



## A qualitative study of patients' and caregivers' perspectives on educating healthcare providers

## Une étude qualitative des perspectives des patients et des aidants sur la formation des prestataires de soins de santé

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Résumé de l'article

**Contexte :** Les patients et les aidants peuvent participer activement à la formation des prestataires de soins de santé (PSS). L'objectif de cette étude était d'explorer le point de vue des patients et des aidants sur leur participation et leur rôle dans la formation des professionnels de la santé.

**Méthodes :** Nous avons invité des patients et des aidants à participer à des entretiens individuels semi-structurés. Nous avons dégagé les thèmes à l'aide d'une analyse de contenu classique des données des entretiens.

**Résultats :** D'après les patients et les aidants, leur implication dans l'éducation des professionnels de la santé : (a) est un défi en raison du déséquilibre de pouvoir entre eux et les professionnels de la santé; (b) nécessite une formation des patients; (c) doit commencer tôt dans le processus de formation des professionnels de la santé; (d) peut améliorer les partenariats entre les patients et les professionnels de la santé; et (e) suppose que les patients soient indemnisés. En ce qui concerne les rôles que les patients peuvent jouer dans l'éducation des professionnels de la santé, nous avons constaté que les patients et les aidants veulent : (a) enseigner aux professionnels de la santé les attentes, les expériences et les points de vue des patients par le biais d'études de cas, de récits et de recherche en éducation; (b) fournir une rétroaction directe aux professionnels de la santé; et (c) donner des conseils pour le développement de comités d'admission pour les professionnels de la santé.

**Conclusions :** Comprendre le point de vue des patients et des aidants sur ce sujet peut aider les éducateurs en poste de gestion et les professionnels de la santé à mieux intégrer la participation active des patients à la formation des soignants. En écoutant la voix des patients et des aidants, nous serons en mesure d'apporter des changements efficaces à la formation actuelle et future des professions de la santé.

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## A qualitative study of patients' and caregivers' perspectives on educating healthcare providers

### Une étude qualitative des perspectives des patients et des aidants sur la formation des prestataires de soins de santé

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#### Abstract

**Background:** Patients/caregivers can be actively involved in the education of healthcare providers (HCPs). The purpose of this study was to explore patients'/caregivers' perspectives on their involvement and roles in the education of HCPs.

**Methods:** We invited patients/caregivers to participate in one-on-one semi-structured interviews. We analyzed the interview data using conventional content analysis to identify themes.

**Results:** In terms of patient/caregiver involvement in the education of HCPs, we identified that patients/caregivers perceive that it: (a) is challenging because of power-differentials between themselves and HCPs; (b) requires patient training; (c) needs to start early in HCPs' education processes; (d) can improve patient-HCP partnerships; and (e) requires compensation for patients. With regards to the roles that patients can play in educating HCPs, we found that patients/caregivers want to: (a) teach HCPs about patients' expectations, experiences and perspectives through case studies, storytelling, and educational research; (b) provide direct feedback to HCPs; and (c) advise on curricula development and admission boards for HCPs.

**Conclusions:** Understanding patients'/caregivers' perspectives on this topic can help educational leaders and HCPs improve active patient/caregiver involvement in the education of HCPs. We need to listen to patients'/caregivers' voices in order to make effective changes in current and future health professions education.

#### Résumé

**Contexte :** Les patients et les aidants peuvent participer activement à la formation des prestataires de soins de santé (PSS). L'objectif de cette étude était d'explorer le point de vue des patients et des aidants sur leur participation et leur rôle dans la formation des professionnels de la santé.

**Méthodes :** Nous avons invité des patients et des aidants à participer à des entretiens individuels semi-structurés. Nous avons dégagé les thèmes à l'aide d'une analyse de contenu classique des données des entretiens.

**Résultats :** D'après les patients et les aidants, leur implication dans l'éducation des professionnels de la santé : (a) est un défi en raison du déséquilibre de pouvoir entre eux et les professionnels de la santé; (b) nécessite une formation des patients; (c) doit commencer tôt dans le processus de formation des professionnels de la santé; (d) peut améliorer les partenariats entre les patients et les professionnels de la santé; et (e) suppose que les patients soient indemnisés. En ce qui concerne les rôles que les patients peuvent jouer dans l'éducation des professionnels de la santé, nous avons constaté que les patients et les aidants veulent : (a) enseigner aux professionnels de la santé les attentes, les expériences et les points de vue des patients par le biais d'études de cas, de récits et de recherche en éducation; (b) fournir une rétroaction directe aux professionnels de la santé; et (c) donner des conseils pour le développement de cursus et les comités d'admission pour les professionnels de la santé.

