

Predialyse: bedenkingen uit de praktijk

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UZ Gent

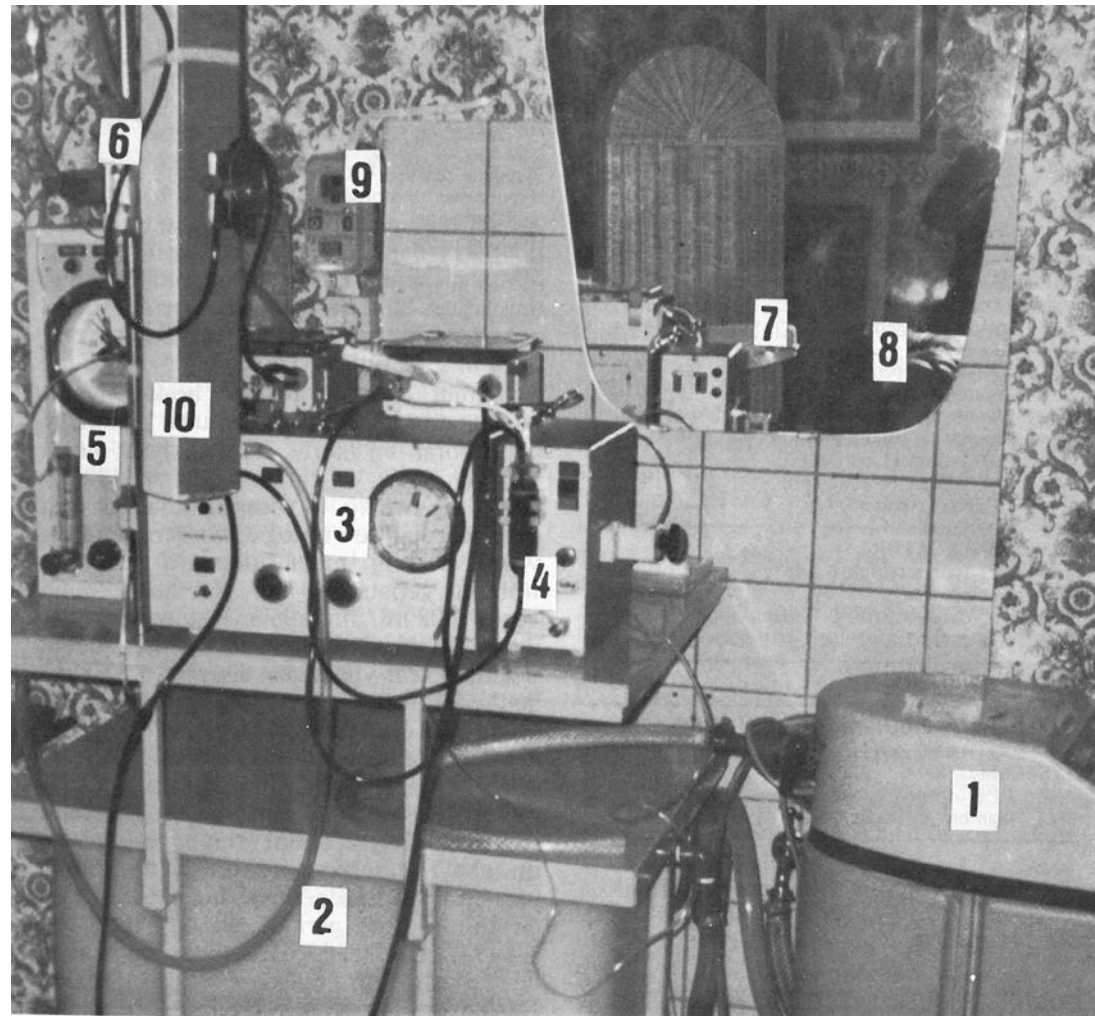
ORPADT 15 mei 2014

Historiek van de dienst

- **1973: Start thuishemodialyse programma**
 - 1975: 5 patiënten werden thuis gedialyseerd
 - 1980: 25 patiënten thuis
 - 1994: laatste patiënt overleden

- **1978: Start peritoneale dialyse programma**
 - 1980: 27 pat. werden thuis behandeld met CAPD

- **2009: Herstarten thuishemodialyse programma**
 - 01/01/2014: 10 patiënten thuis en 1 in opleiding



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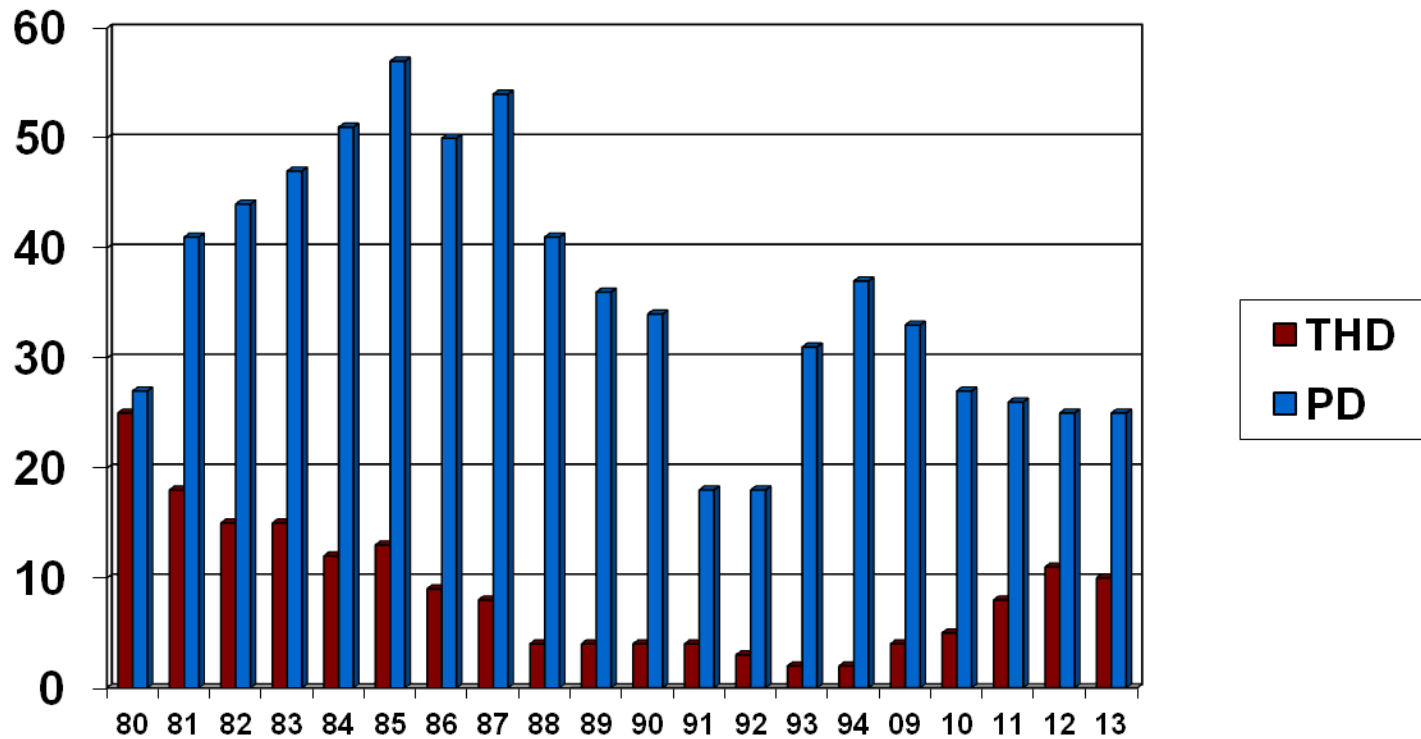
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Verdeling THD/PD

