

# Patient Experience in Health Professions Curriculum Development

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Scott Molley, OT Reg (Ont)<sup>1</sup>, Amy Derochie, OT Reg (Ont)<sup>1</sup>,  
Jessica Teicher, HBArts Sc<sup>2</sup>, Vibhuti Bhatt, Reg CASLPO<sup>3</sup>,  
Shara Nauth, MD, BHsc<sup>2</sup>, Lynn Cockburn, PhD<sup>1</sup>, and Sylvia Langlois, M.Sc<sup>1,4</sup>

## Abstract

To enhance student learning, many health profession programs are embracing involvement of patients in their curricula, yet little is known about the impact of such an experience on patients. **Objective:** To understand the experiences of patients who contributed to the creation of a Verbatim Reader's Theater used in health professions curriculum. **Methods:** A semi-structured interview was conducted with a focus group of 3 patients who participated in curriculum development. The interview was recorded, transcribed verbatim, and analyzed for themes using van Manen approach to hermeneutic phenomenology. **Results:** Five themes emerged: (1) contextualizing contribution, (2) addressing expectations, (3) changing health-care service delivery, (4) sharing common experiences, and (5) coordinating participation. **Conclusion:** Patients had a positive experience contributing to curriculum development and found meaning in sharing their lived experience to shape the values of future clinicians. Strategies to promote continued success in partnership between patients and health professional curriculum developers include clear communication about the project's direction and early discussion of patient role and expectations.

## Keywords

patient engagement, patient experience, health professions curriculum, curriculum development, patient/relationship centered skills, patient expectations, medical education, phenomenology

## Introduction

The concepts of patient-centered care and embedded patient partnerships have been embraced as a foundation for quality health-care encounters; however, the challenge of operationalizing this overarching philosophy is well recognized (1). In this health-care delivery model, the patient is recognized as an equal contributor to the health-care team, with unique expert knowledge informed by their lived experience (2). Although the health-care field has been evolving to integrate patient partnerships over the past 2 decades, an appreciation for the role of partnerships between patients and health-care educators has lagged. Patients have traditionally been seen as the object of learning in both the classroom and at the bedside; however, roles are evolving to more active teaching (3). Additionally, communication in the field is challenged by inconsistent terminology where patients have been described as clients, health mentors, service users, consumers, and corresponding variation in perceptions and roles. For the purposes of clarity, this article will use the term "patients" to describe those who have experienced health

challenges resulting in engagement with the health-care system, although the authors recognize the inherent power differential this term creates.

In the evolving field of patient engagement in curricula, there is a growing body of literature addressing the perspectives of stakeholders (4–8). Within this body, there is a call to develop approaches to patient engagement that are rooted in theories, have enhanced conceptual clarity, and to employ rigorous evaluative methodologies in order to improve the

<sup>1</sup> Department of Occupational Science & Occupational Therapy, University of Toronto, Toronto, Ontario, Canada

<sup>2</sup> Faculty of Medicine, University of Toronto, Canada Faculty of Medicine, University of Toronto, Canada

<sup>3</sup> Department of Speech-Language Pathology, University of Toronto, Canada

<sup>4</sup> Centre for Interprofessional Education, University of Toronto, Ontario Canada

### Corresponding Author:

Scott Molley, 102-110 Oriole Parkway, Toronto, Ontario M5P 2G8, Canada.  
Email: smolley1@gmail.com



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outcome (9). Patients participate in health professions curricula at the invitation of educators, often with limited or no financial remuneration. They are generally seen as providing important contributions to the student-learning process, yet have often not been recognized as partners in the educational process. Moreover, since educators focus primarily on understanding the curricular impact on student learning and implications for knowledge transfer to future health-care practices, they rarely explore the impact on patients. Those who have suggest that patients who participate in curriculum development appreciate the opportunity to share their knowledge and feel empowered; however, these studies are few and lack rigor (10). An appreciation of the impact on patients, as well as the enablers and barriers to participation, will advance an understanding of the notion of partnership.