**Conclusions :** Comprendre le point de vue des patients et des aidants sur ce sujet peut aider les éducateurs en poste de gestion et les professionnels de la santé à mieux intégrer la participation active des patients à la formation des soignants. En écoutant la voix des patients et des aidants, nous serons en mesure d'apporter des changements efficaces à la formation actuelle et future des professions de la santé.

## Introduction

Patients and caregivers (herein referred to as patients), can be actively involved in the education of healthcare providers (HCPs). However, HCPs have traditionally involved patients as passive educators and treated them as teaching or clinical 'material' on which to practice their skills.<sup>1,2</sup> To move beyond this traditional involvement, we need to understand what patients think about their involvement in the education of HCPs and what roles they can have in educating HCPs. Such an understanding will help ensure that patients' involvement provides appropriate benefits and outcomes for all those involved.<sup>3-5</sup>

There are numerous benefits for actively involving patients in the education of HCPs. For example, through such involvement patients can feel empowered, gain new insights into their conditions, improve their communication with HCPs, and experience increased satisfaction in their healthcare.<sup>6</sup> Healthcare providers have also reported that learning from patients increases their overall learning satisfaction, empathy for vulnerable populations, and confidence in clinical skills.<sup>6-8</sup> Despite these benefits, patients' active involvement is seldom sustained in the education of HCPs because of resource and time constraints as well as educators' and learners' perceptions of or knowledge on how to involve patients.<sup>9,10</sup>

Educational leaders also struggle with how to sustain patient involvement in the education of HCPs, in part, because research exploring patients' perspectives on the topic is lacking.<sup>2,5,6,11</sup> To date, researchers have focused primarily on patients' perspectives on their involvement in medical education rather than in the education of all HCPs. For example, Fielden and O'Rourke<sup>12</sup> explored patients' motivations for becoming involved in medical education at a medical school and the impact of this involvement on them. They found that patients participated in medical education because it provided them with a means to reflect on their conditions and experiences and that it positively impacted their health and well-being.<sup>12</sup> Similarly, Stacy and Spencer<sup>13</sup> focused on patients' perceptions of being involved in medical students' community-based projects and noted that patients viewed themselves as teachers who could educate medical students on their conditions and help them develop their professional skills and attitudes. Moreover, Jackson, Blaxter, and Lewando-Hundt<sup>14</sup> investigated patients' views on their active involvement in medical education. In their study, the

patients did not view themselves as educators but rather as individuals who could share information about the psychological, social, and behavioural impacts of their conditions with medical students.<sup>14</sup> While these studies provide patients' perspectives on their involvement in specific medical education contexts, namely medical schools in the United Kingdom, they do not address patients' perspectives on their involvement and roles in the education of all HCPs, especially within Canada. Thus, the purpose of this qualitative study was to explore patients' perspectives on their involvement and roles in the education of HCPs in Canada. It addressed the following research questions:

1. What do patients think about patient involvement in the education of HCPs?
2. From patients' perspectives, what roles can patients have in educating HCPs?

## Method

### Context and sample

We recruited individuals who identified as patients or caregivers from a provincial patient advisory program that focuses on patient engagement in healthcare. Any patient or caregiver who was part of this program was eligible to participate. They did not need previous experience in the education of HCPs. Our initial intent was to recruit these patients or caregivers to participate in an interview to create content for a graduate course at a Canadian university. This course, aimed at HCPs, focuses on the active involvement of patients in health professions education (HPE). This study received REB approval from the University of Ottawa (REB # S-10-19-5137) on 18-11-2019. However, after conducting the interviews for the purposes of creating course content, we recognized the richness of the interview data and sought secondary ethics approval to use the interview data for research. Twenty-seven of the 28 interviewees consented to the secondary analysis of their interviews for research. We then used the complete interview transcripts for these 27 interviewees in the present study.

### Instrument development

Two patients with chronic health conditions assisted us in the development of the 12-question interview guide. The questions focused on the interviewees' perspectives on patient involvement in the education of HCPs, including why patients should or should not be involved and the roles that patients have or could play in the education of HCPs.

