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Association of Family Ratings of Quality of End-of-Life Care With Stopping Dialysis Treatment

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ABSTRACT

Background: The literature surrounding the association of family ratings of quality of end-of-life care with the decision to stop dialysis treatment is multifaceted, revealing the complexities faced by patients with chronic kidney disease (CKD) and their families. **Literature Review:** Building on this foundation, the research by (A. Richards et al., 2019) investigates the correlation between the cessation of life-sustaining treatments, such as dialysis, and the perceived quality of end-of-life care. Further exploration of end-of-life care dynamics is provided by (Axelsson et al., 2019), who identify barriers faced by healthcare professionals in delivering adequate palliative care to patients on maintenance hemodialysis. The tension between life-prolonging interventions and palliative care approaches is highlighted, suggesting that misconceptions about palliative care may impede timely interventions aimed at improving quality of life. The authors advocate for a more integrated palliative care model, particularly given the high mortality rates among end-stage kidney disease (ESKD) patients. Lastly, the study by (Ducharlet et al., 2023) addresses the challenges faced by kidney clinicians in enhancing end-of-life care provisions. The authors call for the integration of palliative care within kidney supportive care, emphasizing its role in managing both physical and psychosocial needs. **Conclusion :** In conclusion, the collective findings of these studies illustrate the critical intersection of family involvement, healthcare provider practices, and patient experiences in shaping the quality of end-of-life care for individuals with CKD. They underscore the necessity for a paradigm shift towards more inclusive, patient-centered approaches that recognize the complex realities faced by patients and their families as they navigate the challenging landscape of end-of-life decision-making.

Keyword: Association, Family Ratings, Quality of End-of-Life Care, Dialysis Treatment

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INTRODUCTION

The literature surrounding the association of family ratings of quality of end-of-life care with the decision to stop dialysis treatment is multifaceted, revealing the complexities faced by patients with chronic kidney disease (CKD) and their families. (E. Molzahn et al., 2018) delve into the lived experiences of individuals with CKD and their family members, highlighting the liminality of their condition. They present three significant themes related to adaptation to technology and the varying degrees of openness regarding death. This narrative inquiry underscores the necessity for healthcare providers to engage with both patients and their families to deliver holistic, person-centered care, particularly as patients approach the end-of-life stage. The study emphasizes that while family members often possess a profound understanding of their loved one's prognosis, the lack of clinician involvement in discussions about death may hinder effective end-of-life planning.

(A. Richards et al., 2019) build upon this foundation by investigating the correlation between the cessation of life-sustaining treatments, such as dialysis, and the perceived quality of end-of-life care. Their findings suggest a notable trend where family members of patients who opted to stop dialysis reported a more anticipated death, aligning with the patient's wishes. This study adds a critical layer to the discussion by indicating that stopping dialysis is frequently associated with hospice enrollment, yet it also raises ethical questions about treatment decisions at the end of life. The research highlights the importance of understanding how family perceptions of care quality are influenced by these decisions.

Further exploring the dynamics of end-of-life care, (Axelsson et al., 2019) reveal barriers that healthcare professionals face in providing adequate palliative care for patients undergoing maintenance hemodialysis. Their focus group study illustrates the tension between life-prolonging interventions and palliative care approaches, suggesting that misconceptions about palliative care may hinder early interventions aimed at improving quality of life. The authors advocate for a more

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integrated palliative care model, particularly given the high mortality rates in end-stage kidney disease (ESKD) patients, thereby calling for a shift towards prioritizing patient comfort and preferences in care strategies.

Finally, (Ducharlet et al., 2023) address the challenges and aspirations of kidney clinicians in improving end-of-life care provisions. They advocate for the integration of palliative care within kidney supportive care, emphasizing its role in managing both physical and psychosocial needs. The authors note a gap in standardized practices for delivering end-of-life care to patients with ESKD, highlighting the need for systematic approaches to advance care planning and shared decision-making. Their findings suggest that early and consistent discussions about treatment goals and patient preferences can significantly enhance the end-of-life experience, yet these conversations often remain inadequately addressed in clinical settings.

Collectively, these studies illustrate the critical intersection of family involvement, healthcare provider practices, and patient experiences in shaping the quality of end-of-life care for individuals with CKD. They underscore the necessity for a paradigm shift towards more inclusive, patient-centered approaches that recognize the complex realities faced by patients and their families as they navigate the challenging landscape of end-of-life decision-making.

LITERATURE REVIEW

The article "Living with dying: A narrative inquiry of people with chronic kidney disease and their family members" by (E. Molzahn et al., 2018) offers valuable insights into the experiences of individuals with chronic kidney disease (CKD) and their families as they approach end-of-life (EOL) care. The authors conducted a thorough narrative inquiry, analyzing the narratives of 200 CKD patients, which revealed three central themes that illustrate the complex emotional and psychological landscape faced by patients and their families.