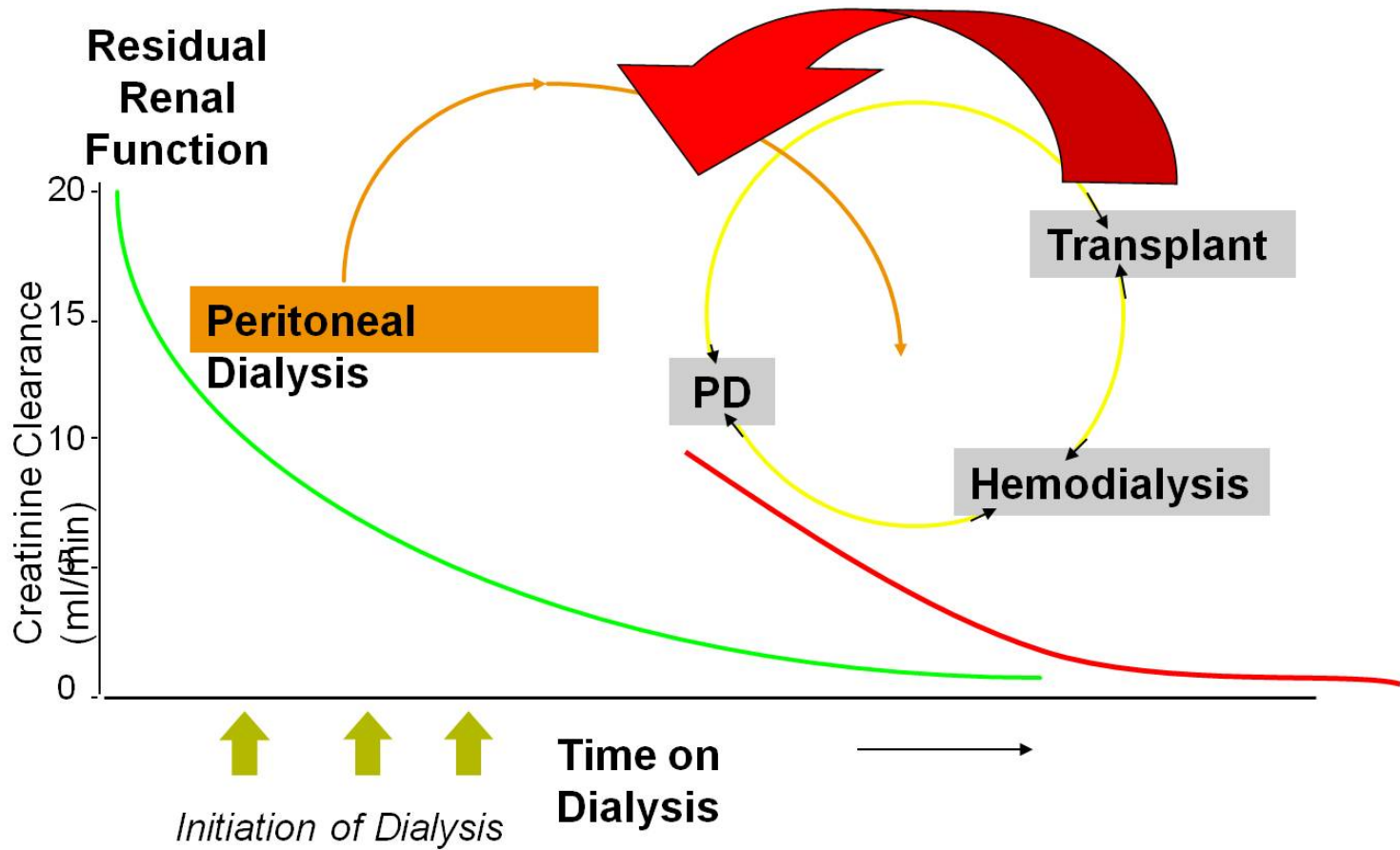


Hemodialyse thuis of in het centrum?

- ➔ **1973: editoriaal La Nouvelle Presse Médicale, A. Baglin, Boulogne sur Seine**

“ Au total, la dialyse à domicile, la dialyse en centre et la transplantation renale ne doivent pas être considérées comme compétitives, mais au contraire comme complémentaire”

The Context - within the Integrated Care Model



Informeren van patiënten bij switch dialysemodaliteit

- ➔ **Info over nieuw voorgestelde techniek**
- ➔ **Implicaties voor de thuissituatie**
- ➔ **Inschatten mogelijkheden van patiënt en familie**
- ➔ **Opbouwen wederzijds vertrouwen**

Predialyse doelstellingen Patiënt

- ➔ **Betere overleving**
- ➔ **Betere gezondheid**
- ➔ **Betere zorg**
- ➔ **Inschatten financiële gevolgen**

Predialyse doelstellingen

Medisch

- **Goede bloeddruk controle**
- **Correctie van de renale anemie en ijzerstatus**
- **Correctie van metabole acidose**
- **Rookstop al dan niet ondersteund door een rookstop programma**
- **Zorgen voor een goede nutritionele toestand en ondervoeding voorkomen**
- **Bij diabetes: goede regeling van de glycemie**
- **Vaccinatie voor hepatitis B waar nodig**

Predialyse doelstellingen Team

- ➔ **Informatie over verschillende behandelingsmodaliteiten**
- ➔ **Begeleiden in maken van therapiekeuze**
- ➔ **Tijdige aanleg van toegangsweg**
- ➔ **Start pretransplant onderzoeken**

Educatie

- ➔ **Team**
- ➔ **Patiënt**
- ➔ **Familie en omgeving van de patiënt**
- ➔ **Huisarts**
- ➔ **Andere zorgverleners**

Het multidisciplinaire team

Het team bestaat meestal uit:

- ➔ **Artsen**
- ➔ **Verpleegkundigen**
- ➔ **Diëtiste**
- ➔ **Sociaal werkers**
- ➔ **.....**

Het multidisciplinaire team

Het team kan ook ruimer gezien worden:

- ➔ **Artsen**
- ➔ **Verpleegkundigen**
- ➔ **Diëtiste**
- ➔ **Sociaal werkers**
- ➔ **Psycholoog**
- ➔ **Liaison geriatrie**
- ➔ **Patiëntenparticipatie**
- ➔ **.....**

Volwasseneneducatie

“Het organiseren van voorzieningen en activiteiten gericht op vergroting van kennis, inzicht en vaardigheden, door volwassenen voor zichzelf of voor anderen”

Te maken keuzes

- ➔ **Kiezen voor behandeling thuis of in het ziekenhuis**
- ➔ **HD of PD (beide met alle mogelijke varianten)**
- ➔ **Behandeling 's nachts of overdag**
- ➔ **Is er mogelijkheid voor niertransplantatie?**
- ➔ **Wat met levende nierdonatie?**
- ➔ **Wat is de impact op het gezin – het werk – hobby's – de financiële toestand?**

The need for a patient based survey to identify the opportunities for Kidney disease improvement in Europe

- **Lars Engberg**
- **Vice-president, CEAPIR**

www.ceapir.org

Patient choice and access to treatment of kidney disease across Europe

Who is CEAPIR?

- ➔ **Umbrella organization for European kidney patient organizations**
- ➔ **21 member organizations**

- ➔ **Mission:**
 - ➔ Improving treatment and conditions for kidney patients by
 - ➔ Exchange information and experience between member organizations
 - ➔ Influencing decision makers on a European level

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Patient choice and access to treatment of kidney disease across Europe

Minimum requirements

- ➔ **12 minimum requirements, among others:**
 - ➔ Early detection through training of GP's
 - ➔ Clear, precise information and education delivered to patients
 - ➔ Equal access to suitable quality treatment, regardless of age, culture, mental and social conditions

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Patient choice and access to treatment of kidney disease across Europe

Why patient involvement ?

➔ Patient involvement has a positive effect:

- ➔ Quality of life and patient satisfaction
- ➔ Clinical outcome
- ➔ Patient safety

(Coulter A., Ellins J.: Patient-focused interventions – A review of the evidence. London: The Health Foundation, 2006, Baumann, A. E. et al., Getting it right: why bother with patient-centered care? The Medical Journal of Australia 2003)

- ➔ Patients have a different perspective than professionals
- ➔ Patients can identify events that may affect treatment
- ➔ Patient experiences complement health professional knowledge

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Patient choice and access to treatment of kidney disease across Europe

Unequal treatment for European kidney patients – Patient survey and analysis of renal care across the European Union

- ➔ **Kajsa Wilhelmsson**
- ➔ **Edelman**

www.ceapir.org

Patient choice and access to treatment of kidney disease across Europe

Changes needed

- **Complete and understandable information about kidney disease needs to be put in place.**
- **Patients must be informed in a clear, understandable and unbiased way about all treatment options.**
- **Patients need to be informed about their rights as well as responsibility to be involved in decisions.**
- **Healthcare professionals must accept the well-informed patient as a partner in decision-making and a manager of their own care.**
- **All countries must achieve accepted standards of quality of treatment whilst at the same time making care affordable and accessible.**
- **Identifying kidney disease earlier than stage 4 is necessary in order to improve kidney care for patients in Europe.**

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Patient choice and access to treatment of kidney disease across Europe

