The International Journal of
WHOLE PERSON CARE
VOLUME 13 • NUMBER 1 • 2026 • 11-17

ARE WE “REAL FRIENDS”? SEARCHING FOR COMMUNITY IN MEDICAL ANTHROPOLOGY

Olivia Alvarez Gaughran, MPhil
Seattle-Denver Health Services Research and Development Center of Innovation, Veterans Affairs Puget Sound Health Care System, Seattle, Washington, USA
University of Washington Department of Medicine, Division of Nephrology, Seattle, Washington, USA
olivia.gaughran@gmail.com

KEYWORDS: Ethnography; Nephrology; Care; Research; Anthropology

When I think about community in whole person care, I think about Roy.

Roy was a Black, gay American Veteran and a founding member of the first LGBTQ+ church in his city of birth, where he practiced his Christian faith with other queer people for over fifty years. He was a decorated go-go dancer in his youth and received many trophies and accolades for his characteristic charm, good looks, and gilded fashion sense.

Roy was a singer, dancer, tailor, charmer, and sarcastic smartass. Always donned in his signature black-and-white two-piece tracksuit and black cap, Roy reprimanded me many times with a cavalier glare and a stern, *Luvvvvvie…*

It was clear what he meant by that warning: I was talking too much and asking too many questions. Every time, though, I was forgiven with a barking laugh and a tender pat on my hand. Roy was of cantankerous mind and tender soul, which quickly endeared him to the people around him.

I met Roy at an interesting and intimate time in his life. Roy, willful and radiant as he was, was facing imminent kidney failure. I came to know Roy in a research context, working with him as a medical anthropologist on an ethnographic research study focused on care for patients with very advanced chronic kidney disease who forgo dialysis.

In-center hemodialysis is the predominate approach to treating kidney failure, in which treatments usually last 4 hours and occur 3 times per week, although there are different forms of dialysis that can be done at home or in specialized facilities. Dialysis can offer relief from some symptoms of kidney failure and extend the lives of many who receive it. But for older and sicker patients, the amount of “added life-time” gained with dialysis can be small while quality of life declines.[1]

Life on dialysis can feel circular, unending, and difficult; it is, of course, not the right choice for everyone.[2] Ultimately, about 7 percent of people with kidney failure elect not to do dialysis and pursue conservative kidney management instead.[3] Conservative kidney management is a holistic, person-centered approach to caring for those with stages 4 to 5 advanced kidney disease who do not want to pursue maintenance dialysis.[4] The focus is on relieving symptoms and maintaining independence and function through medicines, lifestyle changes, and other services.

There are many reasons why one might not choose to treat their kidney failure with dialysis. Values besides longevity are an essential element of whole person care and often go underappreciated in clinical environments where life-extending therapies remain the norm. After all, most Americans get their healthcare in a financially incentivized medical system that prioritizes longevity over other meaningful healthcare values, like comfort, quality of life, or independence.

My research team believes it is possible to make care more person-centered and better resourced for those who do not wish to pursue dialysis. Our research participants help make this vision a reality by volunteering their reflections, experiences, and time with us.

Enter: Roy (and many others, so far).

As part of our ethnographic work, I survey and interview patients about many things: their hopes, fears, and dreams for the future; reflections on their health, the care they receive—what works well, what doesn’t—and what they wish was different. I survey and interview their caregivers and providers. I look inside their medical records to extract chart notes, lab values, and other care-related outcomes like rates of hospitalization, hospice, and intensive care.

Patients invite me to join them in a variety of healthcare settings, such as when they receive care in a clinic or are admitted to the hospital. They show me what it is like to live as a person with kidney disease—I am invited into their homes, and on occasion their workplaces, to spend a part of their days with them.

This juxtaposition of immersing myself deeply within whole-person experiences of illness, contrasted with my external status as a health systems researcher, underscores a persistent fault line underlying my professional identity. I ponder often: to which community do I belong?