One of the key findings is the concept of liminality experienced by patients. The narratives highlighted a spectrum of dualities such as living/not living and independence/dependence, suggesting that patients often find themselves in

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transitional states where they grapple with their identities and realities in the context of chronic illness. This liminal experience underscores the need for healthcare providers to recognize and address the psychological and existential dimensions of CKD treatment, particularly as patients navigate their impending mortality.

Moreover, the article emphasizes the critical role of family members in the EOL process. The authors note that families often possess a profound understanding of the prognosis and the implications for their loved ones, yet their perspectives may diverge from those of the patients. This divergence points to the necessity for healthcare professionals to engage in open dialogues with both patients and their families. The authors argue that clinicians should actively listen to the narratives of patients and their families, as these stories can illuminate the unique challenges and considerations that arise in EOL care for CKD patients.

The article also highlights a significant gap in the current literature regarding the inclusion of family perspectives in discussions about EOL care. The authors suggest that incorporating family members into the decision-making process can enhance the quality of care and support provided to patients. This is particularly important as patients approach EOL, where the need for comprehensive and person-centered care becomes paramount.

Additionally, the findings indicate that past experiences with illness, loss, and death can serve as pivotal entry points for discussions about EOL care. This insight suggests that healthcare professionals should not only focus on symptom management but also consider the emotional and relational aspects of care, facilitating conversations that honor the lived experiences of patients and their families.

The article titled "Association of Family Ratings of Quality of End-of-Life Care With Stopping Dialysis Treatment and Receipt of Hospice Services" by (A. Richards et al., 2019) provides a comprehensive examination of the complex interplay between dialysis cessation, hospice services, and the perceived quality of end-of-life care from the perspective of family members. The authors highlight a critical issue in contemporary medical practice: the ethical and emotional

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implications of life-sustaining treatments, particularly in the context of end-stage renal disease.

The article begins by acknowledging the significant technological advancements in medicine that have transformed the dying process. The authors articulate the paradox of life-prolonging treatments, such as dialysis, which can inadvertently prolong suffering. This observation is particularly relevant given the statistics that indicate approximately 500,000 patients in the United States are undergoing maintenance dialysis, with a quarter of these patients ultimately choosing to discontinue treatment ((A. Richards et al., 2019)). The article effectively sets the stage for exploring the consequences of such decisions on the quality of end-of-life care as perceived by family members.

One of the key contributions of this study is its focus on the association between stopping dialysis and the quality of end-of-life care. The authors reference previous research that suggests family satisfaction with decision-making support is enhanced when life support is discontinued. However, they also note conflicting findings regarding the experiences of family members of patients who cease dialysis compared to those who continue treatment. This discrepancy underscores the necessity for further investigation into how these decisions affect the subjective perceptions of care quality, a gap that (A. Richards et al., 2019) aim to address.

The methodology employed in the study is robust, involving a comparative analysis of family ratings of end-of-life care based on whether the patients stopped dialysis and whether they received hospice services. This approach allows for a nuanced understanding of how these factors interact. The authors' findings indicate that maintaining dialysis is associated with less favorable family ratings of end-of-life care, suggesting that families may perceive a deterioration in care quality when life-sustaining treatments are continued ((A. Richards et al., 2019)). Furthermore, the study reveals that the integration of hospice services plays a significant role in shaping these perceptions, as families of patients who stopped dialysis and received hospice care reported higher quality ratings.

Critically, the article raises important ethical considerations regarding the decision-making process for patients and their families. It emphasizes the need for

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healthcare providers to facilitate discussions about the potential benefits and burdens of continued dialysis versus hospice care. The findings advocate for a more patient-centered approach that acknowledges the emotional and psychological dimensions of end-of-life care.

The article "End-of-life and palliative care of patients on maintenance hemodialysis treatment: a focus group study" by (Axelsson et al., 2019) provides valuable insights into the complexities surrounding palliative care in nephrology settings, particularly for patients undergoing maintenance hemodialysis. The authors conducted a focus group study that highlighted the commitment of healthcare professionals to deliver high-quality care; however, it also illuminated significant barriers that hinder the effective implementation of palliative care practices.

One of the central themes of the study is the tension between life-prolonging interventions and palliative care approaches. The findings indicate that healthcare providers often experience a dichotomy in their understanding of these two paradigms, which can impede timely, patient-centered interventions aimed at improving quality of life. This tension is particularly pronounced in the context of dialysis withdrawal, where the perception of palliative care may be conflated with end-of-life care, thus complicating the decision-making process for both patients and caregivers ((Axelsson et al., 2019)).

