Disclosure of Interests

The University of Sydney – Employment
No relevant disclosures
THE FIRST TIME SOMEONE MENTIONS DIALYSIS AS A REAL POSSIBILITY
Patient perspectives and symptoms – dialysis initiation

Dialysis and symptom burden

The evidence for dialysis and interventions

Shared decision-making

What outcomes matter to patients?
Patient perspectives and symptoms – dialysis initiation

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KDIGO

KDIGO Controversies Conference on Dialysis Initiation, Modality Choice & Prescription
January 25-28, 2018 | Madrid, Spain
Patient-centered care – “no decision about me without me”

“Initiation of dialysis should be a shared decision-making process” – Cabrera 2017 CJASN

Focus on outcomes that matter to patients
Deliberation

- Patients become aware of choice, understand their options, have time and support to consider "what matters most".

Choice talk
- Awareness that choice exists

Option talk
- Patients are informed about treatment options in more detail

Decision talk
- Patients are supported to explore "what matters most"

Decision support
- 1) Brief – used by clinician and patient together
- 2) Extensive – used by patients outside of clinical encounters (videos, booklets)

Initial preferences
- Awareness of options leads to the development of initial preferences based on existing knowledge. The goal is to arrive at informed preferences.

Informed preferences
- Personal preferences based on "what matters most to patients" predicated on an understanding of the most relevant benefits and harms.

Elwyn et al 2012 J Gen Intern Med (adapted)
18 studies, n = 375 patients and n = 87 caregivers
Patient perspectives on informed decision-making surrounding dialysis initiation

N=99 (15 centers, US)
Semi-structured interviews + informed decision-making scores
• 70% risks and burdens of dialysis not mentioned
• N=1 offered the option of not starting dialysis
• 67% felt they had no choice about starting dialysis (alternative was death)

"I should have found out more about it, read up on it, Googled it somewhere before you know, because I went straight from his office to having a shunt or whatever. So I wished I would’ve just waited. But I was tired, nervous and he was like, acted like I was gonna die tomorrow if I didn’t, you know, go ahead with it. So I just went on with it.

"For him to come and say, “If you don’t get on dialysis, you’re gonna die.” I just thought that was the most despicable thing a doctor could ever have said to me. It’s like telling, “You have cancer” and then just walking out. That’s how I felt, like he didn’t care. Like “Oh, well, you’re just another patient.” So, I was very upset and started crying. And he said, “I’m gonna call a social worker” and then left.”

All he said was, “You are going to have to be dialyzed.”"
## Guidelines – focus on QoL/symptoms

<table>
<thead>
<tr>
<th>Organization</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>KDOQI</td>
<td>2016</td>
</tr>
<tr>
<td>CSN</td>
<td>2014</td>
</tr>
<tr>
<td>KHA-CARI</td>
<td>2013</td>
</tr>
<tr>
<td>ERA-EDTA</td>
<td></td>
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<tr>
<td>UK RA</td>
<td>2014</td>
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</tbody>
</table>
The decision to initiate maintenance dialysis in patients who choose to do so should be based primarily upon an assessment of signs and/or symptoms associated with uremia, evidence of protein-energy wasting, and the ability to safely manage metabolic abnormalities and/or volume overload with medical therapy rather than on a specific level of kidney function in the absence of such signs and symptoms. (Not Graded)
Guidelines – focus on QoL/symptoms

For adults with an eGFR < 15 mL/ min per 1.73 m², we recommend an “intent-to-defer” over an “intent-to-start-early” approach for the initiation of chronic dialysis. (Strong recommendation; moderate-quality evidence.)

