Leeds Institute of
Health Sciences

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Enabling Services To Support Patients Making Informed Dialysis Decisions.

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Overview

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What is the problem?

How do people make decisions?

Can we help patients make *informed* dialysis decisions?

Bekker HL, Winterbottom AE, Gavaruzzi T, Mooney A, Wilkie M, Davies from the Yorkshire Dialysis Decision Aid (YoDDA) Research Team. (2015). *The Dialysis Decision Aid Booklet: Making The Right Choices for You.* Kidney Research UK.

English - https://www.kidneyresearchuk.org/DialysisDecisionAid
Spanish - http://www.senefro.org/modules.php?name=noticias&d_op=view&idnew=1350
Italian - http://www.malatidireni.it/filesito/guida_dialisi/Guida_alla_scelta_della_dialisi.pdf

Winterbottom AE, Gavaruzzi T, Mooney A, Wilkie M, Davies SJ … Bekker HL. *Patient acceptability of the Yorkshire Dialysis Decision Aid (YoDDA) Booklet: a prospective non-randomised comparison study across 6 predialysis services.* Peritoneal Dialysis International. 2016; 36 (4)

The Evidence Is…

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- Patient preferences must be included in treatment plans (National and International Clinical Guidelines).
- Variation in peritoneal dialysis uptake *by centre* (3-40%) (UK Renal Registry, 2012).
- Patients happy with predialysis services but want support to make treatment choices (Ormandy, 2013; van Biesen, 2014)
- Patients dialysis choices not informed (Winterbottom et al, 2012)

Leaflet Quality Varies By Unit

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- In UK, over 30 leaflets on dialysis
- Each patient gets 2-3 leaflets
- Purpose leaflet *to inform about one dialysis option:*
- Some written using patient values, most not.

- Difficult to understand (readability = PhD+).
- Purpose not to support decision making between options

(Winterbottom et al, 2007)

How Do People Make Decisions?

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- How did you choose your mobile phone?
- Where did you get your advice?
- Did you know what the consequences were for you?
- What phone will you get next, why?
- Would you get the same phone for your child?

My Smart Phone Decision Making.

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My Broadband

Provider offers

71 smart phones:

That one is pretty

You need to get spotify…

Screen size (4.2-5.5), camera, colour, minutes/ texts/ data, cost (£10-£45), Operating system (ios, android, windows), Aps, battery, zingy (?)…

Everyone in design has iphone

Not too big, can't hold it.

Don't know where you buy windows aps…

My Choice…

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Lots of choice

Lots of information

Lots of advice (opinion)

Lots of non-relevant information

Lots of other people using smart phones

Lots of consequences for my life…

Not helping me make a choice

Stick with ‘non-smart’ phone

Make choice based on camera quality

Decision Scientists Explain How People Make Decisions.

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- Make mental representation of world ‘out there’.
- Information get influences our picture of the world.
- Brain works all the time:
  - Attends to / excludes information.
  - Makes *unconscious judgements*.
  - Limited capacity for conscious attention.
  - Attention focused by external and internal cues.
- Little awareness of what affect our choices.

All People Make Decisions Using The Same Two Strategies.

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Intuitive-experiential (system 1) – automatic, unconscious decision making, *context dependent* and *relies on heuristics* e.g. who presenting the information.

Analytic-deliberative (system 2) – systematic, reasoned and conscious evaluations of the options presented, e.g. weighing up the pros and cons.

We Want To Help People Make *Informed (Deliberative) Decisions*.

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An informed or reasoned decision is one made well:

- Based on information about *all options and their consequences*, without bias.
- Evaluate information *in accordance with own beliefs*.
- *Trade-off these evaluations* to reach a decision.

…collaborate with health professionals to implement choice within care pathway.

But...

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All people make treatment choices using systems 1 & 2:

- Past experience (generic/ expert);
- Someone else's choice or values;
- External cues (e.g. screening invite, symptom);
- Own beliefs about health and illness behaviours;
- Erroneous knowledge, beliefs and preferences;

Decisions 'biased' by information attend to.