The authors argue that misconceptions regarding palliative care stem from a lack of knowledge and education among healthcare providers. Despite some awareness of palliative care principles, the study reveals that the term is frequently misapplied, leading to confusion about its role in the management of end-stage kidney disease (ESKD). This misalignment underscores the necessity for further education and training to ensure that healthcare professionals can effectively navigate the delicate balance between extending life through dialysis and prioritizing patient comfort and preferences.

Moreover, the article calls for an integrated approach to palliative care that commences earlier in the treatment process for patients with ESKD. The authors advocate for a shift from a conventional, disease-oriented focus to one that

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prioritizes the patient's comfort and aligns with their values and desires. This transition is crucial given the high mortality and morbidity rates associated with ESKD, as it allows for a more holistic approach to patient care ((Axelsson et al., 2019)).

The findings also emphasize the need for improved collaboration among various caregivers involved in the treatment of patients on hemodialysis. The study suggests that re-organization of care teams could facilitate more effective palliative interventions, ultimately enhancing the quality of care provided to these patients. The authors recommend further research into different palliative dialysis approaches to better understand how to address the unique needs of this population.

The article "Kidney Clinicians' Perceptions of Challenges and Aspirations to Improve End-Of-Life Care Provision" by (Ducharlet et al., 2023) provides a critical examination of the integration of palliative care within the context of end-stage kidney disease (ESKD) management. The authors emphasize the necessity of incorporating palliative care principles to enhance the quality of end-of-life care for patients undergoing dialysis. They argue that palliative care, which prioritizes symptom management and interdisciplinary support, is not only beneficial but essential for addressing the complex physical and psychosocial needs of these patients.

A significant insight from the article is the recognition of the challenges faced by clinicians in transitioning treatment goals from curative to palliative care. The authors highlight that patients with ESKD on dialysis often experience more aggressive treatment and hospitalizations at the end of life compared to those who receive conservative management. This discrepancy raises critical questions regarding the appropriateness of care and the need for better alignment with patient preferences and values. The statistical findings indicating that 17% to 21% of patients experience "dialysis regret" further underscore the importance of timely and effective communication regarding prognosis and treatment options ((Ducharlet et al., 2023)).

The authors identify several barriers to optimal end-of-life care, including insufficient integration of palliative care into standard practice and a lack of

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systematic approaches to advance care planning. These barriers contribute to late-stage discussions about end-of-life care, which can exacerbate patient and family distress. The article advocates for early and ongoing conversations between clinicians and patients about goals of care, which can facilitate shared decision-making and better align treatment with patient desires. Additionally, the involvement of family members in these discussions is suggested as a means to enhance the support network for patients, although the article notes that this practice is not yet widespread.

CONCLUSION

The literature surrounding the association of family ratings of quality of end-of-life care with the decision to stop dialysis treatment reveals a complex interplay of patient experiences, family involvement, and healthcare provider practices. The narrative inquiry conducted by (E. Molzahn et al., 2018) emphasizes the liminality faced by patients with chronic kidney disease (CKD) and their families, highlighting the necessity for healthcare providers to engage in holistic, person-centered care as these individuals approach the end of life. This study indicates that family members often have a profound understanding of their loved ones' prognosis, yet the lack of clinician involvement in discussions about death may hinder effective end-of-life planning.

Building on this foundation, the research by (A. Richards et al., 2019) investigates the correlation between the cessation of life-sustaining treatments, such as dialysis, and the perceived quality of end-of-life care. Their findings suggest that family members of patients who chose to stop dialysis reported a more anticipated death, indicating alignment with the patient's wishes. This study raises ethical questions regarding treatment decisions at the end of life and underscores the importance of understanding how family perceptions of care quality are influenced by such decisions.

Further exploration of end-of-life care dynamics is provided by (Axelsson et al., 2019), who identify barriers faced by healthcare professionals in delivering adequate palliative care to patients on maintenance hemodialysis. The tension

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between life-prolonging interventions and palliative care approaches is highlighted, suggesting that misconceptions about palliative care may impede timely interventions aimed at improving quality of life. The authors advocate for a more integrated palliative care model, particularly given the high mortality rates among end-stage kidney disease (ESKD) patients.

Lastly, the study by (Ducharlet et al., 2023) addresses the challenges faced by kidney clinicians in enhancing end-of-life care provisions. The authors call for the integration of palliative care within kidney supportive care, emphasizing its role in managing both physical and psychosocial needs. They note a significant gap in standardized practices for delivering end-of-life care, highlighting the necessity for systematic approaches to advance care planning and shared decision-making. Early and consistent discussions about treatment goals and patient preferences are shown to significantly enhance the end-of-life experience.

In conclusion, the collective findings of these studies illustrate the critical intersection of family involvement, healthcare provider practices, and patient experiences in shaping the quality of end-of-life care for individuals with CKD. They underscore the necessity for a paradigm shift towards more inclusive, patient-centered approaches that recognize the complex realities faced by patients and their families as they navigate the challenging landscape of end-of-life decision-making.

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