

Pasientopplæring etter transplantasjon

Fagdager om organdonasjon og transplantasjon

11 og 12 September 2023

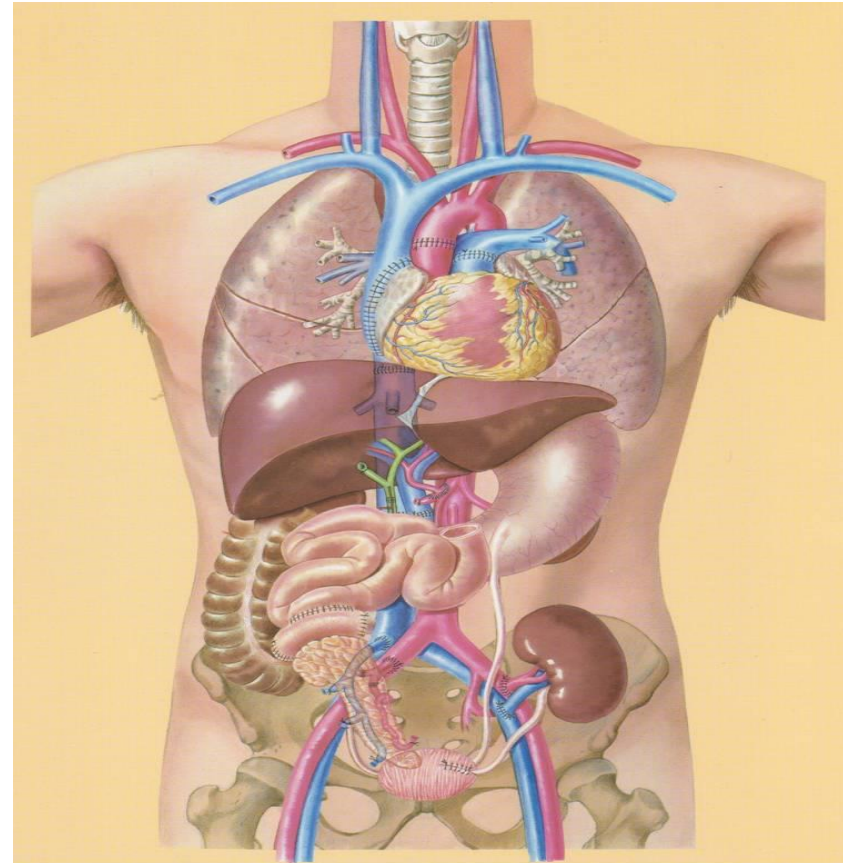
Tone Vidnes – Fagutviklingssykepleier

Transplantasjonskirurgisk sengepost

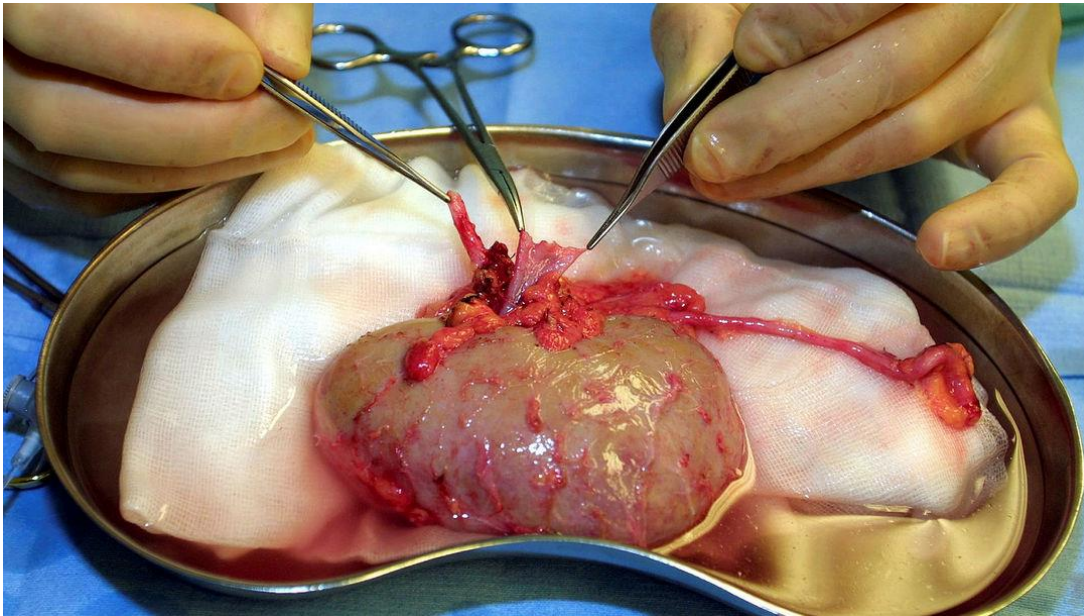


Transplantasjonsvirksomheten

- Ett nasjonalt senter i Norge – to avdelinger thoraxkirurgen og transplantasjonskirurgen
- Transplantasjonstall 2022:
 - 229 nyrer
 - 181 avdød giver
 - 43 levende giver
 - 2 kombinert lever/nyre
 - 3 kombinert nyre/pankreas
 - 92 lever
 - 89 single lever
 - 2 Lever/nyre
 - 1 living donor lever
 - 4 pankreas
 - 1 single pankreas
 - 3 Nyre/pankreas
 - 1 øyceller



