

Predialysis education: some cliffhangers



Options for End-Stage Renal Disease Patients

Transplantation

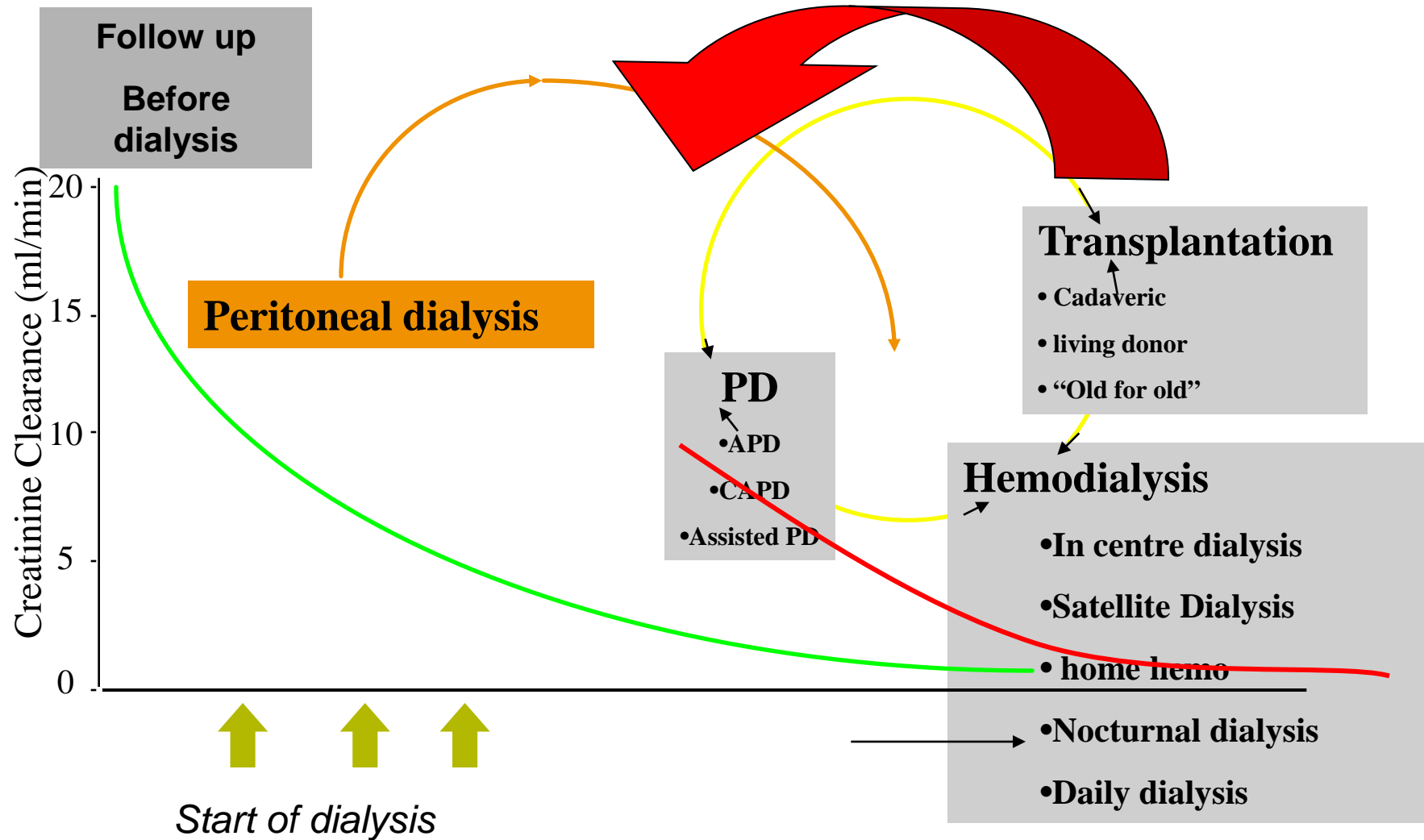
Renal
Replacement
Therapy

Hemodialysis



Peritoneal Dialysis

Integrated care 2010



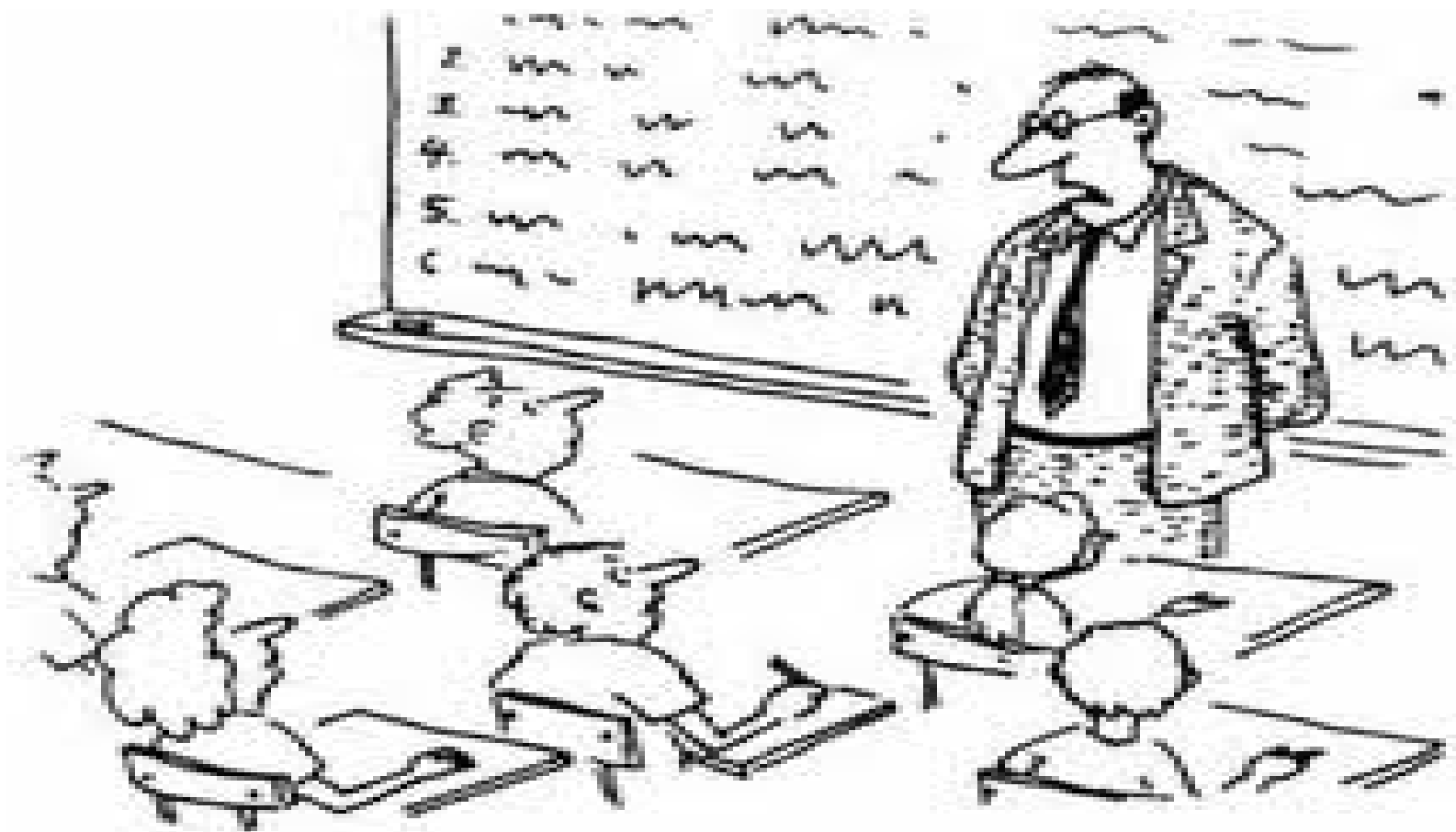


What modality of dialysis should I choose?

Dialysis modality selection:

Clinical advice from the European Renal Best Practice (ERBP) Advisory Board

www.european-renal-best-practice.org



"I expect you all to be independent, innovative, critical thinkers who will do exactly as I say!"

Barriers at the provider level?

Barriers to PD

Table 1. Medical and social contraindications to PD

	Count (%)
Patients assessed for PD	497
Medical conditions	
Obesity	24 (4.8)
Abdominal scarring	22 (4.4)
Ascites	6 (1.2)
Diverticulitis	5 (1.0)
Abdominal hernia	5 (1.0)
Inflammatory bowel disease	4 (0.8)
Ileostomy	3 (0.6)
Colostomy	3 (0.6)
Abdominal aortic aneurysm	3 (0.6)
Abdominal surgery, planned in the future	3 (0.6)
Bowel cancer	3 (0.6)
Gastric tube	2 (0.4)
Ileal conduit	2 (0.4)
Polycystic kidneys	2 (0.4)
Ischaemic gut	2 (0.4)
Other	7 (1.4)
Social conditions	
Residence did not permit PD	13 (2.6)
Employment did not permit PD	1 (0.2)
Total	110 (22)

Contraindications were in the opinion of the attending nephrologist and/or multidisciplinary team. Other medical conditions include one case each of chronic diarrhoea, gastric lymphoma, enlarged spleen, gastroparesis, purulent groin fistula, incontinence and nephrotic syndrome (concern *re*: protein loss).

