



The delicate balance of keeping it all together: Using social capital to manage multiple medications for patients on dialysis

Wendy M. Parker, Ph.D. *, Kristine Ferreira, Pharm.D.,
Lauren Vernon, Pharm.D.,
Katie E. Cardone, Pharm.D., B.C.A.C.P., F.N.K.F., F.A.S.N.

Albany College of Pharmacy and Health Sciences, 106 New Scotland Ave, Albany, NY 12208, USA

Abstract

Objectives: Patients with end-stage kidney disease (ESKD) typically have high medication burdens with numerous medications and specialized instructions. Limited data exist regarding ESKD patient perspectives on medication management. Why can some patients self-manage? Which organizational techniques are used? This project sought to determine experiences and attitudes regarding medication management among hemodialysis patients.

Methods: Group interviews were conducted with adult patients from 3 dialysis facilities. Semi-structured interviews solicited information about medication self-management and views on related services. Interviews were recorded and transcribed and data were analyzed using inductive, thematic coding.

Results: Participants reported medication regimens complicated by the dialysis schedule, co-morbid conditions and multiple prescribers. Patients engaged in various coping strategies, including reliance on activating social capital and/or family social support, to manage their medications and health. When described, most thought medication management services would be beneficial, but not necessarily for themselves, despite some having histories of medication mismanagement.

Discussion: Patients on hemodialysis often develop strategies for managing medications that rely heavily on a social network, and strategies may not be discussed with healthcare providers. Social capital is a useful framework for considering patients' lifestyles and support structure when designing a medication regimen. Future research should explore this idea more proactively.

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Introduction

Chronic kidney disease is estimated to affect 10% of the world's population, and if left untreated, may progress to end-stage kidney disease (ESKD).¹

ESKD requiring dialysis is usually resultant from underlying chronic conditions, most notably diabetes mellitus and uncontrolled hypertension, and represents a significant public health concern.^{2,3}

* Corresponding author.

E-mail address: Wendy.parker@acphs.edu (W.M. Parker).

Once on dialysis, complications from advanced kidney disease make self-management increasingly difficult. Effective self-management behaviors, including medication management, are important for patients on dialysis to prevent undue morbidities and mortality. These patients are frequently hospitalized and are at high risk of re-hospitalization once discharged, and poor management of prescribed treatments may increase risk.²

Medications represent a significant component of the ESKD treatment plan, in addition to dialysis treatments and dietary interventions.⁴ Patients with ESKD typically require complex medication regimens consisting of 10–12 medications, often with specific instructions for timing around dialysis and/or meals. Medication self-management involves obtaining prescription and non-prescription medications (usually requiring an understanding of insurance and payment structures), proper storage, organization of medications, timing medication doses throughout the day, recognizing problems or adverse events, communicating concerns and questions to health-care providers and navigating the prescription refill process.⁵ Managing the overall treatment plan requires patient buy-in, adequate health literacy and education, and involvement of a multi-disciplinary care team and/or caregivers, as needed. However, data are lacking regarding patient experiences with medication use and self-management abilities in the dialysis population.

Research in hemodialysis patients often documents the care patients receive from the perspective of the healthcare system or measures self-management quantitatively.⁶ Fewer studies have directly examined the patient experience to truly understand the everyday practices of patients on hemodialysis.⁷ Yet there have been continued calls for multi-disciplinary interventions to improve adherence for patients on chronic hemodialysis and for heightened patient engagement.⁸ Given the high risk for medication-related problems and associated morbidities, this study explored existing self-management strategies and experiences as well as potential approaches to enhance medication management among patients on chronic outpatient hemodialysis.

Materials and methods

A qualitative interview study was conducted with patients on chronic hemodialysis from three

affiliated, privately owned non-profit dialysis facilities in 2014. A semi-structured interview guide was developed and standard practices for qualitative data analysis were followed.⁹ The study guide asked participants to explain how they currently managed their medications, what existing strategies and/or social support they utilized to manage their health and medications, as well as some questions about what interventions they might have utilized to enhance their medication management and what approaches they might be interested in for the future. This study was reviewed and approved by the institutional review board of our institution.

Participants were at least 18 years old and received chronic hemodialysis at one of the study locations. Participants were excluded if they resided in long-term care or assisted living facilities, or were unable to speak and understand spoken English. Patients identified by staff were approached by an investigator during a routine dialysis treatment. Interested patients were given information regarding the study and were assessed further for study eligibility. Participants were contacted 1–2 days prior to the interview date to remind them of the session.

Interview sessions were scheduled at each of the three dialysis facilities based on the dialysis appointments of potential study participants. Sessions took place in a conference room at each of the study locations and occurred either after or prior to participants' regularly scheduled hemodialysis treatments and were planned to be group interviews. Due to the time intensive nature of dialysis appointments and unanticipated scheduling conflicts, most of the interviews were done with 1–2 participants at a time. Two group (more than 2 participants each) interviews were held to accommodate the needs of participants, but all interviews followed the same semi-structured interview guide and results were analyzed by participant. Interviews lasted approximately 45–60 min each and were audio-recorded, with verbal and written consent being provided before commencement of the session. Additionally participants completed a demographic form to provide basic information to the research team. Two researchers were present during the interviews, a facilitator and a note-taker.

Verbatim statements from the audiotapes and debriefing notes were coded to identify common themes. Both thematic and framework analysis were used in combination to define and map

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