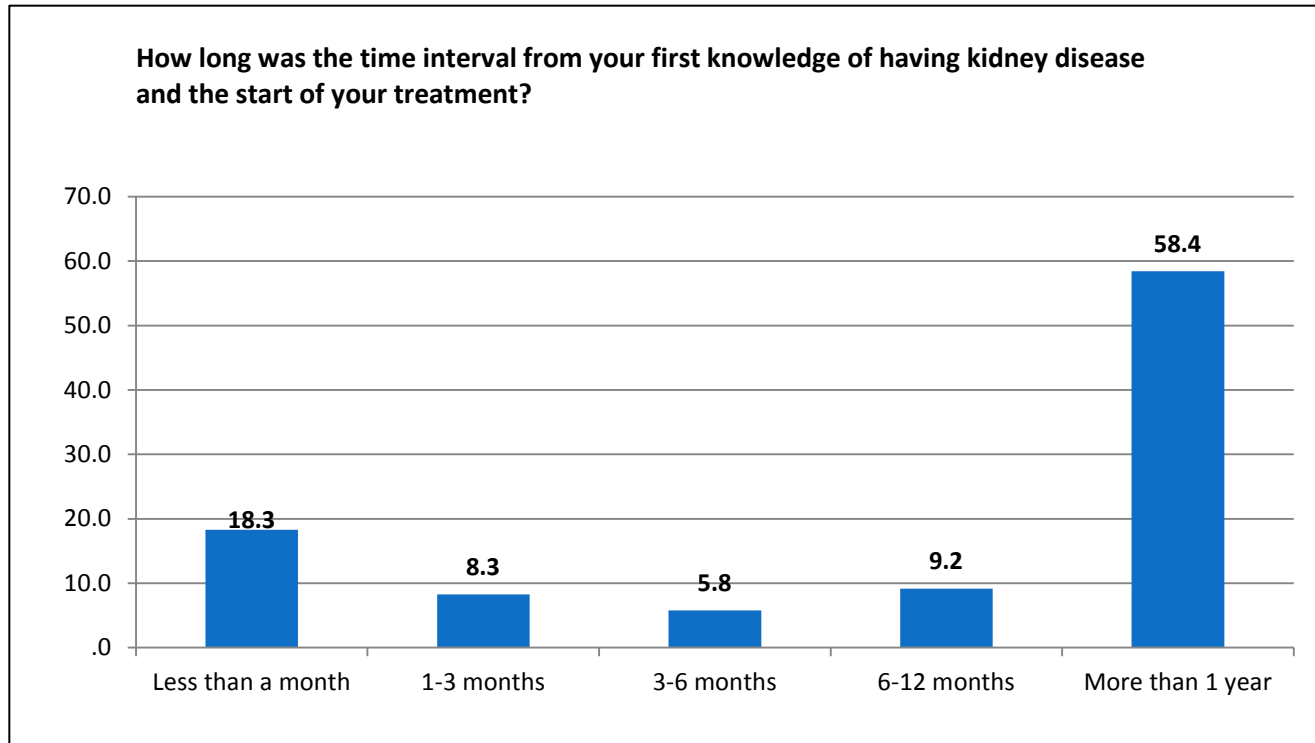
Key Challenges

- ➔ **Challenges identified by the survey correspond to a large extent to the CEAPIR European Country Minimum Requirements, more notably:**
 - ➔ Early detection,
 - ➔ Equal quality,
 - ➔ Access,
 - ➔ Information,
 - ➔ Education of patients.

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Early Detection

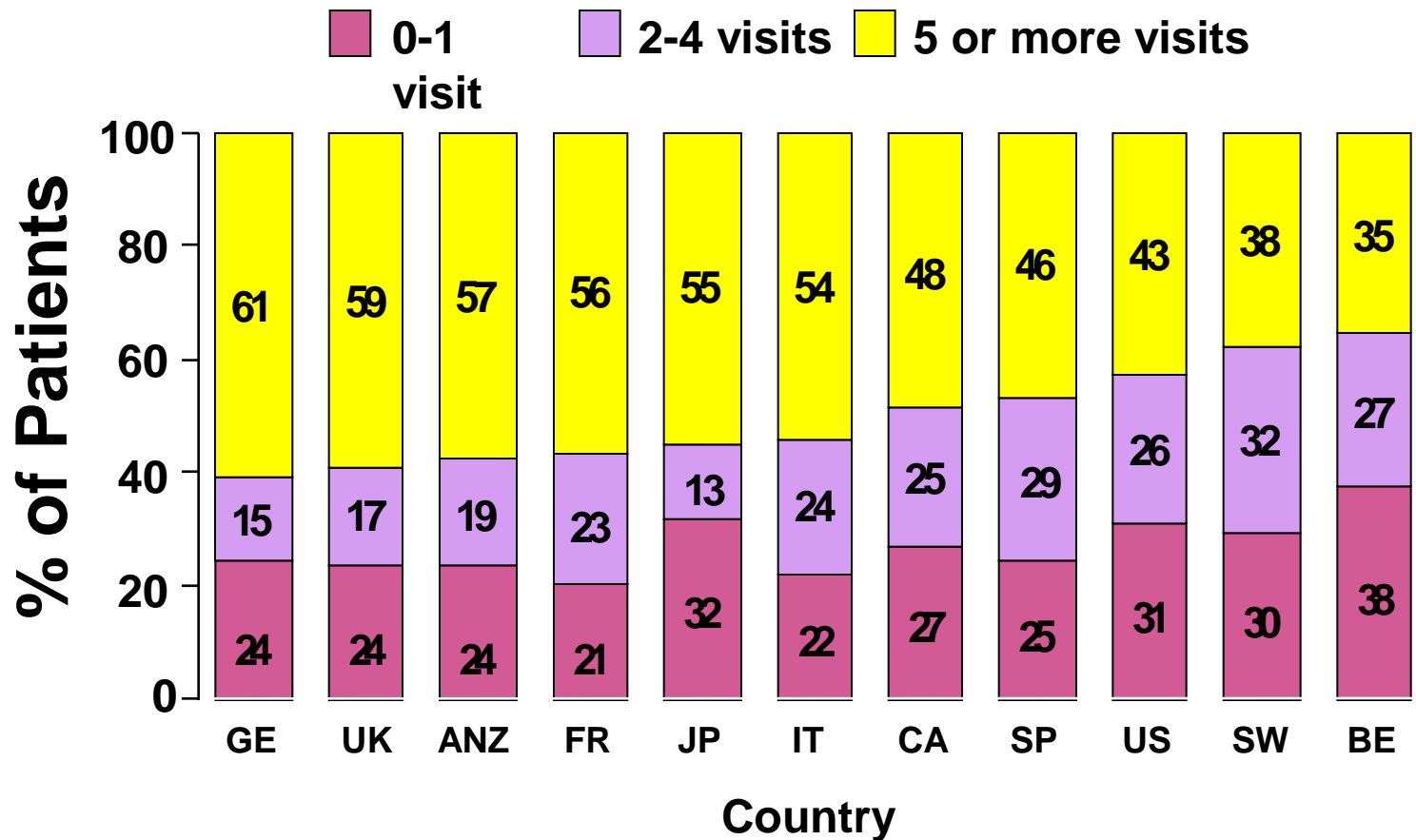


One in four CEAPIR respondents started dialysis in less than three months after they first learned that they had kidney disease.

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Patient choice and access to treatment of kidney disease across Europe

Distribution of Number of Visits with Nephrologist Prior to ESRD Onset, by Country



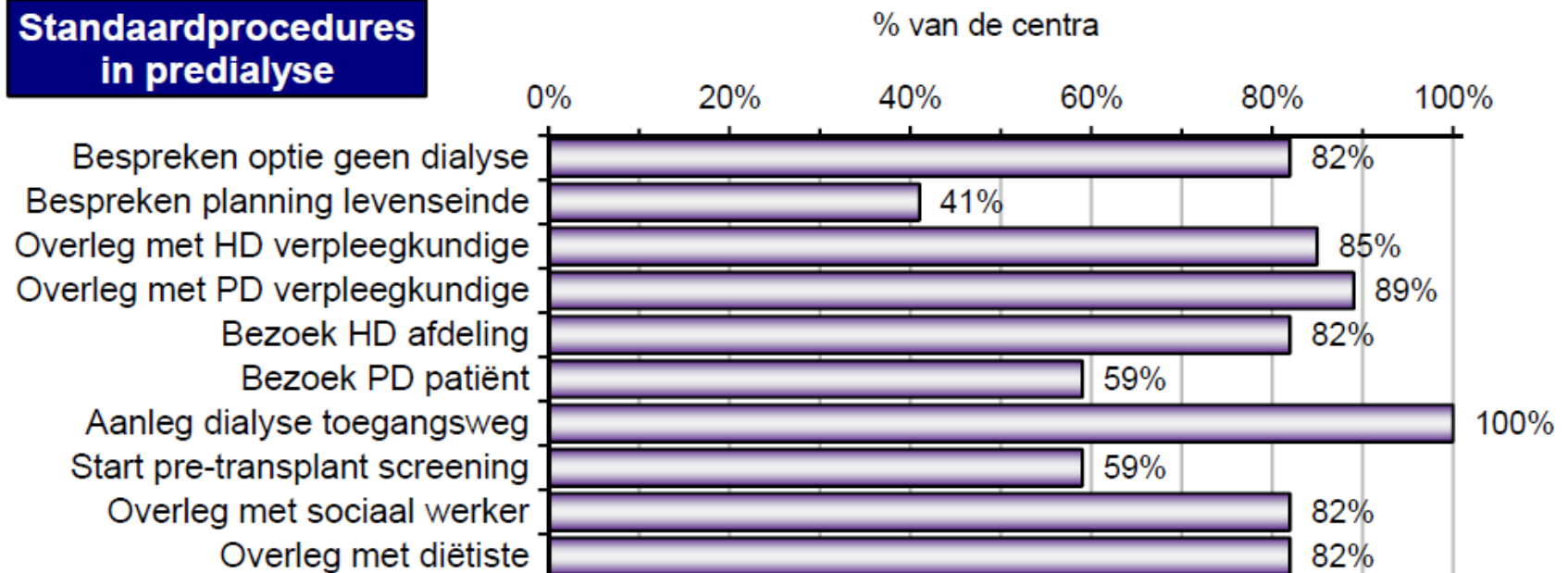


Enquête 2012

Predialyse (1)

- 16/27 centra (59%) hadden een **Klinisch Pad Predialyse** voor de behandeling van patiënten met niet-terminaal chronisch nierlijden (44% in 2009).
- 14/16 centra met Klinisch Pad hanteerden een vaste GFR waarde om patiënten op te nemen in het Klinisch Pad:
 - 3 hanteerden GFR > 30 ml/min (KDOQI 3)
 - 10 hanteerden GFR 15-29 ml/min (KDOQI 4)
 - 1 hanteerde GFR < 15 ml/min (KDOQI 5).