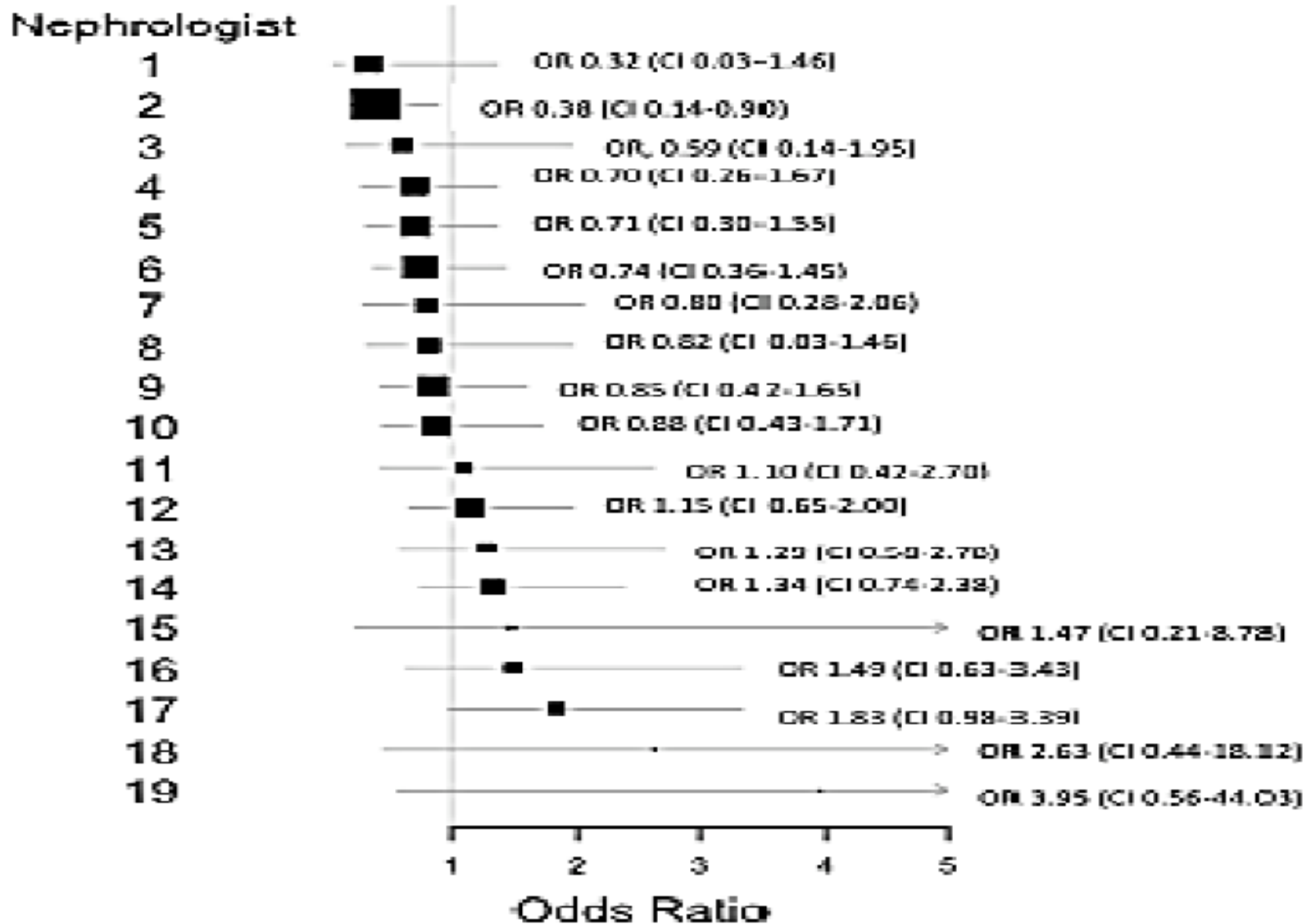
Table 2. Barriers to self-care PD among incident ESRD patients without contraindications to PD

	Count (%)
Patients assessed for barriers	245
Physical barriers to self-care	
Decreased strength	131 (53)
Decreased manual dexterity	105 (43)
Decreased vision	80 (33)
Decreased hearing	38 (16)
Immobility	62 (25)
Poor health/frailty	35 (14)
Poor hygiene	8 (3)
Cognitive barriers to self-care	
Language barrier	38 (15)
History of non-compliance	33 (13)
Psychiatric condition	19 (8)
Dementia/poor memory	19 (8)
Other ^a	20 (8)

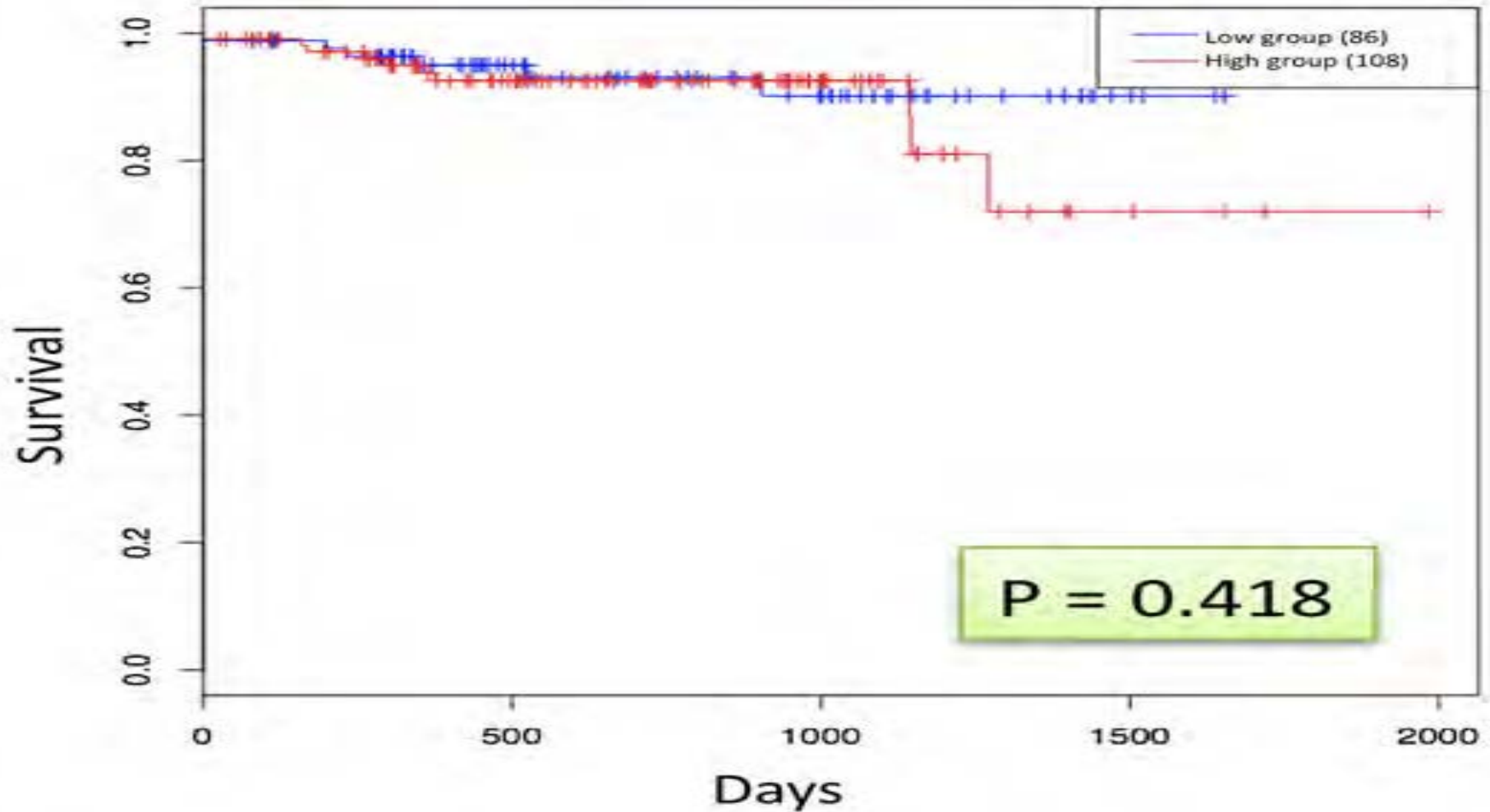
A barrier to self-care PD was defined as a physical or cognitive condition that would significantly interfere with the patient's ability to perform self-care PD in the opinion of the multidisciplinary team. All barriers were discussed and documented at weekly team meetings.

^aOther cognitive barriers were aphasia, learning disability, poor motivation and denial about ESRD.