The questions included prompts with examples of active patient involvement in the education of HCPs in case the interviewees needed clarification. Our intent was not to focus on these examples, but to use them as a mechanism for stimulating discussions with the interviewees. We piloted the interview guide with three patients from a hospital-based patient committee and used the feedback from the pilot to improve the clarity of the guide, including the prompts within it.

### Data collection

We distributed a study information letter via the provincial patient advisory program's listserv. This information letter asked patients to contact the lead author if they were interested in participating in an interview. Two authors (KM and HA) conducted the interviews in person, by phone, or by video conference, depending on each participant's preference. The semi-structured interviews ranged in length from 30 to 60 minutes, were audio or video recorded, and transcribed verbatim (by a Research Assistant). All participants provided verbal consent prior to the interview.

### Data analysis

We used conventional content analysis to analyze the interview data.<sup>15</sup> Our goal was to identify themes present across interviews. Two authors (HA and CG), who are graduate students in health professions education, independently analyzed the interview data and kept memos on their analytic decision making to establish an audit trail and enhance trustworthiness.<sup>16</sup> Interview analysis consisted of listening to or viewing the interview recordings in their entirety. Each author then coded all the data inductively, identifying themes across participants. Given that some participants did not participate by video, they did not analyze the non-verbal cues of participants but instead used only the participants' words to develop their coding schemes.<sup>16</sup> Next, the authors met to compare their coding schemes and resolve any discrepancies among themes, as well as identified exemplar quotations for each theme. The inclusion of two coders added to the trustworthiness of the analysis. To further increase the trustworthiness of the analysis, two other authors (KE & KM), who are professors in health professions education and patient engagement, also independently listened to or viewed all interview recordings to get a sense of the data and the themes within them. They did not access the other authors' coding schemes during this process. All the authors then met to engage in a peer debriefing process,<sup>15</sup> where they discussed and finalized the wording of the

themes, as well as reached consensus on which exemplar quotations to use for reporting purposes.

## Results

### Participants

Throughout their interviews, participants described themselves as activists, advocates, parents, and partners in healthcare. Twenty (74.0%) participants identified as patients, five (18.5%) as caregivers, and two (7.5%) as both patients and caregivers. Twenty (74.0%) participants identified as female.

### What do patients think about patient involvement in the education of HCPs?

We identified that patients perceive that patient involvement in the education of HCPs: (a) is challenging because of power-differentials between themselves and HCPs; (b) requires patient training; (c) needs to start early in HCPs' education process; (d) can improve patient-HCP partnerships; and (e) requires compensation for patients. We summarize each of these themes and present additional supporting quotations in Table 1.

#### ***Patient involvement in the education of HCPs is challenging because of power-differentials between patients and HCPs:***

Participants thought that patient involvement in the education of HCPs is challenging because HCPs are in positions of power over patients. Participants reflected on their past educational experiences with HCPs and believed that HCPs were, at times, condescending to them and viewed the information that they shared as an unnecessary hindrance. As one participant explained, "I think some [HCPs] certainly find [my involvement] a hindrance. I think the more experienced ones think, 'I've been there, done that'" (P25). Further, participants expressed how some patients feel intimidated at the prospect of educating HCPs. As one participant articulated, "I was experienced enough to stand up for myself, you know, to talk at equal levels [with the HCP], but you have to be pretty sure of yourself in order to speak frankly" (P10). Overall, participants noted that some patients are uncomfortable being involved in the education of HCPs given that power-differentials exist.

#### ***Patient involvement in the education of HCPs requires patient training:***

Participants thought that patient involvement in the education of HCPs requires training for patients who want to be involved in it. Specifically, they highlighted that not all patients know how to approach a topic or communicate their stories in educationally

meaningful ways and thus, they need training in storytelling and communication. As a participant exemplified, “I think [the challenge] is how to tell our story so that it’s general enough...[to] be useful across patients...We need education on how to [do this]” (P19). Participants also raised the idea of training the ‘right’ kind of patient to be an educator. They acknowledged that “you have to have patient speakers who are able to stay on track” (P21) and are “able to put their message into a format that will be suitable for the audience” (P18). Overall, participants believed that training would provide patients with the support needed to develop such communication skills for effective teaching.

