

## Tuning into Qualitative Research—A Channel for the Patient Voice

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*Clin J Am Soc Nephrol* 11: 1128–1130, 2016. doi: 10.2215/CJN.05110516

The 2016 White House Correspondents' Dinner will probably be remembered for President Obama's microphone drop. But before this epic exit, between his scathing review of news media when he compared investigative journalism to a fantasy film and his dig at a reporter for leaving journalism to join CNN, President Obama acknowledged the work of the reporters in the room: "At home and abroad journalists like all of you engage in the dogged pursuit of informing citizens and holding leaders accountable, and making our government of the people possible."

It was not mere praise. Woven into his words were the defining characteristics of good journalism: transparency, accuracy, accountability, and equity. These are not dissimilar to the virtues and values of good qualitative research. It could be said that qualitative research is transparent, because it brings patients' stories to light. Being aware of patient needs is the beginning of accountability, because we have a duty to respond to their plight. Understanding patient values and priorities helps us to engage patients in decisions about their treatment, enhancing equity and accountability.

With growing traction for patient-centered care across the whole spectrum of health care, including nephrology, there has been increasing interest in generating and using qualitative evidence on patients' experiences, attitudes, and values to inform patient-focused clinical decision making. Qualitative studies, using interviews or focus groups, for example, allow patients an opportunity to discuss their perspectives with researchers at length and on their own terms. This method brings to the surface the patients' deep-seated values and concerns—which may be self-censored in the clinical setting, because they may feel constrained by time, worry about jeopardizing the relationship with their physician and their care, and want to avoid being perceived as a difficult patient. For patients on dialysis, this may be particularly important given their frequent, intense, and long-term interaction with health care services.

Qualitative studies generate hypotheses and theories to explain social phenomena and are useful for illuminating the reasons for people's behaviors and decisions (for example, why patients refuse or do not adhere to treatment). This mechanistic focus is very similar to basic science research, a comparison that may seem

counterintuitive. Qualitative research is an umbrella term covering a range of methodologies (e.g., grounded theory, ethnography, and phenomenology), which can inform the choice of approach and methods for participant recruitment, data collection, and analysis (1–5). Typically, a purposive sampling strategy is used to select information-rich participants with a range of demographic and clinical characteristics to capture a breadth of data. Recruitment may continue until saturation, when minimal or no new data are being obtained in subsequent data collection. Interviews and focus groups are commonly used in qualitative health research to collect data. Usually, audiotaping and transcription are undertaken to ensure accuracy of data collection and enable the researcher to focus on interacting with the participants. The questions for interviews or focus groups are flexible and designed to probe for detail and clarification of perspectives. Qualitative data analysis generally involves coding of data into meaningful concepts that are inductively derived from the data and grouping similar concepts into themes (i.e., thematic analysis). Patterns and relationships within the data may be identified. Software packages can enable qualitative data management and facilitate efficient and auditable data analysis.

The synthesis of qualitative research is a relatively new and emerging methodology, which began with the work of Noblit and Hare (6) in the late 1980s; they developed metaethnography as a way of "meta-analyzing" interpretive textual data (6). Since then, different methods of synthesis have been developed, but fundamentally, they all combine qualitative studies conducted in different populations and health care contexts to provide new and more comprehensive insights on the research question (7–9). The emergence of qualitative syntheses is increasingly apparent—even within nephrology. In the past 2 years alone, qualitative syntheses involving patients on dialysis have addressed specific topics, including dietary management (10), vascular access (11), waiting for a kidney transplant (12,13), and end of life decision making and care (14,15).

In this issue of the *Clinical Journal of the American Society of Nephrology*, Reid *et al.* (16) take a broader approach and report a synthesis of qualitative studies on the experiences of patients on in-center hemodialysis (HD). Reid *et al.* (16) included 17 studies published since 1998 that involved 576 patients across 10

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countries. Reid *et al.* (16) analyzed the results sections of the articles using thematic synthesis (7), a systematic, transparent, and flexible approach for translating concepts across studies to address questions about people's perspectives and experiences. This technique involves coding textual data from the primary studies line by line and identifying emergent descriptive and analytic themes that address the specific review question with a view to informing practice and policy.

