“Kidney Brothers”: The Case for Peer Support in Kidney Transplant

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A kidney transplant is a miraculous, life-altering event. It can also be profoundly lonely. Although transplantation is inherently a single-rider service, the years spent anticipating the surgery may be similarly isolating for a patient. Daily management of kidney failure is often physically restrictive and emotionally draining. Coping with ESKD has been associated with the decline of mental health and overall quality of life (1).

The story of Tommy and Tyrone is that of an accidental friendship. It began one day in November, when each received a phone call at midnight. The men were 11 years apart in age; one was black, the other was white. After decades of coping with kidney failure and dialysis, both had risen to the top of the organ transplant waiting list. Each signed the paperwork and found themselves in an operating room, where they were prepared to receive a kidney. That day, two lives were saved by the same anonymous donor. And yet both would have left the hospital, nowhere, you got to stay in that position, and that’s it. And it really puts a cramp on your life. If you want to go out of town or you want to go to another state, you got to let them know. The fact that you have so many different restrictions … you have to take those pills to help digest your food … it’s just a hell.

Tommy immediately echoed Tyrone’s experience, comparing it with his own time on peritoneal dialysis. Although acknowledging that peritoneal was “easier,” Tommy affirmed the term “jail”: “You can’t make any long-term plans.” It was clear throughout our interview that Tommy and Tyrone had found in each other a source of validation and consolation in their past challenges and encouragement in the now.

Since undergoing their operations, Tommy and Tyrone have walked the road of recovery together. They’ve supported each other through medication complications, creatinine fluctuations, and personal milestones. Realizing a shared passion for motorcycles, they began to go on rides together. The first November after their surgery, they celebrated with an anniversary dinner. The events reached the ears of an artist—a client of Tommy’s wife, who is a hairdresser. Upon learning their history, she invited Tommy and Tyrone to her studio for a photo shoot, inspiring a painting now shown in Washington, DC.

The fortitude demanded of transplant patients is remarkable. Amid the uncertainties of waiting for a life-saving organ, many manage their anxiety alone, right up to the doors of the operating room. Confidentiality is a hallmark of modern medicine. In 1996, patient privacy as we know it was established by the Health Insurance Portability and Accountability Act. Sharing of health data operates on a “need-to-know” basis, and transplant is no exception. The identities of transplant donors are strictly concealed from the organ recipients at all stages of the process.

Transplant recipients are similarly shielded from one another. In a world bound by minimal disclosure, it is not surprising that institutional spaces for peer support are rare. Yet, these gaps, and their broader costs, are seldom called into question. Although boundaries exist to protect patients, it is worth

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examining what might be lost along the way. Rita Charon has argued that the sharing of stories can offer a deep source of coping and a creation of meaning (2). If connection is a basic human need, shouldn’t it matter in the care of those we hope to heal?

This podcast allows Tommy and Tyrone to share their story and the ways in which their friendship has changed their lives. It is our hope that this interview captures the therapeutic potential of peer support in transplant. Their story articulates a longing to connect with and thank the donors and families who have enabled transformative outcomes. Above all, it celebrates the rare fellow travelers who can see them and join them on the ride.

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Author Contributions

S.G. Mansour was responsible for conceptualization and resources; A.A. Shi wrote the original draft of the manuscript; and both authors reviewed and edited the manuscript.

References


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