

Patient and Family Engagement

Patient engagement is a key element and even a necessary condition for the achievement of patient-centered care (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Institute of Medicine, 2001). Patient engagement is the involvement in their own care by individuals (and others they designate to engage on their behalf), with the goal that they make competent, well-informed decisions about their health and health care and take action to support those decisions (Nursing Alliance for Quality Care, 2013). Emotionally or genetically related family members of patients can have significant influence on the patient's engagement in their own care (Perry, 2013).

People with kidney disease face important choices regarding their dialysis options and the role they play in understanding and making their care most effective. These choices are very personal and have an important influence on their quality of life. In the highly regulated ESRD environment, specific types of information that must be shared with patients and families are mandated, along with an expectation that the patient's voice will be a key determinate in that individual's plan of care. Patient and family engagement are critical in meeting those expectations.

The American Nephrology Nurses Association (ANNA) believes in the commitment of nursing to assist individuals with kidney disease to achieve an optimum level of functioning. As a member of a healthcare team, the nephrology nurse who effectively provides appropriate education and training will encourage people with kidney disease to make informed decisions and remain or become active participants in their own care.

It is the position of ANNA that:

- Education is an essential component of empowering people with kidney disease to become more effective partners in the management of their health care.
- Self-advocacy, self-management, and self-care promote positive patient outcomes and improved quality of life.
- Each comprehensive interdisciplinary patient-specific plan of care must include education and training for patients and families as appropriate for patient self-management, self-care, and adaptation to changes in health status.
- People with kidney disease should have access to their medical records as a way of facilitating participation in their care.
- Patient partners should be encouraged. The family includes immediate family members and/or designated significant other as identified by the patient. Collaboration with and inclusion of the patient/family can enhance communication with the healthcare organization and improve quality of care and patient satisfaction.
- Patients must be offered the opportunity for self-care in any choice of modality.
 - Patients on all types of renal replacement therapy deserve the information necessary to engage in their own treatment decisions. Appropriate payment is essential to ensure qualified registered nephrology nurses have sufficient time and resources to provide safe and effective training.

- Rehabilitation (vocational/physical) to foster the patient's participation in a full and active lifestyle to the extent of their abilities is an important component of the patient's ongoing plan of care.

References

- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. (Eds.) (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. New Jersey: John Wiley and Sons.
- Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academies Press.
- Nursing Alliance for Quality Care (NAQC). (2013, March 25). *Fostering successful patient and family engagement: Nursing's critical role*. Retrieved from <http://www.naqc.org/WhitePaper-PatientEngagement>
- Perry, A. (2013). Caring for families. In P. Potter, A. Perry, P. Stockert, & A. Hall (Eds.), *Fundamentals of nursing* (pp. 116-129). St. Louis: Elsevier.

Suggested Readings

- Curtin, R., Sitter, D., Schatell, D., & Chewing, B. (2004). Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Nephrology Nursing Journal*, 31(4), 378-387.
- Schatell, D., & Alt, P.S. (2008, September). How understanding motivation can improve dialysis practice. *Nephrology News and Issues*, 32-36.
- Stack, A., & Martin, D. (2005). Association of patient autonomy with increased transplantation and survival among new dialysis patients in the United States. *American Journal of Kidney Disease*, 45(4), 730-742.
- Su, C., Lu, X., Chen, W., & Wang, T. (2009) Promoting self-management improves the health status of patients having peritoneal dialysis. *Journal of Advanced Nursing*, 65(7), 1381-1389.

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