**Patient involvement in the education of HCPs needs to start early in HCPs’ education processes:** Participants thought that patient involvement needs to start early in the education of HCPs in order to foster positive mindsets

among HCPs and normalize patient involvement across educational settings. As one participant described:

*[Patient involvement in HPE] would help to take the fear out of it... [Students] kind of say, ‘it was a positive experience...and [now] we welcome [patients’] feedback because we already had exposure’ (P17).*

In addition, participants expressed that early patient involvement helps create a new generation of HCPs who value and respect such involvement in the education of HCPs. For instance, a participant explained:

*[Patient involvement] needs to be at various levels [of HCPs’ education], like...as an introduction when people are considering the healthcare profession... It’s part of the new healthcare, so to embrace that, I think that’s necessary and is a good part of their education (P28).*

Table 1. Patients’/caregivers’ perspectives about their involvement in HPE: themes and supporting quotations

Theme	Supporting Quotation
Patient involvement in the education of HCPs is challenging because of power-differentials between themselves and HCPs	There are some healthcare professionals who regard [patient involvement in HPE] as an opportunity, but there are many others who sort of say, well, what qualifications does a patient have to provide feedback on that and tell us what to do? A patient can’t tell the professional what to do, but they may have some say in how they do it. (P15)
Patient involvement in the education of HCPs requires patient training	I think, sometimes, you know, there is a bit of a power dynamic, where, obviously, I’m not trained in medical education, but I think my opinion is valid and my views are valid, and I think there is a place for always being open to hearing from different perspectives. (P01) I think also that it’s sometimes hard to get patients and people around them to contribute because they have a preconceived notion that the trained healthcare providers know better and more than what they do and so they’re reluctant to give their input. (P16) You have to be armed with some skill, and how to speak to a senior...You have to have the right candidate [patient] to be involved in educating HCPs (P09)
Patient involvement in the education of HCPs needs to start early in the HCPs’ education process	There’s a kind of power-imbalance in the sense that you’re asking for help from someone who has particular training and occupies a particular role, and it’s a bit intimidating. Unless you’ve got some prior working relationship with that person...[it’s] very hard to do. Involving patients in the education of healthcare professionals is going to require some preparation of those patient partners. (P15) When you bring in a patient on your very first day of five years of residency, it sends a very different message about the role that patients play in your medical education than if you just throw them in half way through ...So, I think we need to start early and normalize it. (P02)
Patient involvement in the education of HCPs can improve patient-HCP partnerships	If you’re saying that patients are at the of everything we do, it has to be taken further to the education aspect because, in the education of healthcare workers, it’s better for them to learn before they get out and develop some bad habits. The only way to create a new healthcare system is involving them [patients] in an updated educational plan. (P05) I feel more empowered when I’m in that [patient involvement] setting because I really feel like I’m being heard, I’m being understood, and I feel like it’s a two-directional conversation that we’re having... and the dialogue is much warmer. I feel like I have a better relationship and partnership with them [medical students]. (P24)
Patient involvement in the education of HCPs requires compensation for patients	We are probably at a stage now in many healthcare organizations where there is the opportunity for patients and family members to express their views, but I think that this relationship is evolving from talking to one another, to engaging with one another, and truly starting to develop a partnership of care...I do believe that (P11) Compensation is another factor...I can’t afford to, you know, spend more money, just out of my own pocket. And, I think it is something that researchers should value...If you’re going to involve a parent or a family member, you should also compensate them somehow (P01) It takes a lot of work [to be involved in health professions education], so, you know, naming this work as such, compensating people fairly for their energies, emotional labour, and time they spend in doing the work is really important (P02)

Throughout the interviews, participants highlighted this idea of a new health education system where patients' voices are embedded in all aspects of HPE.

**Patient involvement in the education of HCPs can improve patient-HCP partnerships:** Participants thought that their involvement in the education of HCPs can improve patient-HCP partnerships in clinical settings and thus, improve the healthcare they receive. Participants recounted clinical interactions with HCPs that were “meaningful, honest, [and those which portrayed] transparent communication in real-time” (P11). They also highlighted the importance of recognizing, “[patients’] preferences, their cultural preferences” (P07) in interactions. Participants suggested using their own preferences and past interactions as examples when teaching HCPs about effective patient interactions. Participants believed that, when patients have opportunities to teach HCPs about how to effectively interact with patients, communication between them and HCPs “becomes richer” (P15) and thus, patient-HCP partnerships in clinical settings improve.

