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Palliative and End-of-Life Care Conversations with ESRD Patients: Evidence, Gaps, and Future Directions

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ABSTRACT

Objectives:
To review the existing evidence on palliative care and end-of-life (EOL) conversations in end-stage renal disease (ESRD) patients with regard to timing, key stakeholders, content, barriers, cultural factors, and future directions to improve advance care planning (ACP) and supportive care.

Methods:
We did a narrative literature review to analyze published information on palliative and EOL communication in ESRD. We reviewed and aggregated relevant studies on ACP, conservative kidney management (CKM), communication methods, physician training, viewpoints of patients and families, cultural factors, and therapies that were assessed.

Results:
There is evidence to indicate that palliative and EOL discussions in ESRD are usually delayed and are done following acute illness, rather than being done earlier during the course of the chronic disease. Some of the key barriers that have been reported in relation to palliative and EOL discussions include the uncertainty of prognosis amongst nephrologists, lack of communication skills training, culture and religion regarding death, lack of integration of palliative care, and the absence of an advance care planning process in dialysis. Patients and their families have continuously indicated the need for early and open discussion of prognosis, symptoms, preferences, and quality of life. There has been some success with programs that involve structured ACP, decision aid, communication training, and technology to enhance patient engagement. There are still gaps in the literature, particularly regarding culturally appropriate interventions and outcomes in Muslim/Arab populations.

Conclusion:
Despite the known value of palliative and EOL communication in enhancing patient-centered outcomes, it remains neglected in ESRD care. Early, culturally sensitive, and transdisciplinary approaches to ACP should be included in routine nephrology practice. Further studies are required to test early-intervention models, technology-assisted ACP approaches, and culturally sensitive communication models to improve QOL, promote informed decision-making, and ensure care is in line with patients' values.

Keywords: ESRD, Haemodialysis; Advance Care Planning (ACP) ; conservative kidney management (CKM) ; palliative care; Saudi Arabia; End-of-Life (EOL)

INTRODUCTION

End-stage renal disease (ESRD) is the last stage (stage 5) of chronic kidney disease (CKD). It is marked by a severe and irreversible decline in kidney function, with an estimated glomerular filtration rate (eGFR) of less than 15 mL/min/1.73 m² or the need for dialysis, which means that the kidneys have lost about 85% or more of their normal filtration capacity. (1) This major drop in kidney function is linked to a wide range of systemic problems, such as high blood pressure, anemia, malnutrition, mineral and bone disorders, peripheral neuropathy, and a big drop in quality of life. Therefore, the eGFR is used to determine the stage of CKD: Stage 1 means that the kidneys are working normally or better (eGFR ≥ 90 mL/min/1.73 m²). (2, 3) Stage 2 means that the kidneys are only slightly impaired (eGFR 60–89). Stage 3 means that the kidneys are moderately impaired and is divided into 3a (eGFR 45–59) and 3b (eGFR 30–44). If the person's GFR is between 15 to 29, then it indicates Stage 4 CKD, while a GFR of less than 15 indicates end-stage renal disease (ESRD), which falls under Stage 5 CKD. A patient is said to have CKD if their GFR remains below 60 mL/min/1.73 m² for more than three months. (4, 5)

Chronic kidney disease (CKD) is among the key factors responsible for causing kidney failure. The current health systems are under pressure in trying to deal with this increasingly emerging issue, more so within the low- **and middle-income countries** (LMICs), where there is an increased demand for expensive treatment of the kidneys. (6, 7, 8). End-stage renal disease (ESRD) has become a major public health problem across the world. This is mostly because the population is becoming older and diabetes is spreading around the world (14, 15). A number of people in the Kingdom of Saudi Arabia (KSA) suffer chronic kidney disease (CKD). More than 20,000 people in KSA are on dialysis, while 9,810 people are undergoing follow-up treatment after obtaining a kidney transplant. It is anticipated that 294.3 persons per million in Saudi Arabia need renal replacement treatment (5, 9, 10).