Judgements 'biased' by the way information presented.

Context:
Making Healthcare Decisions.

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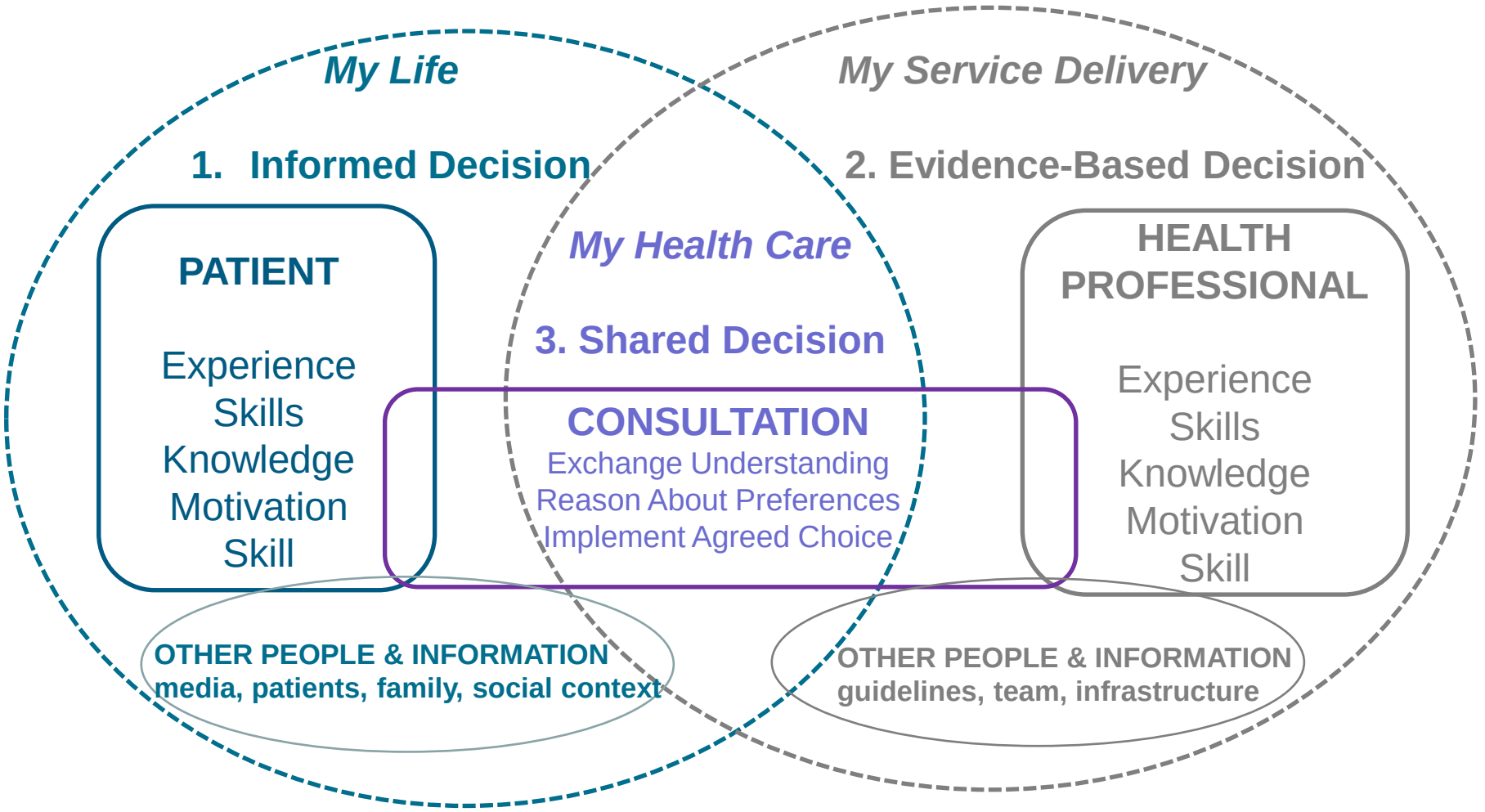

Breckenridge K, Bekker HL, van der Veer SN… Caskey FJ. *NDT Perspectives - How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting.* Nephrol Dial Transplant. 2015; 30: 1605-1614.