This recommendation places a high value on quality of life, by avoiding the burden associated with earlier initiation of dialysis without clinical indications, while avoiding complications of uremia.
Suggestions for Clinical Care: A discussion of the effect of dialysis on quality of life (QOL) should be included in the decision-making process for undertaking dialysis treatment. The discussion should include effect on physical function, burden of treatment, and effect on family and social life. This is best accomplished by a multidisciplinary team of appropriate health professionals.
In patients with a GFR <15 mL/min/1.73m², dialysis should be considered when there is one or more of the following: symptoms or signs of uraemia, inability to control hydration status or blood pressure or a progressive deterioration in nutritional status. It should be taken into account that the majority of patients will be symptomatic and need to start dialysis with GFR in the range 9–6 mL/min/1.73m² (1A Strong recommendation based on high-quality evidence).
The decision to start RRT in patients with CKD stage 5 (eGFR < 15ml/min/1.73m²) should be based on a careful discussion with the patient of the risks and benefits of RRT taking into account the patient's symptoms and signs of renal failure, nutritional status, comorbidity, functional status, and the physical, psychological and social consequences of starting dialysis in that individual (1D).
Mortality rate: 15% per annum and relatively static

"Because we haven’t died yet, but we do experience the other things." (Patient)

Aust 2008 population rates from ABS
### Dialysis Modality Preference of Patients With CKD and Family Caregivers: A Discrete-Choice Study

Rachael L. Morton, PhD,1 Paul Snelling, MB, ChB,2 Angela C. Webster, PhD,1 John Rose, PhD,3 Rosemary Masterson, MBBS, PhD,4 David W. Johnson, PhD,5 and Kirsten Howard, PhD1

<table>
<thead>
<tr>
<th>Population</th>
<th>Modality</th>
<th>Patient Life Expectancy Willing to Forgo (95% CI)</th>
<th>Benefit</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-dialysis patients</td>
<td>Home-based dialysis</td>
<td>23 (19-27) mo</td>
<td>Single-level improvement in travel restrictions</td>
</tr>
<tr>
<td>Pre-dialysis patients</td>
<td>Peritoneal dialysis</td>
<td>16 (13-20) mo</td>
<td>Single-level improvement in travel restrictions</td>
</tr>
<tr>
<td>Pre-dialysis patients</td>
<td>Hemodialysis</td>
<td>29 (28-30) mo</td>
<td>Single-level improvement in travel restrictions</td>
</tr>
<tr>
<td>Pre-dialysis caregivers</td>
<td>Home-based dialysis for</td>
<td>17 (16-18) mo</td>
<td>Single-level improvement in travel restrictions for combined patient and caregiver travel</td>
</tr>
<tr>
<td></td>
<td>patients</td>
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</tbody>
</table>

N=105 pre-dialysis patients
N=73 family caregivers
8 centers, Australia
“I feel my life, especially the ability to participate in joyful activities, energy, and time with loved ones slipping away. At what point is any of this even still worth it?” – patient on dialysis
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NO DIALYSIS: ITS 6AM. YOU CLOSE YOUR EYES FOR 5 MIN, ITS 7:45

AT DIALYSIS: ITS 1:30 YOU CLOSE YOUR EYES FOR 10 MIN, ITS 1:31
Facilitator: How much dialysis-free time would be important? Going from four hours to three hours? Would that be enough? Or four hours to two hours? How much extra time do you want?

Patient: Four hours is a long time

Facilitator: Would going to three hours be better, or two hours, or just one day, how much extra time do you want?

Patient: Anything less than four hours.

“I had possibly underestimated the value that patients place upon their non dialysis time.” (Nephrologist)
Is adequacy adequate?

“When you ask about adequacy, I think, what's my quality of life once I'm leaving the dialysis session? During my treatments that day, am I going to feel well enough to continue on with my day, as far as the adequacy and my feeling well, or am I going to feel tired?” (patient)

“… taking dialysis practice from adequate to rehabilitative.” (patient)

“Dialysis is a form of biological stunning, a hinterland existence” (nephrologist, UK)
Symptoms are:
- Under recognized and underestimated in HD (Weisbord 2007 CJASN)
- Mismatch

Evangelidis et al 2017 AJKD
Mean difference in rating between patients/caregivers and health professionals

**Patients:**

*Travel, even locally, lifts one up and makes a patient stay involved and interested in life.*

*I really do want to be able to travel. Before seeing results, I thought there was no chance anyone would pay attention.*

**Health professionals**

*I underestimated its importance to patients.*

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Evangelidis et al 2017 AJKD
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### Symptoms Reported by Focus Groups

