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Patient-Partners as Educators: Vulnerability Related to Sharing of Lived Experience

Kateryna Metersky, PhD, RN[1], Rezwana Rahman, MN(c), BScN, RN[1], and Jennifer Boyle, PhD[2]

Abstract

Patient-partners are invaluable in health professions' education. Sharing their lived experiences with prospective and current healthcare providers can provide an opportunity for these participants to hone their patient-centric skills. However, sharing stories publicly is a vulnerable role and may feel emotionally risky for patient-partners. Using reflective dialogue, this manuscript outlines recommendations through the Sender-Receiver Model of Communication for Patient-Partners encounters when working with patient-partners in health professions' education. These recommendations include recognizing that:

1. **Patient-partners need to consider if they are ready to share their story.** Some stories are wounds requiring further healing; other stories are scars fully processed by patient-partners and ready to be shared publicly.
2. **The audience should differentiate between questions that can promote critical thinking versus feel like a "personal attack."** Audiences should recognize vulnerability patient-partners may experience in sharing their stories and engage accordingly.
3. **Pre-session and post-session debriefs are important.** Shared stories may elicit intense emotions from patient-partners and audiences. Both groups should be given an opportunity to process and work through emotions.

Keywords

patient satisfaction, patient perspectives/narratives, patient feedback, patient expectations, patient engagement, patient/relationship centered skills, interprofessional education

Introduction to the Issue: Vulnerability Experienced by Patient-Partners

Imagine you just received a chronic illness diagnosis. You can feel the blood rushing out of your body, time stopping, air escaping your lungs, and you going numb. The days that follow are void of any happiness or desire for social interaction until you learn more about the diagnosis that is now a part of your identity. Over time, you learn to live with it, even embrace it, and you find your voice again; you develop the desire to share with the world what it is like living with this chronic condition on a daily basis, hoping to empower the next generation of healthcare providers to be patient advocates. *You become a patient-partner.*

To ensure the healthcare system is centered on understanding, care, compassion, and humanness, it is important to incorporate patient-partners in health professions' education. Patient-partners share their lived experience to provide an opportunity for learners to reflect on and learn with, from, and about each story to enhance their patient-centric skills.[1] Simultaneously, patient-partners experience a sense of pride in their civic contribution by knowing that their lived experience can enrich health professions' education and care delivery for future patients.[2]

Now imagine that you are standing in front of a room filled with learners and sharing your vulnerable life moments as a patient-partner. It took days, months, or years for you to develop courage to formulate and organize your thoughts, feelings and empower yourself that sharing your story can be important. You divulge your whole self through your story and stand alone, awaiting their response

[1] Daphne Cockwell School of Nursing, Toronto Metropolitan University, Toronto, ON, Canada
[2] Centre for Collaborative Healthcare and Education, University of Toronto, Toronto, Ontario, Canada

Corresponding Author:
Kateryna Metersky, Daphne Cockwell School of Nursing, Toronto Metropolitan University, 288 Church St., Toronto, ON, Canada M5B 1Z5.
Email: kateryna.metersky@torontomu.ca

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and connection to what you just shared. Eventually, a hand is raised and the words that follow discredit your lived experience. Your heart sinks and you have an uneasy feeling. You start to doubt yourself and feel like your experiences do not have any value.

Two patient partners, who are also authors of this manuscript, met at a patient-partner event where Kateryna presented their self-constructed poetry detailing their experiences as a patient interacting with an interprofessional team[3]. Subsequently, an audience member provided feedback on the performance that bordered as being criticism of Kateryna's experience. While Kateryna was able to formulate an immediate response to the critique, it left her paralyzed for months from writing more poetry or engaging in further patient-partner events in education.

Jennifer, who was an audience member at the event, "*felt the attack*" because she too underwent a similar situation when sharing her own illness story. After the event, Kateryna and Jennifer connected through Zoom to share in their collective experience. Jennifer divulged undergoing depressive symptoms at the onset of her condition. Jennifer was labeled as a "frequent flyer" due to her multiple encounters with the healthcare system. These symptoms were often minimized by the interprofessional team until it was determined that Jennifer had encephalitis, resulting in seizures and profound retrograde amnesia. Jennifer published a book chapter on the trauma and transformation she experienced living with this condition.[4] However, some readers' responses included comments that centered on Jennifer blaming everyone around her, but herself for her illness trajectory. The feedback sounded like these readers were suggesting how Jennifer should re-write her own illness story. These audience interactions brought Kateryna and Jennifer together to dialogue about how they can better the experience for themselves and future patient-partners to continue to enrich health professions' education.

Key Factors for Consideration

Both patient-partners felt like others *did not hear their story,* and instead, their story was being scrutinized. Through their shared feelings of vulnerability, Kateryna and Jennifer came up with questions for consideration when working with patient-partners to facilitate health professions' education:

- How do patient-partners decide on whether they are ready to share their stories?
- How can facilitators support the audience in asking thought-provoking questions and/or comments that promote critical thinking as opposed to personal attacks?
- How can briefing sessions and debriefing sessions support both patient-partners and the audience?

Are there supports in place for patient-partners? If yes, what are they?

Recommendations

Influenced by Osgood-Schramm's model of communication,[5] the authors reflected on effective ways the sender (patient-partner), receiver (members of the audience), and facilitator (event host) can work together to address feelings of vulnerability that may be experienced by patient-partners. This resulted in original model modification giving rise to Figure 1 that the authors self-constructed. This revised model depicts disruptors and facilitators in patient-partner encounters. The top half illustrates potential disruptors (ie, sharing stories prematurely and audience members asking personal questions), whereas the bottom half of the model explores facilitators in the sender-receiver model (ie, sharing "healed" stories, encouraging audience members to ask questions that provoke critical thinking). Overall, the interplay between the sender, receiver, and facilitator in both effective and ineffective situations is exemplified.