Even if medical technology has gotten better, there is a bigger risk of being sick or dying. People on dialysis have a 6.3 to 8.2 times increased risk of dying from any cause (11, 12, 13). Most persons with this condition that shortens their lives will need hemodialysis (HD) to stay alive (14, 12). The anticipated amelioration of symptoms in ESRD patients undergoing dialysis is not adequately substantiated in the literature. Several studies have shown that patients still have a lot of physical and emotional problems (16). Additionally, caring for patients with a terminal illness involves several things, such as comfort, peace, and respect. When caring for people with life-limiting illnesses, the hardest part is helping them move from life to death. Culture, religion, and society all influence the caring process (17).

Patients with ESKD face numerous distinct challenges in facilitating timely and effective discussions regarding deterioration and end-of-life considerations. Patients with end-stage kidney disease (ESKD) are very likely to need to go to the hospital or the intensive care unit or die. (18, 19) They are more likely to die in a hospital than at home or in a hospice. This difference is even bigger when you compare it to people on a conservative care pathway. People on dialysis are up to 60% more likely to need emergency hospital care and are more likely to die in the hospital with little palliative care. Even so, not many people have timely effective conversations about resuscitation, stopping dialysis, and other things that can improve their quality of life. (20) Therefore, there is an unmet need for palliative care when they come to the end of their life. Besides, the last few years before death have been found to be very costly in terms of hospitalization irrespective of the place of death and any other disease conditions (21, 22).

DISCUSSIONS OF LITERATURE STUDIES

This literature review summarizes current information surrounding palliative and end-of-life (EOL) communication in patients with end-stage renal disease (ESRD). The debate integrates current research on when, what, and who should be involved in these conversations and impediments to implementing these conversations. It also explores the role of health care providers, patients' and families' views, interventions assessed, and cultural impacts on communication practices. Moreover, the existing gaps in the literature are identified in order to pinpoint the areas for further research and improvement.

Timing of Palliative and End-of-Life Conversations along the ESRD Trajectory: Evidence consistently indicates that palliative and end-of-life (EOL) talks within the framework of ESRD are generally commenced late, frequently instigated by acute medical deterioration rather than being proactively integrated into normal ESRD care. A lot of research shows that people frequently start talking about advance care planning when they are in a medical emergency, including when they have to go to the hospital a lot, have heart failure or sepsis, or go to the intensive care unit (27, 28). In these situations, clinicians need to re-evaluate the treatment goals and the prognosis. showed that more than half of the HD patients who died did not have any advance care planning (ACP) done until the last few weeks of their life. Most of the time, people were sent to palliative care after their last hospital stay instead of earlier in the disease process (17, 26). For a long time, recommendations have indicated that persons with CKD stage 4–5 or who are about to start dialysis should seek early palliative care. However, research from the actual world suggests that not many patients have set up ACP conversations before they start dialysis. Most of them start HD without talking about their prognosis, expectations, quality-of-life choices, or the option of conservative renal care (23, 25). They also discovered that ACP is usually absent until deterioration becomes clear. This implies that if you wait too long to talk about it, you might wind up getting high-intensity therapies that don't help you toward the end of your life. Most palliative care consultations in ESRD take place toward the end of life, and the typical period between referrals is days, not months (25, 30). Studies on interpersonal communication in dialysis units indicate that scheduled Advance Care Planning (ACP) reviews are infrequently integrated into standard treatment protocols (24, 27, 28).

Reasons for delayed palliative and end-of-life conversations in ESRD patients: When people are developing ESRD, there are a lot of reasons why they don't talk about palliative care and end-of-life (EOL) care right away. These are factors that happen at the patient, clinician, and system levels that make communication more reactive than proactive. One of the most typical things doctors say when they can't assist is that they don't know what will happen next. ESRD is not like other malignancies since it doesn't always follow the same path. It swings through periods of clinical stability and then sudden, unexpected declines. Nephrologists don't want to talk about prognosis because they don't want to hurt patients' confidence or hope by making inaccurate guesses (17). Nephrologists also indicated they don't know enough about communication and palliative care, which makes them unwilling to initiate sensitive talks like dying, quitting dialysis, or advanced care objectives subjects, which they find emotionally unpleasant and time-consuming (24). Patients and their family might not want to discuss ACP because they don't comprehend it, there are cultural taboos about talking about death, and they wish to keep cheerful. This is especially true for older, weaker, or more conventional persons (17). Dialysis units are sometimes set up at the organizational level to manage both biological and task-oriented duties, such as setting up machines, laboratory goals, and treatment plans. There isn't much time or room for things that are hard to cope with emotionally. There are no clear ACP procedures, the nephrology and palliative care teams don't work effectively together, and referrals only happen when there is a crisis (25).