**Patient involvement in the education of HCPs requires compensation for patients:** Participants advocated that patients need monetary compensation for their involvement in the education of HCPs. They believe it encourages HCPs to view patients' involvement as a formal educational partnership instead of as a “tokenistic activity” (P08). Further, participants articulated that they deserve compensation because they are doing work of faculty through offering HCPs practical education, yet their involvement in the education of HCPs can be more of a challenge due to their illnesses. As one participant expressed:

*The biggest limiter to me not doing more is not getting paid. It devalues anything I say.... If patients are to be seen as integral parts of the healthcare system in educating HCPs, then they need to be paid for their expertise.... Asking me to do more volunteer time is more a hardship on me than on someone healthy, but then someone healthy isn't going to give you the information you need (P06).*

Other participants also reiterated the idea of tokenism in advocating for patient compensation. A participant explained, “patient involvement is seen as this tokenistic activity, rather than really acknowledging them as experts in their own subject” (P08). Ultimately, participants think that patient compensation is one powerful way of showing

patients and HCPs that patient involvement in the education of HCPs is valuable.

**From patients' perspectives, what roles can patients have in educating HCPs?**

With regards to the roles that patients can play in educating HCPs, we found that patients/caregivers want to: (a) teach HCPs about patients' expectations, experiences and perspectives through case studies, storytelling, and educational research; (b) provide direct feedback to HCPs; and (c) advise on curricula development and admission boards for HCPs. In addition to the descriptions below, Table 2 highlights key quotations associated with each category.

**Teach HCPs about patients' expectations, experiences, and perspectives through case studies, storytelling, and educational research:** Participants highlighted how patients can teach HCPs about their expectations, experiences, and perspectives. Specifically, they view case studies (e.g., intensive investigations/reflections on individual patients' healthcare experiences) as one important strategy to teach HCPs because they initiate dialogue between patients and HCPs that support HCPs' understanding of patients' perspectives. Specifically, one participant described:

*I imagine that sort of case studies might be beneficial.... You know, we're going to sit down and assess, here's what the patient heard, here's what the patient understood, here's what the patient's expectations were... As the doctor, what did you see? And here's what the patient saw ... [teaching the HCPs] to see if we can bridge the gap in communication (P25).*

They also suggested that patients can use storytelling to teach HCPs about patients' expectations, experiences, and perspectives. Participants reflected on how they use storytelling at corporate orientations, in training videos, or in social media postings to teach HCPs. Participants think storytelling helps HCPs understand, from patients' perspectives, what they need to change in practice to improve their delivery of care:

*In the academic setting, I think there should be a component where patients provide information to those healthcare providers, like they tell their patient stories. I think that's really powerful, certainly to hear a story in person of things that have gone wrong and also things that went well (P23).*

Furthermore, participants expressed their desires to teach HCPs through engaging in HPE research. They thought that it is important for patients to be involved in HPE research from the outset, including providing input on patient-oriented research objectives and priorities. As a participant summarized:

*You have to start from the beginning. Like, when you have an idea to do the research... You transparently say to them [patients], 'you know, this is my research question, what are your research questions, what do you think this research ought to achieve?' It's really important for patients to be able to shape the trajectory of the research [because] you'd want to see a direct output that will lead to better patient care and experiences (P02).*

Overall, participants highlighted that their roles in research are key to developing patient-centred and relevant

research as well as a way of contributing to the education of HCPs.

**Provide direct feedback to HCPs:** Participants expressed the importance of being able to provide HCPs with immediate real-time feedback in the assessment of intrinsic skills (i.e., the cognitive, social, and personal skills that contribute to safe, efficient, and high-quality health care),<sup>17</sup> such as communication and empathy. In particular, they explained how involving patients as mentors or in role-playing capacities could provide HCPs with valuable, current, and relevant feedback on these skills. As participants shared, “[patient care is] about, how the HCP make[s] me feel” (P26), and it is important for HCPs to “recognize that patients can provide feedback on how a simulated clinical interview went” (P15). Overall, participants believed that their experiential knowledge enriches the feedback provided to HCPs about their intrinsic skills.