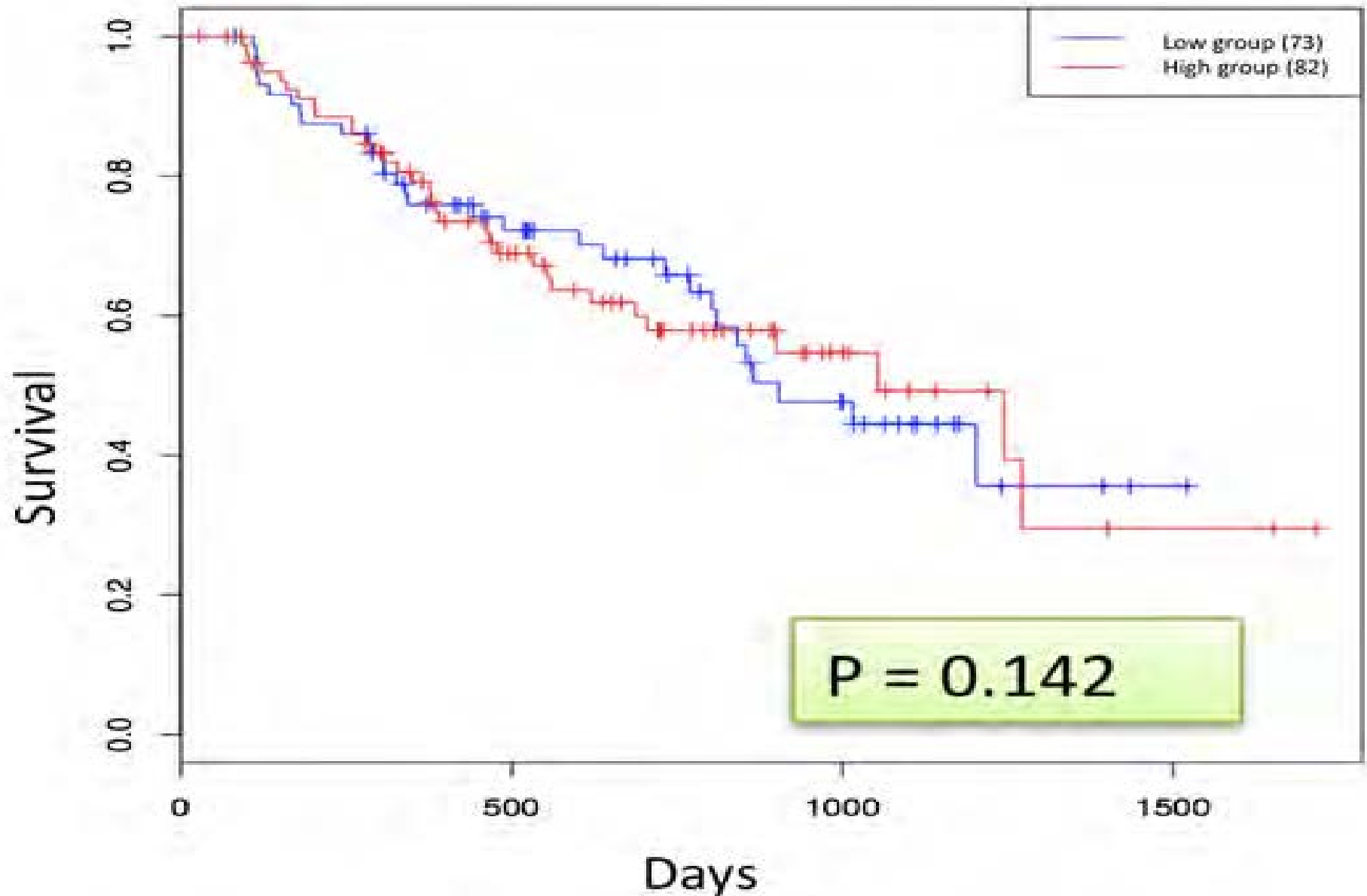
Odds of receiving PD as first line treatment



PD Mortality: Low Vs High Referrers (>90 days on PD)



PD Mortality: Low Vs High Referrers (>90 days on PD)



Technique survival

Attitudes and perceptions of nephrology nurses towards dialysis modality

Tennankore *et al. BMC Nephrology* 2013, **14**:192
<http://www.biomedcentral.com/1471-2369/14/192>

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Table 3 Perceived current and ideal proportion of each dialysis modality stratified by nursing group (median proportion, interquartile range)

	CHD nurses	HHD nurses	PD nurses	Predialysis CKD nurses	P
CHD proportion					
Current	55 (50–60)	50 (50–70)	52.5 (30–60)	60 (57.5–60.5)	0.49
Ideal	45 (30–60)	40 (25–50)	12.5 (0–25)	37.5 (27.5–50)	Comparing CHD to PD nurses: <0.001*
HHD proportion					
Current	10 (10–20)	14 (10–20)	15 (10–15)	16.5 (12–19.5)	0.83
Ideal	20 (10–30)	25 (25–30)	25 (20–30)	20 (20–22.5)	0.50
Self-Care proportion					
Current	10 (5–10)	5 (1–10)	5 (0–5)	7.5 (4–12.5)	0.04
Ideal	10 (5–20)	10 (10–10)	10 (5–10)	10 (10–10)	0.77
PD proportion					
Current	20 (10–25)	23 (10–25)	27.5 (24–30)	17.5 (15–25)	0.05
Ideal	20 (10–25)	20 (10–25)	50 (35–55)	30 (20–40)	Comparing CHD to PD nurses: <0.001* Comparing HHD to PD nurses: 0.001*

*Statistically significant (Bonferonni adjusted P = 0.008).

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search ID: mbcn1344

Barriers at the patient level (?)

Patient perspectives on informed decision-making surrounding dialysis initiation

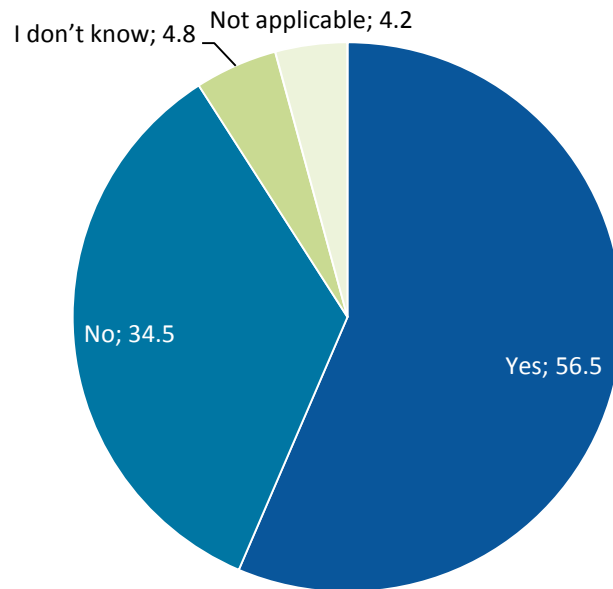
Methods. Ninety-nine maintenance dialysis patients recruited from 15 outpatient dialysis centers in North Carolina completed semistructured interviews on information provision and communication about the initiation of dialysis. These data were examined with content analysis. In addition, informed decision-making (IDM) scores were created by summing

Table 3. Number (%) of patients responding 'Yes' to each informed decision-making item

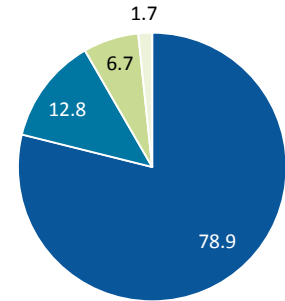
Content of the item	<i>n</i> (%)
1. Condition that led to kidney failure	53 (53.5)
2. How long you would live with or without dialysis	45 (45.5)
3. Dialysis options, such as peritoneal dialysis and hemodialysis	59 (59.6)
4. Benefits and burdens associated with each type of dialysis	32 (32.3)
5. Doctor asked your values and preferences for those dialysis options	20 (20.2)
6. How your daily life might change after starting dialysis	44 (44.4)
7. Need for dialysis for the rest of your life unless you receive kidney transplantation	82 (82.8)
8. Not starting dialysis could be an option	1 (1.0)
9. Doctor tried to make sure you understood what he/she told you	74 (74.7)
10. Doctor tried to understand what was important to you	58 (58.6)

Information about choice

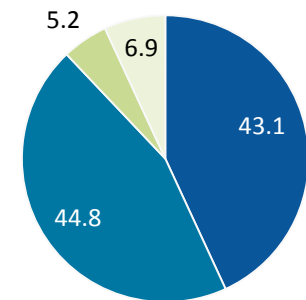
During this treatment time, has anyone ever spoken to you about alternative dialysis options and the possibility of changing treatments?



Hungary



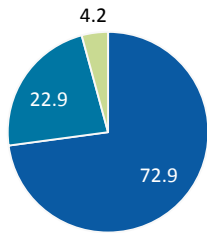
Italy



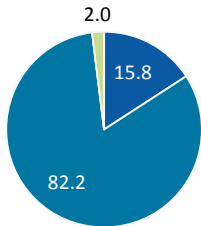
Almost a half of respondents in Europe do not recall having discussed alternative treatment options.