Shared Decision Making.

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"An interactive process in which patients and professionals collaborate to choose healthcare."

(*Charles et al, 1997*)

Consultation conversation, *both* patient and professional:

- *Exchange Information* and knowledge about treatments
- *Express preference* and values about treatments
- Explicit reasoning about treatment choices and preferences
- Agree and implement choice

(Stacey et al, 2009)

Way We Present Information Influences Choie

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Leaking Opinions

"Some people may prefer to go to hospital for hospital haemodialysis, while others want to be more independent and opt for home haemodialysis or peritoneal dialysis"

(*NHS Choices website, January 2009)*

Information Not Passive: Another's Values.

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"Some people may prefer to go to hospital for hospital haemodialysis, while *others want to be more independent* and opt for home haemodialysis or peritoneal dialysis"

(*NHS Choices website, January 2009)*

Pictures, length, and patient story make one option look 'nicer'.

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The treatment of kidney failure

Haemodialysis

This form of dialysis removes waste products from the blood by passing it out of the body, through a filtering system (dialyser) and returning it, cleaned, to the body.

While in the filtering system, the blood flows through tubes made of a membrane that allows the waste products (which are much smaller than blood cells) to pass out through it.

Click the picture to see how haemodialysis works ANIMATION

The waste products pass through the membrane into a dialysis solution (dialysate), then out of the machine. The "clean" blood is carried on through and returned safely to the body.

This happens over and over again throughout the dialysis session. Each time the "clean" blood is returned to the body, it picks up more waste products from the cells it circulates through, and brings these newly-collected toxins back to the dialyser to be removed.

Fresh dialysate is passed through continuously, to make the rate of the cleaning process as fast as possible.

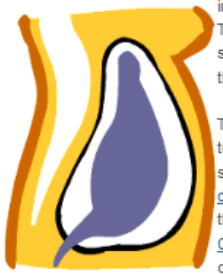
As well as cleaning the blood, the dialysis machine also removes excess water. This part of the process is called ultrafiltration which can be done separately without dialysis.

It takes about 4 hours (perhaps more) to complete a good session of haemodialysis, which needs to be done 3 times a week.

I accept haemodialysis with a very positive outlook. It enables me to lead, as near as possible, a normal life.

The treatment of kidney failure

An Introduction to peritoneal dialysis



With this method, instead of being cleaned by an artificial membrane outside the body, the blood is cleaned inside the body, through the Peritoneum. This is the thin membrane that surrounds the outside of the organs in the abdomen.

The peritoneum allows waste products to pass through it and is very rich in small blood vessels. By running a dialysis fluid into the peritoneal cavity, through a tube called a Tenckhoff Catheter - and then out again - waste can be filtered from the blood.

Click here to see how peritoneal dialysis works ANIMATION

There are two types of peritoneal dialysis:

CAPD - which stands for Continuous Ambulatory Peritoneal Dialysis - happens throughout the day, at home or at work, while the person goes about his or her daily life. Between 1.5 and 3 litres of fluid is run in four times a day, exchanging for the fluid from the previous exchange. This takes about 30-40 minutes.

APD - Automated Peritoneal Dialysis - in which the dialysate solution is changed by a machine, at night, while you are asleep. The machine will exchange 8-12 litres over 8-10 hours and then leave 1-2 litres to dwell during the day.

You will be trained by the PD nurses - the techniques need to be done correctly and in a clean manner - but are designed to be done at home perhaps with the help of a partner. Although you are at home, you will be contacted frequently by the nurses and will come to the out-patient clinic every few weeks.

What is the Peritoneal Dialysis Fluid?

