Pre Dialysis care
Communicating Options and Decision making for treatment

Jyoti Baharani
10/10/2015
Choosing treatment

informed consent
A bit of history

The NHS Plan July 2000

“For the first time patients will have a real say in the NHS”

- Patient centred service
- PALS
- Copying letters to patients
- Better patient information
Drivers for improvement

- July 2000
  The NHS Plan
- June 2004
  The NHS improvement plan
- March 2005
  Creating a patient led NHS

“Patients who are treated considerately, who are not left to endure anxiety and worry, who are treated attentively, who are given full and prompt information, who understand what they are being told and who are given the opportunity to ask questions, are more likely to have better clinical outcomes.”
‘...adults with chronic kidney disease are
to have access to information that enables them with their carers to make informed decisions and encourages partnership in decision making, with an agreed care plan that supports them in managing their condition …’
Decisions, decisions....

- Informed patients feel better about the decision process.
- Their decisions are more likely to match up with their preferences, values and concerns.
- They are more likely to stick with the regimens the treatment requires.
- They often end up rating their health after treatment as ‘better’.
The ideal pathway to choice
Progressive CKD stages 4, 5 or failing transplant

Pre-dialysis (low clearance clinic)
Assess suitability for transplantation

Yes
Pre-emptive live or cadaveric transplant

No
Is dialysis suitable?

No
Reassess treatment options

Yes
Conservative Management

End of Life Care

Assess suitability for home therapies

Yes
Fast-track education

Peritoneal dialysis
• CAPD
• APD
• Assisted PD

No
Unit-based haemodialysis
• Conventional
• Enhanced frequency
• Nocturnal

"Crash Lander" requiring unplanned dialysis?

No
End of Life Care

Yes
Fast-track education

Reassess treatment options
the trouble with inadequate or no information aka the reality in some cases
When given information at a later stage, these patients rarely opt for PD or home HD.
Barriers to CKD education

- Time restrictions
- Old habits
- Being MUM
- Inability to interact
- Lack of feedback on what works
- Resistance to change
Communication

“Just a tip, never be the bearer of bad news – people will automatically blame you for it…”

See, Bernard? Julia’s approach was just a tad more sensitive.
OK – so who wants another crack at breaking the bad news?
Barriers to communication

• Insufficient time
• “Trust me I’m a doctor”
• Disempowered patients
• Desensitisation
  • Lack of empathy
  • The invisible patient
Consultations

- Your kidney function is x %
- You will need dialysis
- You could also have a transplant
- Some people don’t do well on dialysis
- You can't travel
- Which dialysis would you like
- Do you have a donor
- No coffee/chocolate/tomato's

.....
Making decisions

"When we want your opinion, we'll give it to you."

The NHS wants patients to make more decisions about their treatment... so here's your blood tests and a prescription pad, I'll be back later.
Types of patient/doctor interaction

After Tannebaum and Schmidt

Level of decision made by Consultant

Level of choice for Patient

1. Tells
2. Sells
3. Consults
4. Shares
5. Delegates

Enablement
Empowerment
The evolution of decision making

<table>
<thead>
<tr>
<th>Models of decision making</th>
<th>Professional choice</th>
<th>Professional as agent</th>
<th>Shared decision making</th>
<th>Consumer choice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician decides, patient consents</td>
<td>Clinician elicits patient’s views, then makes decision</td>
<td>Information shared, both decide together</td>
<td>Clinician informs, patient makes decision</td>
<td></td>
</tr>
<tr>
<td>Paternalism</td>
<td></td>
<td></td>
<td>Consumerism</td>
<td></td>
</tr>
<tr>
<td>Passive</td>
<td></td>
<td></td>
<td>Autonomous</td>
<td></td>
</tr>
</tbody>
</table>

Do patients want choice?