Standaardprocedures in predialyse

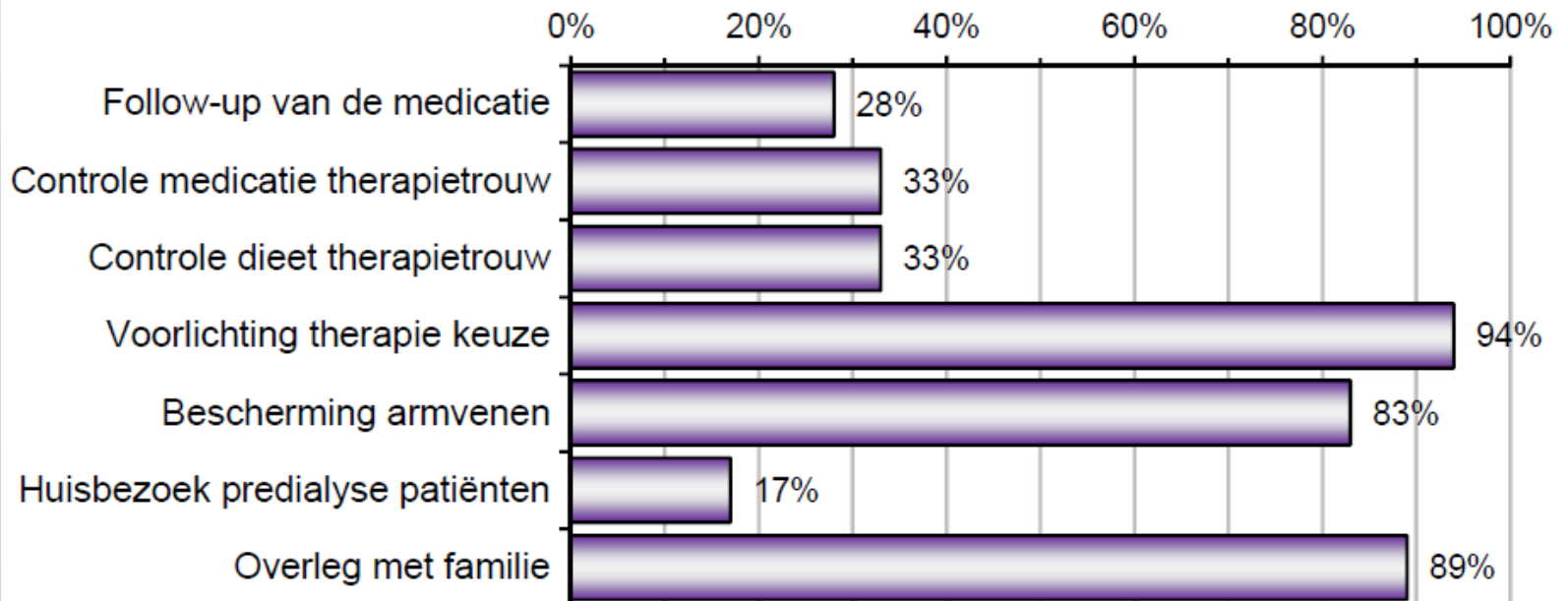


Predialyse (2)

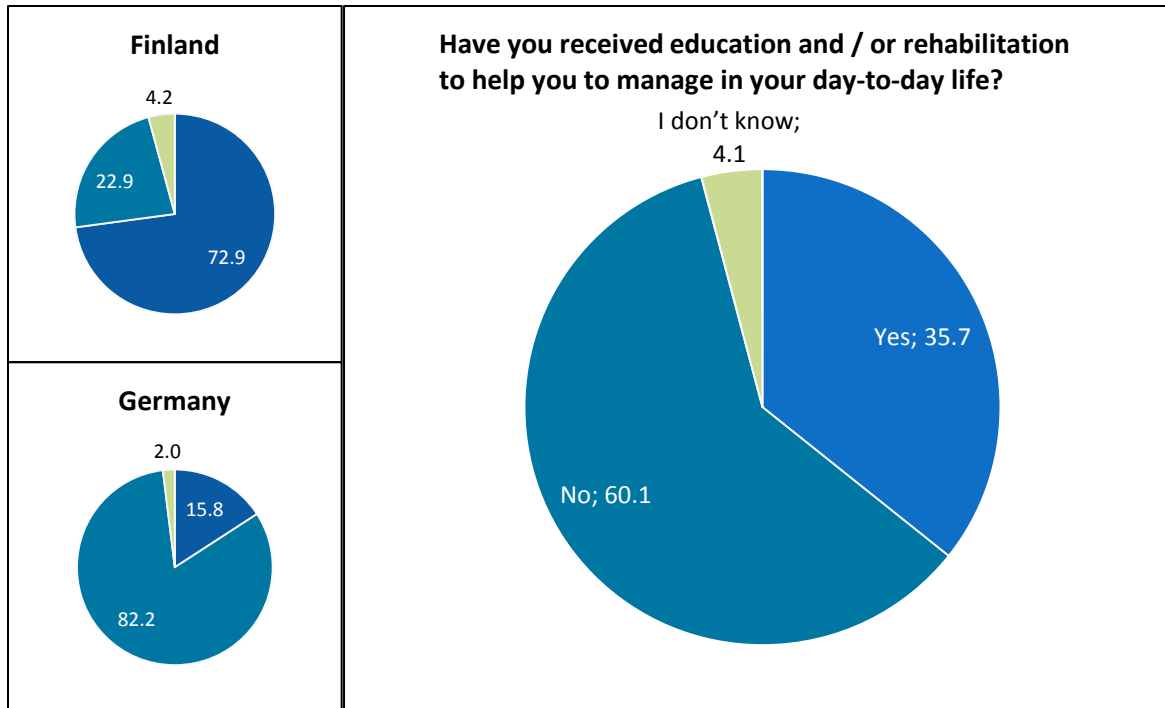
- 18/27 van de centra (67%) beschikte over een 'predialyse' verpleegkundige.

Specifieke taken van predialyse verpleegkundige

% van de centra (n=18)

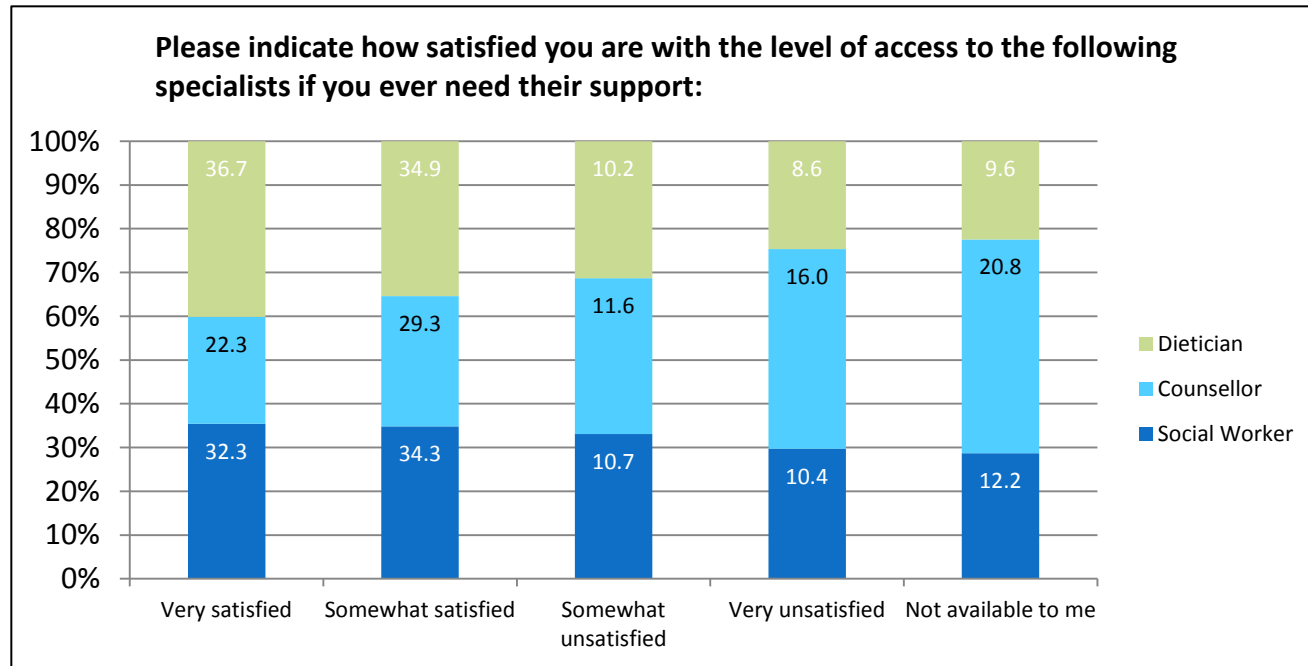


Equal Quality



Nearly two-thirds of patients did not receive the education or rehabilitation they need to help reconcile their kidney condition with their day-to-day life.