Initiators of Palliative and End-of-Life Conversations with ESRD Patients: Advance care planning (ACP) discussions generally fall under the domain of nephrologists. Therefore, they are considered who should discuss the diagnosis, treatments available, prognosis, and continuation of dialysis. However, even though this task is considered vital, various studies have demonstrated that nephrologist-led advance care planning (ACP) tends to be infrequently performed, inadequately formalized, and initiated inappropriately at a later stage. This is normally triggered after acute exacerbation experiences instead of incorporating it as part of the standard care protocol (23,24). Social workers in the United States and Europe assist patients in the preliminary stages of ACP, including advance directive completion, caregiver identification, and surrogate designation. Therefore, they can facilitate discussions but rarely initiate discussions on prognosis and treatment goals (31). Palliative care specialists conduct the most structured and comprehensive ACP discussion focused on symptom burden, values clarification, and future plans. Nevertheless, referral to palliative care is uncommon and typically occurs late, usually weeks prior to death (17).

Core Topics Addressed in Palliative and End-of-Life Conversations for ESRD Patients: In end-stage renal disease (ESRD) facilities, when end-of-life (EOL) and palliative discussions occur, these tend to revolve around a narrow yet essential set of clinical and existential concerns. Yet, the depth and frequency of such dialogues may be highly variable. Prognosis is undoubtedly a vital topic, but it is often discussed superficially or too late in the course. As demonstrated by numerous studies, most hemodialysis (HD) patients desire more information regarding their prognosis, progression of disease, and functional status, while nephrologists usually neglect these topics in favor of detailed prognosis since they find it difficult to provide (23, 24). Moreover, it is crucial to address the patient's symptom burden, including pain, pruritus, dyspnea, fatigue, depression, and spiritual distress, which is comparable to the symptom burden associated with advanced cancer cases. Nonetheless, studies reveal that such conversations are frequently disorganized and reactive rather than part of a systematic palliative evaluation process (17). Advance care planning (ACP) is another important part, and it includes figuring out what the patient values, finding surrogates, making emergency decisions (like whether or not to resuscitate), and writing advance directives. However, the use of ACP documents is still low around the world . Discussions may include end-of-life treatment options, such as conservative kidney management (CKM), which is a non-dialytic, comfort-oriented approach that is especially useful for frail or elderly patients. However, many studies show that CKM is not often offered as a valid option during standard nephrology consultations (25). Dialysis withdrawal, a critical juncture in end-stage renal disease (ESRD), is often considered only upon noticeable deterioration, despite guidelines recommending the earlier assessment of patients' perceptions of acceptable quality of life and the circumstances under which they may choose to cease dialysis. There are also discussions regarding hospice care and where the person will die (home, hospital, or hospice centre), but these normally arise late and only when the person is going to grow worse (17).

Desired Versus Actual Content of Palliative and End-of-Life Discussions Among Patients With ESRD and Their Families: Patients with end-stage renal disease (ESRD) have demonstrated a necessity for transparent, candid, and empathetic discourse on prognosis, including functional deterioration, disease advancement, and realistic future expectations. They want to discuss how dialysis affects their quality of life, how tired, painful, itchy, and short of breath they feel, and how these things affect their everyday life and independence (17). A lot of patients and their families also want to talk about their beliefs, aspirations, and what a good quality of life is, including when to keep going with life-prolonging treatments, stop them, or end them (22). They frequently inquire about conservative kidney management (CKM) as an alternative to dialysis, encompassing the nature of supportive care, symptom management, and the potential for improved quality of life without the burdens of treatment (25). Families frequently seek information on advance care planning (ACP), surrogate decision-making, and expectations at the end of life, encompassing hospice care and chosen site of death. What really happens, on the other hand, is far more constrained and generally takes longer. Research shows that nephrologists seldom start in-depth talks about prognosis. They often say this is because they are unsure of the prognosis and don't want to make the patient less hopeful (10). People frequently discuss the technical features of dialysis, such as lab objectives, vascular access, fluid control, and session management, instead of values and the future. There isn't much space for preparing for the future or talking about ambitions. When people talk about ACP, they typically talk about paperwork instead of having actual conversations. When a patient's health is plainly growing worse, only then do the possibilities of hospice or CKM come up. Many people with HD say they were never told they could stop dialysis or that there were other options to get comfort (22). Families often report they weren't ready for crises because they didn't discuss dying, how symptoms might become worse, or what kind of care they wanted until the last days or weeks of life (25).