Peritoneal dialysis fluid is a sugar (glucose) solution containing other salts. Bags come in 3 strengths (1.36%, 2.27% and 3.86% or light, medium and heavy) - the "heavier" the bag (ie.3.86%), more water will be removed from the body.

If you have a lot of fluid in the body, you would use heavy bags to remove fluid. If you are dehydrated, you would use some light bags so that the dialysis does not remove fluid.

The sugar solution can be a problem for diabetic patients and changes in therapy may be needed. New solutions are being developed - Protein or starch.

How good is peritoneal dialysis?

Peritoneal dialysis can provide good, efficient dialysis but needs to be monitored carefully. It needs to be performed daily with breaks only because of unusual circumstances.

The nurses and doctors will measure how effectively the dialysis is being performed and change the volume and strength of the fluids.

If good dialysis cannot be achieved it is important to think about a change - from CAPD to APD or to haemodialysis.

What are the problems with peritoneal dialysis?

There can be problems with fluid leaks in the groin or around the catheter when dialysis starts. These problems can be managed easily.

Infections are the major risk - either in the exit site or most importantly in the tummy itself, peritonitis. This shows as tummy pain, a fever and a cloudy fluid bag. It is important to ring the kidney unit immediately if a cloudy bag develops. Peritonitis is treated with antibiotics added to the bags and may need admission to hospital for a few days. Rarely, the infection may be so bad that the catheter has to be removed.

In the long term, there can be a thickening of the peritoneal membrane so that it does not work efficiently. The dialysis fluid may need to be changed or switched to haemodialysis.

Having a Tenckhoff catheter

The Tenckhoff Catheter provides permanent long-term access to the peritoneal cavity. It is a thin, non-irritating, flexible tube. One end of this tube rests in the peritoneal cavity, while the other extends from the body by about 4 inches, so that it can be attached to the dialysis fluid. This end is sealed off when fluid is not being run in or out of the abdomen.

The catheter can be put in place either under sedation, with a local anaesthetic (patients describe it as an uncomfortable procedure rather than painful). Or it can be done as a minor surgical operation under general anaesthetic. Once in place, however, it will not be used for 2 weeks, to allow healing.

Group Care Options Changes Focus of Attention.

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Treatment Type (haemodialysis/ peritoneal dialysis)

Location Care (hospital dialysis/ home dialysis)