Our research team has a running joke that most of us are “certified clinical nobodies.” The implications of this in terms of community, and what it means for people like me to participate in whole person care, are vast.

Like many healthcare professionals, I know my way around hospitals, sit in clinic rooms, and spend hours with patients. I sleuth around medical records and document findings. I debrief visits with providers, present work at medical conferences, and laugh at the punchline of kidney puns.

But I do not wear a white coat; I am not involved in direct patient care. I do not diagnose, treat, nor rehab the patients I work with. I do not call patients with good or bad news. I cannot provide medical advice.

Like other researchers, I work under stringent oversight, am beholden to strict laws around patient information, and keep up to date on best clinical research practices. I publish, present, and push for change. However, as there are many kinds of research, important distinctions are quickly flattened by the title “researcher”.

And finally, like many other anthropologists doing ethnographic work, I am a kind of friend, a sort-of companion. I am familiar with participants’ homes; I know where they keep their coffee mugs. I park in their driveways, admire their family photos, and shake the hands of their children and grandchildren. I talk with them in waiting rooms and cafeterias. I witness as they wrestle with what it means to experience kidney failure. Ultimately, I help reconstruct the meaning of all this data put together to “throw light on the issues” with which our team is concerned.[5]

Qualitative researchers and anthropologists have long been wrestling with what it means to spend extended time in the lives of participants contending with emotionally-charged phenomena. This kind of study necessarily brings the lives of the researched into a sensitive social landscape with the “ambiguity of the researcher who plays a (purported) nonparticipant role”.[6] Purported, indeed. I am often, involuntarily and voluntarily, *participating*, both in the social worlds I observe, and in whole person care more generally.

Through my experience as an ethnographer, I have realized I cannot truly belong to something I cannot fully experience. My belonging in community is parsed out and incomplete. And yet it is incredibly meaningful to find belonging, however temporary, in many spaces, with many people, in many contexts.

I spent some time in the home of a participant named Nora, who faces many barriers to care. Nora lives alone, two and a half hours from both medical centers where she receives care. When she enrolled in the study, I was the first person she had invited into her apartment in over eight years. We spent time together cleaning it up in preparation for an upcoming inspection that she was very worried she would fail.

I told myself that this time together spent was a “day in the life”; that time together, so long as I was invited, is an important element of our data collection. When I was there, we talked about her health, yes, but we also talked about other things: her faith, her life as a nurse, her time overseas, her strained relationships. We played music and hummed Christmas carols. And we cleaned.

The process was sweaty and arduous; I was physically participating in Nora’s life, and it made me feel proud and helpful, but disoriented. We were most certainly beyond the scope of non-participant ethnographic observation. I felt the boundaries between researcher and *me* blurring. One anthropologist writes, “Doing fieldwork is a personal experience. Our intuition, senses, and emotions…are powerfully woven into and inseparable from the process.” [7]

One evening, Nora called and left me a voicemail, wanting to add an addendum to a recent interview. In her message, she shared her thoughts for a minute or two before closing with, “Thank you. Appreciate you very much. And I kind of wish you weren't on the study because then we could be friends. I mean real friends. All right, talk to you later. Bye.” Her voice sounded very sad.

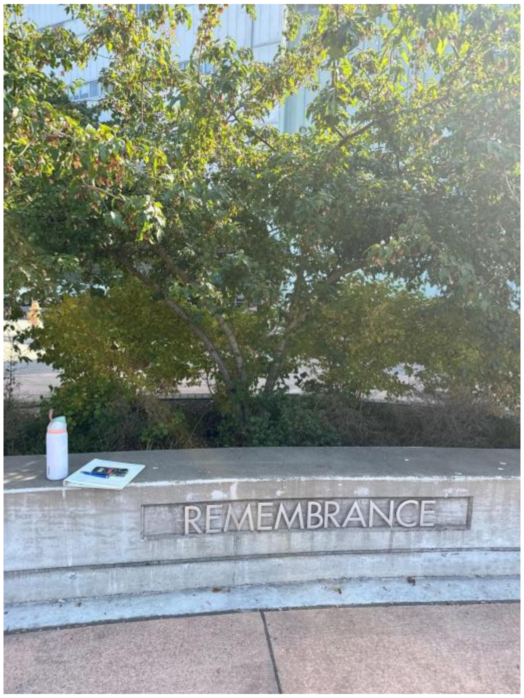
I wondered: Am I a “real” friend? The thought made me cry. I occupy some liminal social position: researcher, colleague, friend, companion, observer, stranger? ‘The girl from the kidney research’, they often call me. I can fix nothing; I can change nothing. I am a non-member of their care team, a fly-on-the-wall, a caring witness. But not, perhaps, a “real” friend.