Perceptions of End-of-Life Conversations Among ESRD Patients and Their Families: Research over the past ten years shows that patients with ESRD and their families have different and often competing ideas about end-of-life conversations. This is because advanced renal disease is very emotional and communication tactics don't always work. Numerous patients with ESRD perceive end-of-life talks as advantageous, elucidative, and comforting, particularly when commenced promptly, delivered with empathy, and centered on patient values. These talks help patients grasp their prognosis, be ready for the future when their kidneys aren't working as well and make choices that are in line with their values and what they think is an acceptable quality of life (17).

Families also feel that talking openly with each other makes things less confusing, makes them trust healthcare staff more, and helps them better assist the patient. However, the literature also shows that patients find these conversations scary or too much to handle, especially when they start quickly during an acute medical emergency. Several qualitative research studies have highlighted that patients perceive these discussions, when commenced during hospitalization or near the end of life, as hurried, upsetting, or conveyed in a manner that diminishes hope, leading some patients to evade these conversations (24). The most common finding across research is that respondents consider EOL interactions "too late" or "not offered at all." A lot of patients with HD say they are startled when they have to talk about discontinuing dialysis or the prognosis. They add that no doctor had ever told them how ESRD may kill them or make them sick (23). Families often feel unprepared when things suddenly go worse, and they blame this on not having had the chance to prepare for the end of life gradually. Some individuals argue that talking late at night is hazardous for your mental health because it makes you make decisions in a crisis instead of allowing you time to think about them (25).

Evaluated Interventions in ESRD: Effects of Communication Training, Structured ACP Programs, Decision Aids, Digital Tools, and Conservative Kidney Management Models on Patient, Family, and Health-System Outcomes: These interventions usually result in increased documentation of ACP, improved knowledge regarding prognosis and treatment options for the patients, and increased probability of receiving treatments that match their desires. Moreover, the initiatives are associated with satisfaction among family members and reduced instances of disagreement regarding decisions (17). Patient decision aids that present a clear description of the advantages and disadvantages of dialysis treatment versus CKM include printed material and videos. The use of such patient decision aids has been proven effective in improving patient comprehension of their treatment choices, realistic expectation setting, and collaborative decision-making. Research indicates that elderly or frail patients are more likely to choose CKM upon obtaining complete information on its pros and cons (25). Digital ACP interventions, including web-based applications and patient portal tools, as well as tablet-based surveys conducted in dialysis clinics, have been developed in order to promote easy documentation and value clarification. The early results show that such technologies can increase patients' interest in ACP and can help patients to participate in it, but very few studies are available in terms of how these technologies affect the utilization of hospitals and ICU. (31, 25)

Evidence from Diverse Cultural Contexts: Insights from Muslim/Arab and Asian Settings: Cultural variables have a significant role in determining the implementation of palliative and end-of-life care discussions for ESRD patients and their families, as well as their participation in these discussions. Muslim Arabs, Asian people, and Western countries are quite different from each other. In Arab and Muslim civilizations, it was typical for families to make decisions together. People thought it was better to talk about hope than death or a bad diagnosis. Families also told healthcare personnel not to deliver patients bad news (25). The premise behind "protective buffering" is that hiding terrible news from loved ones will make them feel better. Some individuals also believe that discussing death might make it happen, which hurts their faith. Because of their religious beliefs, including **"Qadar,"** which implies trusting God to take care of things, and their ideals of patience and the obligation to obtain treatment, it is hard for them to discontinue dialysis or manage their kidneys conservatively. Studies conducted in the Gulf area and Middle Eastern nations indicate that patients prioritize open communication; yet, there are significant delays in the Advance Care Planning (ACP) process and a deficiency in ACP implementation. Families also depend a lot on what the physicians say when they make choices (17,33). There were, however, certain things that were the same and some things that were different about the cultures of Asian countries, including Japan, South Korea, China, and Singapore. In many of these areas, respect for filial piety and the value of family peace are highly essential. The family has more say than the patient when it comes to making decisions regarding treatment and end-of-life care. Research in East Asian countries revealed that families choose indirect communication concerning the patient's prognosis since they perceive it may have detrimental psychological consequences and reduce the patient's desire to live. Like in Western society, persons in Japan and Korea are also less likely to be culturally sensitive when they quit dialysis. The South and Southeast Asian populations in India and Malaysia don't always have enough resources. People here don't know anything about computers either. People in these cultures are less likely to get early ACP because they have strong religious beliefs. Asian patients with HD are usually willing to discuss their future care, although they aren't always encouraged to do so, like in Arab culture. Because of this cultural dilemma, doctors and nurses in this region of the globe have a hard time balancing their cultural commitments with their medical ethics. (35) The research in this study indicates that while culture influences end-of-life care, Muslim/Arab and Asian patients have a similar necessity: the establishment of trust, the demonstration of compassion, and the promotion of dialogue between family and patient (34).