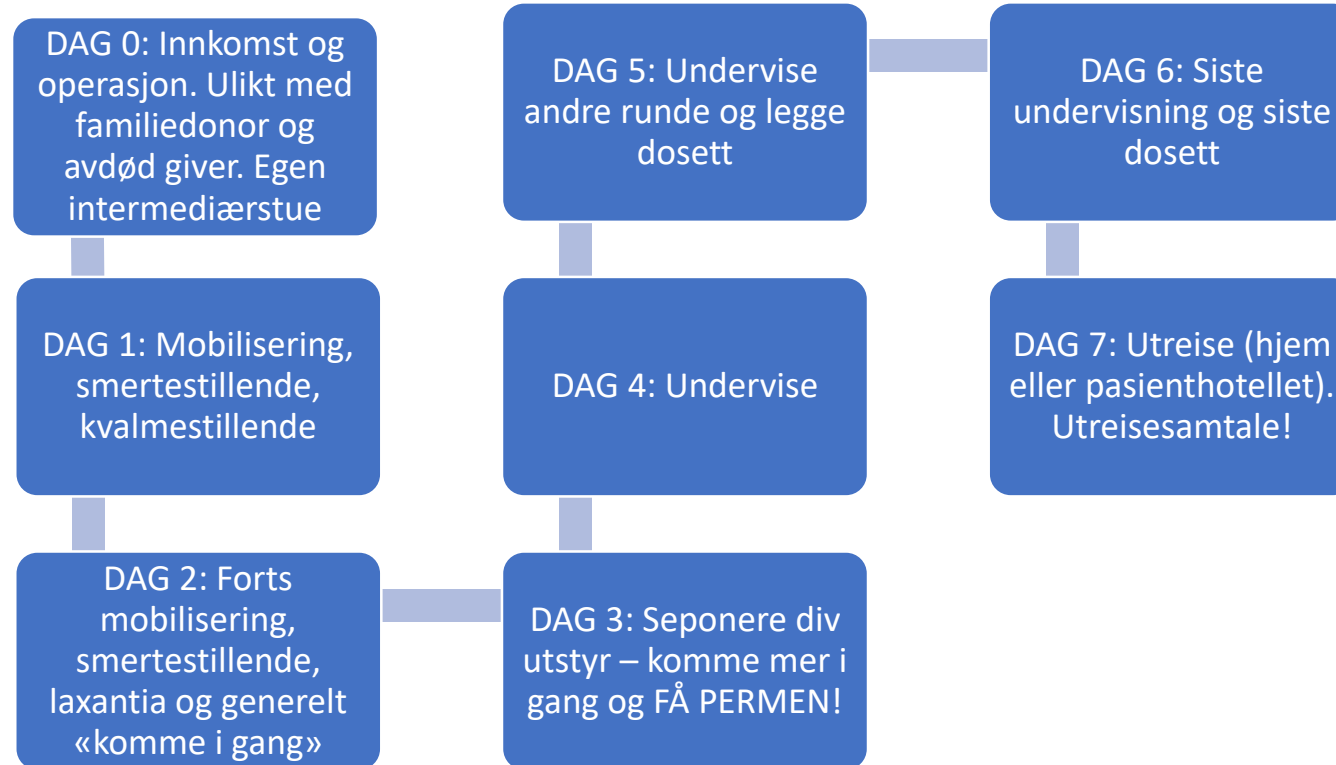
Transplantert = frisk?



- «En generell oppfatning i befolkningen, er at det settes likhetstegn mellom det å bli transplantert og det å bli frisk»
- Hva betyr det egentlig å bli transplantert?