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Renal Providers</th>
<th>African American Patients</th>
<th>White Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td>-</td>
<td>-</td>
<td>Y</td>
</tr>
<tr>
<td>Sweats</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Restless legs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Bone/joint pain</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Feeling drowsy</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Swelling of arms/legs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Feeling bloated</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Vomiting</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Decreased interest in sex</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Impotence</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Fatigue/lack of energy</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Dry skin</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Can't stay asleep</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Lightheaded</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Can't fall asleep</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Feeling sad</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Lack of appetite</td>
<td>Y</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Nausea</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Itching</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Numbness/tingling</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Muscle soreness</td>
<td>Y</td>
<td>-</td>
<td>Y</td>
</tr>
<tr>
<td>Worrying</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Feel anxious</td>
<td>Y</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dizziness</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Muscle cramps</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Problems with sex</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Changes in skin</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Pain</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Change in skin color</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Easy bruising</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Headaches</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Heartburn</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Thirst/dry mouth</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Easy bleeding</td>
<td>-</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Change in taste</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Loss of taste</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Cold intolerance</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Blurred vision</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Crying spells</td>
<td>Y</td>
<td>Y</td>
<td>-</td>
</tr>
<tr>
<td>Cough</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Chest pain</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</tbody>
</table>

Y = symptom reported; - = symptom not reported.
• What are the most important to patients? (not just prevalence)
• How severe is it?
• What impact does it have?
• Does it change?
1. Fatigue / energy

2. Resilience/coping (survival)

3. Ability to travel

4. Dialysis-free time

5. Impact on family

6. Ability to work

7. Sleep

8. Anxiety/stress

9. Drop in blood pressure

10. Lack of appetite

14. Mortality

22. Potassium

23. Phosphate

31. Calcium

32. Parathyroid hormone
"If I am overwhelmed with fatigue, I have no quality of life so why continue treatment?"

"The more I have dialysis, the more valuable my freedom and hence mobility become to me."

"It has surely changed my life upside down lost marriage, lost a child who is not with me stays with my ex in-laws and I cant spend quality time with my other son to coz of dialysis."

"The pain shouldn't be considered normal in hemodialysis, with pain you are not able to do a normal life."
What is the most important patient-reported outcome for patients on PD?

A. Ability to work
B. Fatigue
C. Gastrointestinal symptoms e.g. constipation
D. Mobility
E. Pain (including cramps)
“Because without that [flexibility with time, energy, mobility] you’re really just sitting at home not doing anything. You have no energy. You’re not able to go and do whatever you need to do like access to social things and so forth, or work, or whatever.”

“I was close to giving up dialysis last year, because I was on bags during the daytime… I just couldn’t work. It was driving me nuts.”

“It restricted me for a while, but I’ve gotten used to carrying around a bag and a knapsack. I just go off and do whatever I got to do, so I’m getting mobilised again.”
Patient-reported outcomes (<10% trials)
- Quality of life
- Appetite
- Pain (non-PD related)
- PD-related pain
- Fatigue
- Costs
- Treatment adherence
- Strength/endurance
- Dizziness
- Physical function/mobility
- Cognition
- Treatment satisfaction
- Sleep
- Sexual function
- Ability to work

Groups of outcome:
- Surrogate (n=26)
- Clinical (n=23)
- Patient reported (n=15)

NB: Proportion are expressed in a x10 log scale to display proportion <1%
Do dialysis patients feel normal? Many patients live normal lives except for the time needed for treatments. Dialysis usually makes you feel better because it helps many of the problems caused by kidney failure. You and your family will need time to get used to dialysis.

Myth: Dialysis is painful.
Fact: Dialysis treatments should not be painful. If you experience pain during or after treatment you should tell your healthcare team right away. Some patients may have a drop in their blood pressure that could lead to nausea, vomiting, headaches or cramps. However, by following your kidney diet and fluid restrictions these types of side effects can be avoided.

Myth: Dialysis is a death sentence.
Fact: Dialysis is a treatment that helps clean your blood of fluid and toxins when your kidneys are no longer able to do their job well. Needing to start dialysis can feel overwhelming and scary but dialysis treatments allow you to live
https://www.youtube.com/watch?v=mi34xCfmLhw&feature=youtu.be
My kidneys

My lifestyle

My Life Now
My life now is targeted at understanding the person’s daily routine, lifestyle priorities and the important people in their life.