• Deber et al, 2007
  – 2,704 (breast cancer, prostate disease, fractures, continence, orthopaedic, rheumatology, multiple sclerosis, HIV/AIDS, infertility, benign prostatic hyperplasia, cardiac disease)

  • autonomous 1%
  • shared decision making 78%
  • passive (older & less educated) 20%

• Greater familiarity with a health condition increases a desire to participate
As part of seeing which factors predicted choice; satisfaction with treatment was also assessed.

- >300 patients

Vast majority of patients satisfied that they had been adequately involved in the DM of RRT modality and given a free choice.
• 22 Patients;
• Qualitative interview study of elderly patients at time of starting RRT and 6 months after starting treatment 2006/7
• 90% were optimistic about treatment and felt that had made a shared decision to start
• Only 45% agreed to the above at 6 months after starting treatment
• Questionnaires to >200 patients

• 2009

• Looked at factors affecting modality choice including those who chose not to have dialysis

• 92% of all those responding felt involved in the decision making process
A service evaluation conducted within Heart of England dialysis units to assess patient experience of shared decision making when selecting the treatment modality for end stage kidney disease

Hannah Davis: 1006285; 4th year medical student

- Service evaluation in 2011
- 20 patients
- >90% satisfaction that the decision to start RRT on that modality was SDM
How busy is your hospital?

The pressure on acute hospitals recorded on Wednesday, March 2, 2011 at 9.30am.

This information is provided by the Regional Capacity Management Team for the West Midlands.

The gauges show how busy acute hospitals in the West Midlands are.

Level 1 = Hospital working
Is shared decision making always correct?

"You want to speak to the head of the household? There is no head of the household. My parents are into shared decision making."
What is the purpose of pre-dialysis ‘education’?

• Primary goal- provide information about choices of therapy
• Many secondary goals
  ❑ Ease the process of acceptance
  ❑ Help integrate CKD/RRT with patients 'life
  ❑ Avoid admission with emergent start of dialysis
  ❑ Avoid temporary HD access
How I deliver choice

• What's the most important thing in your life?
• What do you want to be able to continue to do?
• How important is independence to you?
Most patients want information

<table>
<thead>
<tr>
<th>Information</th>
<th>Do NOT want to know</th>
<th>Would like to know</th>
<th>Absolute need to know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life expectancy on dialysis</td>
<td>3%</td>
<td>46%</td>
<td>51%</td>
</tr>
<tr>
<td>Limitations on quality of life</td>
<td>1%</td>
<td>45%</td>
<td>54%</td>
</tr>
<tr>
<td>What it does to the body</td>
<td>3%</td>
<td>44%</td>
<td>53%</td>
</tr>
<tr>
<td>What it will accomplish</td>
<td>4%</td>
<td>43%</td>
<td>53%</td>
</tr>
<tr>
<td>Possible side effects</td>
<td>4%</td>
<td>48%</td>
<td>48%</td>
</tr>
</tbody>
</table>

And for the physician to provide it without having to be prompted

What are the choices?

- Home therapy- PD, APD, HD, NHD, DHD
- Satellite HD
- In centre HD
- Transplantation – C, LR, LUR, Altruistic
- Conservative management
What is the modality of choice?

- Evidence inconsistent
- Modality choice should be dictated by patient not the centre
- Few absolute CI for any treatment
Informed patients more likely to chose PD
Is PD better?

• Better early survival

• Better preservation of RRF

• Better transplant success

• Better preservation of vascular access

• Clinical outcomes comparable to HD – same survival at 2 and 5 years
Why PD?

Catheter Event & Complication Rates For PD Versus HD

FIRST YEAR DIALYSIS PATIENTS

HD Catheter Events
- Removal
- Replace w/ catheter
- Replace w/ internal device
- Sepsis

PD Catheter Events
- Removal
- Replace with PD catheter
- Replace with HD catheter
- Replace with internal HD access
- Sepsis

Patients treated with PD have better early survival than those treated with Conventional HD

Cohort period = 2001-2004

Adjusted cumulative hazard ratio (PD:HD)

Months of follow-up

Adapted from Yeates K et al. 1
PD preserves RRF for the future

RRF is better preserved in patients treated with PD compared with those treated with CHD\textsuperscript{10*}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{chart.png}
\caption{Time (months) vs. rGFR, mL/min/1.73m\textsuperscript{2}}
\end{figure}

RRF contributes to successful fluid management and to increased phosphate and serum β2-microglobulin removal
PD use prior to transplant is associated with better patient and similar graft survival.