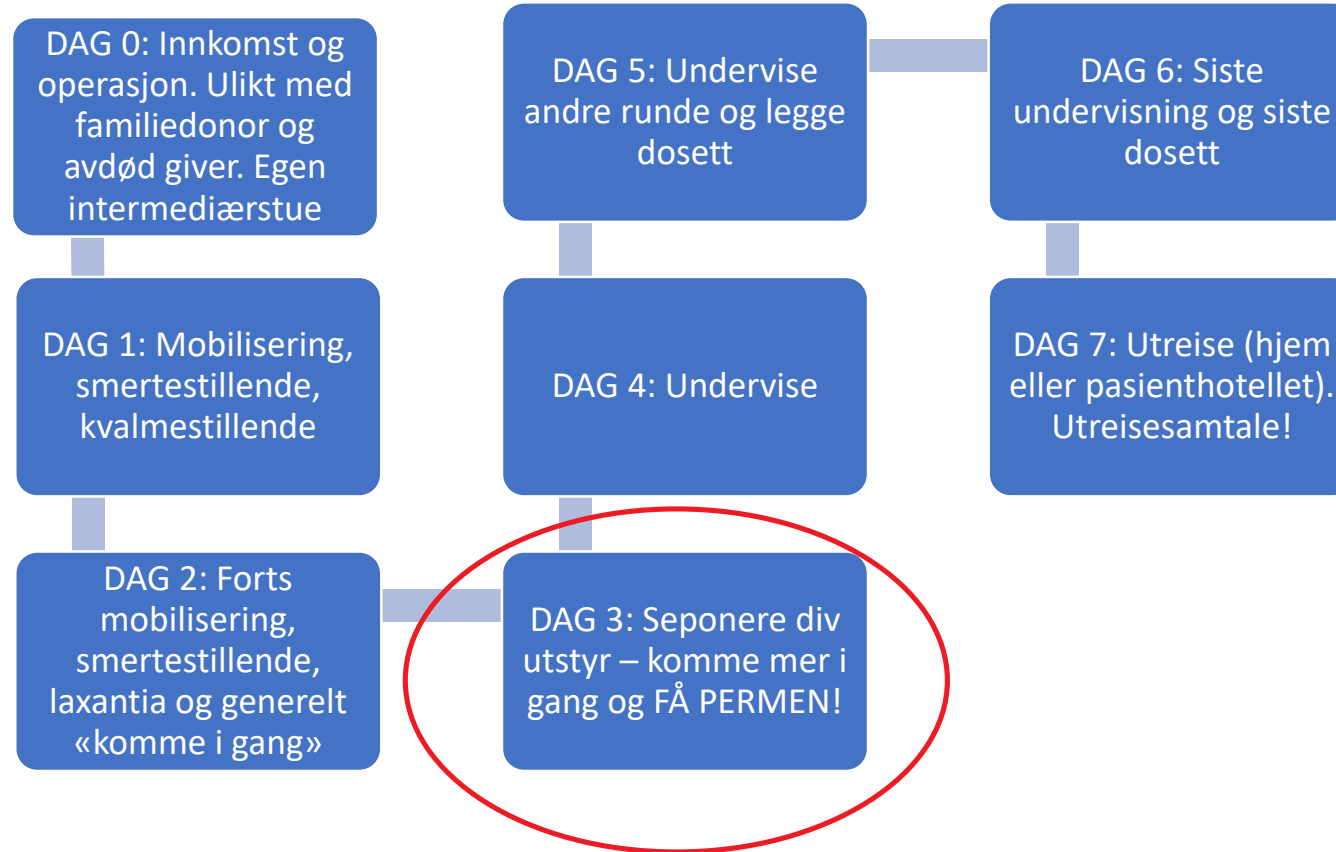
Forventet forløp på nyretx

(uten komplikasjoner)

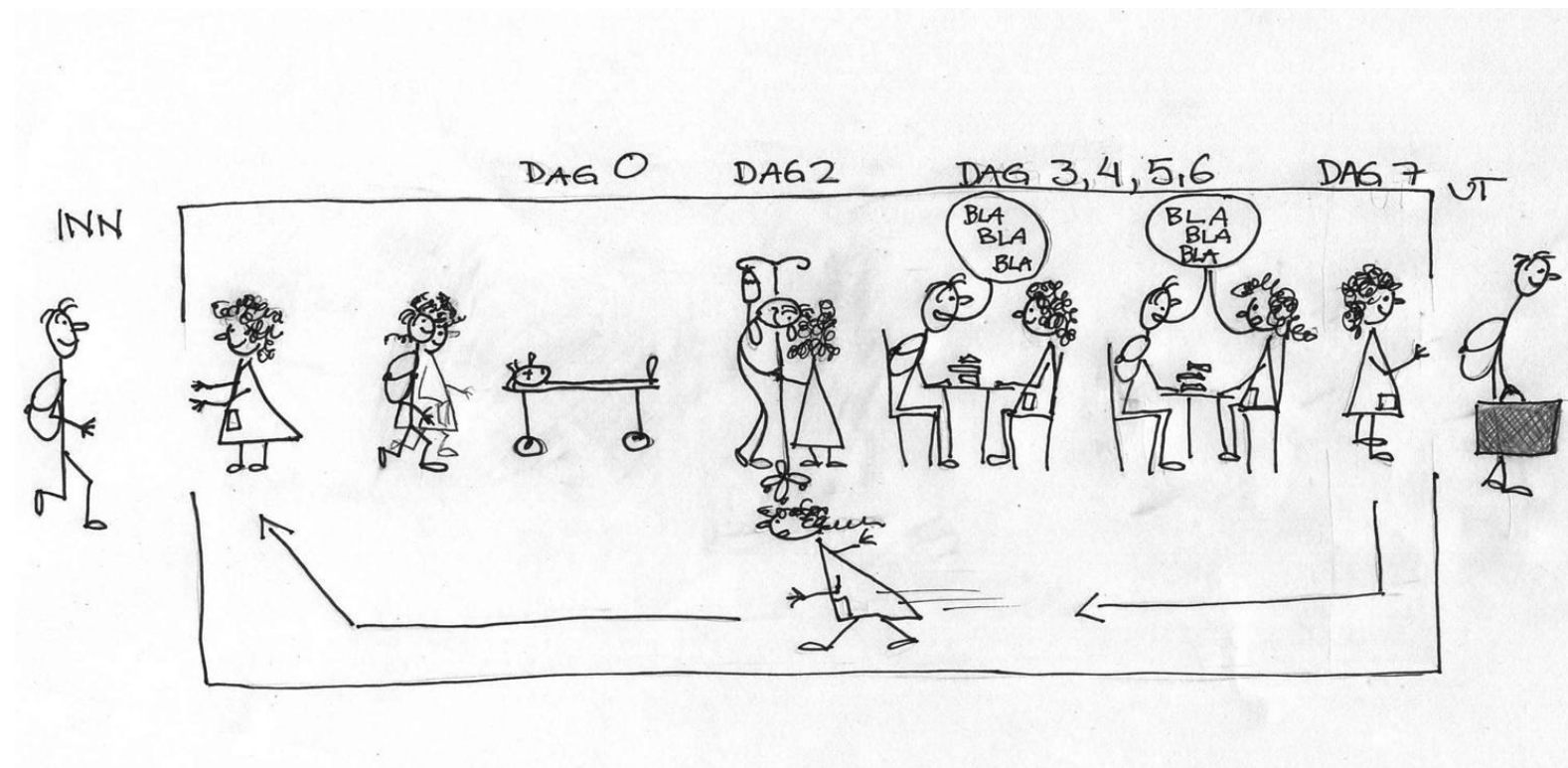


Forventet forløp på nyretx

(uten komplikasjoner)



Beskrevet på en annen måte



Behov for opplæring?

- Transplantasjonen er en fantastisk start, men bare en begynnelse....
- Opplæringen legger grunnlag for videre gevinst av transplantasjonsvirksomheten
- Nødvendigheten av pasientundervisning til pasienter med kronisk sykdom blir understreket både i «Lov om Specialisthelsetjenesten» (LOV-1999-07-02-61) og «Pasientrettighetsloven» (LOV-1999-07-02-63)



Opplæring av pasient og pårørende er en av våre fire hovedoppgaver

Helse Sør-Øst RHF skal sørge for at helseforetakene gir pasienter og pårørende opplæring som kan bidra til å håndtere sykdom og fremme helse i hverdagen. Opplæring av pasient og pårørende er en av våre fire hovedoppgaver.