An opportunity to study the patient experience during curriculum development arose in 2016 when a group of patients was involved in creating an addition to the interprofessional education (IPE) curriculum for health profession students at the University of Toronto. The goal of IPE is to develop student competencies related to team-based collaboration among professionals as well as with patients and family members. A group of health profession students (2 occupational therapy, 2 medicine, and 1 speech-language pathology), guided by a faculty member, interviewed patients and practitioners to generate a Verbatim Reader's Theater (VRT) script, which would be used to explore an understanding of partnerships in health-care delivery. Verbatim Reader's Theater blends 2 types of theater: Verbatim Theater and Reader's Theater. Verbatim Theater is a type of documentary theater where a script is constructed exclusively with words from interviewed subjects (11). In Reader's Theater, audience members read from a script without the use of props, sets, or costumes, and typically engage in a facilitated critical discussion of the script's content (12). As a combination of the 2, VRT offers an opportunity for students to cognitively engage in a text-derived directly from participants. The script, built on the interviews with 5 patients and 3 health-care practitioners, as well as accompanying discussion questions, was added to the IPE curriculum (13). All script informants were invited to attend the curriculum session which used their contribution. Upon completion, the authors, with the addition of 1 more faculty member, explored the lived experience of the patient contributors.

## Purpose

The purpose of this study is to explore the experiences of patients who contributed to curriculum development (VRT script) at the University of Toronto.

## Methodology

The authors selected a hermeneutic phenomenology approach, as developed and described by van Manen, to analyze the transcribed interview texts because of its

attention to exploring meaning. This methodology focuses on describing how the human experience of a phenomenon was lived, as well as its effect on the person (14). Hermeneutic phenomenology allows researchers to reduce the experiences of many individuals who have interacted with a phenomenon into a description of its essence. The foundational interpretive philosophy that underpins this approach allows meaning to arise from emergent descriptions and human constructs (15). The University of Toronto Research Ethics Board granted approval for this study.

## Informants

They were originally recruited to contribute to the curriculum development through their work as volunteers in the Health Mentor Program, where they shared their experiences with chronic illness and the health-care system with health profession students from the University of Toronto (dentistry, kinesiology and physical education, medical radiation sciences, medicine, nursing, occupational therapy, pharmacy, physical therapy, physician assistant, social work, and speech-language pathology) on a longitudinal basis. Three of the 5 patients were available and consented to participate in this study. Patients included 2 females and 1 male ranging in age from 40 to 65 years. All 3 live with chronic illnesses (2 living with rheumatoid arthritis and 1 living with Crohn disease). One of the 3 patients attended the first iteration of the curriculum.

Following implementation of the curriculum, investigators conducted a focus group with the patients, allowing them to build off one another's lived experiences as they reflected on their own (16). The focus group lasted approximately 1 hour and used a semi-structured interview guide (Appendix A) followed by probing questions. Discussions were recorded and transcribed within 1 week. Pseudonyms were used in the transcription to enhance anonymity.

Once transcribed, patient responses were analyzed using van Manen 6-step process for hermeneutic phenomenology (Table 1). Under the guidance of authors S.L. and L.C., authors S.M. and A.D. initiated the process by independently reading the transcripts and highlighting specific sections which spoke to the human lived experience of contributing to curriculum development. Both authors tried to suspend their professional biases as much as possible when reading to allow meaning to present itself within the context of lived experience. These quotations were labeled with a code, which, upon multiple rereadings, were coalesced into concepts. S.M. and A.D. crafted definitions of these concepts, reread texts, and journaled their thoughts as to how they added to the description of the meaning of lived experience. To help reflect on the meaning, both authors imagined how the concepts differed when components were removed, in order to identify the essential elements (17). With concepts created, S.M. and A.D. compared notes to ensure they had captured as much richness from the text as possible. A unified list of concepts and definitions was created, and the authors J.T., V.J., and S.N. were engaged to collapse

**Table 1.** Van Manen 6-Step Approach to Hermeneutic Phenomenology (15,17).

Steps	Definition
1. Turning to the nature of lived experience	Formulating a research question.
2. Investigating experience as we live it	The phenomenon is captured through methods of investigation (eg, interviews, focus groups).
3. Reflecting on the essential themes which characterize the phenomenon	The overall meaning of an informant's experience is sought when reflecting on the themes.
4. Describing the phenomenon in the art of writing and rewriting	Through the process of writing, the intention is to make visible the feelings, thoughts, and attitudes of the informants.
5. Maintaining a strong and orientated relation to the phenomenon	The researcher must strive to remain focused on the research question.
6. Balancing the research context by considering the parts and the whole	The researcher is asked to "constantly measure the overall design of the study/text, against the significance that the parts must play in the total textual structure" (18).

concepts into like-concepts and then into 5 themes. This process was cyclical, with authors often contrasting concepts to the structure of the research project and vice versa.

