

# Renal Palliative Care – where to after the PACKS study?

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# Palliative Care in chronic Kidney diSease - the 'PACKS' study

Quality of life, decision-making,  
costs and the impact on carers  
in people managed without dialysis

*Noble, H, Agus, A, Goodfellow, N, Guiney, M, McCourt, F, McDowell, C, Normand, C, Roderick, P, Maxwell, AP, Yaqoob, MM (2015). Palliative Care in chronic Kidney diSease: the PACKS study - quality of life, decision making, costs and impact on carers in people managed without dialysis. BMC Nephrology 16:104 Online - <http://www.biomedcentral.com/1471-2369/16/104>*

**National Institute for Health Research (£512,000)**

# Primary and secondary outcomes

**Primary Outcome:** Quality of life of patients at 3 months from baseline measured using the EQ-5D-5L visual analogue scale.

**Secondary outcomes:**

- Report QOL and symptoms, cognition, frailty and performance
- Understanding of the decision making process that precedes referral to CKM
- Patient satisfaction with decision-making
- Health and social care costs pts & carers
- Changes in QOL for carers
- Mortality



# Where we are at with PACKS

Open 18 months.

Closed to recruitment: May 2016

Final data collected: Aug. 2016

Analysis: Autumn

Report: Dec. 2016



# Understanding of the decision making process from the practitioner perspective

Qualitative interviews with staff (n=27)

CNS=15; Nephrologists=12

Transcribed data; Line by line coding

Themes

- Frequent changing of mind regarding treatment options
- Paternalistic approach to decision-making
- Intricacy of the decision
- Little use of guidelines/decision aids

# Frequent changing of mind regarding treatment options

## Denial and fear

*They might be in denial. Their educational level might not be that good. Also, there could be a language barrier. So, for all those reasons, I don't think it is 100% (CNS04).*

*It's people who are brought back continually to clinic, and keep coming back, because they're well, ...they will not decide until nearer the time if they really do want dialysis, and if in their hearts they don't know they might stop coming – they will cancel their appointments (CNS10).*

## Influences from families and other patients

*Sometimes they start to hear things or see things from other patients, if they're around the hospital and talk to other people (CNS06).*

*I think a lot of elderly people are forced into dialysis when they would otherwise not have preferred to have dialysis. Their families are keen for them to live longer and so they're pressured into getting dialysis (N13).*

## Clinician encouragement to change mind

*It's really only when you're in it that you're truly informed [laughing], no matter how much education you've had about something (N13).*

*You really hope in your heart though that they don't change their mind because, obviously, you know, getting a line in, last minute, unplanned, isn't good but you do tell them they can change their mind (CNS21).*

# A Paternalistic Approach to Decision-making

## In the patient's best interests

*I feel our patients are aware of some treatment options, but maybe not all treatment options. There is a slight bias with the doctors probably in giving treatment options out because we sometimes make assumptions that some treatment options may not be suitable (N16)*

*So I think, as a Renal Team, we do have to be very careful that we don't go in with our fixed ideas, and we do have to listen to the individual because they are an individual, and that has challenged us (CNS20).*

## Influencing the decision

*We keep telling them that, you know, you need to be realistic, you're still well, you're working, you're very active, so, I think the best thing would be to embark on active treatment, but, some patients will just say... "No, I don't really want it. But we keep on, telling them that you really need it at the moment "No, we really need to be realistic – you need to make a realistic decision regarding your care." A patient recently said, "I'm doing this for you," and I said, "No, it's not for me, it's for your own good (CNS01).*

## Withholding of information

*You know, an elderly, frail patient, you're not going to overload them with a lot of scary complications and side-effects because you might potentially upset them... So, again, there's a wee bit of bias in patient selection as to how much negative information you want to give a patient (N16).*

# A Momentous Decision

*This is one of the most complex areas in medicine to make decisions on, and it's becoming more complex because of the types of patients we're now being asked to deal with... No consultant I know can make these decisions easily. If they do make them easily, they're doing it wrong. They take hours of talking. (CNS02).*

*Once you initiate treatment, it becomes really difficult to stop it again, so we do not want to initiate treatment inappropriately in patients. It's one of the most difficult areas in medicine to explore. It's also an extremely expensive therapy that we don't want to use inappropriately in a very cash-strapped NHS (N06).*

## Re-evaluating life

*To come to that, you would have had to re-evaluate where you are in life and what you hope to gain from living longer, and so, you know, it's that crossroad where you say, right, I'm at the point when my physical and mental health is such that I don't think it's worth living that much longer and I accept what I've got at present and so be it (N13).*

*If they're given the information in the proper way, they're beginning to face the reality that life is fragile, very fragile, and I think they probably are to be very much admired, for the decisions that they make. It's so unpredictable, renal failure as a whole, so unpredictable, ... it's not easy (CNS20).*

# Decision Aids

## **Cochrane review of decision-aids to help people who are facing health treatment**

*(Stacey D, et al (2014). Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews, Issue 1 . Art. No.: CD001431)*

1. Improve knowledge of the options offered and reduce decisional conflict.
2. Encourage people to be more actively involved in decision making and improve risk perceptions and congruence between the choice made and patient values.
3. Improve communication between patients and health care practitioners.

# What next?

- ❑ Clinicians are managing a very difficult and complex decision-making process
- ❑ Attempt to act with good intent
- ❑ May prefer to avoid difficult discussions about prognosis and the end of life
  - Patients are unlikely to fully appreciate the severity of their condition
- ❑ Decision aids may be useful