Access to care



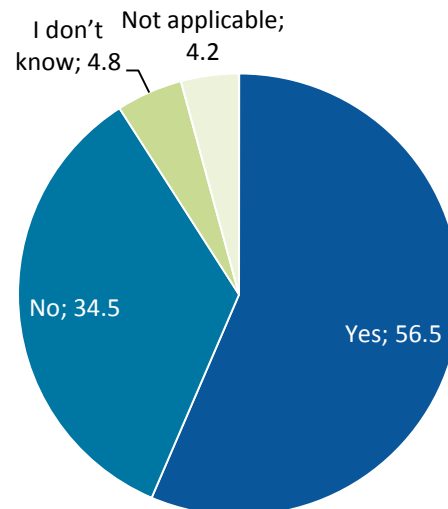
Nearly a half of patients are unsatisfied with the access they have to a counsellor, or do not have access to one at all. About a third of patients do not have access or are dissatisfied with their access to a dietician and a social worker.

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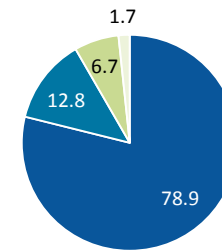
Patient choice and access to treatment of kidney disease across Europe

Information about choice

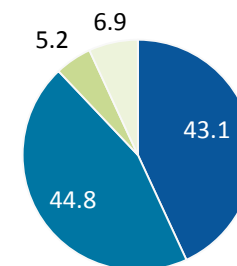
During this treatment time, has anyone ever spoken to you about alternative dialysis options and the possibility of changing treatments?



Hungary

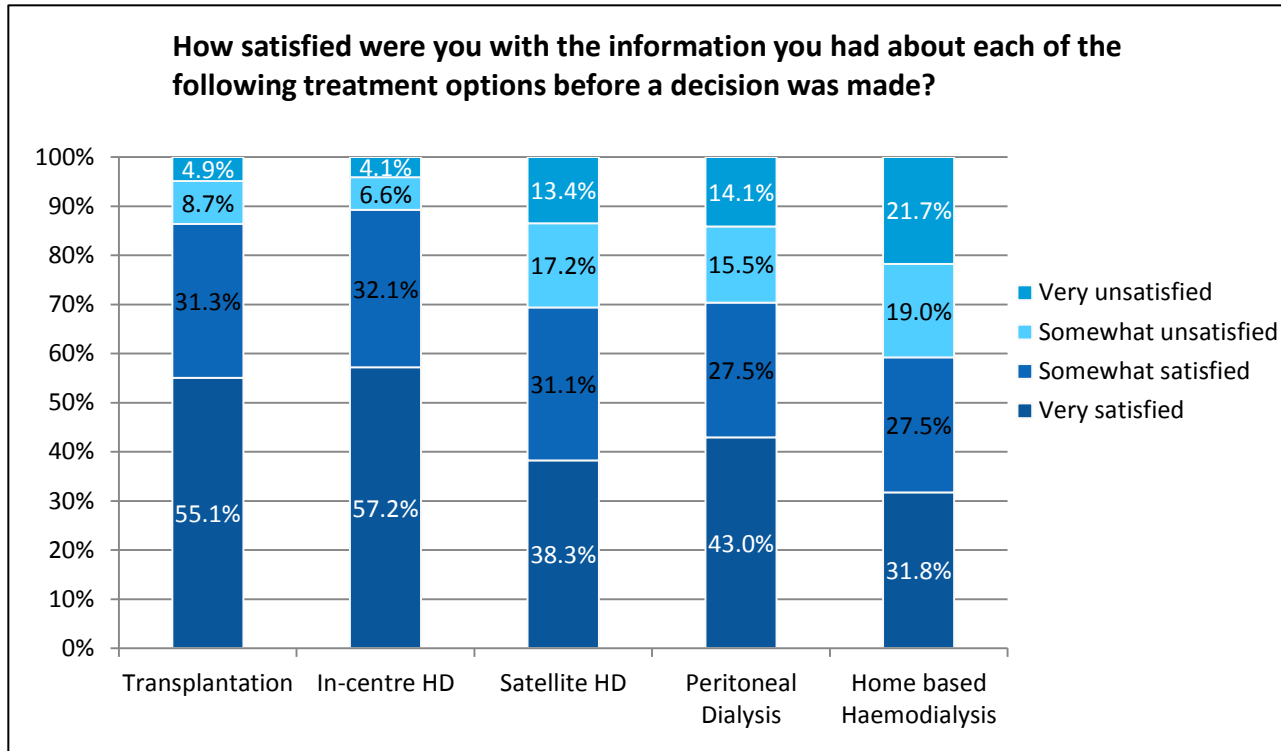


Italy



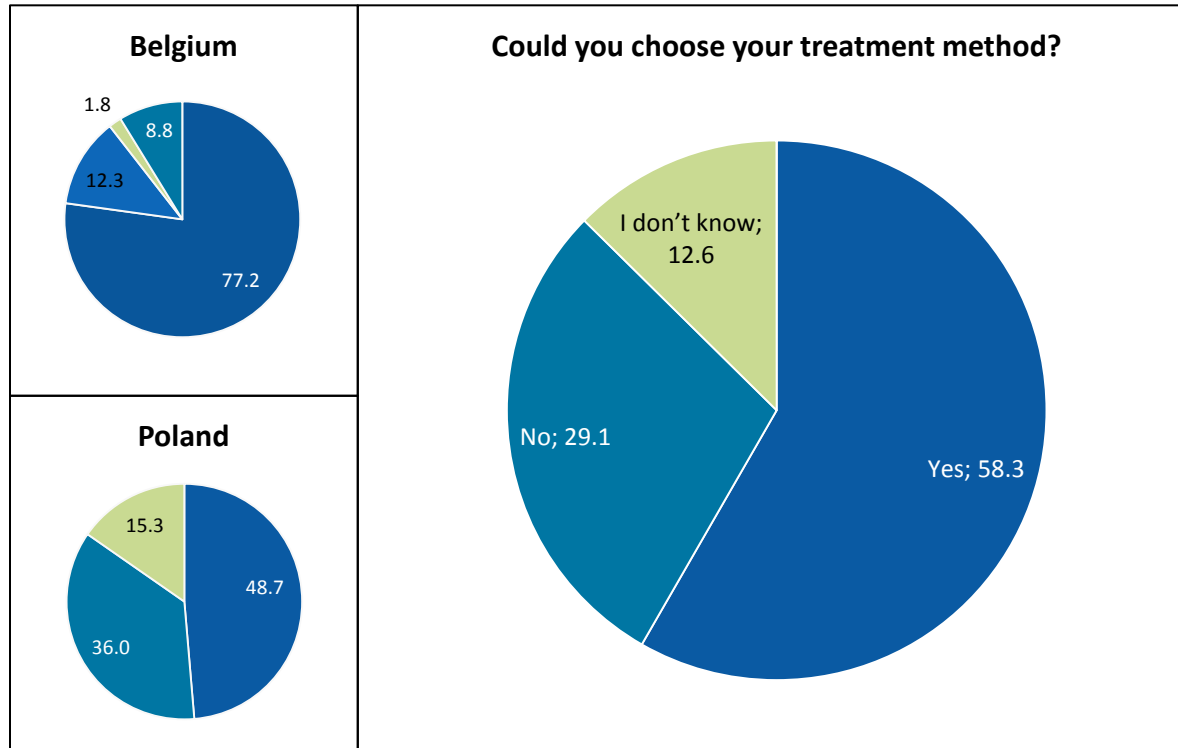
Almost a half of respondents in Europe do not recall having discussed alternative treatment options.