Table 2. Patients'/caregivers' perspectives about their roles in HCP: themes and supporting quotations

Theme	Supporting Quotations
Teaching HCPs about patients' expectations, experiences, and perspectives through case studies, storytelling, and educational research	<p>The work of teaching medical professionals, in any kind of a way, is an emotional labour. And, I think we must name it as such. Storytelling shouldn't be the only form of educating that we're doing, but inevitably, storytelling plays an important role. And to tell one's story, and to present it in a 'palatable and socially acceptable way,' it takes a lot of work. (P02)</p> <p>I think we're doing it [involving patients and caregivers] in real time, in the hospital floors, in doctors' offices...that is one method of doing it. I think though...[we] need to identify ways and means of consciously incorporating it into the curriculum and in the teaching process... I think that case studies offer one mechanism to bring to the attention of aspiring healthcare workers, how a certain situation, a certain challenge, was confronted and how the involvement of patients and their families made that a more satisfactory...I would be a strong proponent of engaging patients and their families in working with healthcare providers to develop case studies that can then become the content for certain coursework. (P11)</p>
Providing direct feedback to HCPs	<p>What if patients had a safe manner in providing direct feedback to the students? Setting that up may be challenging to make it safe, and my one concern is that it be non-evaluative [pause]. I don't feel comfortable if I'm giving feedback to say, 'you did a good job [or] you did terrible.' What I am perhaps more effective and trained in is to say, 'this made me uncomfortable [or] this part made me feel really comfortable' [pause]. So, content-based feedback, but not evaluative... (P19)</p> <p>I think being able to get patient feedback before they leave the hospital or wherever they are. Give them the opportunity to provide feedback, whether they're given an iPad, they can quickly check things off, whether they prefer to fill out a short form, which helps to indicate to us [HCPs] how to ask those relevant questions as far as whether their HCPs are engaging them more in their care process (P23)</p>
Advising on curricula development and admission boards for HCPs	<p>I think having a focus group or a group of patients review the curriculum to see what aspects of it touch on patient engagement...For example, if they are having to learn a clinical skill, how do they engage the patient in the care process, and the treatment process, the discharge process? Because I think, certainly that's a challenge for many healthcare providers now. (P23)</p> <p>For admission criteria, I'd be inclined to have expert patients sitting in on interviews or the designing of the process. One of the things that [you could do] is a role-play, and just see how they interact. Do they have that empathy? So that's something I would definitely be looking for in healthcare workers. (P06)</p>

**Advise on curricula development and admission boards for HCPs:** Participants expressed wanting to be involved, as advisors, in curricula development and on admissions boards for HCPs. In terms of curricula development, they noted a desire to review and improve existing curricula rather than develop it from scratch. They explained how “We were provided the content, to, then critique...” (P17) and how “[they] could insert patient experience to improve the curriculum” (P05). Overall, participants thought the incorporation of patient experience into curricula was a way to enrich it.

Participants also expressed the importance of having patients advising on admission review boards for HCPs’ regarding the assessment of candidates’ intrinsic skills. For example, one participant exemplified:

*Perhaps the patient partner could be part of a reviewing panel, looking at somebody’s statement of intent, why they want to be involved in the program.... If candidates could be given feedback on [what it] feels like from the point of view of ... a patient, that could be really helpful (P15).*

In sum, the participants noted that their expertise offers invaluable knowledge for improving curricula as well as screening HCP applicants to ensure that they have appropriate intrinsic skills that will enhance healthcare delivery.

## Discussion

This study adds patients’ perspectives to the conversation on the involvement and roles of patients in the education of HCPs in Canada. Similar to other work in this area, the participants (i.e., patients) noted that patient involvement in the education of HCPs is challenging because of power-differentials that exist in healthcare.<sup>6,9,18</sup> To overcome these barriers and facilitate patient involvement in the education of HCPs, it is important to offer training to patients on how to effectively use storytelling and other communication strategies.<sup>19,20</sup> Such training can reduce patients’ anxieties about educating HCPs, enable them to modify their teaching strategies, and become legitimate partners in educational processes.<sup>6,20</sup> However, while training is important, extensive amounts of training can result in patients becoming professional educators, which can detract from the authenticity of their involvement in the education of HCPs.<sup>11</sup> To maintain authenticity, studies suggest that ‘peer-led’, rather ‘faculty-led’, training for patients involved in the education of HCPs is essential.<sup>21,22</sup>

In addition to patient training, there is the need for patient compensation; an important area raised by the participants in the present study. Researchers describe how compensation for patients helps HCPs legitimize patients’ active involvement in the education of HCPs<sup>6</sup> and makes them equal partners in educational processes.<sup>20,23,24</sup> Nevertheless, how patients should be compensated for their involvement is not unanimous.<sup>22</sup> Some patients advocate for monetary compensation,<sup>25</sup> an academic title,<sup>6</sup> or sufficient funding to ensure that they are not incurring costs (e.g., travel, food, caregiving costs) while engaging in educational activities whereas others believe that compensation negates their altruistic act of giving back to the community.<sup>19,25</sup> As such, it is important to ask patients who are involved in the education of HCPs what form of compensation they need and deem acceptable.<sup>6,22</sup>

