Lay summary - Original

Background:

The qualitative literature on solid-organ transplantation increasingly features the stories and voices of patients. There is growing interest in understanding the patient experience to promote long-term adherence, quality of life, donation and education related to transplantation. These aspects of patient experiences however are often dealt with in isolation of each other and divided based on the solid-organ group. While there are unique similarities and differences between solid-organ groups, the need for accessible knowledge and support regarding transplantation can be facilitated through community connection and storytelling.

Objectives:

To amplify the voices of patients in community, and clinical settings by (1) embedding patient-experience into educational and communal platforms related to transplantation; (2) encouraging conversations between patients, clinicians, and solid-organ groups.

Methods:

Critical discourse analyses (CDA) of transplant-educational material were conducted to identify the gaps and strengths between solid-organ groups. Ethnographic interviews were held with patients from heart, liver, lung, and kidney transplantation programs from the Ajmera Transplant Centre at the University Health Network. Arts-based methods were included in the ethnographic interviews. Two additional digital storytelling workshops were organized over eight-weeks.

Results:

The main themes that emerged from the CDA of transplant manuals and eighty-four ethnographic interviews demonstrated the transformative experience of transplantation, the overwhelming emotions, and the interpersonal or professional misunderstandings. Eight digital stories were created and screened by transplant patients with the Liver Transplant Program at the Toronto General Hospital, and the Canadian Donation and Transplantation Research Program (CDTRP). Arts-based methods facilitated patients to engage in redefining their transplant narrative through unspoken emotional experiences such as anger, grief, and loss, which sit alongside the more spoken feelings of gratitude and hopefulness for the future.

Conclusion:

Community-based learning emerged from sharing patient-experience and knowledge. The digital storytelling workshops and ethnographic interviews empowered patients by regaining control over their stories and engaging in multiple transplant narratives.

Lay Summary – Editted

Digital stories are short videos using sound, image, rhythm and narration to tell a story. Words can fail to articulate difficult experiences, and in their place sound and image can convey unspoken emotions like anger, grief, and loss. Our team aimed to 1) include patients in the creation of potential educational material for the transplant community; 2) encourage conversation between patients, clinicians, and different solid-organ groups in the process. We examined the stories in transplant manuals to identify what experiences were missing in the educational and information materials given to patients. Over the course of 8-weeks, liver transplant recipients created a digital story about their transplant experience with the technical assistance of 3 filmmakers. These films were then screened and shared with healthcare professionals for their impact. While the 8 digital stories each held unique perspectives with varying audiences and messages, they came together to demonstrate the many sides and stories of transplantation.