Treatment Type Picture

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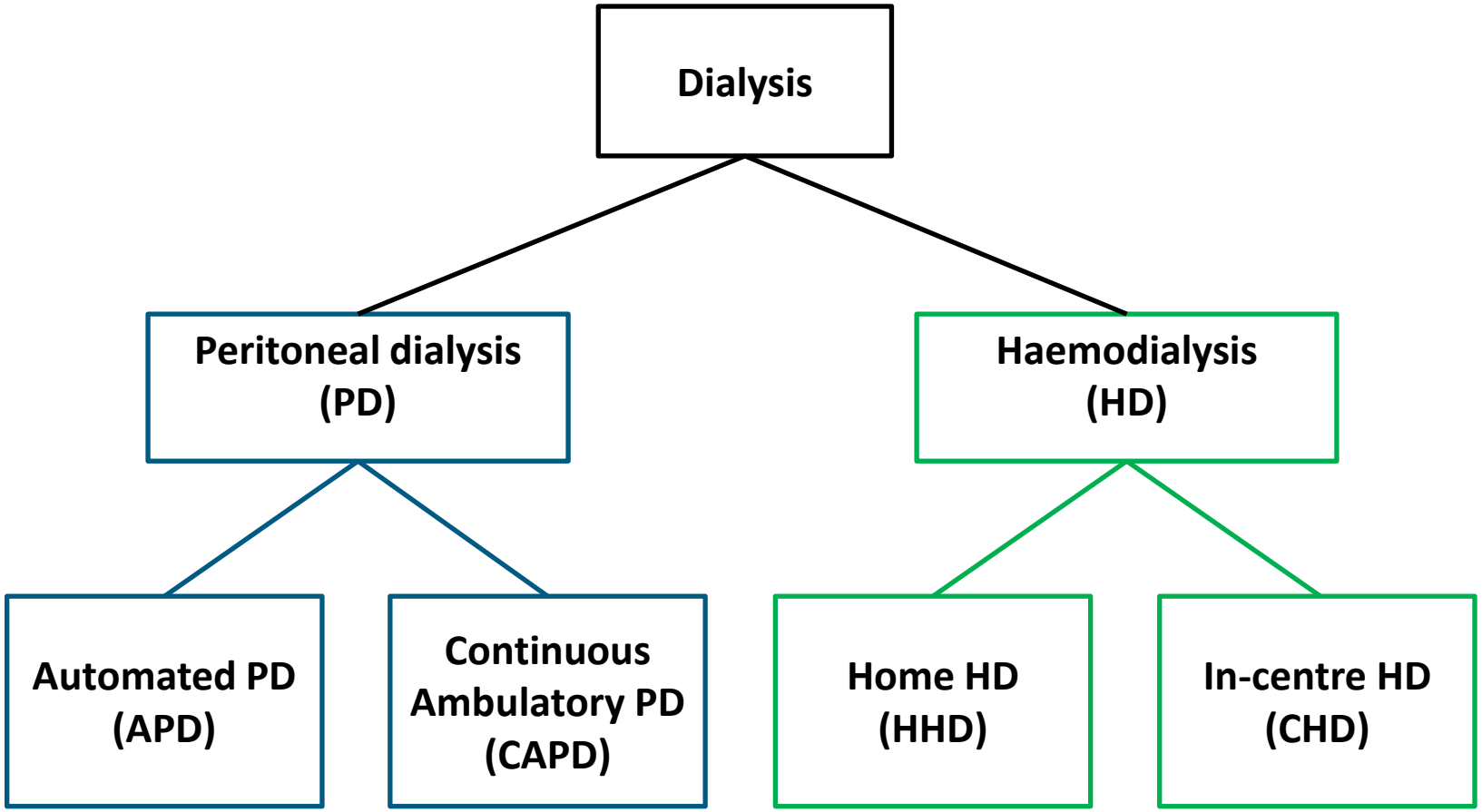

