Review Article

Shared Decision-Making, Advance Care Planning for Chronic Kidney Disease Patients

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Abstract

Advance care planning (ACP) is a process by which clinicians together with patients and families reflect on and outline care goals to inform current and future care. ACP or shared decision-making is not only about key medical decisions, such as decision about continuing dialysis, or agreement for "not for resuscitation" order when in hospital. The importance of its role in chronic kidney disease (CKD) patients is less known and not being well practiced in our country. When done well, it involves enhancement of final days, weeks, and months with positive decisions about family relationships, resolution of conflict, and living well until end of life, improved quality of life, decreased anxiety and depression among family members, reduced hospitalizations, increased uptake of hospice and palliative care services, and care that concurs with patient preferences. It lays out a set of relationships, values, and processes for approaching end-of-life decisions for the patient. It also includes attention to ethical, psychosocial, and spiritual issues relating to starting, continuing, withholding, and stopping dialysis. This workshop was done to sensitize ACP as a standard of care intervention in the management of CKD in our country.

Keywords: Advance care planning, chronic kidney disease, end-stage renal disease, hemodialysis, shared decision-making

Introduction

Advance care planning (ACP) and shared decision-making are part of standard of care for cancer in our country. For chronic kidney disease (CKD), it is being practiced in very few western countries. We have guidelines from KDIGO and Renal Physicians Association for the same.[1,2] Although the concept of ACP among CKD patients has been around for many years, it is still in infant stage in India.

CKD with its high prevalence, morbidity and mortality, is becoming an important public health problem in low- and middle-income countries, including India.[3-6] As our country moves toward universal health coverage, the health and economic burden in particular how to take care of patients with CKD creates challenges for health systems.[4] Despite efforts to subsidize care, the economic sustainability of chronic dialysis in these settings remains uncertain.[7] A notable finding in Shaikh *et al*. was significantly poor survival and high dropout rate in spite of government-funded dialysis program, with only 53% patients continuing dialysis for >6 months.[6] A systematic review from Africa also showed a high mortality and dropouts among patients who received dialysis for CKD Stage 5D.[8] For patients with CKD Stage 5D, with mortality exceeding that for most types of cancer, dialysis may extend life but it might not improve the quality of survival time. So having ACP and shared decision-making may have significant impact in quality of life (QOL) and patient care in patients with CKD Stage 5D. Keeping this in mind, the aim of this workshop was to sensitize and recommend ACP as a standard of care intervention in the management of CKD in nephrology practice in India.

The following are the important consensus points raised and suggested during the meeting which included nephrologists,

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palliative care physicians, nephrology fellows, dialysis nurse, and technicians.

Definition

Advanced care planning and shared decision-making are a process of detailed discussion between a patient, the family (or other caregiver), and treating staff for the purpose of clarifying preferences in relation to future treatment options, prognosis including end-of-life care. It helps to identify their future health priorities and make advance decisions like; to refuse a specific treatment (an advance directive); or to appoint someone with lasting power of attorney.[1,2,9-13]

Need for advance care planning in our chronic kidney disease patients

The following points define the importance of having ACP in our routine clinical practice, especially a developing country like India.

- In developing countries like India, maintenance hemodialysis may not have survival advantage[4-6]
- From western literature, it has shown that having ACP in clinical practice has better outcome and useful, especially psychosocial aspects and QOL[13,14]
- It will have positive impact on doctor–patient relationship
- To improve adherence and consequences
- Impact on caregivers can be positive and less frustrating
- Helpful both during initiation and maintenance hemodialysis
- In CKD, death could come as a course of this illness and can be sudden and preceded by a period of inability to make proper decisions before death occurs
- Lack of knowledge/unawareness among patients on finiteness of the dialysis treatment and ignorance of rough complications that occur during the course of illness, which may ultimately lead to irreversible deterioration and death
- This also helps the family for finance and resource provision. When the family become aware, care providers can fund appropriately at time
- A proper briefing about cost and disabilities in terms of work and physical wellness can be conveyed to patients so that they are aware what is going to come
- It helps patients and relatives to well prepare for situations such as withdrawal of dialysis, life support, intensive care unit admissions, and terminal events such as stroke, heart attack, and sepsis
- It also helps to know and better prepared for deceased donor transplant physically and financially.

Introduction of advance care planning in chronic kidney disease Stages 4 and 5

- It should be started when patient reaches CKD 4 and 5
- It is not just going to help patient to prepare for the end-of-life care, hemodialysis initiation or not, it also can impact and help patients to go ahead with decisions like having fistula first concept, preemptive transplantation when they reach CKD5
- It is not a one-time discussion, it is a continuous process and should be done periodically.