For the Patient-Partner

Existing literature on patient-partners and continuing professional development (CPD) experiences focuses on providing material support to patient-partners including travel and parking expenses.[6] Although providing such supports before CPD sessions is touched upon,[6] what is not discussed is whether patient-partners are supported in their process of choosing what lived experience story they can share.

The analogy of a *wound* or *scar* can be helpful for the patient-partner to determine whether they are ready to share their story. Wounds are stories that may be too premature to share as they may be about an encounter that patient-partners are not fully healed from, making them too traumatic to share openly. On the other hand, scars are stories that patient-partners healed from and had the chance to process what happened to them. They feel fully ready to share these stories, knowing that they cannot be rescinded once shared.

For Members of the Audience

Audiences need to differentiate between questions and comments that may come across as critiques of patient-partners' lived experience from those that demonstrate critical thinking or constructive discussion, contributing to a rich, productive, and transformative educational experience. For example, stating "What was your role in your healthcare experience?" versus "You complain a lot about your healthcare providers. What did you do to help yourself?" can create dialogue that is focused on gaining knowledge from the patient's experience. Previously, individuals who received destructive criticism resorted to avoidance as opposed to collaboration, experiencing lower perceived task ability and negative emotional

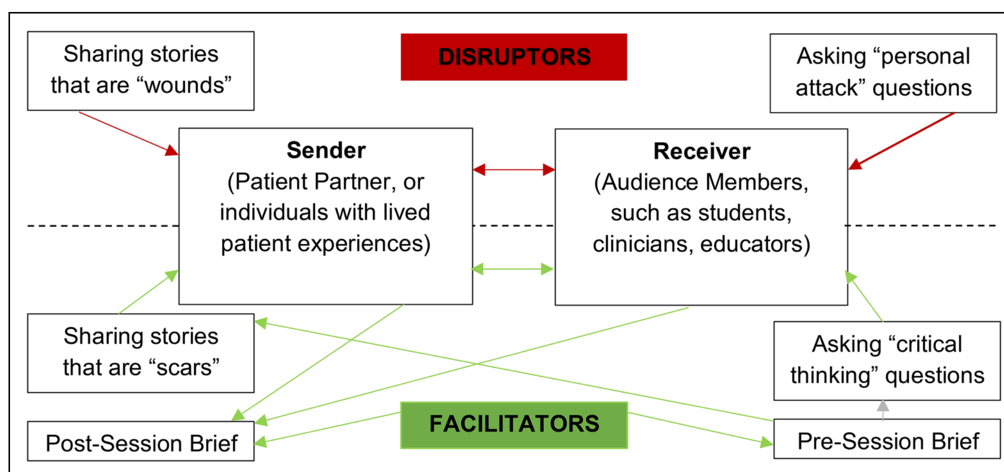

Figure 1. Sender-receiver model of communication for patient-partners encounters.

reactions.[7] When destructive comments are made, they may prevent patient-partners from opening up about their experiences further, limiting the learning process significantly. In the case of Kateryna and Jennifer, these created writer's block and a form of temporary paralysis from sharing their lived experiences with audiences.

For the Facilitator

Facilitators play an integral role in addressing feelings of vulnerability experienced by patient-partners, such as through pre-session and post-session debriefs. As a part of the pre-session brief, the facilitator can encourage audiences to realize that the patient-partner is sharing vulnerable moments from their lived experience which takes a lot of strength, energy, and courage. A small discussion can be generated on comments and questions that can facilitate learning with, from, and about the patient-partner versus those that can hinder the educational process. For the pre-session brief for the patient-partner, the facilitator can help them focus on aspects of their story that are scars versus wounds.

The facilitator should provide a post-session debrief for the patient-partner and audiences. Stories shared by patient-partners can elicit strong emotions from audiences who may relate to aspects of the stories. A post-session debrief provides audiences with an outlet to share such connections, instead of directing their emotions toward patient-partners during the session, detracting from a meaningful education discussion.[8] Likewise, patient-partners may experience enhanced emotions and vulnerability having shared their story publicly. These feelings may become suppressed and affect their ability to engage in future such opportunities. A post-session debrief provides them with a safe space to process such emotions.

Conclusion

Kateryna and Jennifer experienced vulnerability in sharing their story, having received feedback that negated their lived experiences as patients. Their desire and passion to share their lived experience, through poetry, presentations, and publications were severely impacted by feedback that was provided by audiences. They were left alone to process this feedback and the experience led to feelings of anxiety about how others may receive their lived experiences in the future.

Through this dialogical and reflective process on their shared vulnerability, Kateryna and Jennifer expressed that they are *willing to try to share their stories once again* under the right conditions and with appropriate processes in place. Such processes include patient partners receiving support from facilitators in differentiating whether their stories are scars or wounds, briefing students on critical thinking questions versus personal attack questions and creating pre-session brief for the audience and post-session brief for presenters. Future research should examine the effectiveness of briefing and debriefing sessions, explore the role of facilitators, and enhance the patient-partners' decision making abilities pertaining to stories they choose to share. Ultimately, sharing stories of illness can be extremely valuable for patient-partners to make sense of their experiences, but also for audiences to learn with, from, and about them.

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ORCID iD

Kateryna Metersky https://orcid.org/0000-0002-2738-0256

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