Danish Society of Renal Nurses Conference
Thursday 28th September 2017 (10:45-12:00)


Professor Hilary L Bekker
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Chair in Medical Decision Making

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Collaborators since 2002:

The Yorkshire Dialysis Decision Aid

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:
Teresa Gavaruzzi, Anna Winterbottom,
Barbara Summers; Anne Stiggelbout.

Health Services Research:
Louese Dunn; Paul Baxter, David Meads.

Health Informatics:
Susan Clamp, Owen Johnson.

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

What is the problem?

How do people make decisions?

Can patients be helped to make informed dialysis decisions?

The Dialysis Decision Aid Booklet: Making The Right Choices for You.

English - https://www.kidneyresearchuk.org/DialysisDecisionAid

The Problem.

Renal Service Policy.

• Treatment plans must include patient preferences
• Information and education must facilitate patient decisions

Renal Professionals

• Variation in peritoneal dialysis uptake by centre (3-40%)
• Staff worries about delivering best end of illness service.

Renal Patients

• Happy with renal care but want support to make decisions.
• Patients not making informed dialysis decisions
• Conflict and regret about making dialysis decisions
Winterbottom et al, 2007 reviewed UK renal leaflets. Over 30 leaflets on dialysis; most patients got 2+ leaflets

Leaflets designed to inform:

- Local services, manage dialysis, cope / adjust to illness.
- Written by service delivery, and some patient, experts.

Difficult to understand (readability = PhD+)

Incomplete information about treatment options

No awareness of decision science…
How did you choose your first *smart* phone?
Where did you get your advice?
Did you know what the consequences were for you?

Would you get the same phone for your child?
Would you make the same choice again, now?
My Smart Phone Decision Making (2015)

My Broadband Provider offers 71 smart phones:

- That one is pretty
- You need to get spotify…
- Everyone in design has iphone
- Screen size (4.2-5.5), camera, colour, minutes/ texts/ data, cost (£10-£45), Operating system (ios, android, windows), Aps, battery, zingy (?)…
- Not too big, can’t hold it.
- Don’t know where you buy windows aps…
My Choice…

Lots of choices
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…

But… not helping me make a choice
So … stick with ‘non-smart’ phone (until 2015)
Brain creates mental representation of world ‘out there’.

Information given affects ‘our pictures’.

Brain works all the time to:

- Attend to / excludes information.
- Make *unconscious judgements*.
- Limited capacity for conscious attention.
- Uses external/ internal cues to attend

We have little insight into what influences on our decisions.
We All Make Decisions Using Two Types of Strategies.

**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.

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.
All people make treatment choices using systems 1 & 2:

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

Decisions ‘biased’ by information attend to.

Judgements ‘biased’ by the way information presented.

1. Informed Decision
   - PATIENT: Culture, Experience, Skills, Knowledge, Motivation, Skill
   - OTHER PEOPLE & INFORMATION: media, patients, family, social context

2. Evidence-Based Decision
   - HEALTH PROFESSIONAL: Culture, Experience, Skills, Knowledge, Motivation, Skill
   - OTHER PEOPLE & INFORMATION: guidelines, team, infrastructure

3. Shared Decision
   - CONSULTATION: Exchange Understanding, Reason About Preferences, Implement Agreed Choice

Shared Decision Making.

“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)
“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)
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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 dialysate 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.

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**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, 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 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 5-12 litres over 8-10 hours and then leave 1.2 litres to dwell during the day.

You will be trained by the HD nurses - the techniques need to be done correctly and in a clean manner - and are designed to be done at home with the help of a partner. Although you are at home, you will be contacted frequently by the nurses and will come to the outpatient 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% light, medium, and heavy) - the “heavier” the bag (10.38%), more water will be removed from the body.

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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 - Provysol 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 tunnel itself, portaflow. This shows as tummy pain, fever and a cloudy fluid bag. It is important to ring the dialysis unit immediately if a cloudy bag develops. Portaflow is treated with antibiotics added to the bag 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-inflating, 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 if 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 anaesthesia. Once in place, however, it will not be used for 2 weeks, to allow healing.
Framing Care Options.

Treatment Type:
Haemodialysis versus Peritoneal Dialysis

Service Delivery/ Location Care:
Hospital dialysis versus home dialysis
Group by Treatment Type (even choices)

Dialysis

- Peritoneal dialysis (PD)
  - Automated PD (APD)
  - Continuous Ambulatory PD (CAPD)
- Haemodialysis (HD)
  - Home HD (HHD)
  - In-centre HD (CHD)

Gavaruzzi et al, 2014
Group by Location Care
(uneven choices)

Dialysis

In-centre
- In-centre HD (CHD)

At home
- Home HD (HHD)
- Continuous Ambulatory PD (CAPD)
- Automated PD (APD)
Findings.

When framed as treatment type, people had…

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

... than information framed as location of care.
Components To Boost Reasoning

- Describe disease within common sense model of illness.
- Make explicit causal links between disease and its consequences and treatments.
- Balanced, accurate and neutral information of all options.
- Describe decision in within care/ disease pathway (picture).
- Statements on how to make a decision (active thinking).
- Prompts to focus on what important in their life (values, trade-offs, and preferences).

(Bekker et al, 1999; 2010; 2013)
Patient Decision Aids

PtDA - designed to help people make informed decisions between treatment options (Stacey et al, 2017; Cochrane Review).