Equal Quality

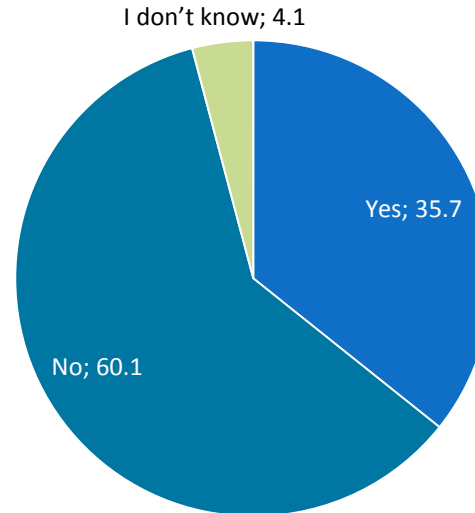
Finland



Germany



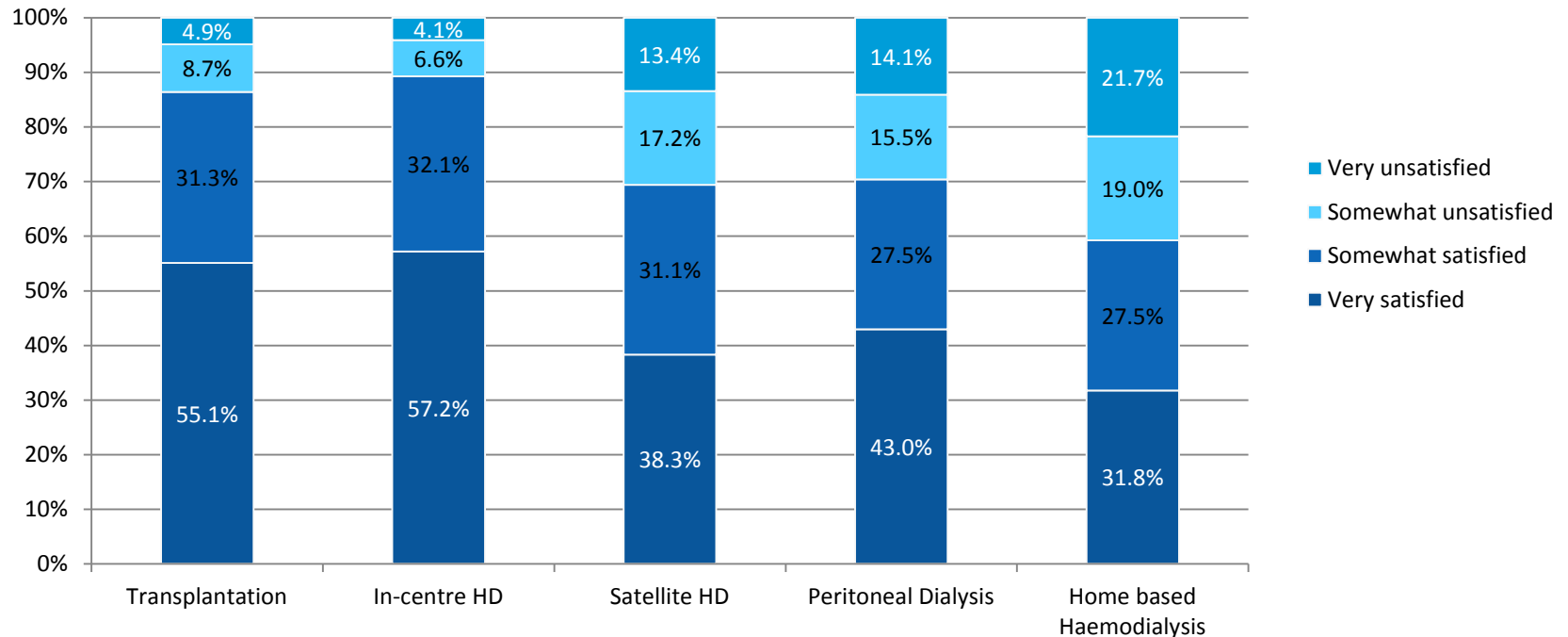
Have you received education and / or rehabilitation to help you to manage in your day-to-day life?



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.

Is all information Equal?

How satisfied were you with the information you had about each of the following treatment options before a decision was made?



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

The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

Lack of information—Eleven of 18 studies reported that patients or their carers did not have the information they wanted on treatment options, regardless of whether transplantation, dialysis, or palliative care was preferred. Family members of patients were especially concerned about their lack of knowledge of the different treatments available and the practicalities in managing each treatment.

The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

Timing of information—Ten studies reported the importance of the timing of information on treatment options. Patients recounted being too unwell to take in the information presented or too rushed into making a decision without having time to discuss the options with their families. Information about kidney transplantation was commonly introduced to patients after dialysis had been established. For some patients information about treatment options came after undergoing surgery for vascular access.

Maintaining lifestyle—The medical outcomes of treatment were considered less important than the effect of the treatment on the patient's lifestyle—that is, patients were less concerned about their longevity than they were about their quality of life. Treatment choices were based on minimising disruption to usual activities, upholding responsibilities, and maintaining personal interests. Examples of this included the ability to continue working, maintain a social life, or care for grandchildren (see table 4).

Patient Information: Predialysis

1. Patients do not recall having been informed at all
2. Patients are informed “too late” i.e. in a state when they are uraemic, desperate, depressed by their diagnosis....
 - Language too difficult
 - Irrelevant information
 - Too much information
3. There is a “communication problem” between medical staff and patients on which topics/factors to value
 - Empathic listening
 - Motivational interviewing
4. Patients tend to make heuristic, not objective decisions
 - Danger of exposing them to other patients

The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

Peer influence—Patients were greatly influenced by the experiences of other patients. They imagined themselves in a similar position (for example, looking really well after transplantation or managing a Tenckhoff catheter) and described being inspired to carry out dialysis themselves. Similarly, some patients dismissed a particular therapy after seeing complications in other patients, such as refusing haemodialysis after seeing a swollen and disfigured arm following a fistula operation.

Shared decision making

Shared decision making

- 1. Making the options clear**
- 2. Help the patient with making an informed choice**
 - 1. Elicit patient preferences**
 - 2. Avoid bias by your own beliefs and values**
 - 3. Suggest solutions that fit these preferences**
 - 4. Facilitate decision making**

Shared decision making

1. Making the options clear
2. Help the patient with making an informed choice
 1. Explore patient preferences
 2. Present solutions that fit these preferences
 3. Facilitate decision making

Inform

Information leaflets VS Decision Aids

Methods

We designed a decision aid comprising a complementary video and informational handbook. We based our development process on data previously obtained from qualitative focus groups and systematic literature reviews. We simultaneously developed the video and handbook in “stages.” For the video, stages included (1) directed interviews with culturally appropriate patients and families and preliminary script development, (2) video production, and (3) screening the video with patients and their families. For the handbook, stages comprised (1) preliminary content design, (2) a mixed-methods pilot study among diverse patients to assess comprehension of handbook material, and (3) screening the handbook with patients and their families.

Results

(but **the** information does not exist)



www.european-real-best-practice.org

(but **the** information does not exist)

Is APD better than CAPD?



www.european-real-best-practice.org

Relative risk CAPD vs APD

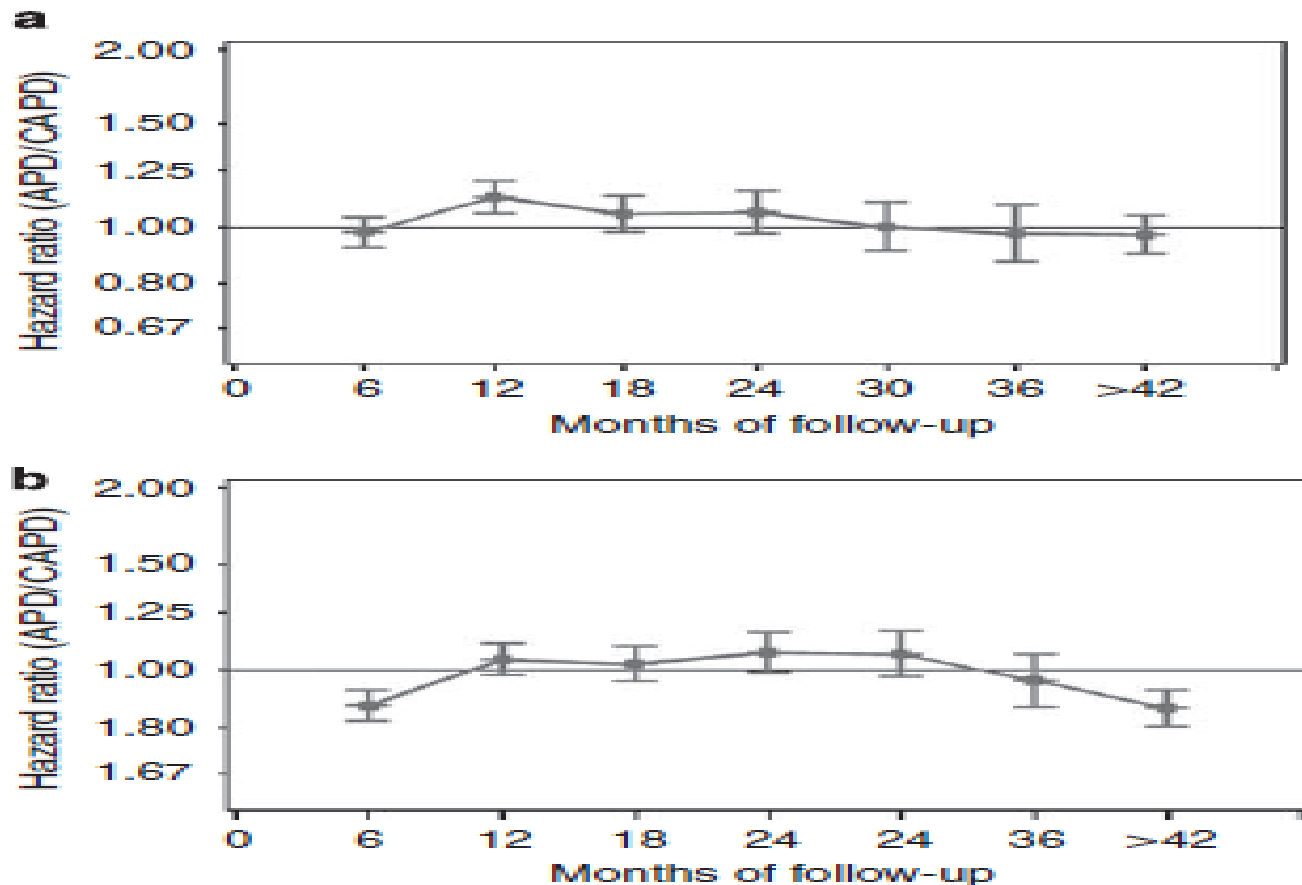


Figure 2 | Adjusted hazard ratio for death, using non-proportional hazards, among patients undergoing automated peritoneal dialysis compared with those undergoing continuous ambulatory peritoneal dialysis between 1996 and 2004. (a) Intent-to-treat and (b) as-treated analyses. Data are adjusted for cohort period, demographics, clinical, laboratory, and baseline facility characteristics.

