

ADVANCE CARE PLANNING in PATIENTS with END-STAGE RENAL DISEASE:

WHAT is MOST IMPORTANT to the PATIENT ?

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Introduction

Advance Care Planning (ACP) is a process that involves reflection, understanding, discussion, and communication between a patient, their family, doctors and nurses, for the purpose of clarifying goals for end-of-life care, and treatment preferences. ACP helps communicate patients' end-of-life care preferences when they are no longer able to do so themselves.

ACP is integral to providing high-quality ESRD care, particularly for older ESRD patients, as they near the end of life. Although the *End Stage Renal Disease Workgroup on End-of-Life Care* recommends that dialysis units facilitate ACP, the literature suggests that the majority of ACP discussions are inadequate in preparing ESRD patients for dialysis and for informing about care at the end of life.



Taking into account that 15-29% of deaths of (ESRD) patients result from a decision to discontinue dialysis, stopping dialysis is an option to be explored. ACP allows ESRD patients to prepare for death, strengthen relationships with loved ones, achieve a sense of control, and relieve burdens

Method

Prospective qualitative study carried out on selected ESRD patients from a dialysis unit. The interviewer was an experienced qualitative interviewer and ACP facilitator with no prior relationship to the participants. **Two semi-structured interviews** with each patient were performed, including their relatives if they preferred.

The aim of the study was:

- **to determine what was most important to the patient**
- **if they wanted to participate in decision-making process**
- **what medical conditions they would want treated**
- **what degree of functional impairment they would consider intolerable.**

We asked them if there were any situation in which they would want to stop dialysis because they considered that dialysis could no longer provide any benefit to their health and enjoyment of life.

All interviews were transcribed and validated against the recorded material by the interviewer. We used inductive analysis to create an account of hope in the context of advance care planning that consisted of identifying and coding the transcribed text into themes that were synthesised to develop a cohesive conceptual description.

Results

From May to November 2012 **fourteen patients** (9 male and 5 female) were interviewed: seven patients on haemodialysis and seven on peritoneal dialysis, with an average age of 66 years.

Two interviews were performed with each patient, mean duration 31 and 35 minutes.

- They very much trust the doctors and nurses who care for them.
- They express that the initiation of dialysis causes a great emotional suffering.
- Their hope is to receive a trasplant that allows them to recover an independent life, free of dialysis machines or hospital care, but there is no information about the plan of care if a trasplant is not a real option or if dialysis treatment can't reach the target of maintaining a good quality of life from their point of view.
- Although their knowledge about ACP is poor, they would like to participate in decisions concerning their care and end-of-life.
- They would want to keep on with dialysis treatment while their quality of life continues to be acceptable for them. That means being in a good mental frame of mind that allows them to recognize family and friends, being able to talk and understand others and, being independent in terms of walking or eating unaided. When they can't do these kind of things, patients would prefer to withdraw dialysis.
- Respecting end-of-life care, dying without pain and to be cared for at home -if it does not lead to a substantial burden for caregivers- are the most important points for them.
- Patients think that doctors don't speak to them about bad news or end-of-life because they are focused on other aspects of care and they do not want to cause them any feelings of sadness or depression.

Conclusion

- **Patients with ESRD are a group of chronic patients that can benefit from ACP process because it allows them to share their opinions with doctors, nurses and relatives.**
- **Although there are great opportunities to talk with ESRD patients about end-of-life care**, taking into account the time spent in hospital, trust in doctors and nurses and patients' wishes to talk about it, **this is often not done.**
- **Implementing a successful renal ACP program requires attention to ACP facilitation skills training; such training for nephrology staff is currently inadequate.**
- **Some living conditions with severe cognitive impairment are unacceptable to ESRD patients: in these cases they would prefer to withdraw dialysis. Then they wish to receive care in order to relieve suffering or pain, at home if possible. The best way to achieve this is by integrating palliative care into dialysis units and home care.**

Grant