## Findings

The following 5 themes emerged: (1) contextualizing contributions, (2) addressing expectations, (3) changing health-care service delivery, (4) sharing common experiences, and (5) coordinating participation. Illustrative quotes found in Table 2 supplement the following descriptions.

### Contextualizing Contributions

Patients highlighted the importance of ensuring the final curriculum product delivered sufficient context to students to preserve the intended meaning of their contributions. Some expressed concern that without this contextualization, students may apply their own personal experiences and misinterpret the main message. One patient explained that the final VRT script included only a part of her story, and the exclusion of the rest of the story meant to her that the context got "lost in translation." The patients found meaning in having their voice authentically represented and wanted to ensure that their message was not lost on students.

### Addressing Expectations

Critiques shared by patients regarding the curriculum development process stemmed from unmet expectations of the

**Table 2.** Patient Themes and Supporting Quotes.

Themes	Informant Statements
Contextualizing contributions	Patient 2: "In the short space that I have, I can just maybe give you a little bit of a glimpse [...] but it has so much implication in years of my life. [...] I should have mentioned this to give it a little more context."
Addressing expectations	Patient 1: "[Member checking] was pretty framed, I just thought you were getting me to check it for accuracy, I didn't feel that you were inviting me to add more [...] other than is this accurate or not?"
Changing health-care service delivery	Patient 3: "If this is a way to reach young health-care professionals at the early stages of their career and their professional training and to get them to understand this voice, this is going to be their guide, for you know, for their entire career, and this is where the change really happens."
Sharing common experiences	Patient 2: "It's like 'Oh it's not just me, they also feel the same way!' It's like validation that yes, so it's not just me." Patient 3: "What I found really enriching was reading the other quotations and seeing other people's take on similar themes. So certainly, you know the narrative component, I think is the strong component of the foundation of the project."
Coordinating participation	Patient 1: "You don't usually get such a platform where you can just say what you think about a certain topic, you know, so it's a unique experience. Usually it is a struggle to get your 2 cents in there." Patient 2: "The time that you [curriculum developers] gave us was reasonable and reminders were very helpful because life can get busy so you were aware and conscious that there was holidays and I appreciated that very much."

scope of their role in shaping the outcome of the project. One common message was that patients would have liked more control over how their contributions were incorporated in the curriculum. In this case, researchers involved in script development applied their lens to lift salient stories and arranged them to highlight key messages. Patients felt that when the authors reached out to them for feedback with drafts of the curriculum during the member-checking stage, they were only being asked to verify spelling and grammar; this felt restrictive and unfulfilling. When patient expectations were unmet, it led them to reconsider the value of their participation.

### Changing Health-Care Service Delivery

The patients were hopeful that their participation in curriculum development could contribute to changing students' values and thereby lead to improved patient care in the future.

They were hopeful that this early exposure to a new set of attitudes would inform the students' approach to service delivery and would establish the foundation of their professional development. While optimistic, the patients also recognized that cultural change at the individual and systems levels is a long process. Despite knowing that the results of their efforts would not be evident in the short term, patients still felt their contributions to this goal were meaningful.

### *Sharing Common Experiences*

All patients identified the importance of feeling connected with others who shared similar lived experiences. The patients expressed a feeling of connection when they read other contributors' words in the final VRT script. They identified that the shared opinions and emotions represented in the VRT script were a source of validation and support. Differences in how each patient described their experiences in the health-care system also created an opportunity to gain new perspectives. Patients found this experience enriching because it offered a sense of belonging and deepened their understanding of their own experiences.

### *Coordinating Participation*

The patients appreciated the sensitivity with which the educators approached the coordination of partnership. While both patients and researchers had unpredictable schedules, the patients found the researchers' willingness to work around their schedules to be critical in having their voices heard during the creation process. The researchers' efforts to reschedule meetings and provide timely follow-up created a sense of purposeful contribution to curriculum development for patients and provided validation of the importance of their contribution.