Survival CAPD vs APD

Clin J Am Soc Nephrol 4: 943-949, 2009

Similar Survival in APD and CAPD

947

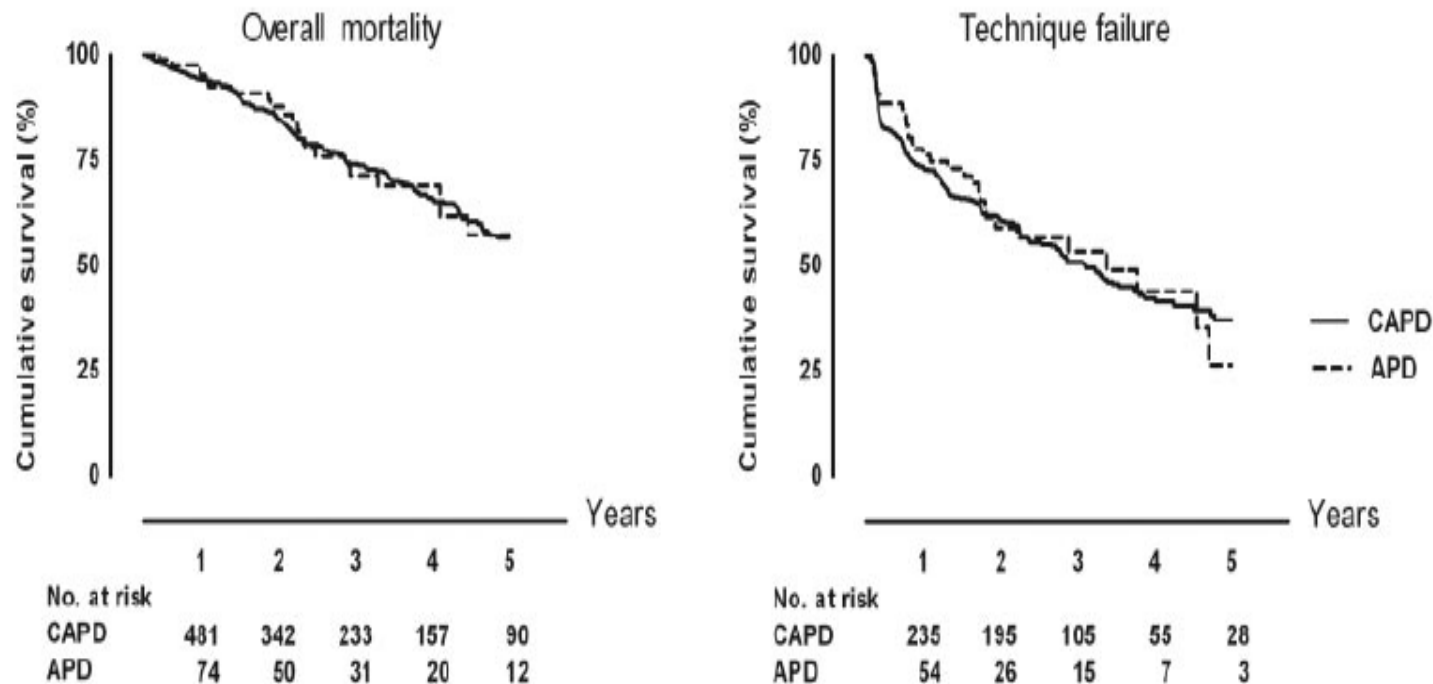


Figure 1. Left: Kaplan-Meier curve of overall mortality on automated peritoneal dialysis compared with continuous ambulatory peritoneal dialysis. Right: Kaplan-Meier curve of pure technique failure on automated peritoneal dialysis compared with continuous ambulatory peritoneal dialysis. The numbers under the graphs show the number of patients at risk.

Survival CAPD vs APD

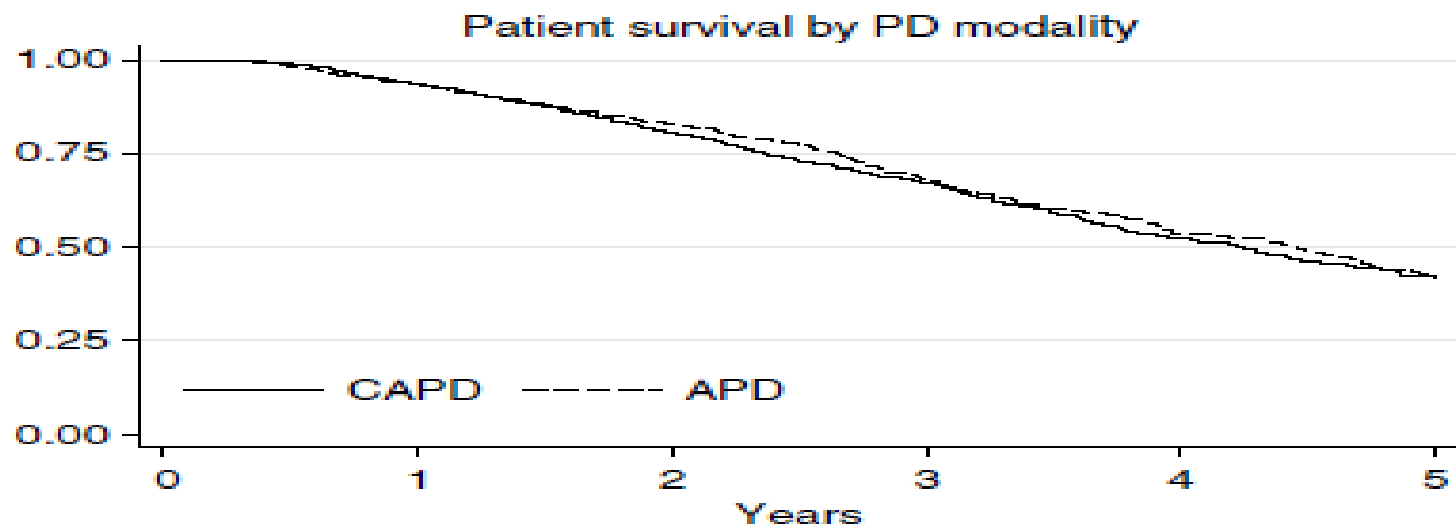


Figure 1 | Kaplan-Meier graph showing patient survival: patient survival was comparable during CAPD and APD treatment modalities.

Table 4 | Crude death-censored technique failure rates and relative risk by PD modality and at specified time intervals

Time interval	Failure rate per 100 person-years		Relative risk	95% CI
	CAPD	APD		
0-1	14.8	18.8	1.27	1.02-1.59
1-2	22.8	22.6	0.99	0.80-1.21
2-3	19.7	22.6	1.14	0.86-1.51
> 3	24.9	30.4	1.22	0.96-1.55