Helseforetakene skal tilby opplæring av pasienter og pårørende innenfor somatikk, psykisk helsevern og rusbehandling. Tilbudene utvikles i et likeverdig samarbeid mellom fagpersoner og pasienter og pårørende.

Opplæring gis både individuelt og i grupper, og tilbys personer med en bestemt diagnose eller kan være diagnoseuavhengig.



Pasient- og pårørendeopplæring

Hva er det egentlig pasientene våre forventer av en nyretransplantasjon?

Format: Abstract - Send to -

[BMJ Open](#), 2018 Jun 22;8(6):e021275. doi: 10.1136/bmjopen-2017-021275.

Older kidney transplantation candidates' expectations of improvement in life and health following kidney transplantation: semistructured interviews with enlisted dialysis patients aged 65 years and older.

[Lønning K^{1,2}](#), [Midtvedt K¹](#), [Heldal K^{2,3}](#), [Andersen MH^{1,4}](#).

Ⓜ Author information

Abstract

OBJECTIVE: The aim was to study the expectations of improvement in life and health following kidney transplantation (KTx) in a population of wait-listed patients ≥65 years with end-stage kidney disease.

DESIGN: Qualitative research with individual in-depth interviews.

SETTING: Patients on dialysis enlisted for a KTx from a deceased donor were included from an ongoing study of older patients' perspectives on KTx. Qualitative face-to-face interviews were conducted in a safe and familiar setting, and were analysed thematically using the theoretical framework of lifespan.

INFORMANTS: Fifteen patients (median age 70 years, range 65-82) from all parts of Norway were interviewed. Informants were included consecutively until no new information was gained.

RESULTS: Two main themes were evident: receiving a kidney is getting life back and grasp the chance. In addition, the themes 'hard to loose capacity and strength', 'reduced freedom' and 'life on hold' described the actual situation and thereby illuminated the informants' expectations. The informants tried to balance positive expectations and realism towards KTx, and they were hoping to become free from dialysis and to live a normal life.

CONCLUSION: This study shows that older KTx candidates comprise a heterogeneous group of patients who take individual approaches that allow them to maintain autonomy and control while waiting for a transplant. This study provides new knowledge about the older KTx candidates relevant for clinicians, patients and researchers.

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KEYWORDS: end stage kidney disease; older renal patients; patient perspective; qualitative research; renal transplantation

PMID: 29934388 PMCID: [PMC6020885](#) DOI: [10.1136/bmjopen-2017-021275](#)

[Free PMC Article](#)

[f](#) [t](#) [v](#)

[Nephrology \(Carlton\)](#), 2018 May 21. doi: 10.1111/nep.13405. [Epub ahead of print]

Children's experiences and expectations of kidney transplantation: A qualitative interview study.

[Walker RC¹](#), [Naicker D²](#), [Kara T²](#), [Palmer SC^{3,4}](#).

Ⓜ Author information

Abstract

RATIONALE AND OBJECTIVE: Kidney transplantation offers improved quality of life and life expectancy compared with dialysis for children. This study aims to understand the experiences and expectations of children during the kidney transplantation process to inform clinical care.

STUDY DESIGN: Face-to-face, semi-structured interviews.

SETTING AND PARTICIPANTS: We interviewed 13 children and adolescents aged between 7 and 17 years old in New Zealand who had received a kidney transplantation.

ANALYTICAL APPROACH: We conceptualised the findings using thematic analysis with inductive coding.

RESULTS: We identified three major themes: transplant as the goal (the only real treatment and escaping dialysis); dealing with negative emotions (coping with anxiety and fear, guilt for siblings and burden of parent as donor); and enhancing understanding and knowledge (individualised education and reassurance from peer support).

LIMITATIONS: Study conducted in New Zealand therefore, the transferability of findings to other populations is unclear.

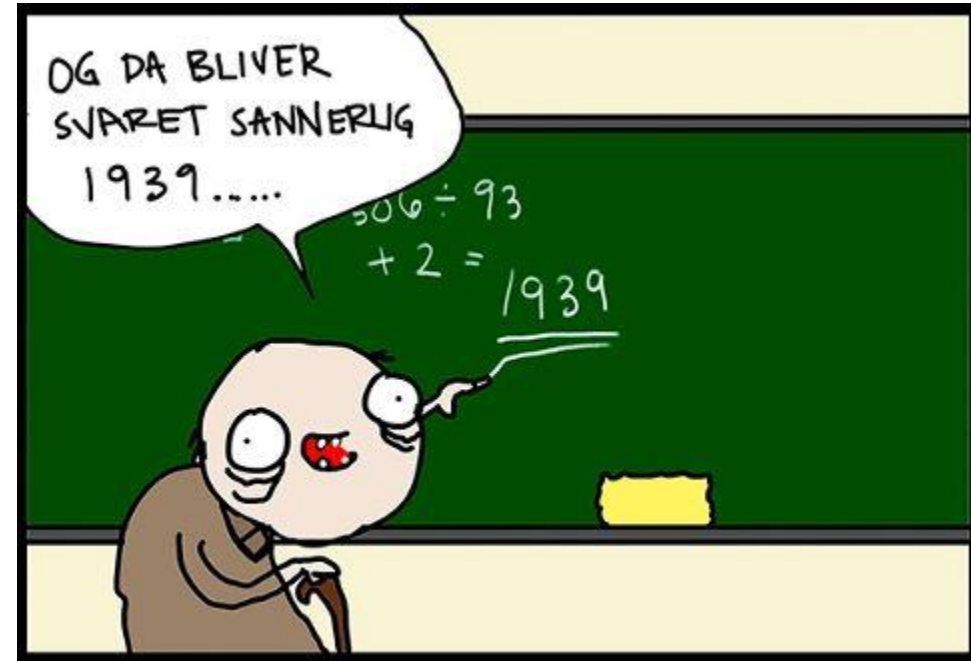
CONCLUSIONS: Children and adolescents view transplantation as freedom from dialysis and return to a more normal life. Children focus on the positive aspects of transplantation to reduce anxiety and be reassured in the face of uncertainty. Complex emotions arise when thinking about their donor. Children recognise transplantation is not a return to full health and actively seek out ways to self-manage their care, while remaining anxious about their future. This article is protected by copyright. All rights reserved.