Reid *et al.* (16) developed four analytic themes reflecting patients' experiences of in-center HD. "A new dialysis-dependent self" described the effect of HD on the identity of the patient and their family roles and relationships as well as changes in their social world and future (16). "A restricted life" entailed the constraints of HD on time and dietary intake and the loss of choice and freedom (16). "Regaining control" was the acceptance of being dialysis dependent, adjusting to and accommodating dialysis, and gaining expertise in doing dialysis (16). "Relationships with health professionals" involved information sharing, building relationships, balancing power, and seeking expertise (16).

The themes reiterate findings from a prior synthesis of qualitative studies on the lived experiences of patients on HD by Bayhakki and Hatthakit (17), in which patients described dialysis as a "shackle" and used different psychosocial coping strategies to try and attain "optimum life satisfaction" (17). The synthesis by Reid *et al.* (16) adds to the existing work by highlighting the potential effect of the patient-provider relationship on the patients' journey of change. Reid *et al.* (16) provide a selection of participant quotations from the original studies that not only support to their findings but also, allow us to hear the perspectives of patients.

Reid *et al.* (16) have also developed a useful framework to target important issues for patients, such as maintaining roles within their family and community, minimizing lifestyle restrictions imposed by dialysis and symptoms, and having a relationship with their health care provider in which they receive adequate information, communication, and support to improve their sense of control over their health and treatment.

Although Reid *et al.* (16) state that the themes identified were evident across multiple studies included in the review, they also noted that the primary studies included in the synthesis did not always report key characteristics of the population, such as sex, ethnicity, educational attainment, and duration of dialysis, and they were, thus, unable to assess the appropriateness of the recruitment strategies and the approach to data collection and analysis. A lack of contextual detail about the participants and setting in the primary studies and inadequate reporting can limit the ability to assess the transferability of the findings to different populations and contexts as well as the rigor of the study. In fact, the problem of inadequate reporting has also been noted in other reviews and syntheses of qualitative studies. On this point, the Enhancing the Quality and Transparency of Health Research network recommends the Consolidated Criteria for Reporting Qualitative health research for primary qualitative studies that use interviews or focus groups (4).

The scope of the data contributing to the synthesis on patients' experiences of in-center HD may be potentially limited, because Reid *et al.* (16) excluded studies that were not published in English as well as studies that involved

participants with different CKD stages or who were on modalities other than in-center dialysis or involved health professionals. Also, most studies were conducted in high-income countries. The search strategy did not include text words and additional terms related to qualitative research (*e.g.*, focus groups, thematic, grounded theory, and phenomenology) and social phenomena (*e.g.*, perspectives, social psychology, knowledge, health belief, social adjustment, communication, and interpersonal relations) (8); therefore studies may have been missed. Consequently, we may not hear the entirety of patients' perspectives on in-center HD.

Nevertheless, the synthesis by Reid *et al.* (16) loudly calls for the need to empower patients on in-center HD to maintain their identity, lifestyle, sense of control, and relationships within their social networks and with health care providers. The work by Reid *et al.* (16) challenges the predominant focus on medical outcomes by urging efforts to maximize psychosocial and lifestyle outcomes for patients requiring HD—flexible dialysis schedules, access to mobile dialysis, better education, effective communication, psychosocial support, and self-management programs (some of which were suggested by Reid *et al.* [16]).

We are still caught in a grim reality. Mortality, health, and quality of life outcomes in patients on HD have not substantially improved over the past few decades. But what if we tune into qualitative research? It is a channel for the patients' voice. We hear that some changes can be made now—in how we provide care and how we communicate—to make life better for patients who want to be empowered to live well with dialysis. Perhaps then we can, like President Obama, drop the proverbial microphone on patient care.

#### Acknowledgments

A.T. is supported by a National Health and Medical Research Council fellowship no. 1106716.

#### Disclosures

None.

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Published online ahead of print. Publication date available at [www.cjasn.org](http://www.cjasn.org).

See related article, "A Thematic Synthesis of the Experiences of Adults Living with Hemodialysis," on pages 1206–1218.