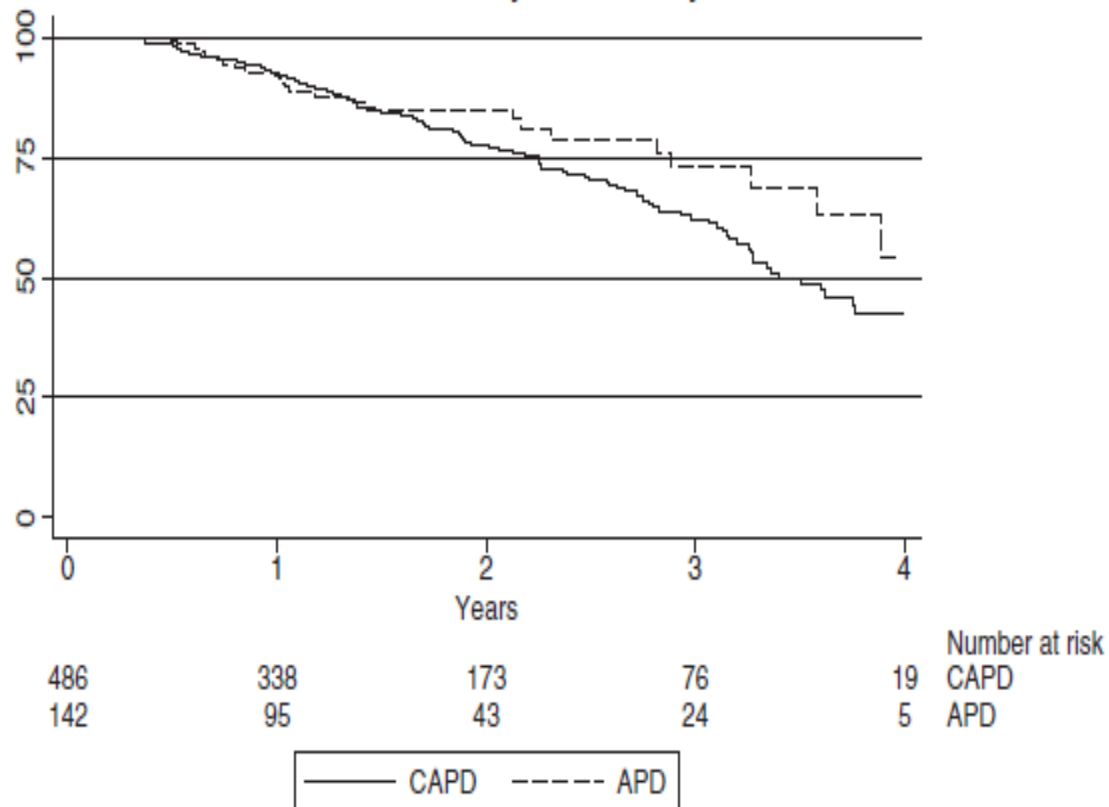
APD, automated peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis; CI, confidence interval; PD, peritoneal dialysis.

Survival fast transporters APD vs CAPD

Table 2. Results of intention-to-treat Cox proportional hazards model analyses of the relative hazard of APD *versus* CAPD for patient survival, according to peritoneal transport group

Transport group	Univariate analysis			Multivariate analysis		
	HR	95% CI	P	HR	95% CI	P
High (n = 628)	0.57	0.35–0.94	0.03	0.56	0.35–0.87	0.01
High-average (n = 1936)	0.98	0.72–1.34	0.9	1.08	0.81–1.45	0.6
Low-average (n = 1146)	0.70	0.46–1.07	0.1	0.98	0.66–1.45	0.9
Low (n = 196)	2.21	1.24–3.93	0.007	2.19	1.02–4.70	0.04

Patient Survival by PD Modality



APD survival superior in fast transporters, but CAPD better in slow transporters

(but **objective** information does not exist)

The risk of dying with the surgery is 10%

(but objective information does not exist)

The probability of survival with the surgery is 90%

Study Conclusion: The probability of survival with the surgery is 90%

Difference in

- presentation (harm vs benefit)
- Relative risk vs absolute risk

Gigerenzer, G., & Hoffrage, U. (1995). How to improve Bayesian reasoning without instruction: frequency formats. *Psychological Review*, 102, 684-704.

“Phraming” information

1. Positive vs negative
2. Loss vs gain
3. Relative vs absolute (more wary)
4. Graphical vs numerical
5. More vs less details and data points (more wary)
6. Numerical vs linguistic (many, some, often, rarely)(more wary)
7. Abstract vs “emotionalised”
8. Lay vs medical terminology
9. Use of anchoring points

Semantic problems...

leading to ethical problems

“median survival on HD and PD is less than 5 years”

Semantic problems... leading to ethical problems

“median survival on HD and PD is less than 5 years”

Table 3 Qualitative feedback from handbook development Stage 2 (Phases 1 and 2)

Patient Concerns	Representative Quotes	Specific Challenges Encountered	Solutions
Patients did not know their treatment options	“First, can you explain the two treatments? What is the difference between those two treatments?”	• Defining patients’ various treatment options	• Added a treatment definition page (“What are the Treatments?”)
		• Making complex medical terminology memorable	• Replaced all abbreviations with actual treatment names • Color-coded each treatment option • Associated each treatment with its own icon
Intimidating amount of complex information	“And I just feel like this is so much information that’s written that is not going to be taken in.”	• Translating research evidence into plain language	• Developed a question and answer format in plain language • Revised the language in the to achieve a fourth grade reading level • Created a new section (“What is on Each Page?”) to introduce and define research quality
		• Communicating research quality	• Used pictures of “real” doctors and patients diverse in age, sex, and gender • Placed tabs throughout the handbook to divide it into smaller sections
		• Making the handbook user-friendly	• Added an interactive value clarification exercise (“How Do I Choose a Treatment?”)
Understanding numerical information or statistical	“I don’t want these chances or things...it’s real confusing. I want	• Presenting graphical illustrations of data	• Used graphical presentations patients responded to most positively • Supplemented graphical presentations with text to reiterate the intended message

Semantic problems... leading to ethical problems

“median survival on HD and PD is 5 years”

- “camouflaging language” vs “speaking out loudly”



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56



Does narrative information bias individual's decision making?

A systematic review[☆]

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Shared decision making

Inform

1. Making the options clear
2. Help the patient with making an informed choice
 1. Elicit patient preferences
 2. Suggest solutions that fit these preferences
 3. Facilitate decision

Deliberate

The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

Modality and reasons for choosing or not choosing modality	Participants' quotes
Peritoneal dialysis	
Reasons for choosing modality:	
Self capability v depending on care from strangers	I like taking responsibility for my own care . . . ²⁰
Managing illness in privacy of own home	With haemodialysis there's no partition, no privacy. I couldn't even meditate ³⁶
More freedom or flexibility	"Mainly because it [peritoneal dialysis] gives me a little bit more freedom. Being able to do it at home I wouldn't have to come to the hospital ²²
Less time in hospital	I am a pharmacist . . . worked eight hours in the hospital. I did not want to spend the rest of my time in hospital again ³⁵
Ability to travel	It would allow me if I wanted to take a trip, to go somewhere and basically do it myself, instead of having to try to find a facility that could accommodate me ²²
Ability to continue part time work	I need flexibility to go where the meetings are and to get up and move around. CAPD [continuous ambulatory peritoneal dialysis] seemed like it would allow me to function in those capacities ³⁰
Ability to continue care giving for children	I have a son and I would have to go to the hospital every other day for haemo. It was real hard for me. With peritoneal, I could be in my own surroundings at home ³⁰
Reasons for not choosing modality:	
Concerns about having Tenckhoff catheter	It makes me feel uncomfortable to see that thing that comes out of your stomach. It gives me a funny feeling like someone scratching a chalkboard ³⁰
Concerns about sterility in home and getting an infection	Peritoneal dialysis is sterile and can't be done at my home ²⁶
Inability to store dialysis supplies	Where we were living previously there was no space [for peritoneal dialysis supplies]. We couldn't get one iota of anything else in that place ³⁶

The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies

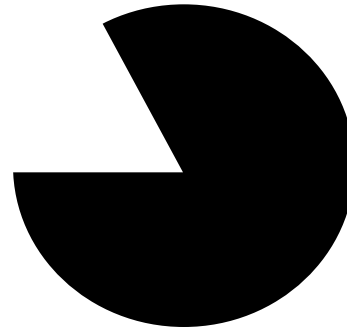
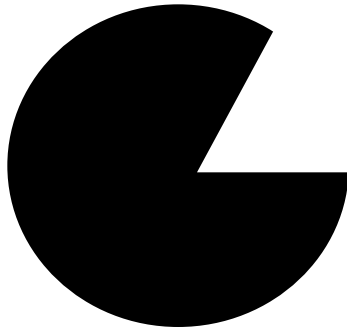
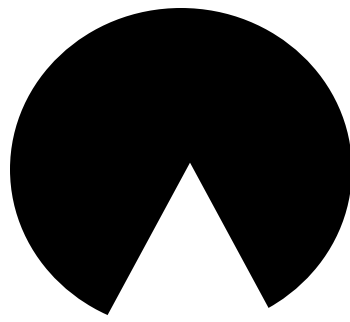
Haemodialysis