Does information matter?



Respondents are unsatisfied with information on satellite haemodialysis, home-based haemodialysis and peritoneal dialysis.

Does choice matter?

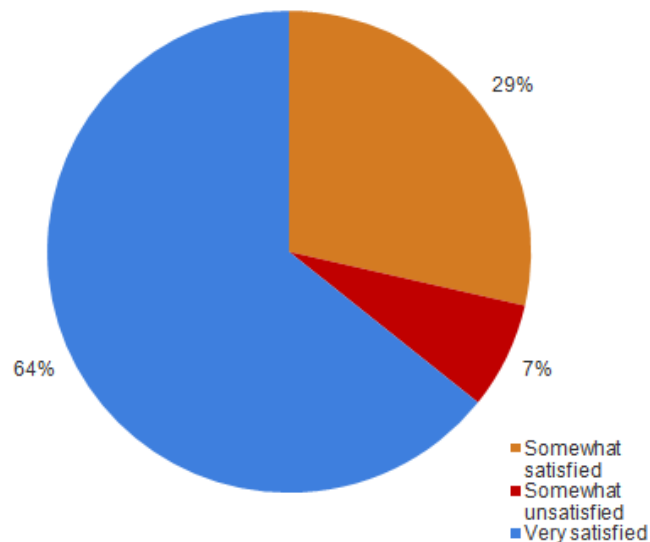


One in three patients in Europe cannot choose their treatment method or is not sure about how much their choice counted.

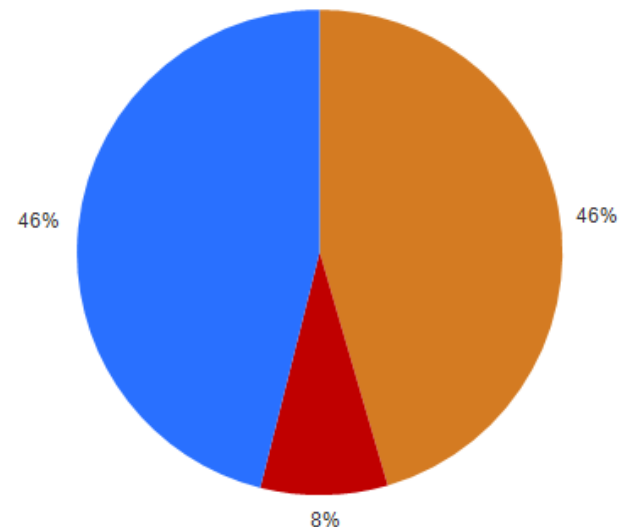
Yes – informed choice matters

Q12. How satisfied were you with the overall level of care you have received for your kidney disease?

Peritoneal Dialysis (PD)



Haemodialysis (HD)



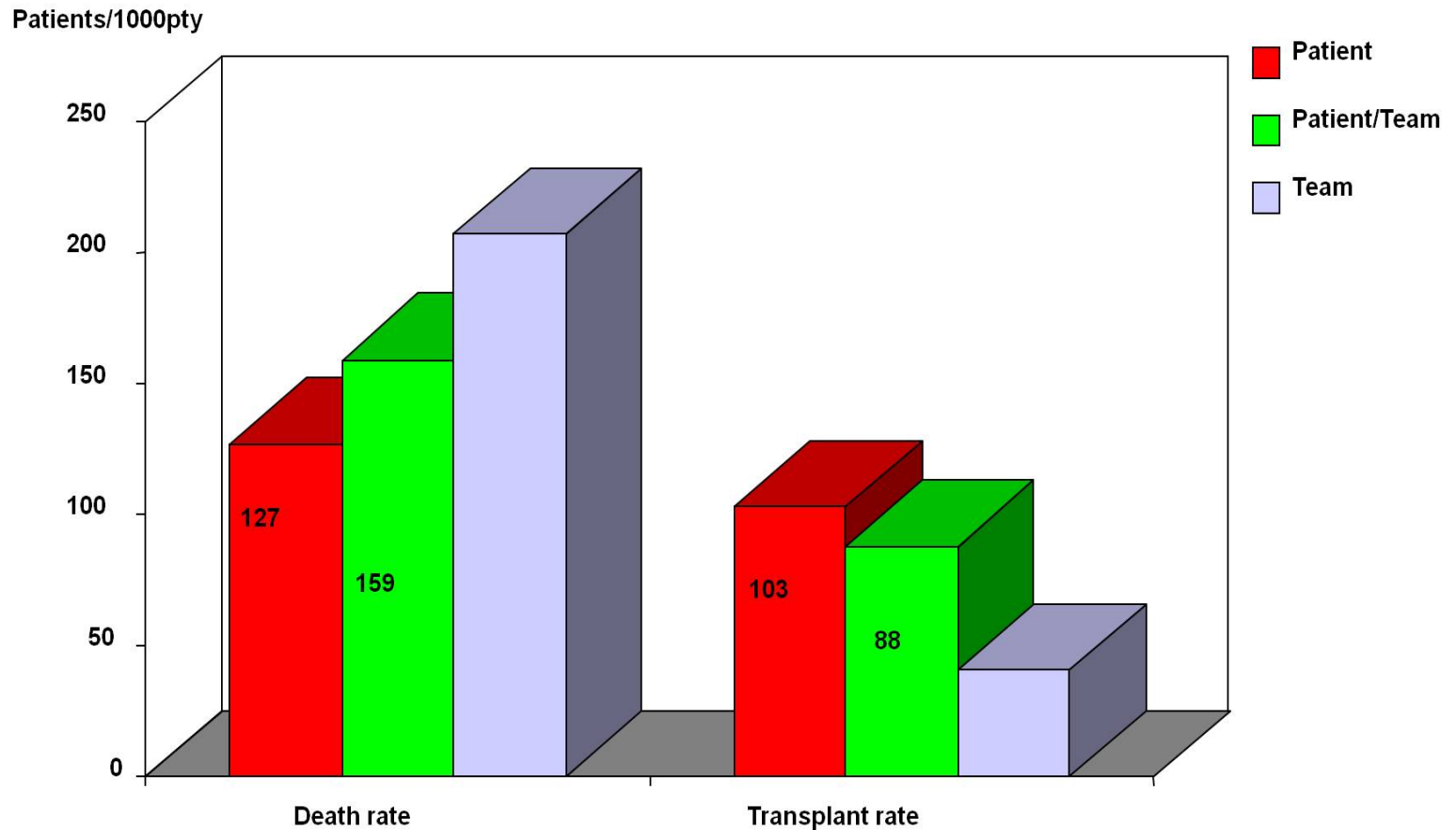
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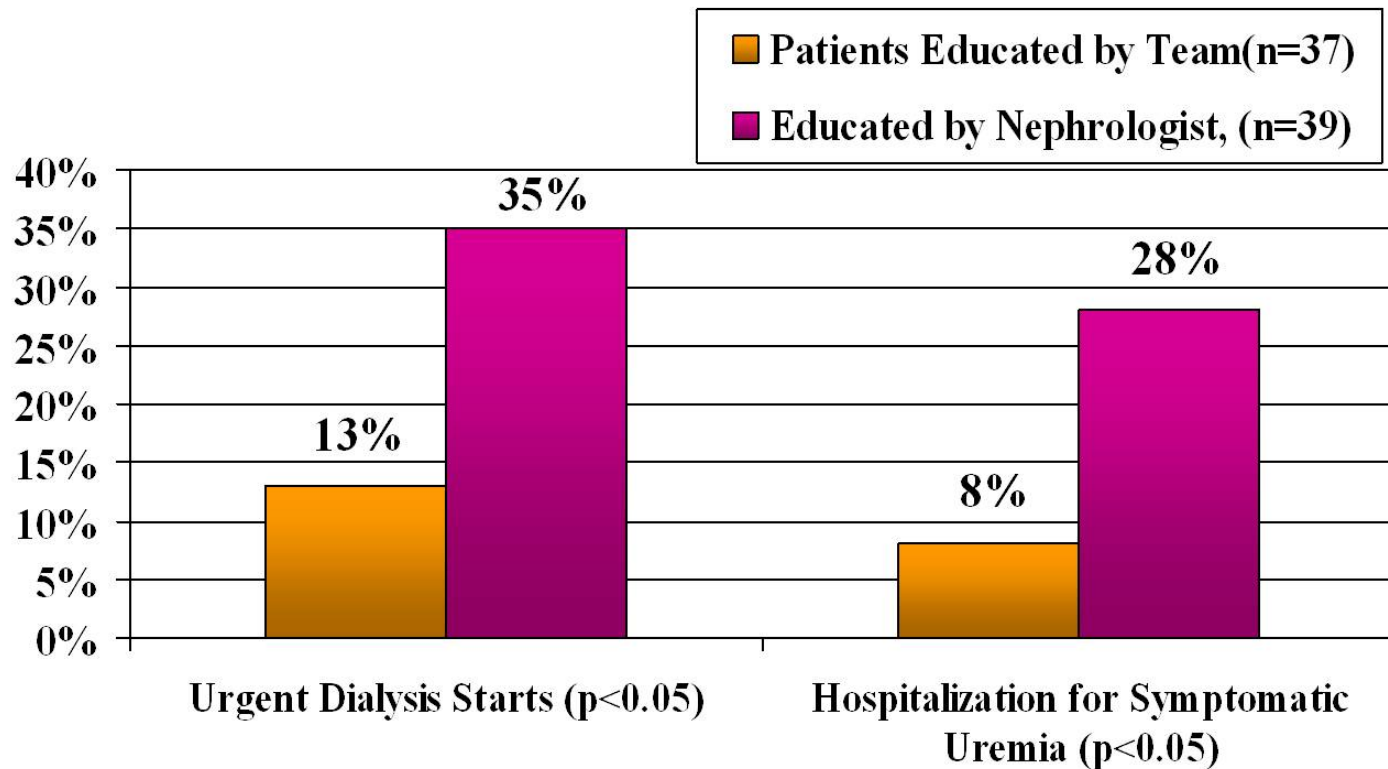
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Empowerment and Outcome