How I Feel About Myself
How I feel about myself may reveal interesting information and open discussion about issues that are of a current concern and may impede the ability to make a decision. In the ideal world of finite resources concerns raised in this area may prompt referral to a psychologist or a social worker.

My Life in The Future
My life in the future deliberately highlights some main points of difference between treatment options and may help to focus the education discussions. It was not an exclusive list about expected changes but a step to make the person start to look into the future.
How will you feel after starting dialysis?

Each person may feel differently when they start dialysis. You might feel scared, overwhelmed, angry, or depressed. Emotions will usually shift over time as you adjust to dialysis. After they start dialysis, some people have more energy and feel like they think more clearly.

I look at my life in energy modules. I get really tired, and I have to limit what I can do. For example, I have an 8-year-old son. If I know he has a lacrosse game, I know I have to take it easy during the day so that I’ll be able to rally to go and watch the game, participate in his life, and make dinner. So, I need to make sure I have enough modules for the things I need to do.

Other factors not directly related to dialysis treatment will impact your everyday life. Common for people on both HD and PD are: diet, finances, and the impact on your loved ones.

Diet

Dialysis can only remove a limited amount of wastes and water, so people on dialysis need to limit the amount of fluids they drink and specific types of food. Maintaining a healthy diet is very important.
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Role of dialysis – patient-centered outcomes

No definitive evidence re timing of dialysis ➔ QoL/symptoms e.g. fatigue, cognition, neuropathy, pruritis, sleep disturbances, dialysis (CHOICE, IDEAL)

- Fatigue 1 yr after dialysis initiation: 24% reported improvement, 27% reported worsened vitality (CHOICE)

Early-start dialysis (eGFR > 10 ml/min/1.73m²) ➔ no sig. improvement in mortality, CVD, infection, QoL (IDEAL, USRDS, Canadian Registry)

Time-limited trial of dialysis

Incremental – gradual increase of dialysis prescription

Challenges:

- Multifactorial or unknown causes – comorbidities, medications, complications (anemia, volume overload etc), psychological status
Interventions for symptom control: what’s the evidence?

- 24 studies (n=1787)
  - High/unclear risk of bias
  - Low quality evidence → pain, fatigue, depression, sleep disturbance, pruritus

- 4 studies (n=170)
  - Low/ungradeable evidence → QoL, headache, sexual dysfunction, nausea
  - May reduce depressions scores (1 study, n=43)

- 9 studies (n=220)
  - Moderate/high risk of bias
  - Small/short studies – inconclusive

**Acupuncture and related interventions for symptoms of chronic kidney disease (Review)**

Kim KH, Lee MS, Kim TH, Kang JW, Choi TY, Lee JD

**Antidepressants for treating depression in adults with end-stage kidney disease treated with dialysis (Review)**


**Interventions for chronic kidney disease-associated restless legs syndrome (Review)**

Gopaluni S, Sherif M, Ahmadouk NA
Fatigue

- 18 RCTs in HD
- Interventions:
  - CAM e.g. aromatherapy, acupuncture, massage
  - Exercise e.g. aerobic exercise
  - Pharmacological e.g. EPO
  - Dialysis e.g. membrane, ultrafiltration
- Small studies, mostly inconclusive

Ju et al 2017 AJKD Nov 29 epub
Summary

• Shared-decision making with explicit consideration of patient-important outcomes (e.g. fatigue, sleep, pain, mobility + burden of dialysis)
• Lack of definitive evidence on the role of dialysis initiation on patient-centred outcomes (e.g. QoL, symptoms); early-start dialysis not shown to improve outcomes
• Access to individualized and flexible dialysis options (time-limited, incremental) + evaluate patient-centred outcomes
• Routine assessment of high-priority patient-reported outcomes
• Reduce burden of dialysis and symptoms
“It’s living a normal life. Having energy, control, and time away from dialysis. It comes down to being able to work. It’s normal things rather than the absence of cramps, headaches, and those sorts of things. It’s actually those intangible, normal things people value”.

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