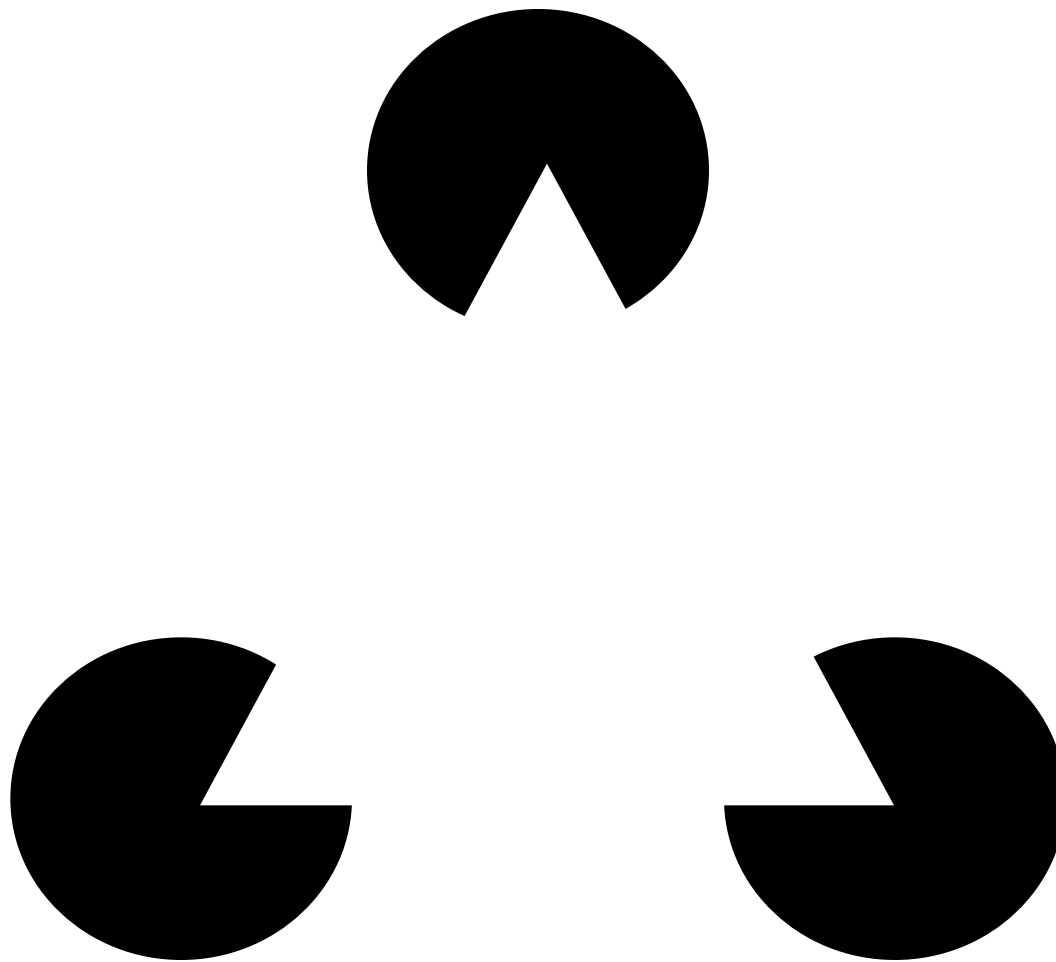
Reasons for choosing modality:

Liked others caring for them	I know we couldn't do CAPD [continuous ambulatory peritoneal dialysis]. No, I sooner trust the girls, because they're supposed to know about it ³⁰
Preferred a planned schedule	Since I usually control the scheduling of my job, the time to spend in the hospital is OK for me ³⁵
Free days with no dialysis	[Haemodialysis] would be less disruptive of our life. Two, three hours a day, every other day, and then you can go on with your life in between times ²⁵
Perception of haemodialysis as a "better" therapy	I suppose the blood one is probably the proper one, I don't know ³⁴
Previous knowledge of haemodialysis from family member	I decided to take it with the machine because I already knew what it was like ³⁰
Could go swimming	You can't go swimming with that damn thing [peritoneal dialysis catheter]. This way, I don't have no openings, I can go swimming anytime I want, I don't have to worry about dirty water or whatever getting into it ³⁰
Convenience	The haemodialysis centre's right close to my home. It's real convenient ³⁶

Reasons for not choosing modality:

Needle phobia	There's a big machine and you see blood and for me its scary. With haemo there's more needles involved, its more dangerous ³⁰
Looking like a "patient"	My mother said that having a fistula on the arm would show I was a patient. However, with an abdominal catheter on the belly people would not know ... ³⁵
Fear of cross infection	Haemo is pretty dangerous because you don't know whose blood is where. What assurance would I have that somebody else's blood was not in the machine somewhere ³⁰



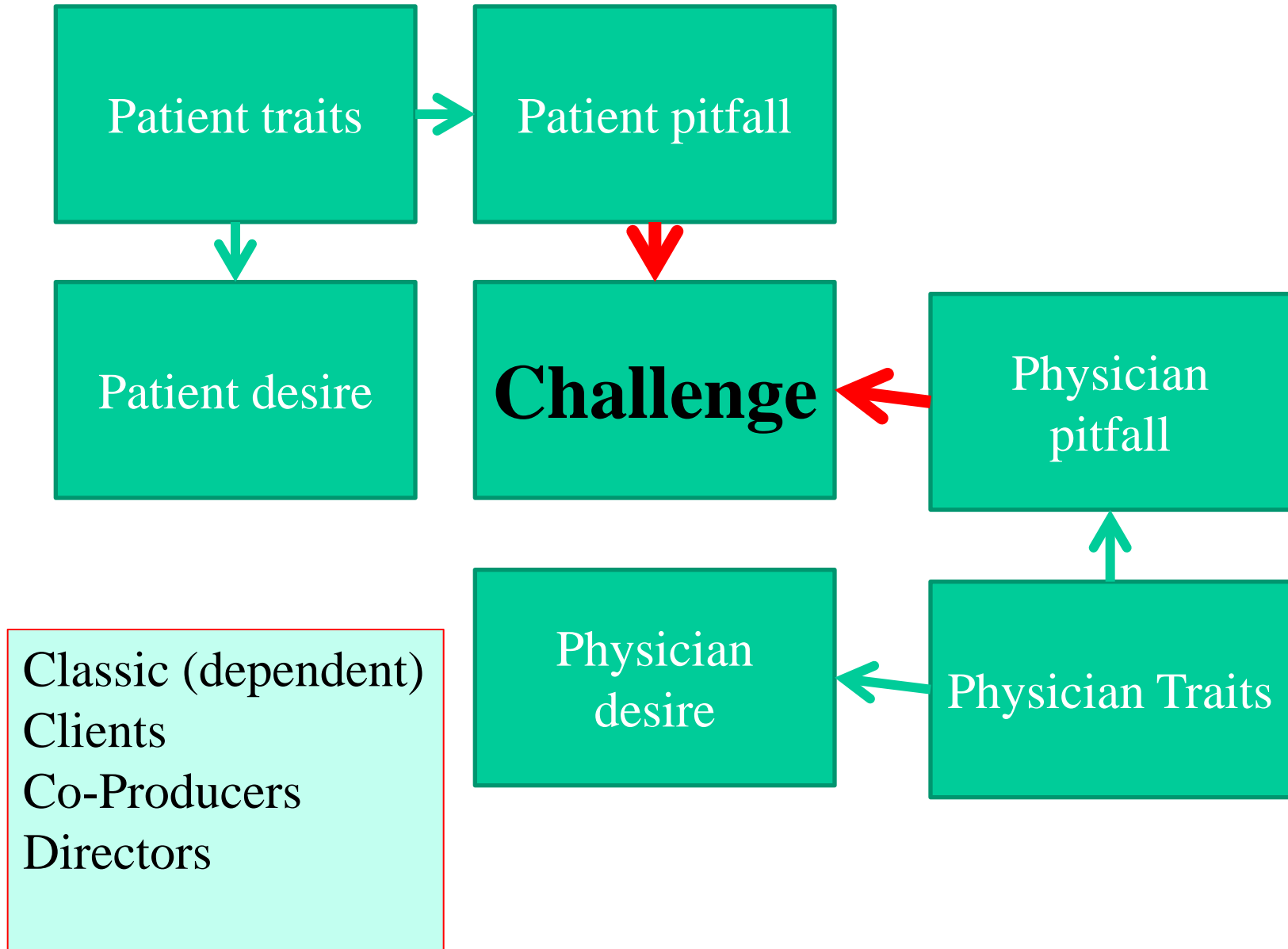


Anchoring (+Halo effect)

Attribution

Availability

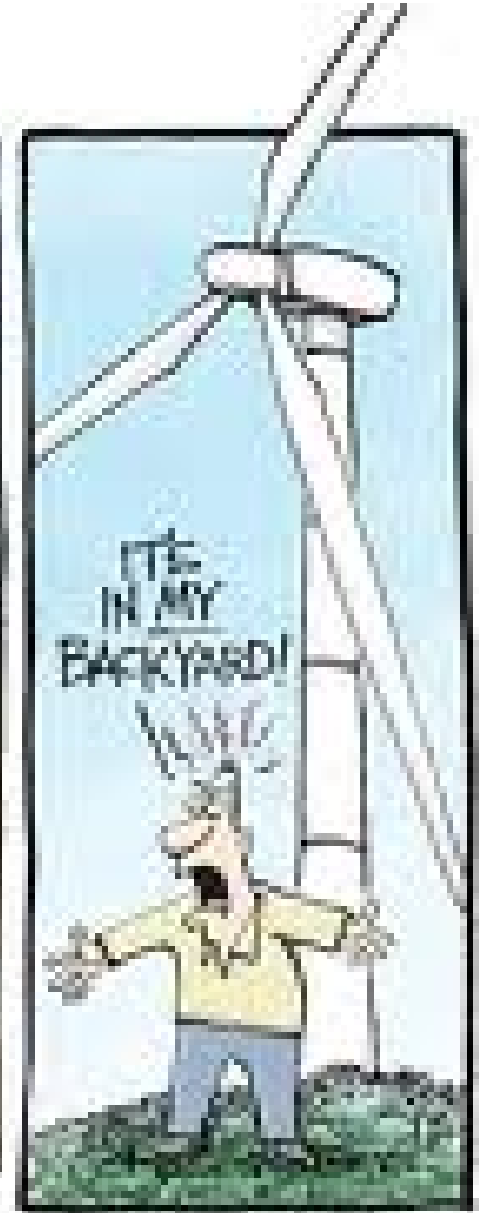
Patient and physician archetypes and roles



Shared decisions: some factors at play.....