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Og hvordan skal vi kunne fylle slike krav?

Opplæring av sykepleiere

- Nyansatte får 6 måneder opplæring/oppfølgingstid
- Pasientundervisning først etter 3 mnd
- Veiledningsdag med undervisnings-sykepleier først
- Egen behandlingsplan i DIPS Arena som går på tvers av samarbeidspartnere (med sengepost gastro/nefro og poliklinikken)
- Betydelig del av tiden til spl brukes på pasientundervisning



Innholdet i pasientopplæringen

Skriftlig informasjon

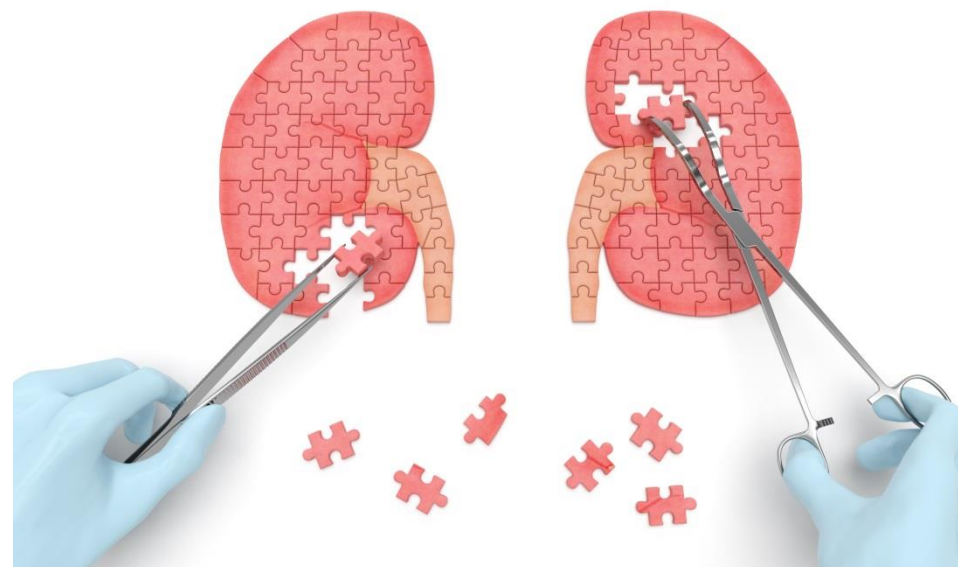
- Immundempende medisiner
- Medisintider
- Avstøtningstegn
- Forebygging av bivirkninger
- Kostveiledning
- Infeksjoner, vaksiner, immunforsvar, hudbeskyttelse, reiseliv, alkohol, røyk/snus, samliv og seksualitet, helsekost, sosiale medier, nettvett.....

Praktiske øvelser

- Føring av dagbok
 - Temperatur
 - Drikke
 - Diurese
 - Vekt
- Dosett

Pasientens ulike behov

- Store ulikheter i forhold til egen kapasitet
 - Dårlig etterlevelse etter tidligere transplantasjon?
 - Lang tid i dialyse før transplantasjon?
 - Kan alt?
 - Gått nyreskole?
 - Alder



Hvordan undervise?



- Utgangspunkt i behandlingsplan
- Skriftlig informasjon
- Pasienten leser på egenhånd
- Individuelle samtaler (alltid)
 - Tolk?
 - Ønsker de ha med pårørende?
- Tilpasset undervisning med skjermet tid og rom

Veien videre

- Skriftlig informasjon
- Organspesifikk
- Kortversjon
 - Oversatt til ni språk (pdf på OUS nettsider)
- Omfattende og grundig
- Stor revidering 2015
- Nå, kontinuerlig behovsrevidering
- Til ode og eie
- På nett på OUS nettsider
- Video fra KEF
- Ønske om flere videoer

Oslo universitetssykehus

Veien videre - Informasjon til deg som har fått et nytt organ

Sengspost Transplantasjon
Kvalitetssertifikat
Tilrettelagt av: Sengspost
Dokumentnr: 02776