Location Care Picture

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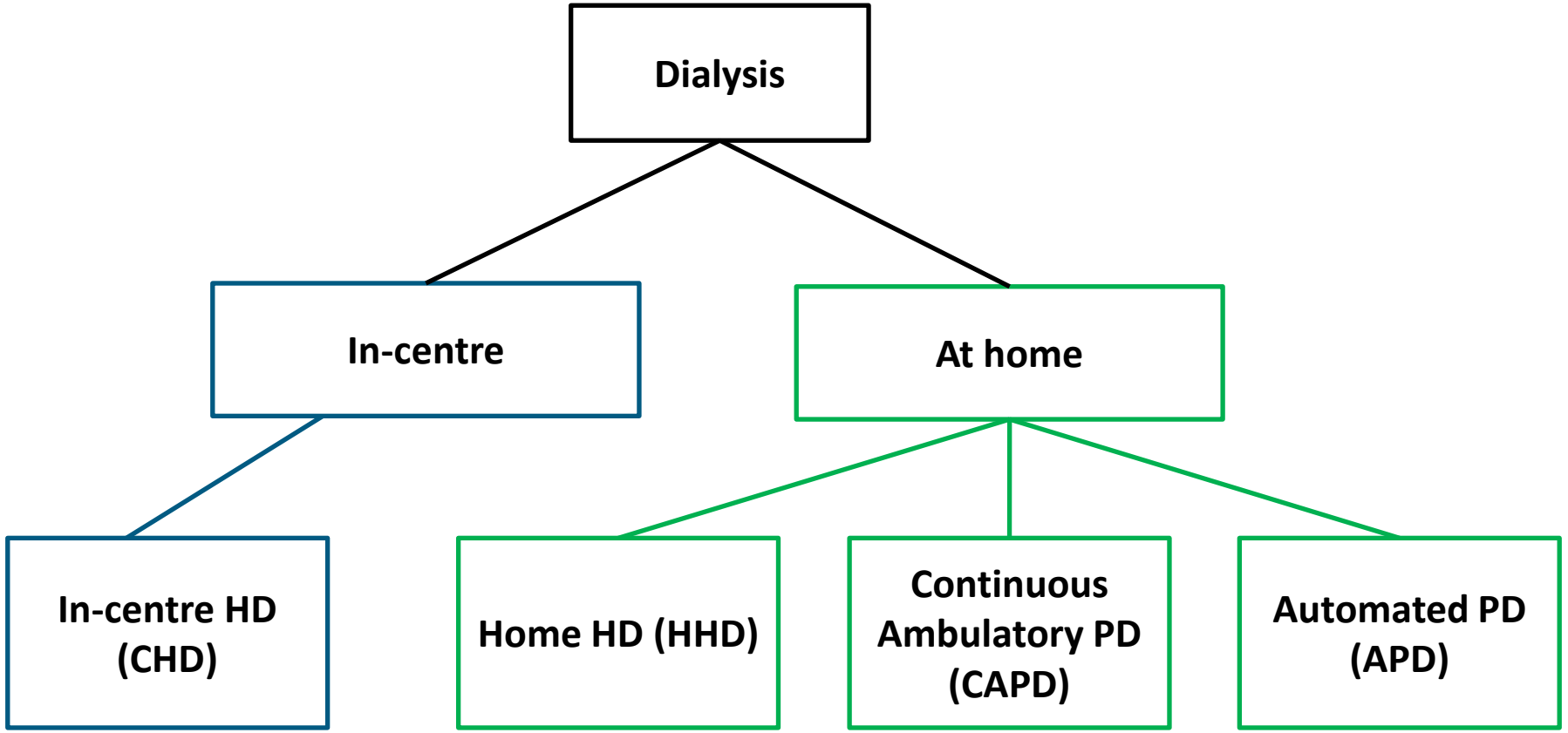

Affects Patient Understanding

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Dialysis Treatment Groups Had

- Higher knowledge of all options
- Information perceived as more balanced
- Higher association between choice and values

Than Location Care Groups

Patient Decision Aids

[*Stacey et al, 2014; (n=115)]*

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Evidence-based information to help people make informed decisions between treatment options.

- Increase knowledge/ understanding risk perception
- Choices more likely to be based on own values
- Increase feeling informed
- Increase perceived usefulness information.
- Decreased decisional conflict

(IPDAS - International Patient Decision Aid Standards Collaboration)

Active Components Decision Aids

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- Balanced and neutral information about all options.
- Health problem and treatment options structured by how people make decisions and sense of illness.
- Prompts to ‘see’ choices in disease context (e.g. map).
- Statements about how to make a decision (guidance).
- Prompts to focus on what is important in their life (values, trade-offs, and preferences).

(Bekker et al, 2013)

The Dialysis Decision Aid: Decision Map.

