

Journal Club Discussion - Spring 2010 Summary.

The discussion was based on the article: "Patient Views About Treatment of Stage 5 CKD: A Qualitative Analysis of Semistructured Interviews" by Rachel I. Morton et al., published in "American Journal of Kidney Disease", volume 55, Issue 3, March 2010, pp.431-440. (1)

Edited by Jenny Rovner (1), based on contributions from Diane Walker (2), Milo Elisheva (3) and John Sedgewick (4).

Israel (1,3), UK(2,4)

### **Summary:**

Three responders from two different countries participated in the discussion and provided their opinions and evidences.

The discussion was focused on topics such as understanding patients that we take care of and especially reasons for choosing between different types of treatments.

**Key words:** types of treatments, patient education.

### **Introduction:**

The authors of the article state: "How patients choose between alternative treatments for kidney failure is poorly understood. Recent studies of chronic kidney disease show that clinical outcomes, such as life expectancy, are rarely reflected in patient's decision for type of treatment compared with nonclinical outcomes...."

According to the article, patients preferred type of treatment is one that enhances their convenience and has minimal effect on their own life and lives of their families.

### **"Do we really understand our patients?":**

Elisheva Milo commented: 'We, as caregivers, tend to say to patients that we do understand how they feel but they need to do certain things. I remember one of my teachers in the post basic nephrology course, telling us: 'Never say to your patients that you understand them because you do not really understand, you've never been in their place'. Regarding our experience at work we tend to say that we know how they feel, but knowing is not the same as really understanding. I can say this from personal experience. Few years ago I had a very bad accident which resulted in some broken bones and inability to move and perform daily basic tasks by myself for 6 months. Only then I remembered this teacher and really understood how right she was. We do not know what it feels like to be dependent on someone all the time, not to be able to do what you want, when you want.'

John Sedgewick added: 'This is a very difficult question to answer and unless one has been immersed in the issues that face patients and their families, in my opinion it's very difficult to say we understand. We certainly can show empathy towards the patient – we need to 'climb down into the patient's world' and try to see it from their perspective.'

**"What general guidelines should we follow while instructing our "pre-dialysis" patients?":**

**John Sedgewick** wrote: 'The essence of pre-dialysis care should center around the whole process of enabling patients and their families to make the right choices and decisions that 'fit' the context of their own lives. We know that late referred patients have a very different experience of preparing for possible RRT, but with adequate timing patients can have the time to consider the options. When discussing options we must include all possible types of management which for some patients may include non-dialytic ones.'

**Diane Walker** commented: "I treated every patient and his family differently depending on how the education went on the first visit – with 22 years in renal nursing I was able to pass on my experience and hand out information that I myself had found helpful to use when advising patients.

When young patients ask me what should they do after they have had the information, I usually advise them to have some form of PD to preserve their renal function while they explore transplantation possibilities, if they have not already done so. I inform them as well that they could also receive a Cadaveric Tx on PD while still relatively healthy and stay on PD for a maximum of 5 years.

PD is a good introduction to self care and therefore if and when the time comes they need HD they can be trained in self care with the hope of going onto Home HD.

I have been promoting an informational forum (online conference), over a year now, which lasts for half a day and covers all aspects of treatments including the dietician, pharmacological treatment, social work and introduction to renal psychologists. I have found that the main thing the patients get out of the forum is the ability to ask questions without the time constraints of a clinic. I also bring along patients with experience that are good at explaining and answering questions that only another patient could answer.

I always include the family and give them my contact details if they feel they need to talk at any time."

**Elisheva Milo** said : " I believe, that we should start with PD first even if it is for short time only. This way we preserve our patient's blood vessels, giving them more time. There is always the possibility to change the treatment. We should always try to keep the patient independent and in control of his health and life. Of course it depends on the patient's condition."

**"Do we have structured patient education program regarding all kinds of renal replacement therapies?":**

**John Sedgewick** commented:" Education programs must be designed in such a way to capture as far as possible both disease specific information and information which will enable patients to continue to hold onto some degree of control over their lives. Providing education which is directed to the stage of the CKD has been shown to be beneficial. We must never lose sight of the importance of tailoring information to 'fit'

the needs of the patients and the families. An area that I feel is not acknowledged sufficiently within the whole education process is the impact of mild cognitive impairment which has been shown to be present in early stages of CKD – the impact of altered cognition upon learning is an area that needs to be upper most in patient pre-dialysis assessments.

Patients and families really want time to explore possibilities in an unhurried manner if they are to make effective choices. Consideration must be given to providing patients with information concerning both the benefits, risks and possible harm of treatment – the use of well developed decision tools can greatly assist this process. Central to the Shared Decision-Making model is providing patients with such complete information – when this is absent it could be argued that patients are not making an ‘informed decision’. We also must not lose the sight of the fact that for some patients, while they may not actually want to make the final decision regarding treatments (they prefer ‘the expert’ to make it) they do wish to be fully informed and engaged in a consultation process."

**Elisheva Milo** shared the experience from her unit: "We do have an educational programme including a video that we made with our patients undergoing treatment. In reality some of the patients do get a good education before starting RRT and take part in the decision regarding treatment mode, but many of our patients arrive with ARF and stay chronic or do not apply to the pre - dialysis clinic at all, and just "drop" into the treatment completely unprepared".

**"Are we, as caregivers, able to touch upon such sensitive issues as patient's sexuality and family support via prism of patient education?"**

**John Sedgewick** referred to the topic: " Dealing with sensitive topics such as sexuality can be very challenging for the unit team – some staff are very skilled at handing this domain, but it is important that when needed we know who is available to support the patient. Developing skills and competencies in sexual counseling (as applied to patient's condition) requires specific preparation both to ensure that the staff are competent and capable and that patients receive the most up to date appropriate support available. Some units have access to specifically trained staff that can be a major source of primary support."

**Diane Walker** added: "We have a specialist here at the RFH to whom we can refer patients with specific sexual needs should a nurse feel unable to deal with it."

**Elisheva Milo** said: "Some of us do more than others, but still this is a sensitive issue connected not only to us as caregivers, but to the patient's beliefs, traditions, status, age etc."

### **Discussion:**

All the participants of the discussion stressed the importance of patients and their families education as a base for "informed decision". The process should be structured and involve both medical information and also patient's personal characteristics such as age, sex, life style, beliefs and convenience. Patients should have full range of information in order to make wise choice.

Covering sensitive issues, such as sexuality, is an important issue in patient counselling. Nursing staff should have special training on this subject or should be able to refer patients to appropriate specialists.

### **Conclusion:**

Making choice regarding type of treatment is a very hard task. As caregivers we often consider medical characteristics a major factor while making the decision. Current article clearly states that personal convenience, beliefs, traditions and culture have great impact on the final choice. As professionals, we should be aware of this fact and take it into consideration while instructing patients.

Reference:

1. [http://www.ajkd.org/article/S0272-6386\(09\)01580-7/fulltext](http://www.ajkd.org/article/S0272-6386(09)01580-7/fulltext)