## **Discussion**

As health education programs consider approaches to partnering with patients to develop curricula, it is important to understand the impact this process has on patients so that a meaningful experience can be facilitated throughout. To avoid the tokenistic use of patients, their unique expertise needs to be supported and better incorporated into curricular goals (19,20). To this end, this study explores how patients experienced their involvement in a health professions curriculum development process. While patients enjoyed contributing to curricular development overall, their experiences were complex and special attention must be paid to how patients drew meaning through the process.

### *Meaning of Participation*

An essential element to the patients' positive experience in curriculum development came from their perceived influence in shaping the practice of future health-care providers. Patients understood that students are at a critical stage in

their professional development and felt that the messages delivered in the curriculum would have a long-term impact on students' future careers. They saw potential to alter future practice by becoming the students "guide" to professional education and service delivery. All patients hoped that their contribution to the curriculum would ultimately lead to better experiences for future health-care users. Patients who have contributed to health professions education in other contexts, but with similar proximity to affecting student learning, have also expressed a similar view (21–23). In contexts where there is more distance between patients and students, such as consulting on precreated content, patients seem to experience less meaning in their contributions (24). While patients in this study felt their contributions were meaningful, they did not expect systemic health care changes to be immediate. They understood the limitations of education within a larger system, yet these constraints did not detract from the meaning they drew from the experience.

Patients emphasized the importance of retaining authenticity and their original intent. The less they saw of themselves and their stories in the script, the less meaning they attributed to the contribution. Even the removal of small words, a decision made by the educators to create a script that could be used within the time constraints of the learning activity, altered importance nuances in their original intent. The patients' emphasis on reaching students at an early stage may have also contributed to their concerns regarding contextualization of their contributions. They realized that there are few opportunities to impact students and their future careers, placing greater importance on ensuring that the final product reflected their original intent as much as possible. To facilitate authentic representation and limit potential misinterpretations of patient contributions, the context of contributions should be considered when developing curriculum. Where possible, patients could provide feedback on the creative construction of the curriculum, allowing for enhanced partnership.

Patients also found the process of sharing their stories with each other to be meaningful. Although others have described that patients appreciated and felt empowered by sharing their knowledge and having their stories heard, they did not elaborate on the reason (25,26). This study suggests that empowerment is grounded in the use of the patient words. Being able to identify their specific contribution in the final product facilitated their sense of meaning in the process. Sharing stories also added to their feeling of validation when their thoughts were echoed by others, although the themes of navigating vulnerability and personal learning were not as prominent in this study as in others (27). Patients in this study were not directly speaking to students, so the context did not lend itself to self-exploration in the same way; however, it could also be argued that the patients recruited for this study had already experienced self-exploration in previous educational opportunities (28). While future studies could clarify this discrepancy, these findings were still cause for reflection as the educators were

concerned with patient anonymity during curriculum development. This study suggests that sharing personal stories with other patients can positively contribute to meaningful participation and may not pose as much of a risk to confidentiality as previously thought. Future educators may consider, where appropriate, a model of participation with more openness between patients to foster a sense of shared experience.

### **Managing Expectations**

Patients highlighted the impact that their expectations had on their experience. When expectations were not met, patients responded with a reduced sense of meaning in their contribution. For example, patients seemed disappointed that students might not interpret their contributions as originally intended. In contrast, educators value the deeper reflection and constructed learning that comes from a diversity of interpretations. Addressing each group's expectations of the project outcomes before beginning the process could mitigate incongruent expectations. In this case, patients felt limited to checking grammar and accuracy in the member-checking phase, yet educators were seeking feedback on both structure and content.

While negotiating the partnership in curriculum development, clarity regarding the project and what each partner contributes is essential. Curriculum developers and patients should have a shared understanding of each other's roles as well as the goals of the project to minimize the risk of confusion and unmet expectations (25,29). Strategies to identify expectations and work toward these shared goals might include task descriptions, structured decision-making frameworks, and improved orientation to the curriculum.

### **Limitations**

As this study focused on the patient experience during of a particular curriculum development, it has inherently limited transferability. Data collection was also limited to verbal focus group interviews with a small group of patients. Patients contributing to this learning activity may not have been representative of those contributing to the broader network of curricular opportunities.

Future research should investigate the experiences of patients in a variety of contributory roles across different educational mediums in order to draw stronger conclusions. Investigating the long-term impact on patients or students from involvement in a patient-directed curriculum would also add to understanding the complexity of the patient experience.