Moreover, the participants in our study emphasized that patient involvement needs to start early in HCPs’ education processes. While the concept of early involvement is not well-studied within the literature and requires additional research, Towle et al.<sup>6</sup> acknowledge that HCPs need to become used to active patient involvement in education processes so that they can accept it as the norm and not assume that patients are devaluing or challenging the quality of their training. However, this normalization process is challenging, especially for those who have completed their initial training.<sup>21</sup> As such, innovations need to focus on patient involvement within continuing education. Once patient involvement in the education of all HCPs and at all levels of training becomes the norm, we may, as the patients in this study suggested, see the positive impacts of it on patient-HCP partnerships in clinical settings.<sup>7,18,26,27</sup>

In terms of the roles of patients in the education of HCPs, the participants in our study emphasized patients’ abilities to teach and assess HCPs’ intrinsic skills through case studies and storytelling. Cheng and Towle<sup>19</sup> support the use of such strategies and describe how they stimulate HCPs’ critical-reflection and self-awareness. These skills are essential to productive dialogues between HCPs and patients<sup>28</sup> and ultimately, improve the delivery of patient-centred care.<sup>29</sup> In addition, the participants believed that patients’ expectations, experiences, and perspectives can guide HPE research. While the involvement of patients in HPE research is novel and not well-researched,<sup>30</sup> there is substantial evidence on the benefits and challenges of patient involvement in health and clinical research. Such involvement can help funders identify patient-pertinent



research proposals, enhance study design, implementation, and dissemination activities,<sup>23</sup> and improve long-term patient-oriented research outcomes.<sup>31-33</sup> However, it is important for researchers to further explore how to meaningfully involve patients in HPE research teams.<sup>34,35</sup>

Lastly, the participants described how patients could play advising roles in curricula development and on admissions committees. This suggestion aligns with other studies that explain how patients believe their roles in curricula development promote student-centred learning, stimulate critical reflection among HCPs, and help bring a degree of realism to HCPs' education that improves patient-centred care.<sup>1,35,36</sup> Further, studies have highlighted that patients' participation in the admission interview process can help identify candidates who exemplify the core components of patient-centred care.<sup>9,37,38</sup> Unfortunately, however, faculties and educators have greatly underutilized patients' involvement in such roles.<sup>6,37,38</sup> Thus, we hope that individuals responsible for curricula development and admissions committees, especially within Canada, will use this study to stimulate, among other things, discussions and ideas on how to initiate and sustain patient involvement in curricula development and admissions committees.

## Limitations

Our sample of 27 patients consisted of predominantly Caucasian female patients and thus, the findings may not represent all perspectives. This study could benefit from expanding our recruitment of patients to diverse community-based organizations.<sup>8,39</sup> As such, we recommend conducting additional studies with diverse groups of patients on their involvement and roles in the education of HCPs. Second, patients' and caregivers' perspectives were presented together. Given that five participants in this study identified as solely caregivers, it would be interesting to delve deeper into differences in caregivers' experiences compared to patients' experiences. In addition, this study was based on secondary data analysis. As such, we could not use an iterative process that would have enabled us to revise the interview questions during data collection and clarify or gain deeper insight into our initial findings. Moreover, we did not have ethics approval to collect specific demographic details about participants. Therefore, demographic data, including the type of educational experiences participants had in educating HCPs, was not included in this study. This

information, however, could have added context to the participants' views. Finally, due to an extended period of time between data collection and the secondary data analysis, we decided not to involve participants in the analysis of the data. Such involvement would have enriched the study and its findings.<sup>32,33,35</sup> However, this study illuminates that patients want to be involved as partners along the HPE research continuum.

## Conclusion

This study highlights that many patients want to be actively involved in the education of HCPs in meaningful ways to them. It suggests that patients' involvement in the education of HCPs can improve patient-HCP partnerships and enrich patients' healthcare experiences, especially if we introduce it early in HCPs' education processes and strive to sustain it. Although there are challenges associated with how to support and facilitate patients as educators, helping HCPs understand why and how patients want to be involved in the education of HCPs can help facilitate it.

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