- Increase knowledge/ understanding risks
- Choices more likely to be based on own values
- Increase feeling informed/ usefulness of information
- Decreased decisional conflict/ regret

IPDAS resources - checklist, reporting guidelines, decision science evidence summaries of components that boost reasoning and decrease bias (see OHRI website)
The Dialysis Decision Aid: Decision Picture.

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

<table>
<thead>
<tr>
<th>Haemodialysis (HD)</th>
<th>Peritoneal dialysis (PD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>The names</strong></td>
<td></td>
</tr>
<tr>
<td>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.</td>
<td>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.</td>
</tr>
<tr>
<td><strong>How dialysis works</strong></td>
<td></td>
</tr>
<tr>
<td>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”.</td>
<td>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”.</td>
</tr>
<tr>
<td>Place of dialysis care</td>
<td>Haemodialysis (HD)</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td></td>
<td>Haemodialysis At a hospital or centre (CHD)</td>
</tr>
<tr>
<td></td>
<td>People travel to a hospital or specialist centres for dialysis session.</td>
</tr>
<tr>
<td></td>
<td>People have dialysis sessions at home.</td>
</tr>
<tr>
<td>How dialysis works</td>
<td>Attaching to a machine for 4 hours per session by the arm or leg.</td>
</tr>
<tr>
<td></td>
<td>Attaching to a bag of fluid for about 40 minutes per session by the belly.</td>
</tr>
<tr>
<td>Usual number of sessions in a week</td>
<td>3 days in a week</td>
</tr>
</tbody>
</table>
## Values Clarification.

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

<table>
<thead>
<tr>
<th>LIST</th>
<th>Hobbies (e.g., gardening, fishing, music, knitting)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Socialising (e.g. with friends and/or family)</td>
</tr>
<tr>
<td></td>
<td>Holidays, Trips Away (e.g. locally, abroad)</td>
</tr>
<tr>
<td></td>
<td>Local travel (e.g. public transport, driving)</td>
</tr>
</tbody>
</table>

2. List the questions or worries you have about dialysis treatments

<table>
<thead>
<tr>
<th>Questions or Worries</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Access Point (arm, leg, belly)</td>
</tr>
<tr>
<td>The Place of Dialysis (home, hospital, work, trips away)</td>
</tr>
<tr>
<td>The Timing of Sessions (days, length, night, day)</td>
</tr>
</tbody>
</table>
### Making A Decision At This Point: What Fits Best In Life.

<table>
<thead>
<tr>
<th>Method</th>
<th>No Not at all</th>
<th>No Maybe</th>
<th>Unsure</th>
<th>Yes Maybe</th>
<th>Yes Definitely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haemodialysis - Centre (machine at hospital)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haemodialysis - Home (machine at home)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peritoneal Dialysis – Continuous Ambulatory (bag at home or any clean place)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peritoneal Dialysis - Automated (machine at home or any clean place)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Quasi experimental study in six predialysis centres, Yorkshire (UK), 2012-2013:

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

Patient questionnaires at: consent (C), after education consultation (T1), after six weeks (T2)

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)
97% read the dialysis decision aid booklet

66% more than once.

72% showed it to someone else (family, spouse)

23% wrote notes in it.
### Increase in Understanding CKD and Dialysis

<table>
<thead>
<tr>
<th></th>
<th>Usual Care (0-6)</th>
<th>+YoDDA (0-6)</th>
<th>P&lt;0.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easy to understand info.</td>
<td>4.4</td>
<td>4.7</td>
<td></td>
</tr>
<tr>
<td>Helped understand kidney</td>
<td>4.4</td>
<td>4.9</td>
<td>✓</td>
</tr>
<tr>
<td>Helped understand dialy.</td>
<td>4.5</td>
<td>4.9</td>
<td>✓</td>
</tr>
<tr>
<td>Helped think dialy. dec.</td>
<td>4.3</td>
<td>4.6</td>
<td></td>
</tr>
</tbody>
</table>
## Increase in ... Reasoning About Decision

<table>
<thead>
<tr>
<th>Items scored:</th>
<th>Usual Care M (SD)</th>
<th>+YoDDA M (SD)</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not At All</td>
<td>0-1-2-3-4</td>
<td>Very Much</td>
<td></td>
</tr>
<tr>
<td>Help you recognise that a decision needs to be made?</td>
<td>2.91 (0.96)</td>
<td>3.12(0.92)</td>
<td>✓</td>
</tr>
<tr>
<td>Help you think about the advantages and disadvantages of each option?</td>
<td>2.77 (1.05)</td>
<td>3.09(0.93)</td>
<td>✓</td>
</tr>
<tr>
<td>Help you organize your own thoughts about the decision?</td>
<td>2.72 (1.03)</td>
<td>3.03(1.02)</td>
<td>✓</td>
</tr>
</tbody>
</table>
Patients’ Value Receiving Dialysis Decision Aid

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
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.
Other Dialysis Patient / Shared Decision Making Aids


Choosing Dialysis (http://choosingdialysis.org/ Tentori et al, Arbor, USA (2014+)

Options: Older Adults with End Stage Kidney Disease (Brown et al. Brisbane, Australia, 2016+)


Leaflets and Information can proactively support patients to make informed dialysis decisions.

- Aspects service delivery, staff training and policy can bias people’s thinking/ discourage active thinking
- Patient Decision Aids, Skills training and system changes can boost patients’ thinking
- Decision and psychological sciences help services deliver information more effectively.
Thank You For Your Attention