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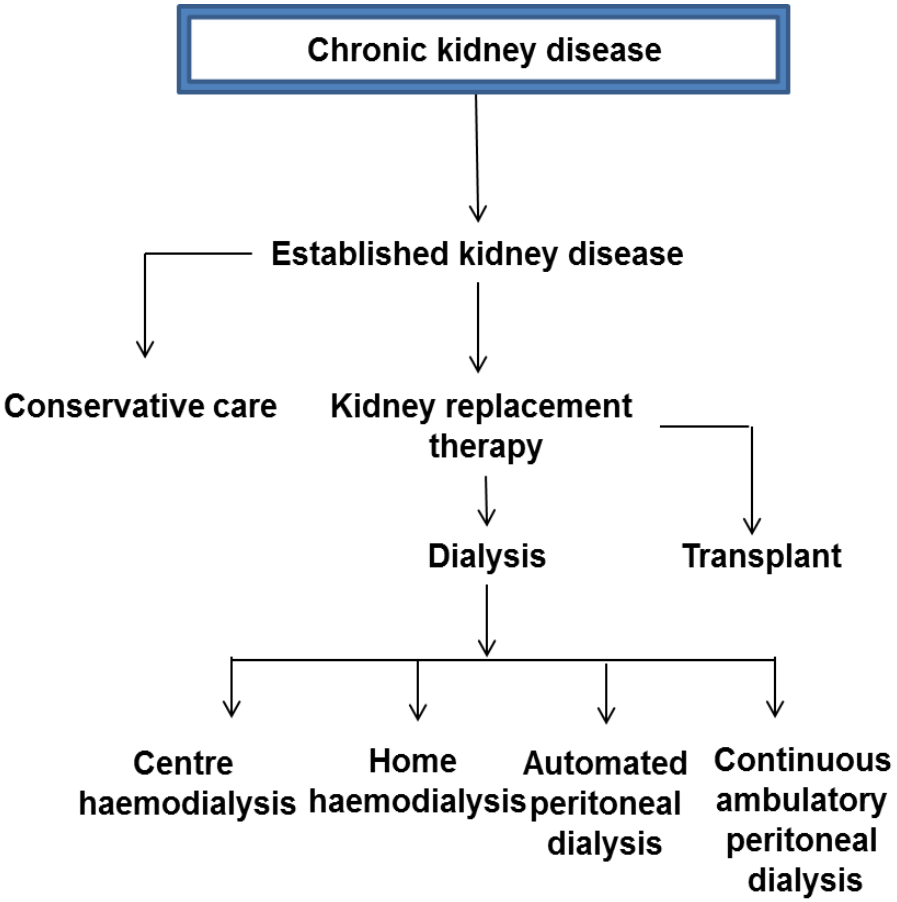

- Making explicit the options.
- Making explicit the decisions.
- Linking with changes in kidney disease.
- Signposting what the information describing.

Separate Care From Choosing Between Options.

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Contact with Health Professionals

- People on dialysis will be seen regularly by their kidney health professionals at hospital for their kidney disease check-ups.

Operation for the access point

- People on dialysis need to have an *access point* made to take the fluid ... an operation to make the access point.

Caring for the access point

- People must keep their access point clean. Kidney healthcare professionals help people learn how to carry out dialysis safely and keep the access point clean. If bacteria get into the access point, the bacteria can cause a serious infection.

Balanced Information – All Options and Consequences.

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	Haemodialysis (HD)	Peritoneal dialysis (PD)
The names	Haemodialysis filters the waste products and extra fluid from the blood using a salt liquid (dialysate) and an artificial membrane with a machine outside the body.	Peritoneal dialysis filters the waste products and extra fluid from the blood using a liquid (dialysate) which is placed inside the belly and then removed.
How dialysis works	Blood is pumped out from the body to a machine. The machine contains several membranes that separate the blood from liquid called dialysis fluid or dialysate. The membranes filter out waste product and extra fluid from the blood. These waste products pass into the dialysate. The used dialysate is then pumped out of the machine and thrown way. The cleaned blood is pumped back into the body.. .This is called a “dialysis session”.	Blood moves around the internal organs and intestines naturally inside the body. The membrane covering these organs is called the peritoneum. There is a space in the body made by the peritoneum called the peritoneal cavity. Liquid known as dialysis fluid or dialysate is put into this space. The peritoneum is a natural filter and allows the waste products and excess water to be drawn out of the blood into the dialysis fluid... The draining out of used liquid and the adding of fresh liquid is called a dialysis session or an “exchange”.

Summary Tables: Compare Across Options

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	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.
Usual number of sessions in a week	3 days in a week	At least 3 times a week (night or day)	Every day	Every night

Values Clarification.

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1. List the activities you do now and want to keep doing when you are on dialysis.	LIST
Hobbies (e.g., gardening, fishing, music, knitting)	
Socialising (e.g. with friends and/or family)	
Holidays, Trips Away (e.g. locally, abroad)	
Local travel (e.g. public transport, driving)	

2. List the questions or worries you have about dialysis treatments	Questions or Worries
The Access Point (arm, leg, belly)	
The Place of Dialysis (home, hospital, work, trips away)	
The Timing of Sessions (days, length, night, day)	

Making A Decision At This Point: What Fits Best In Life.