Multi-Disciplinary Team-Based Pre-ESRD Education Leads to Better Clinical Outcomes



Aanvraag predialyse begeleiding

NEFROLOGIE UZ GENT

AANVRAAG PRE DIALYSE BEGELEIDING

NAAM PATIENT: DATUM UUR

ARTS

A. Vroegtijdig gesprek (bedoeld voor patiënten met Crea < 30ml en evolutief)

- Overzicht problematiek terminaal nierlijden
- Overzicht nierfunctievervangende therapieën
 - Alle
 - Geen PD
 - Geen HD
 - Geen TX
 - Andere opmerkingen:
- Noodzaak hepatitis B vaccin: ja neen
- Arm sparen links rechts

B. Gesprek i.f.v. keuze dialysemodaliteit

(dit gesprek dient te worden voorafgegaan door een consultatie bij een vast stafflid nefrologie, die het gesprek op rails zet)

- Voorkeur arts:
 - Contra indicaties voor:
 - HD
 - PD
 - TX
- Reden:

C. Verpleegkundig verslag:

Predialyse programma

Zou moeten starten bij alle ambulante patiënten met een **creatinine klaring < 30ml/min**

- Leren inspuiten van EPO
- Educatie rond het belang van goede bloeddrukcontrole
- Belang van het sparen van een arm voor vasculair access
- Hepatitis B vaccinatie
- Aandacht voor de voeding

Predialyse programma

Wanneer creatinine klaring

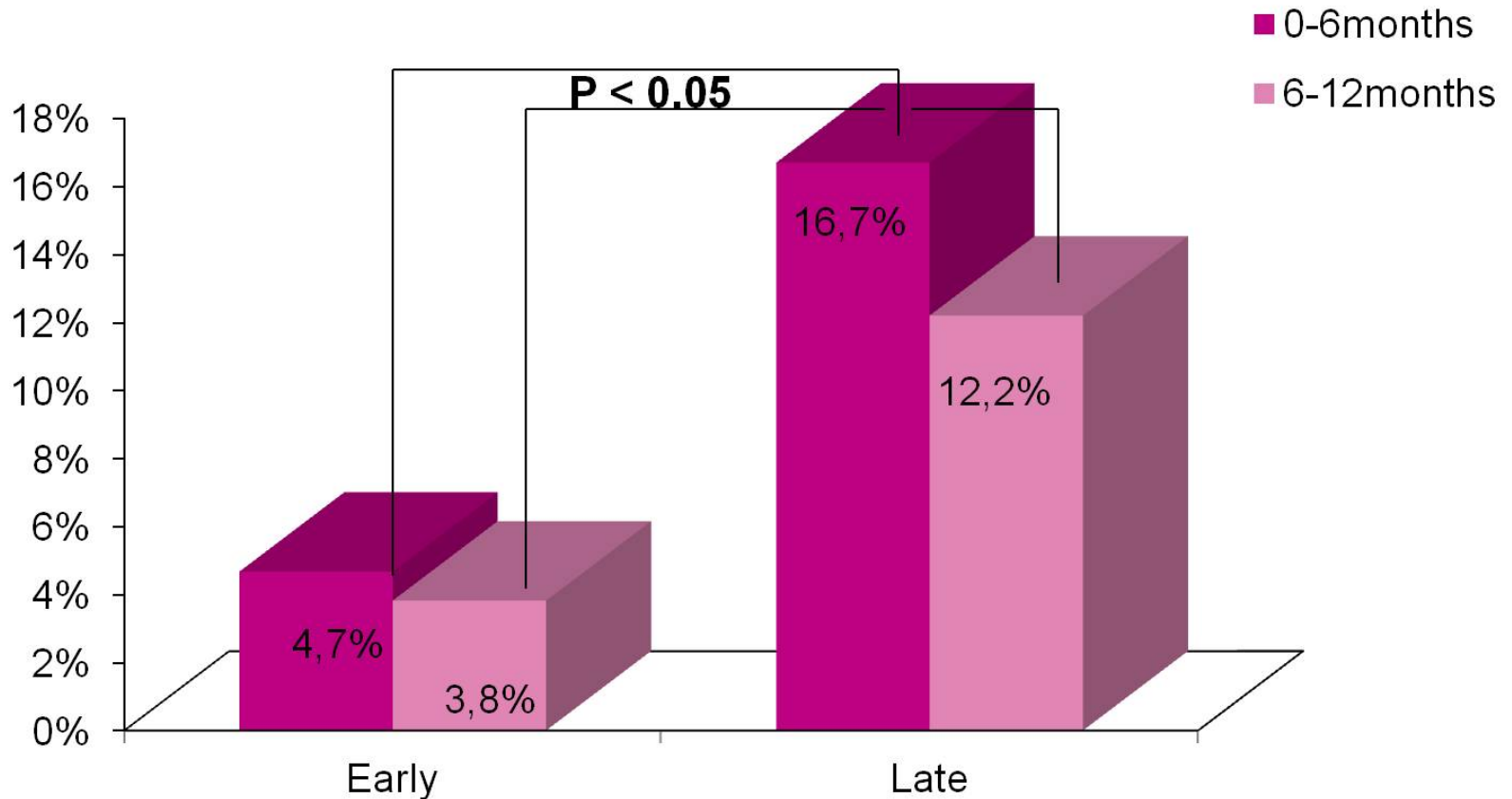
< 20ml/min: gesprek i.f.v. keuze

- Behandeling thuis - ziekenhuis
- HD of PD
- Behandeling 's nachts of overdag
- Mogelijkheid tot transplantatie?
- Wat met levende nierdonatie?
- Impact op gezin – werk – hobby's - financiën