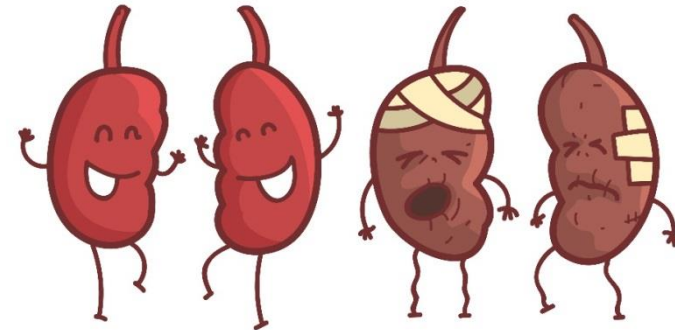
Veien videre
Veien videre
Veien videre

Oslo universitetssykehus
www.ous-universitetssykehus.no

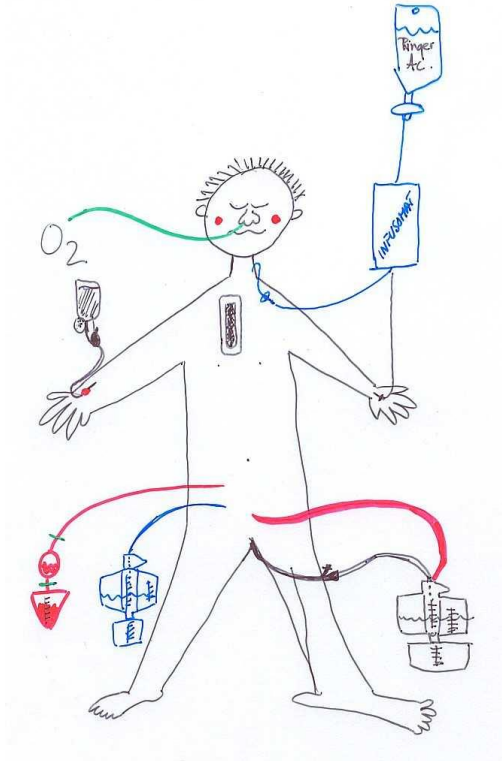
Oslo universitetssykehus er et helse sår-delt og består av blant annet Åker sykehus, Ulmål sykehus, Vikholmsparket og Radikumbusparket.
Post til forretningsforretning: Oslo universitetssykehus, Postboks 4474 Nydalen, 0404 Oslo. Leiarbord: 02776.

Hva er hensikten? Hva er målet?

- At den som har fått et nytt organ skal kunne leve et godt liv
- At pasienten mestrer livet som transplantert og beholder organet så lenge som mulig
- Konsekvensen av dårlig etterlevelse kan bli store



Utfordringer for pasienten



- Nyoperert
- Forventninger til transplantasjonen
- Ny livssituasjon, mange endringer
- Behov for støtte fra pårørende/helsepersonell
- Klar til å stå på egne ben?
- Ny rolle
- Mye informasjon på kort tid

Utfordringer for sykepleier

- Mye informasjon som skal gis på kort tid
- Krav til effektivitet og individuelle behov hos pasienten. Hvordan prioritere?
- Når er pasienten «utlært»? Stort ansvar for aktuell sykepleier
- Behov for mer opplæring
 - Kapasitet i posten/ekstra liggedøgn
- Flerkulturelle pasienter
 - Behov for tolk?
 - Hvordan kvalitetssikre undervisningen ved bruk av tolk?
 - Skriftlig informasjon på morsmålet?
 - Ulik sykdomsforståelse
 - Har sykepleier nok kompetanse om aktuelle kultur?

Endret opplegg for pasientundervisning etter doktorgrad i 2014



- Nytt samarbeid om opplæring med nyremedisinsk poliklinikk høsten 2014
- Samarbeid og pasientflyt mellom kirurgisk og medisinsk sengepost
- Felles behandlingsplan og strukturert opplæring
- Fortsatt kurs på LMS

Adherence - etterlevelse

ORIGINAL ARTICLE

Evaluation of tools for annual capture of adherence to immunosuppressive medications after renal transplantation – a single-centre open prospective trial

Marte Theie Gustavsen^{1,2}, Karsten Midtvedt¹, Kjersti Lønning^{1,3}, Thea Jacobsen², Anna Varberg Reisaeter^{1,4}, Sabina De Geest^{5,6}, Marit Helen Andersen^{1,7}, Anders Hartmann^{1,3} & Anders Åsberg^{1,2,4}

SUMMARY
Annual assessment of adherence would strengthen long-term outcome assessments from registry data. The objective of this study was to evaluate tools suitable for annual routine capture of adherence data in renal transplant recipients. A single-centre open prospective trial included 295 renal transplant recipients on tacrolimus. Two-thirds of the patients were included 4 weeks post-transplant, randomized 1:1 to intensive or single-point adherence assessment in the early phase and 1-year post-transplant. One-third were included 1-year post-transplant during a cross-sectional investigation. Adherence was assessed using multiple methods: The "Basel Assessment of Adherence to Immunosuppressive Medication Scale" (BAASIS[®]) questionnaire was used to assess self-reported adherence. The treating clinician scored patient's adherence and tacrolimus trough-concentration variability was calculated. In the analyses, the data from the different tools were dichotomized (adherent/nonadherent). The BAASIS[®] overall response rate was over 80%. Intensive BAASIS[®] assessment early after transplantation increased the chance of capturing a nonadherence event, but did not influence the 1-year adherence prevalence. The adherence tools generally captured different populations. Combining the tools, the nonadherence prevalence at 1 year was 38%. The different tools identified to a large degree different patients as nonadherent. Combining these tools is feasible for annual capture of adherence status.

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Key words
adherence, Basel Assessment of Adherence to Immunosuppressive Medication Scale, clinician's score, tacrolimus variability

Transplant International 2019;
Received: 15 September 2018; Revision requested: 19 October 2018; Accepted: 11 February 2019

- Av 403 pasienter som ble nyretransplantert 2014-2016
- 295 nyretransplanterte inkludert – ulike grupper og ulik målemetode for adherence
- 1 år 38% non-adherence prevalence

Health literacy / Helsekompetanse

Strategier på flere nivåer – WHO – HOD - OUS



Helsekompetanse hos nyretransplanterte

Research

Identifying Core Variables Associated With Health Literacy in Kidney Transplant Recipients

Kari Gire Dahl, RN, MA^{1,2}, Marit Helen Andersen, RN, PhD^{1,2}, Kristin Hjorthaug Urstad, RN, PhD³, Ragnhild S. Falk⁴, Eivind Engebreetsen, PhD¹, and Astrid Klopstad Wahl^{1,2}

Abstract
Background: A kidney transplantation requires complex self-care skills. Identifying strengths and limitations in different aspects of health literacy can help improve health care. The objective of this study was to identify core variables following a kidney transplantation. **Methods:** A single-center cross-sectional study of transplant recipients answered the Health Literacy Questionnaire (HLQ). Multivariate analysis was used to investigate variables possibly associated with the 9 domains of scores in "appraisal of health information" and "navigating the health system." **Conclusions:** The HLQ provides a more complex picture of strength and limitations in health literacy (HL) in kidney transplant care.