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	No Not at all	No Maybe	Unsure	Yes Maybe	Yes Definitely
Haemodialysis - Centre (machine at hospital)	○	○	○	○	○
Haemodialysis - Home (machine at home)	○	○	○	○	○
Peritoneal Dialysis – Continuous Ambulatory (bag at home or any clean place)	○	○	○	○	○
Peritoneal Dialysis - Automated (machine at home or any clean place)	○	○	○	○	○

YoDDA Evaluation: UK Predialysis Services.

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• Prospective non-randomised comparison study, carried out in six predialysis centres in Yorkshire (UK), 2012-2013:

Usual Care (n = 105); *Usual Care* +*YoDDA* (n = 84)

• Participants completed consent (C), questionnaire after consultation (T1), questionnaire six weeks later (T2)

- Average age = 63 years (19-93);
- 66% male; 69% married; 93% white.
- eGFR = 14.5 (S.D. 4.22); EQ-5D = 0.71 (S.D. 0.25)

Use Decision Aid Booklet?

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- 97% read the dialysis decision aid booklet
- 66% more than once.
- 72% showed it to someone else
- 23% wrote notes in it.

Higher Score for Understanding CKD and Dialysis

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	Usual Care (0-6)	+YoDDA (0-6)	P<0.05
Easy to understand information	4.4	4.7	
Helped understanding kidney disease	4.4	4.9	✓
Helped understanding dialysis	4.5	4.9	✓
Helped thinking about the dialysis decision	4.3	4.6	

Higher Score for Reasoning About Decision

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Items scored: Not At All 0-1-2-3-4 Very Much	Usual Care M (SD)	+YoDDA M (SD)	(p)
Help you recognise that a decision needs to be made?	2.91 (0.96)	3.12(0.92)	✓
Help you think about the advantages and disadvantages of each option?	2.77 (1.05)	3.09(0.93)	✓
Help you organize your own thoughts about the decision?	2.72 (1.03)	3.03(1.02)	✓

Patients' Comments

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All the information included was explicit, useful and informative I don't feel the booklet could be improved upon. Perfect.

Useful, factual, neutral

Good overview to use in conjunction with face to face meetings with renal team, nurses etc

Explanation of dialysis treatment. Well set out. Covered every aspect of kidney treatment

Staff Comments

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I found that everybody that actually read YoDDA …found it really helpful because we [have] our own book. They read that and then they read this and this was more detailed and this actually clarified things and that bit.

Some people...or relatives need that much information and they're ready for that much information. Sometimes its family members ..so I think [its] certainly supportive for people like that.

I think we'd probably say we'd like to have it available working alongside of the work that we've done.

Conclusions

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- The Dialysis Decision Aid helped patients make sense of dialysis decisions in context of their lives.
- Patients valued receiving The Dialysis Decision Aid Booklet from their predialysis team.
- Predialysis staff used the Dialysis Decision Aid alongside their usual predialysis education.
- Predialysis services using The Dialysis Decision Aid more likely to meet best practice clinical guidelines.

Thank You For Your Attention

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YoDDA Funders: Kidney Research UK with partners; The Yorkshire Kidney Research Fund; The Informed Medical Decisions Foundation; ESRC.

YoDDA TEAM.

Clinical Experts: Andrew Mooney, Martin Wilkie, Simon Davies, Lorraine Edwards (renal); Gary Latchford (clinical psychology); Nigel Mathers (general practice).
Kidney Patient Representatives: Ken Tupling, Dennis Crane.
Decision Scientists: Hilary Bekker, Teresa Gavaruzzi, Anna Winterbottom, Barbara Summers; Anne Stiggelbout.
Health Informatics: Susan Clamp, Scott Jones.
Health Services Research: Louese Dunn; Paul Baxter, David Meads.