Roy joined our study a month before he enrolled in hospice, as he was contemplating Washington’s Medical Assistance in Dying (MAID) program. I watched as he actively reconciled what it meant to have advanced kidney disease and forgo dialysis. He felt ready to die. But he also loved people, just as he loved living. He made it emphatically clear: he did not want to go before it was time. But he did not want to hold on to life.

He asked a lot of questions about how he would know when he was ready to die. The hospice nurses gave him simple answers: *You will just know. You will feel a difference in yourself*. I could see him struggle not knowing when that time would be. Roy liked to be in control. Choosing to forgo dialysis and instead enroll in hospice, and MAID, without knowing exactly what the end would look or feel like when it comes, gave him a sense of empowerment and control over the end.

Conservative kidney management confronts us with our own assumptions, biases, and beliefs about how to live and die. Kidney failure throws into sharp relief the irreconcilable paradox of death—that we will die—and yet that death is often understood as a failure. Roy did not see it that way. He had a community waiting to welcome him in death, and he was eager to join them. To die on his own terms would indeed be a great success.

One sunny August morning, I was sitting in the lobby of the primary care clinic, after Roy invited me to attend a routine visit with him. I had alerted his provider that I would be there, and we were both expecting Roy any minute—he was always extremely punctual. His provider came out to the waiting room a few minutes after the hour. In looking at her face, I knew that Roy was not running late. I felt a strange, irrepressible grief rising in my chest.



Later, I sat down in the center of the hospital courtyard on a concrete bench imprinted with the word ‘*REMEMBERANCE’*. I cried, feeling Roy missing from the flurry. I was gutted that my small corner in his vast, expansive life was now devoid of purpose; my role complete in an unfinished job abruptly ended by his passing.

No one noticed me sitting there, it seemed; my tears reflected an untrained disciple of medicine. I felt there was something truly pathetic about me on that bench that would likely repel people away from the area, away from me. The stained red streaks on my cheeks reflected my inexperience with loss in a professional setting, in this medicalized place. All that signaled me as a worker and not a visitor was my government badge hanging around my neck, an emblem of my professional role that somehow felt deeply personal.

What would I have said, should someone have stopped to ask what was wrong? “I just lost a patient” feels untrue. Roy was not just “a patient” to me, nor “mine” to lose. He was a collaborator, a co-conspirator, an interlocuter. He was familiar to me in a whole-person way, in the way where I knew what mattered to him outside of this place.

Roy was looking forward to dying, eager to be reunited with Jesus and his mother. He yearned for heaven, and told me so emphatically, repeatedly, and enthusiastically. I yearned to know if he had made it through the gates of Heaven like he so desperately wished.

That morning, I felt I had been inducted into a club with no living members. Who could I cry with? A member of a care team with no care responsibilities; a life witness with no life ties. I could not call Roy’s family. I could not share in my grief with my colleagues. They knew what I meant but they did not feel what I felt. Roy, I felt, was the only one who might have understood this feeling.

When I think of community, I think of all the healthcare workers that know patients as whole-persons but are not necessarily responsible for whole person care. Those that know what it is like to love people who do not “belong” to you, in any normative clinical sense. The relationship I had with Roy and the fondness I felt for him eluded the traditional landscape of relationships in medicine, work, and research. Perhaps the deep loss I feel when patients like Roy invariably pass away or complete the study reveals how the community that I have been seeking in whole person care already exists right in front of me. Our relationship *is* the community.