Keywords
health literacy, the health literacy questionnaire, kidney transplantation

PROGRESS in TRANSPLANTATION
Progress in Transplantation 1-10
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DOI: 10.1177/1526924819899285
journals.sagepub.com/home/pt
SAGE

RESEARCH ARTICLE

The trigger-information-response model: Exploring health literacy during the first six months following a kidney transplantation

Kari Gire Dahl^{1,2a}, Marit Helen Andersen^{1,2a}, Kristin Hjorthaug Urstad³, Ragnhild S. Falk⁴, Eivind Engebreetsen¹, and Astrid Klopstad Wahl^{1,2a}

^aDepartment of Transplantation Medicine, Oslo University Hospital, Oslo, Norway
^bThe Department of Interdisciplinary Health Sciences, Institute of Health and Society, Faculty of Medicine, University of Oslo, Oslo, Norway
^cThe Faculty of Health Sciences, Department of Quality and Health Technology, University of Stavanger, Stavanger, Norway
^dOslo Centre for Biostatistics and Epidemiology, Oslo University Hospital, Oslo, Norway

Patient Education and Counseling 104 (2021) 1814-1822

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Changes in Health Literacy during the first year following a kidney transplantation: Using the Health Literacy Questionnaire

Kari Gire Dahl^{a,*}, Astrid Klopstad Wahl^{a,b}, Kristin Hjorthaug Urstad^c, Ragnhild S. Falk^d, Marit Helen Andersen^{a,b}

ARTICLE INFO
Article history:
Received 24 March 2020
Received in revised form 29 October 2020
Accepted 28 December 2020

Keywords:
Health literacy
The Health Literacy Questionnaire
Kidney transplantation
Kidney transplant recipients
Prospective design

ABSTRACT
Objectives: The study aimed to identify changes in health literacy (HL) and associated variables during the first year following a kidney transplantation.
Methods: A total of 196 transplant recipients were included in a prospective follow-up study. The patients answered the Health Literacy Questionnaire (HLQ) at 5 days, 8 weeks, 6 and 12 months following the kidney transplantation. Mixed linear models were used to analyze changes in HL and backward elimination was used to identify variables associated with HL.
Results: Two main patterns of change were identified: a) HL increased during the first 8 weeks of close follow-up and b) in several domains, the positive increase from 5 days to 8 weeks flattened out from 5 days to 6 and 12 months. Self-efficacy, transplant-related knowledge, and general health were core variables associated with HL.
Conclusions: Overall, HL increased during the 8 weeks of close follow-up following the kidney transplantation, while 6 months seem to be a more vulnerable phase. Furthermore, low self-efficacy, less knowledge, and low self-perceived health may represent vulnerable characteristics in patients.
Practical implications: Future kidney transplant care should take into account patients' access to and appraisal of health information and social support, and draw attention to potentially vulnerable groups.
© 2021 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

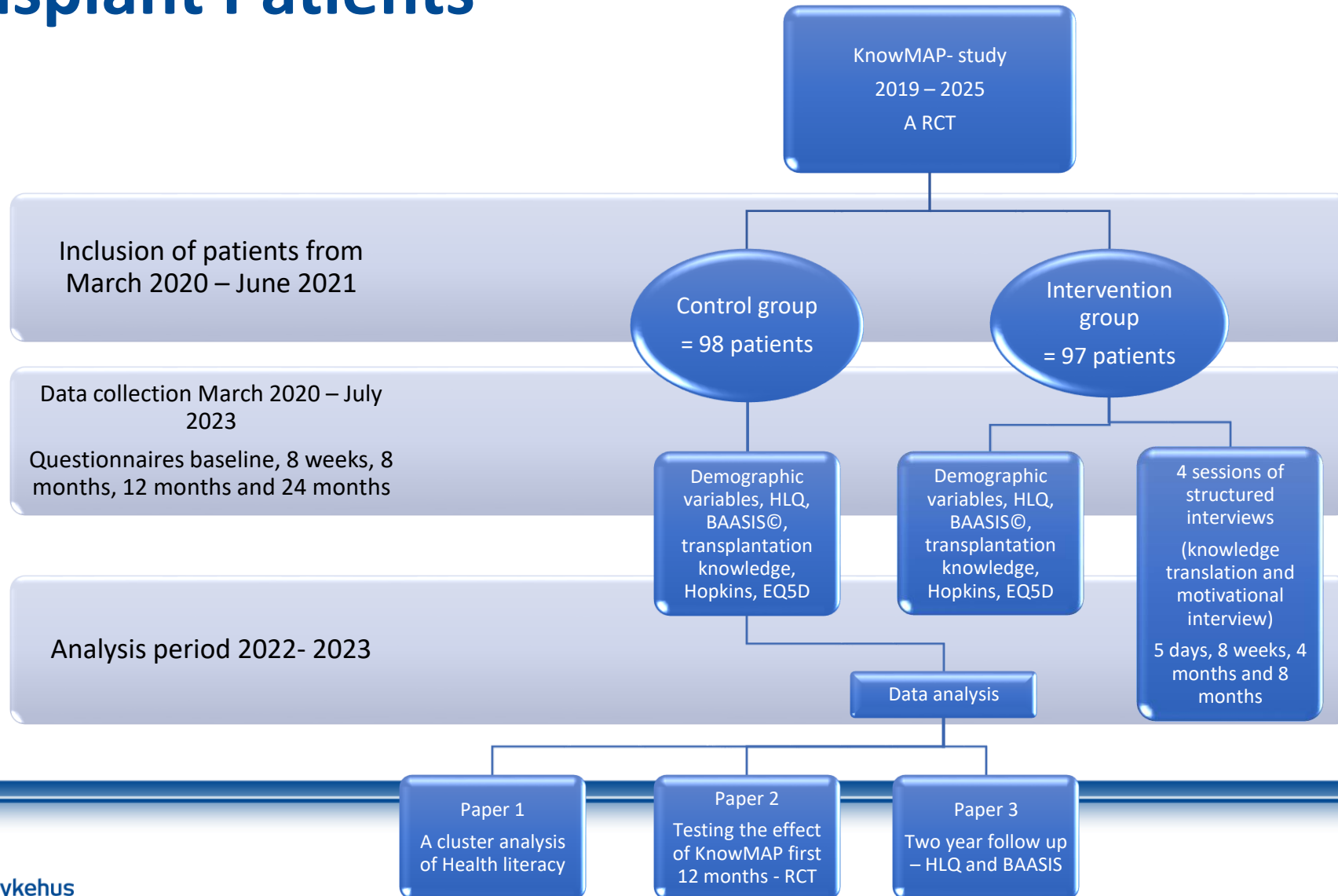
Hvorfor er helsekompetanse så viktig?

