

Qualitative Analyses to Amplify Patient and Care Partner Needs for Self-Management in Glomerular Disease



Amanda Grandinetti¹, Abebech Waktola² and Devika Nair^{2,3,4}

¹Northern Illinois University, Dekalb, Illinois, USA; ²Division of Nephrology and Hypertension, Department of Medicine, Vanderbilt University Medical Center, Nashville, Tennessee, USA; ³Vanderbilt O'Brien Center for Kidney Disease, Nashville, Tennessee, USA; and ⁴Vanderbilt Center for Health Services Research, Nashville, Tennessee, USA

Kidney Int Rep (2022) 7, 13–14; <https://doi.org/10.1016/j.ekir.2021.11.017>

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Self-management refers to behaviors needed to manage the symptoms, treatments, lifestyle changes, financial issues, and psychosocial consequences of a chronic medical condition.¹ Self-management allows patients to modify individual factors that can affect their risk of disease progression and outlines steps needed for patients to live well despite their disease. In the case of glomerular diseases of autoimmune etiology, such factors include managing adverse medication reactions, monitoring for infection from immunosuppression, and learning on how to seek timely medical attention during episodes of relapse.

Evidence-based, person-centered behavioral and therapeutic strategies to address patients' specific self-management needs in autoimmune

glomerular disease are lacking. Given the complex medication regimens and unpredictable disease course associated with glomerular diseases of autoimmune etiology, factors important in self-management must be amplified. In this issue of the *KI Reports*, Carter *et al.*² move to fill these gaps by applying qualitative methods to deeply explore patient and care partner barriers and facilitators to successful self-management in autoimmune glomerular disease. The investigators conducted 16 focus groups of 101 adults with glomerular disease (ranging from individuals with nondialysis chronic kidney disease to those receiving hemodialysis, peritoneal dialysis, and kidney transplantation) and 34 care partners across Australia, Hong Kong, the United Kingdom, and the United States. The analysis used grounded theory, meaning the investigators used inductive reasoning to construct a new conceptual framework based on common themes that emerged from participant quotations.³

Qualitative research analyzes thematic data from individual interviews, focus groups, or other non-numerical media to understand the patient experience. Qualitative research also helps investigators unearth new or surprising areas emphasized by participants which may not have been prespecified in their hypotheses. Researchers and clinicians may be well-versed in the long-term biological sequelae of glomerular disease, but patients are the domain experts of the day-to-day lived experience of the disease. As such, only a qualitative form of investigative inquiry would have allowed Carter *et al.*² to deeply explore patients' perspectives and achieve their study aims.

The investigators identified 4 major themes and multiple subthemes, outlining what might facilitate, determine, and impede patients' self-management capabilities. Some themes that emerged, particularly those related to the need for patient confidence and self-empowerment, are not specific to glomerular disease and have recently been gaining recognition in nephrology.⁴ Other themes and subthemes emerged that are unique to the lived experience of autoimmune glomerular disease are the following: worries on the physical side effects of immunosuppression, the need to avoid high-risk activities, and the constant mental toll of impending disease relapse.

The study has several important strengths. The investigators not only used focus groups as an efficient means for data collection from participants across multiple sites but also capitalized on the unique insights and collective views gained from communication between participants.⁵ Participants

Correspondence: Devika Nair, Division of Nephrology and Hypertension, Vanderbilt University Medical Center, Vanderbilt Center for Health Services Research, 2525 West End Ave, Suite 450, Office 416, Nashville, Tennessee 37203, USA. E-mail: devika.nair@vumc.org

living with an array of glomerular diseases were included, including those facing focal segmental glomerulosclerosis, lupus nephritis, IgA nephropathy, or anti-glomerular basement membrane disease. Participants' comorbidities were representative of the comorbidities of many existing adults living with glomerular disease. Perspectives of care partners and Spanish-speaking adults, both under-recognized in nephrology, were purposefully included.

Future investigations that build on the work of Carter *et al.*² should take care to include patient and care partner perspectives of those who identify as belonging to under-represented groups and those who live in low- and middle-income countries. Although the purposive sampling technique of using nephrologists to identify participants likely allowed for rich data, it may have introduced selection bias by favoring those who were already familiar with research participation or well-integrated in the health system. Further qualitative analyses should focus on key determinants of glomerular disease self-management that emerged in this study but remain under-investigated in patient-oriented kidney disease literature. These themes include identifying sources of information for self-management needs, exploring financial worries such as the cost of medications, amplifying personal sacrifices such as travel limitations and infertility, and outlining care coordination-related issues such as navigating the insurance system. Once each theme is clearly defined, a Delphi technique should be used to ensure that patients ultimately agree and validate the themes. A

graphic, visual analogue scale, or patient-reported outcome assessment could be developed from each theme to help patients identify specific areas of concern for successful glomerular disease self-management. If validated and implemented in clinical practice, such tools could be used clinically to generate dialogue and partnerships between patients and nephrology clinicians.

Patient-reported outcome assessment in glomerular disease is nascent, and existing tools mostly inquire on symptoms and daily tasks.^{6,7} Current tools do not thoroughly capture patients' relationships with friends and family, their ability to participate in recreational tasks, or their capacity to achieve their life goals. What is lacking are specific tools to evaluate the life impact of living with glomerular disease. As the investigators acknowledge in their Discussion section, further research must also explore barriers to self-management, such as frustrations with care fragmentation and difficulties with navigating health system-level processes, and facilitators to self-management, such as peer patient networks that encourage empowerment and activation. The ultimate goal must be to develop comprehensive self-management programs that address multilevel needs. Qualitative research is the first step in developing a tool to measure, monitor, and intervene on the self-management needs of patients with glomerular disease. Now, the nephrology community must move toward measuring the life impact of autoimmune glomerular disease and move from an approach focused on the individual patient to one that acknowledges their

roles in the communities and health systems they navigate.

DISCLOSURE

All the authors declared no competing interests.

ACKNOWLEDGMENTS

AG is a patient and kidney transplant recipient who lives with glomerular disease. Funding to K12HS026395 to DN.

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