The challenges in implementing advance care planning and shared decision-making in nephrology practice in India

With the present patient load and varied type of practice (individual/institute based), lack of awareness, and knowledge among both doctors and patients, it will be a huge task to implement ACP in routine practice. The committee discussed and brought out the following points as shown in Table 1 as the common challenges with patient, family members, doctor, and organization perspectives

The proposed steps to implement advance care planning

- The ACP and shared decision-making are always a team effort with patient being the center of the team
- Keeping in background of our varied clinical practice and previous recommendations from KDIGO and RPA, we suggest following members to be there in the team
- We classified them minimum, desirable, and the best as shown below in Table 2.

Steps to Perform Shared Decision-Making/ Advance Care Planning

Interview delivered by a trained facilitator to patients and their surrogates to help prepare surrogates to make decisions that honor the patient's preferences for care, leading to documentation of preferences.

1. Develop a patient–physician relationship for shared decision-making
2. Inform regarding diagnosis/prognosis/all treatment options/goals of care in a systematic way
3. Discuss estimate prognosis specific to their condition
4. Discuss psychosocial and financial aspects
5. Options of foregoing dialysis in those with poor prognosis or when dialysis cannot be provided safely such as cancer, CLD, severe malnutrition, and cachexia
6. There should be a system for conflict resolution if patient/relative is not fully convinced about the suggestion before making an ACP. If in conflict, trial of treatment or second opinion can be considered
7. Dedicated ACP discussion with periodic review by a team
8. It is desirable to develop a team lead by social worker or a nurse to provide continued ACP periodically to review the patient and family mindset
9. It is preferable to be recorded
10. Make clear to family that they are free to change the plan of course any time.

Steps for program implementation

1. Education of medical team members and patients
   - General education
     - To include in curriculum of MSW/BSc RRT/BSc Nursing/MBBS/MD/DM/DNB.
   - Specific education

Table 1: Challenges in implementing advance care planning/shared decision-making in clinical practice

Patient perspective
Lack of education
No independent decision
Collusion between family and doctors on withholding information about disease and its severity to the patient
Preference/leaning to alternative medicines by patients for a cure
Multiple opinions
Comorbidities
Unrealistic expectation, hope for cure
Failure of treatment and possibility of death
Nephrologist perspective
Lack of time in their busy workload
Fear of giving wrong prognosis
Fear of losing the patient
Lack of awareness on ACP and its importance and lack of communication skills to convey the same
Hospital/administration perspective
Lack of policies on ACP and shared decision-making
To make them aware and getting them into confidence for implementation
Lack of funded training opportunities
Administrative and legal complexities around advance care planning
The prioritization and pressures of routine care
A focus on technological (rather than personal and spiritual) aspects of care
Conflict of interest
Family perspective
Family ignorance
Family interference with doctors and bullying the patient
Cultural issues

ACP: Advance care planning

Table 2: The members of an advance care planning team

Minimum: Nephrologist/patient/family (caretaker) or surrogate caretaker
Desirable: Nephrologist/patient/family (care taker) or surrogate care taker+medical/social worker/nurse/dialysis nurse/transplant coordinator
Best: Nephrologist/patient/family (care taker) or surrogate care taker+medical/social worker/nurse/dialysis nurse/transplant coordinator+palliative care physician/psychiatrist/clinical psychologist/pain specialist

- Training course on ACP in nephrology
- Workshop: Training for clinical staff that addresses concerns, optimizes skills, and clarifies processes
- ACP should be recognized as a core competency and it should become an essential component of continuing medical education for practicing nephrologists, as well as the nephrology curriculum for trainees.

- Patient education
  - Group teaching/pamphlets with FAQs answered.
  - ACP should be a part within the outpatient visit workflow as standard of care
  - Making it simple/culturally appropriate/individually tailored/local language
  - Keeping documents short was thought to encourage completion
  - Minimizing administrative and legal complexities.

2. Making it part of standard of care and implementing in organizations then with private nephrology practitioners
3. Trained palliative care nurse/transplant coordinator who are in the existing present team in nephrology department should be trained well, and they should be the center of the clinical team under the guidance of palliative care physician and nephrologist
4. Wherever facilities are there, the palliative care physician and treating nephrologist should be part of the team, especially in the initial meeting. The periodic assessment/meeting can be done by the trained nurse or coordinator, but the change in decisions should be made in presence of the treating nephrologist.

Conclusion

It is time to look beyond our routine care of medical and renal replacement therapy-focused practice. The incorporation of advanced care planning as a standard of care in our country may change and have a significant impact on QOL, socioeconomic status of our CKD patients and their families.

The shared decision-making is essential to align treatment with patient and family goals, values, and preferences. It should start early in the illness trajectory. Since patients' health status, preferences, and treatment options may change over time, shared decision-making requires a flexible approach of reevaluation and redirection. We should always ensure that the goals of care and treatment plans remain aligned with patients' values and preferences.

The participants in the workshop anticipate that above suggestions will provide the impetus to study and implement advanced care planning and shared decision-making for patients with advanced CKD in our country as well as in many developing countries. We believe that through continued education and clinical trials across the country advances can be made in designing, implementing, and testing effective and efficient models of ACP for CKD populations.

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Conflicts of interest

There are no conflicts of interest.

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