- Personer med lav helsekompetanse og sosial isolasjon er i risiko for tidlig død
- Flere sykehusinnleggelser og reinnleggelser
- Går glipp av dialysebehandling
- Større bruk av akutttilbud som legevakt
- Dårligere helse og høyere dødelighet
- Non-adherence
- Økte kostnader for helsevesenet
- Sosiale ulikheter



Miller-Matero, Bryce et al. 2016
Smith et al 2017
Taylor, Fraser et al. 2017

KnowMAP – Knowledge MAnagement for renal transplant Patients



Takk for oppmerksomheten!

Spørsmål?

tvidnes@ous-hf.no



De yngre?

Prøver å fokusere på det positive og la ikke noe vekt på det negative, som risiko for bivirkninger som tx kunne medføre.

Håndtere negative følelser (mestre angst, frykt, dårlig samvittighet for donor som var en forelder)

Transplantasjon som eneste mål (eneste behandling for å slippe dialyse)

Påpekte viktigheten av individuell opplæring

Format Abstract - Send to -

BMJ Open. 2018 Jun 22;8(6):e021275. doi: 10.1136/bmjopen-2017-021275.

Older kidney transplantation candidates' expectations of improvement in life and health following kidney transplantation: semistructured interviews with enlisted dialysis patients aged 65 years and older.

Lenning K^{1,2}, Mithvedt K¹, Heistol K³, Andersen M^{1,4}.

Author information

Abstract

OBJECTIVE: The aim was to study the expectations of improvement in life and health following kidney transplantation in wait-listed patients ≥65 years with end-stage kidney disease.

DESIGN: Qualitative research with individual in-depth interviews.

SETTING: Patients on dialysis enlisted for a KTx from a deceased donor.

INFORMANTS: Fifteen patients.

RESULTS: In addition, the themes 'hard to lose' and 'guilt for siblings and burden of parent as donor' were highlighted. The informants' expectations. They were hoping to become free from dialysis and to live with a transplant.

CONCLUSIONS: Older kidney transplantation candidates comprise a heterogeneous group of patients who take individual approaches that vary in their expectations of improvement in life and health following kidney transplantation. This study provides new knowledge about the older KTx candidates and researchers.

KEYWORDS: end stage kidney disease; older renal patients; patient perspective; qualitative research; renal transplantation

PMID: 29934388 PMCID: PMC6020955 DOI: 10.1136/bmjopen-2017-021275

Free PMC Article

Children's experiences and expectations of kidney transplantation: A qualitative interview study.

Walker RC¹, Naicker D², Kara T², Palmer SC^{3,4}.

Author information

Abstract

RATIONALE AND OBJECTIVE: Kidney transplantation offers improved quality of life and life expectancy compared with dialysis for children. This study aims to understand the experiences and expectations of children during the kidney transplantation process to inform clinical care.

STUDY DESIGN: Face-to-face, semi-structured interviews.

SETTING AND PARTICIPANTS: We interviewed 13 children and adolescents aged between 7 and 17 years old in New Zealand who had undergone kidney transplantation.

RESULTS: We conceptualised the findings using thematic analysis with inductive coding.

CONCLUSIONS: Major themes: transplant as the goal (the only real treatment and escaping dialysis); dealing with negative emotions (including guilt for siblings and burden of parent as donor); and enhancing understanding and knowledge (including peer support).

LIMITATIONS: Before, the transferability of findings to other populations is unclear.

CONCLUSIONS: Children focus on the positive aspects of transplant as freedom from dialysis and return to a more normal life. Children focus on the negative aspects of transplant as the uncertainty of the future. Complex emotions arise when thinking about their future. Children recognise the importance of health and actively seek out ways to self-manage their care, while maintaining a positive outlook. This study provides new knowledge about the experiences and expectations of children during the kidney transplantation process to inform clinical care.

De eldre (>65)?

Så på transplantasjonen som en sjanse til å få tilbake livet

Dialyse var en begrensende faktor for det sosiale livet

Vanskelig å miste kapasitet og styrke

Kunne ikke fokusere på ventingen, men måtte holde det gående i den situasjonen de var