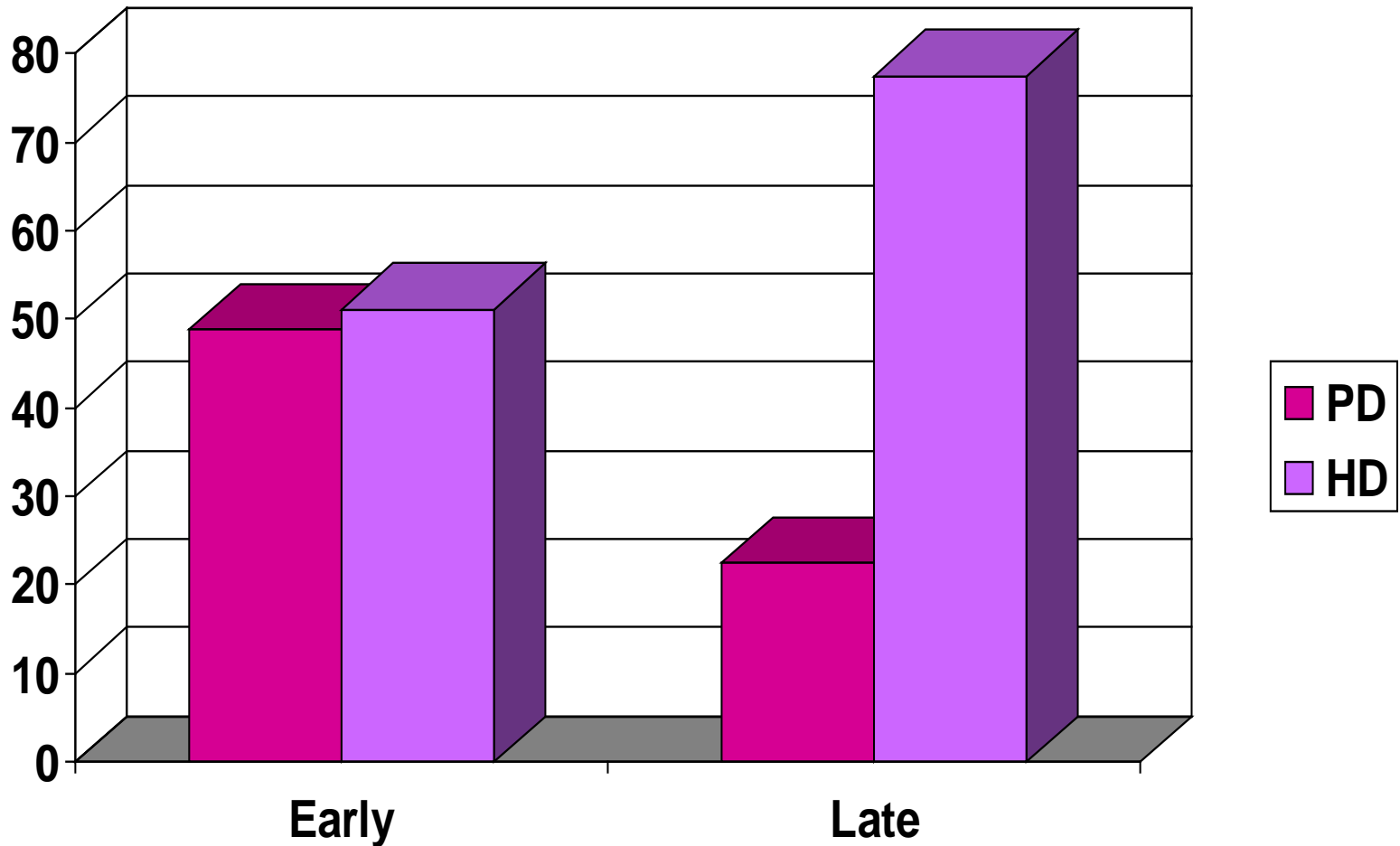
Predialyse programma: problemen

Acute patienten en late doorverwijzing

Referral and mortality



Modality choice



Predialyse programma:problemen

Acute patienten en late doorverwijzing:

**Iedere patiënt die als “late referral”
start aan HD moet ook educatie
krijgen over PD**

Predialyse programma: problemen

Wat met de ouderen?

Late referral in the elderly

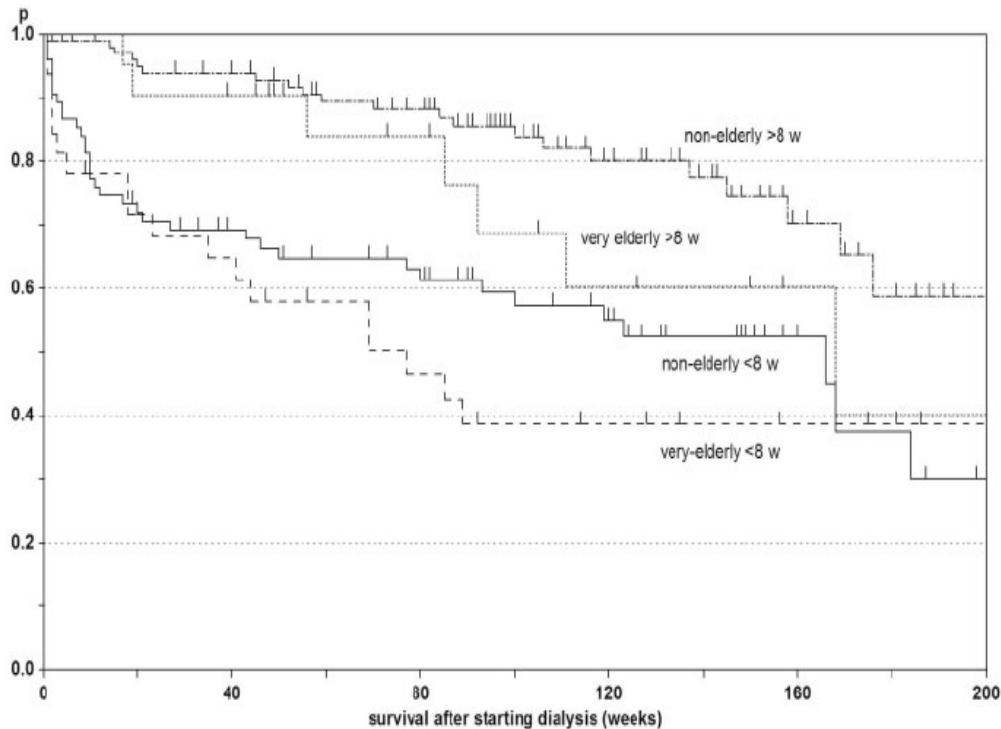
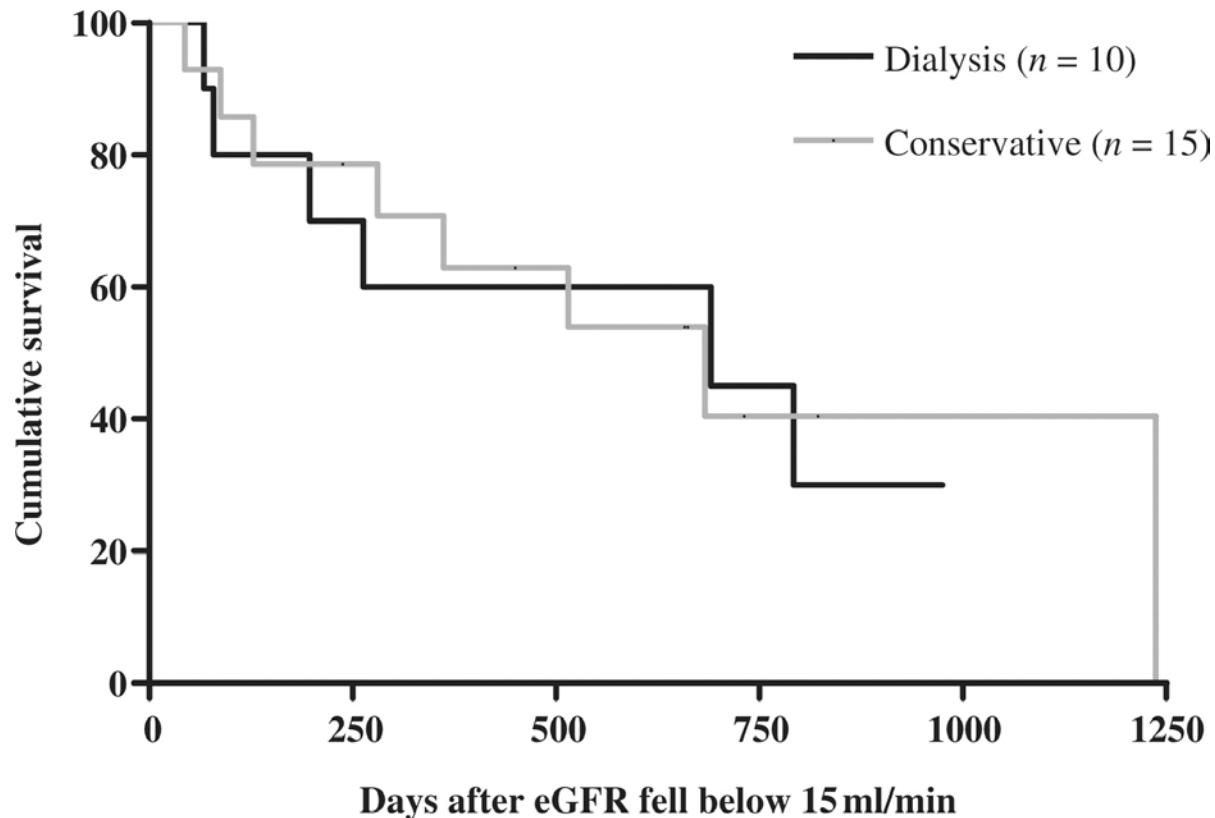


Fig. 1. Survival of very elderly (≥ 75 years) compared with non-elderly patients (< 75 years) according to time of referral (≤ 8 vs > 8 weeks prior to start of dialysis) ($P = 0.0001$, log-rank-test). Non-elderly < 8 w: non-elderly patients who started dialysis ≤ 8 weeks after referral; non-elderly > 8 w: non-elderly patients who started dialysis > 8 weeks after referral; very elderly < 8 w: very elderly patients who started dialysis ≤ 8 weeks after referral; very elderly > 8 w: very elderly patients who started dialysis > 8 weeks after referral.

Survival on dialysis or conservative care if > 75 yrs and 2+ comorbidities



Predialyse programma:problemen

Transitie pediatrie



Predialyse programma: problemen

Post transplantatie

Values at start of dialysis failed TX vs new RRT

	Post TX	No TX	p-value
Urea (mg/dl)	249	214	0.018
Ccrea (ml/min)	9	13	0.048
Kt/V	1.4	1.65	0.01
Hb (g/dl)	8.9	10.2	0.04

Predialyse programma

Besluit