Major Evidence Gaps in Palliative and End-of-Life Communication for ESRD Patients: Despite the increasing awareness among more and more people of the importance of EOL and palliative communication in the ESRD context, there are still substantial gaps in literature making it impossible to develop an effective and culturally competent model of communication practice in this regard. One of the key gaps is the fact that very little research has been done in relation to proactive interventions at stages 4-5 of CKD or the beginning of dialysis treatments. Most of the existing studies consider only late-stage and crisis-based communication, and there is an obvious lack of well-designed trials exploring structured communication approaches for early interventions (23). Another gap has to do with the insufficient diversity of the sample, which fails to include non-Western groups, including Muslim/Arab, African, South Asian, and East Asian populations. These groups' unique cultural norms, family and religious obligations, and health systems' specifics significantly influence patients' decisions concerning their health and treatment, but most existing research focuses on North America, Europe, and Australia. There is a noticeable absence of outcome assessments that are holistic: while there are a significant number of interventions like advance care planning programs, decision support tools, and online services that improve knowledge, satisfaction, or documentation, there is a paucity of information related to patient outcomes such as quality of life, symptom experience, regret about decisions, congruence between patient preferences and care received, and health care utilization rates. Likewise, there are not many studies on family outcomes such as grief and bereavement or family decision readiness when it comes to ESRD care decisions. (37, 39.40) The other major issue is that there is a lack of communication between the nurses and the other professionals who work in the dialysis centers. (24, 36) The nurses spend all their time with the patients and have all the information at their fingertips about whether the patient is experiencing pain and can help the patient in addressing the issue. However, not enough research has been done on the topic of the role of nurses and advanced care planning interventions, training for effective communication, or the definition of roles in the interprofessional teams (38, 39).

CONCLUSION

Talking to patients who need haemodialysis about palliative and end-of-life care is an important part of treating and managing end-stage renal disease (ESRD). This isn't receiving enough attention. Evidence indicates a prevalent trend wherein end-of-life care and advance care planning typically occur at a somewhat advanced phase of the disease trajectory, frequently triggered by an acute medical crisis or a decline in the patient's clinical condition. Many variables can change how people plan for and take care of themselves as they become older. These include problems with patients, families, doctors, and dialysis units. Cultural variables, particularly those associated with Arab/Islamic and Asian groups, significantly influence end-of-life care and advance care planning. This shows that we need to take a more family-friendly and open-minded approach to advance care planning. There are significant gaps in the information on implementing early intervention Advance Care Planning (ACP) with patients from diverse cultural backgrounds, with nurses, and with technology. It is essential for dialysis specialists to emphasize transdisciplinary, culturally sensitive, and technologically advanced models of care with the inclusion of early EOL discussion within the process of dialysis treatment as a primary consideration instead of the secondary one when it comes to EOL issues. In future studies, researchers should concentrate on applying methodology in exploring varying levels of care provided for patients, their family members, or healthcare organizations as a whole with a view to enhancing quality of life, making patients ready to make their decisions, and increasing agreement between the patient's values and the treatment received. Enhancing communication about EOL concerns is vital for delivering kidney care oriented toward the patient with an eye to upholding his/her dignity, reducing suffering, and facilitating sound decision-making.

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