- **Buridan's donkey**
- **Immediate vs anticipated emotions**
- **Hyperbolic distorsion**
- **Harm vs benefit**

ARGUMENTS AGAINST-



ARGUMENTS AGAINST-

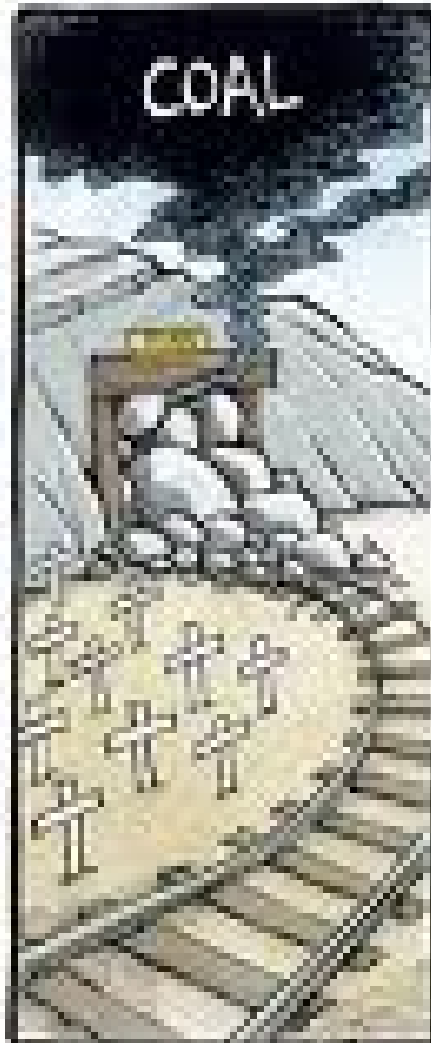
NUCLEAR



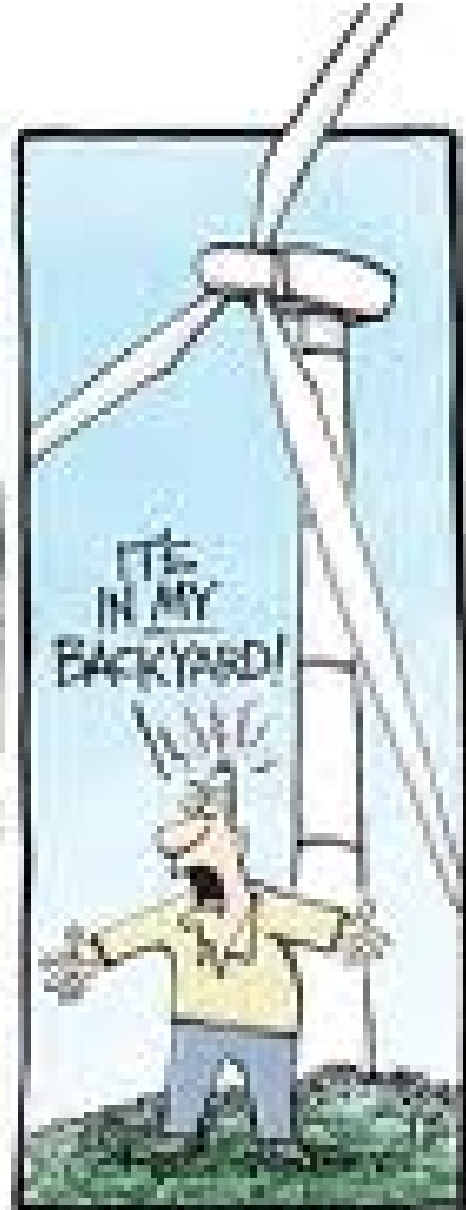
OIL



COAL



IT'S
IN MY
BACKYARD!



JOE BLOOMER

Shared decision making

1. Making the options clear
2. Help the patient with making an informed choice
 1. Explain patient preferences
 2. Present solutions that fit these preferences
 3. Facilitate decision making

Inform

Deliberate

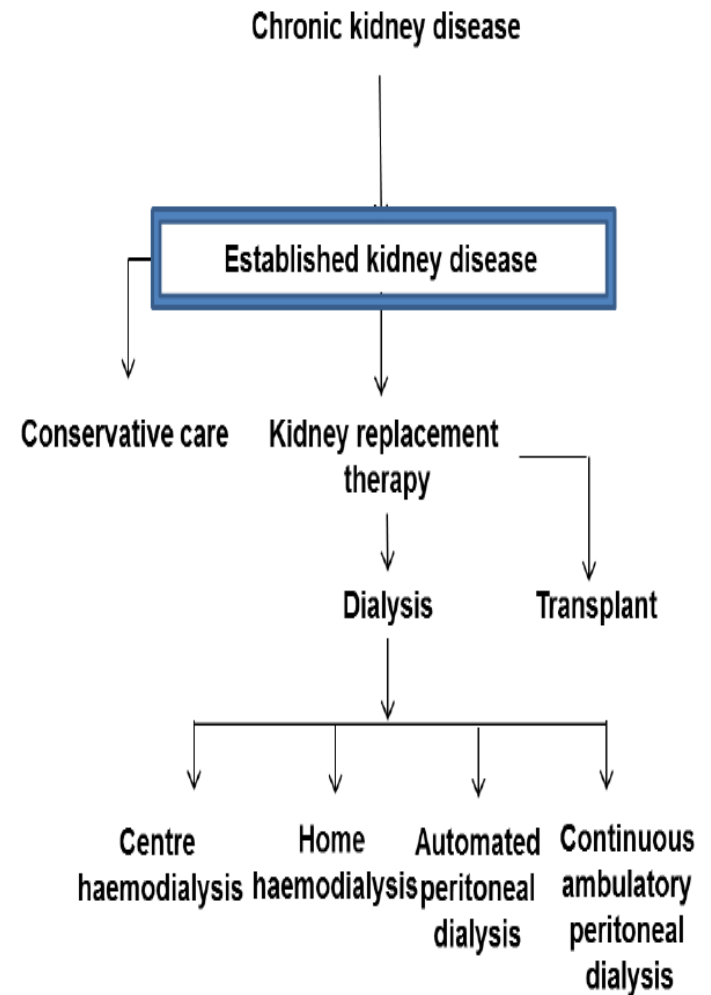
Decide

Yodda: inform

The kidneys are reddish in colour and shaped like kidney beans. Each kidney is about the size of a clenched fist (picture 2).



Picture 2: Diagram of the kidney and how it works



Yodda: deliberate

Haemodialysis

Peritoneal Dialysis

Dialysis access points

Usually people have a *fistula* made in their arm. The fistula allows access to the blood. The access used for usual blood tests is not enough because only a small amount of blood flows slowly through the veins.

There are several ways of accessing the blood stream. The most common is called a *fistula* or the arterio-venous (AV) fistula. A fistula is made by a surgeon joining a vein and artery together under the skin, usually in the forearm.

People have a *peritoneal catheter* attached to their abdomen (belly). This catheter allows access to the peritoneal cavity. Access to the peritoneal cavity is needed for PD.

A plastic tube called a catheter is put into the abdomen (belly) by a surgeon. About 7-10 days after the catheter operation, the stitches are removed. People are taught how to clean the area around the catheter and how to cover the access point so that it stays clean. The area around the catheter is called the *exit site*.

Yodda: deliberate

This table compares features of all four dialysis treatments. What you like about the way dialysis is carried out may be different from what other people like.

	Haemodialysis (HD)		Peritoneal dialysis (PD)	
	Haemodialysis At a hospital or centre (CHD)	Haemodialysis At home (HHD)	Peritoneal Dialysis Continuous Ambulatory (CAPD)	Peritoneal Dialysis Automated (APD)
Place of dialysis care	People travel to a hospital or specialist centres for dialysis session.	People have dialysis sessions at home.	Most people choose dialysis sessions at home or work. Can be any clean place.	Most people choose dialysis sessions at home or work. Can be any clean place.
How dialysis works	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a bag of fluid for about 40 minutes per session by the belly.	Attaching to a machine for about 9 hours per session by the belly.

Yodda: helping in decision

10. Making the Dialysis Decision.

This chapter asks you to write down what is important in your life at this time, your views about the dialysis options, and which treatments you think will fit best into your life. People find it useful to talk about these views with their kidney team and family.

1. List the activities you do now and want to keep doing when you are on dialysis.

Socialising (<i>e.g. with friends and/or family</i>)	
Hobbies (<i>e.g., gardening, fishing, music, knitting</i>)	
Leisure (<i>e.g. walking, cycling, swimming, sport</i>)	
Holidays, Trips Away (<i>e.g. locally, abroad</i>)	
Local travel (<i>e.g. public</i>	

Yodda: helping in decision

3. How much do you think each dialysis treatment will let you carry on doing the activities that are important to you? *Circle one number for each treatment.*

	Not at all Completely						
Haemodialysis - Centre <i>(machine at hospital)</i>	0	1	2	3	4	5	6
Haemodialysis - Home <i>(machine at home)</i>	0	1	2	3	4	5	6
Peritoneal Dialysis - Continuous Ambulatory <i>(bag at home or any clean place)</i>	0	1	2	3	4	5	6
Peritoneal Dialysis - Automated <i>(machine at home or any clean place)</i>	0	1	2	3	4	5	6



ERBP

“Shared Decision Making”