Follow-up time (years)

Log-rank test: $P=0.02$. 

Cumulative Survival

Follow-up time (years)
PD avoids the risks associated with vascular access

Patients on PD have better survival than those patients on hemodialysis using a central venous catheter\textsuperscript{19}

![Graph showing survival rates over time for PD, HD-CVC, and HD-AVF/AVG patients.](image)

<table>
<thead>
<tr>
<th>Year</th>
<th>PD (N)</th>
<th>HD-CVC (N)</th>
<th>HD-AVF/AVG (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>7412</td>
<td>24,437</td>
<td>6663</td>
</tr>
<tr>
<td>1 Year</td>
<td>5502</td>
<td>15,620</td>
<td>5114</td>
</tr>
<tr>
<td>2 Year</td>
<td>3761</td>
<td>10,320</td>
<td>3663</td>
</tr>
<tr>
<td>3 Year</td>
<td>2390</td>
<td>6541</td>
<td>2480</td>
</tr>
<tr>
<td>4 Year</td>
<td>1487</td>
<td>3961</td>
<td>1564</td>
</tr>
<tr>
<td>5 Year</td>
<td>831</td>
<td>2167</td>
<td>945</td>
</tr>
</tbody>
</table>

Adapted from Perl J et al.\textsuperscript{19}
Risk of Bacteremia/Hospitalized Septicemia*

*Results expressed as a hazard ratio, which is the relative risk of developing a bacteremia or hospitalized septicemia episode for a particular catheter compared to an arteriovenous fistula.

What drives choice?

- Education
- Targeted information
- What peers say
- What the nurses say
- Family
- Support
- Medical advice
A good pre-dialysis service = Patient centred care
Letters to Patients

The Heartlands Experience
Copying letters to patients

- Mandated in the NHS Plan – July 2000
- Lots of attempts with limited success
- Problems
  - Consent
  - Confidentiality
  - Cost
  - Administration
  - Language difficulties
    - Medical jargon
    - Literacy in English
  - Patient support and backup
The Heartlands project
*Writing to patients and copying letters to GPs*

- Patients given information sheet on arrival in clinic
- Doctor registers consent on clinical letters system
- Doctor dictates an appropriate letter after the consultation
- System automatically generates correct letters and copies
- Letters include a contact number and go out with an optional feedback form
- Evaluation for 6 months
Dear Jean

DOB 29/08/1948, NHS Number xxxxxxxxxxxxxx, PID xxxxxxxx
739 xxxxxxxxxxxxx Road, Ward End, Birmingham B8 XXX

Clinic attendance: 26 October 2005  Clinic number: 02434

Diagnosis:  End stage renal failure on home haemodialysis
            Multiple myeloma and previous peripheral blood stem cell autograft
            Type II diabetes (diet controlled)
            Previous fracture right femur (pinned)
            Right superior vena cava stenosis

Medication:  Phosex increased to 2 tabs three times a day with food
            Atorvastatin 40mg once a day
            Erythropoietin (NeoRecormon) 6000 units three times a week
            Aspirin 75mg once a day
            Gabapentin 300 mg after dialysis
            1-alfacalcidol 0.25 μg once a day

Thank you for coming to see me in clinic today. I was very sorry to hear that Tony has been unwell and that you are now dialysing in the hospital because he cannot help you at home. I wish him all the best and hope he gets better soon.

Your phosphate has been too high recently (2.02 mmol/l) and this can be bad for your bones and circulation if it is not corrected. We agreed to increase your dose of Phosex which will help reduce the phosphate level.

In most respects things are going very well. I am pleased that your new fistula is working well and that we have been able to remove your permcath. Your blood pressure was good (124/78 mmHg) and your haemoglobin is much better (11.3 g/dl).

