negativna percepcija KP**
 - Individualna (opustitev zdravljenja)
 - družbena (strah pred mnenjem okolice)
- Pomanjkljivo **razumevanje** KP in/ali paliativne oskrbe
 - pomanjkljiva ali prepozna edukacija
 - strah in nezaupanje

Nefrolog

- Še vedno ne **priznavajo KP** kot metodo zdravljenja
- **Negativna percepcija KP** (pasivna metoda - „Primum Non Nocere“)
- Pozna ocena bolnika
- Pomanjkljivo **znanje o KP glede:**
 - prognoze in izhoda (rezultati) KP
 - veščin za izvajanje pogovora in obravnave KP
 - obravnave KLB specifične paliativne oskrbe
 - poznavanja zakonskih določb o bolnikovih pravicah

Zaključki

- Odločitev o nadomestni metodi ob KOL je sprejeta zmeraj skupaj z bolnikom – metoda naj bi zagotavljala boljšo kvaliteto življenja glede na njegove vrednote in življenjski slog.
- Temelj oskrbe je spoštovanje bolnikove avtonomije.
- Celovita oskrba ne rešuje le problemov in zapletov ledvične bolezni, ampak zdravi bolnika v holističnem smislu.
- Potreba po kompleksni organizaciji, ki vključuje usklajeno delovanje različnih profilov v obliki multidisciplinarnih timov.
- Potrebne so še številne izboljšave na področjih:
 - standardizacije postopkov izvajanja KP
 - boljše organizacije delovanja in izvajanja KP
 - izobraževanje in sprememba razmišljanja izvajalce KP
 - ustrezno finančno ovrednotenje vseh postopkov KP

DODATNA ZNANJA IZ PALIATIVNE OSKRBE

“Korak za korakom”



Slovensko združenje
paliativne in hospic oskrbe

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