I attended Roy’s celebration of life a few weeks later. The urn that held his ashes gleamed prettily in front of the room. The funeral home was quaint and warm that morning, quiet with just a few handfuls of people who knew and loved him. I slipped into the back. Some of his doctors and nurses came in shortly afterwards and sat in the row just ahead of me; they acknowledged me wanly. We came from the same place, grieved the same person, but we did not overlap beyond that. We did not share the same experience, and were not close to each other in this.

Nonetheless, everyone present sang his favorite songs, shared stories, cried, laughed, and ate together as we quietly remembered and celebrated a beautiful person.

Attendees were invited to take a token of Roy’s to remember him by. I chose a small ceramic plate that read, *A day hemmed in prayer seldom unravels*, and hung it by my bedside. Attending his memorial was the closest thing to gathering in community I could think of—the one place I could think of to honor the whole-person that I knew Roy to be. And still, as I mingled and answered the question, “So, how did you know Roy?”, the lonely feeling inside me did not budge.

My participation in “whole person care” as a medical anthropologist and ethnographer thwarts community in the traditional sense. I wonder if there will ever be a day where I feel in community with others like me; I ask my therapist about this often. Are there classes for people like me? Affinity groups? Focus groups? Online groups? Groups, groups, I keep looking for groups. Who will understand me? However, no matter how lonely I sometimes feel, I possess a deeply unshakeable sense that I am never truly alone. Through this work, my participants and I become community to each other as we both seek a place to feel understood. I feel myself in affinity with those who experience this work with me. Because we are, just for a moment, together. ■

References

1. Montez-Rath, M. E., Thomas, I. C., Charu, V., et al. Effect of starting dialysis versus continuing medical management on survival and home time in older adults with kidney failure : A target trial emulation study. Annals of internal medicine 2024;177(9): 1233-1243. https://doi.org/10.7326/M23-3028
2. Russ, A. J., Shim, J. K., & Kaufman, S. R. “Is there life on dialysis?": time and aging in a clinically sustained existence. Medical Anthropology 2005;24(4):297-324. https://doi.org/10.1080/01459740500330639
3. Scherer, J. S., Bieber, B., de Pinho, N. A., et al. Conservative kidney management practice patterns and resources in the United States: A cross-sectional analysis of CKDopps (Chronic Kidney Disease Outcomes and Practice Patterns Study) data. Kidney Medicine 2023;5(11):100726. https://doi.org/10.1016/j.xkme.2023.100726
4. Wong, S.P.Y, Rubenzik, T, Zelnick, L, et al. Long term outcomes among patients with advanced kidney disease who forgo maintenance dialysis: a systematic review. JAMA Netw Open 2022;5(3):e222255. https://doi:10.1001/jamanetworkopen.2022.2255
5. Hammersley, M., & Atkinson, P. Ethnography: Principles in Practice. London, UK: Routledge 2019:1-292. https://doi.org/10.4324/9781315146027
6. Gilbert, K. R. The Emotional Nature of Qualitative Research. Boca Raton, FL: CRC Press 2002:1-224. https://doi.org/10.1201/9781420039283
7. Madison, D. S. Critical Ethnography: Method, Ethics, and Performance. Thousand Oaks, CA: SAGE Publications 2005:1-285. https://doi.org/10.4135/9781452233826

Biographical Note

Olivia Alvarez Gaughran is a medical anthropologist and ethnographer in Seattle, where she conducts mixed-methods qualitative research across a range of subjects, including conservative kidney management, organ transplantation, and palliative care. Olivia holds a master’s degree in social anthropology from the University of Cambridge, specializing in exploring patient experiences and health systems through ethnographic approaches. She is also a writer (www.theollyproject.com) and academy soccer coach. She aims to bring her love of learning, connectedness, and authenticity to all aspects of her life. This work was supported by grant funding from the Veterans Health Administration.