SAS Preston
Renal Patient View

Renal Information Exchange
Group
RIXG
What PPC is and why it matters

- Knowing, not guessing what patients want
- Affording people dignity, respect and compassion
- Offering coordinated care, support and treatment
Dialysis—perhaps life preserving but definitely life-changing!
I am more than my kidney failure.

Linda's story.
It's good to talk

He didn't wait to hear what I had to say! Maybe I'm just another lab result to him...

What was that? I got so nervous! My patients are going to hate me!
<table>
<thead>
<tr>
<th>Medical Model</th>
<th>Patient-Centered Model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s role is passive (The patient is quiet)</td>
<td>Patient’s role is active (The patient asks questions)</td>
</tr>
<tr>
<td>Patient is recipient of treatment (The patient doesn’t voice concerns, even if there’s a problem)</td>
<td>Patient is partner in treatment plan (The patient asks for information about other options)</td>
</tr>
<tr>
<td>Provider (usually a doctor) dominates as decision-maker (The provider does not offer options)</td>
<td>Provider collaborates with patient in making decisions (The provider offers options and discusses pros and cons)</td>
</tr>
<tr>
<td>Disease-centered (Dialysis is the focus of daily activities)</td>
<td>Quality-of-life-centered (The patient focuses on family and other activities)</td>
</tr>
<tr>
<td>Provider does most of the talking (The provider does not allow time for questions)</td>
<td>Provider listens more and talks less (The provider allows time for discussion)</td>
</tr>
<tr>
<td>Patient complies (or not) (Patient does not comply with diet)</td>
<td>Patient adheres to treatment plan (Diet is flexible to accommodate culture and family traditions)</td>
</tr>
</tbody>
</table>
Compliance

Obedience or compliance does not equate to patient engagement
Ask 3 questions

Ask 3 Questions

Normally there will be choices to make about your healthcare. Make sure you get answers to these three questions:

- What are my options?
- What are the pros and cons of each option for me?
- How do I get support to help me make a decision that is right for me?

Shared Decision Making

AQuA
NHS
"Thank you to the Glaxo Renal Unit - Heartlands Hospital"

Response from Jyoti Baharani, Consultant Physician and Nephrologist, Renal Heartlands Hospital on 22/01/2013 at 13:51

Dear Father Sid,

Firstly can I thank you so much for taking the time to write such a detailed feedback. I will be sure to pass this on to all the staff in Glaxo. It is really good to see praise from patients such as yourselves in writing.

They are a dedicated bunch and this feedback will help us to strive harder.
Keeping patients informed

Kidney Concerns

In this Issue...

There is No Place Like Home

I grew up clicking my heals together repeating those six words over and over. And the meaning changed as my life circumstances changed. When I moved out on my own for the first time, home was my old bedroom. When we moved across country, home was where I grew up. And now home is my little corner of the world where everything is familiar and I feel some measure of control.

There is a push in the renal community towards home dialysis. This is one of the many forms of dialysis that you perform in the comfort of your own home. You control when and where, and in some instances, how often. But the key point is that you are in control.

Home dialysis might not be a good option for everyone, but for many it is a very real option. I urge you to seriously consider the idea. The benefits to your health and well being are huge, and your quality of life can be greatly improved. After all, isn’t that what we are looking for? A better quality of life?

Renal Network 11 is going to be focusing on home dialysis during the upcoming year. They will be exploring and dispelling some of the myths surrounding this topic and attempting to make the referral process easier to understand. Network 11’s Consumer Committee is kicking off this project with this issue of Kidney Concerns. Notice that we have a new name and logo. Please take time to read each article carefully and with an open mind.
Does PCC affect outcome?

Engaged empowered patient  Organised proactive system  =  Better outcomes

Partnership
Measuring outcomes

You can’t manage what you don’t measure.
Thanks for listening

IF “Plan A” Didn’t Work. The alphabet has 25 more letters! Stay Cool.

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