### **Conclusion**

Elevating the patient voice in curricula is crucial to improving health professions education. Curriculum developers should pay close attention to effective and meaningful

collaboration to avoid tokenistic participation. Curriculum developers should determine what makes participation meaningful to patients and ensure their methodology reflects these values. Negotiation of the partnership, where each patient in the process has a clear appreciation of the project and expectations, is essential. Contributing factors and how they are managed will be guided by the nature of the curriculum to be developed. Open and clear communication about project direction and patient expectations prior to commitment is an important determinant of meaningful partnership. This study suggests that sharing personal experiences to shape the values of future clinicians contributed to positive and personal engagement for patients. By reflecting on the findings of this study, curriculum developers can consider how patients participating in curriculum development feel a deeper sense of value in contribution to health professions curricula.

## **Appendix A**

### **Focus Group Questions**

1. Think back to your experience being interviewed and then hearing your voice during the Verbatim Reader's Theater. How was the experience overall for you?
2. Why did you choose to participate in this educational project? Can you tell me a bit more about this choice?
3. What were some of the factors that contributed to making you participate in this educational project more or less successful? What enabled successful participation? What were the challenges?
4. Interview process:
  - a. How was the interview process for you?
  - b. How did you find the member-checking process? Did you feel the process was appropriate?
  - c. What were some of the positive experiences? What were some of the more challenging moments?
  - d. Do you have any suggestions for changing the process?
5. Final script:
  - a. Did you feel your voice was appropriately and accurately represented?
  - b. How much did you feel you were able to shape the final script?
  - c. How did you feel about the resulting script?
  - d. What were your thoughts about how students would respond to using the script as a learning tool?
6. Response to the student session:
  - a. How did you feel participating in the session with the students?
  - b. Were there any surprises in this experience?

- c. How did you feel when hearing students read your words?
  - d. How did you feel when you watched students respond to your words?
  - e. Is there anything you would have done differently? Why?
  - f. Would you participate again, if given the opportunity? Why or why not?
  - g. What did you think about the format of Reader's Theater as an educational methodology (before and after you observed it)?
  - h. From your perspective, is this a session U of T should continue? Why or why not?
  - i. Once you saw the session, did you think that the quotes selected worked well?
7. How did you feel about contributing to this learning activity for health profession students?
    - a. Describe any benefits you had from being involved.
    - b. Describe any challenges that resulted in you being involved.
  8. Any recommendations for future iterations of the program?
  9. Any other comments?

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### Author Biographies

**Scott Molley** is an occupational therapist working in the field of community mental health. His interest in both patient-centre care and the arts led him to join the efforts to expand the breadth and depth of health-professional education.

**Amy Derochie** is an occupational therapist working in the community, with a wide range of disciplines. She is a strong advocate for her patients in the healthcare system, and has thus sought out a novel way to reach out and include patients in health-professional education.

**Jessica Teicher** is a fourth year medical student at the University of Toronto, entering residency in paediatrics at the University of Toronto. She brings experience both as a performing artist and in using theatre for research dissemination. Her research interests include exploring the social determinants of health, patient partnership, and the health humanities in medical education.

**Vibhuti Bhatt** speech-language pathologist practising in neuro rehabilitation. She is well known for her dedication to patient-centred care, and is passionate about supporting the patient voice in healthcare.

**Shara Nauth** is completing her first year of residency in internal medicine at the University of Toronto. Her interest in education and passion for the arts are a perfect fit for innovating with health humanities in medical curriculum development.

**Lynn Cockburn** is a faculty member and occupational therapist engaged in education and research in the Department of Occupational Science and Occupational Therapy, and the International Centre for Disability and Rehabilitation at the University of Toronto. Her research interests include mental health, community development, diversity, and interprofessional education in occupational therapy, rehabilitation, disability inclusive development, and global health.

**Sylvia Langlois** is a faculty member in the Department of Occupational Science and Occupational Therapy, University of Toronto. She is also the Faculty Lead, IPE Curriculum and Scholarship at the Centre for Interprofessional Education. Her research interests include the investigation of novel approaches in interprofessional education, engagement of voice of patients in health profession education, assessment of collaboration, and advancing diversity and inclusiveness in educational contexts.