RESEARCH

"We're back in control of the story and we're not letting anyone take that away from us": patient teacher programs as means for patient emancipation

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Abstract

While patient engagement in healthcare professions education (HPE) has significantly increased in the past decades, a theoretical gap remains. What are the varied reasons as to *why* patients get involved with HPE programs? With a focus on understanding what drives patient involvement with HPE programs, this study examined how a patient as teacher (PAT) program was experienced by medical students, patient teachers, and faculty within a medical school. Through a phenomenographic approach, this study captures and describes the different ways our study participants experienced a PAT program (the 'phenomenon'). 24 semi-structured interviews were conducted in total, comprised of interviews with patient teachers ($N=10$), medical students ($N=10$) and program facilitators ($N=4$) who participated in a PAT program. Our focus was on participants' description of the program and was grounded in their experiences of as well as their beliefs about it. Our findings captured 4 *layers* representing the qualitatively different (yet interrelated) ways in which participants experienced/perceived and conceptualized the various aspects of their experience with the PAT program: (1) A productive disruption of the learning space (2) A re-humanization within healthcare (3) A means of empowerment and agency (4) A catalyst for change and emancipation. Our outcome space results can be visually illustrated by a nesting "Matryoshka" doll, representing the four layers and depicting the process of uncovering the less conscious layers of sense-making within this phenomenon. HPE programs that are co-produced with patients and actively involve patients as teachers have the potential, but not guarantee, to be emancipatory. To engage in PAT programs that exhibit an emancipatory potential, we need to consider transformative paradigms of education, which are aligned with social change, and disrupt the traditional teacher-learner hierarchy.

Keywords Patient emancipation · Patients as teachers · Patient engagement · Patient educators · Health professions education · Medical education · Transformative education · Patient-centredness

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Introduction

A growing body of scholarship examines the benefits of involving patients in educational program delivery in health professions education (HPE). These 'patient as teacher' (PAT) programs may offer empowerment and healing to patients and increased empathy and improved communication skills to students (Bleakley & Bligh, 2008; Jha et al., 2009, 2013, 2015; Kumagai, 2008; Kumagai et al., 2009; Towle & Godolphin, 2013; Towle et al., 2010, 2014; Luckner et al., 2012; Agrawal et al., 2016; Regan de Bere & Nunn, 2016; Henriksen & Ringsted, 2011, 2014). The benefits of actively involving patients in HPE have been reported since the 1970s (Gordon et al., 2020; Wykurz & Kelly, 2002). Missing from this growing knowledge base is a broad and nuanced understanding of what drives patients to get involved with HPE.

Calls for moving towards more patient/person-centered and more inclusive healthcare are not new and while the inclusion of patients in HPE would appear to align with the aims of patient-centred care, "there is still insufficient knowledge regarding how to create good designs to optimise learning patient centredness" (de Groot et al., 2020, p. 380). Although patients are increasingly being recognized as experts in their experiences and as relevant partners in developing and delivering more humanistic medical curricula (Fielden & O'Rourke, 2016; Gordon et al., 2020; Towle et al., 2010), there remains a multitude of issues related to how to partner with patients in HPE.

Benefits notwithstanding, HPE programs involving patients have also been problematized and critiqued due to the complexity of their implementation. There are also various ethical concerns to consider. These include the emotional challenges of sharing illness stories (Hawthornthwaite et al., 2018), lack of coherent frameworks for PAT program delivery (Towle, 2007), and lack of training and support for patient educators (Dorozenko et al., 2016). Perhaps most importantly, critiques also focus on the risks of misleading learners about "*the* patient perspective," as a singular and all-encompassing perspective representing a whole demographic (e.g. a disease or social group) (Lefkowitz et al., 2022; Rowland et al., 2017). Related to this critique is the significant concern for a lack of diversity in PAT programs (Rowland & Kumagai, 2018).

To build off both the benefits and concerns, it is essential to empirically explore patients' diverse motivations for participating in PAT (and other HPE) programs through a critical lens and with appropriate methodology. Our study uses a phenomenographic approach, and focuses on programs that actively involve a patient in the teaching process by foregrounding their personal knowledge. Much like Lefkowitz et al. (2022), we acknowledge that multiple terms are used in the literature when describing those who share their illness experiences within HPE (e.g. patient, service user, client, consumer). For simplicity's sake, we use the term 'patient,' acknowledging the term can be problematic and may be seen as passive. Following a definition of Towle and Godolphin (2013), we are referring to programs in which a "student learns with, and from, the patient in a setting distinct from that of patient care." This practice inverts the common hierarchical student–teacher structure, because "the role of the patient is that of educator, an expert by experience; the role of the professional is as collaborator, to enhance the patient's autonomous and authentic voice" (Towle and Godolphin, 2013, p.145). In this, the professional refers to the student, who usually learns with and from the patient in a clinical setting wherein the patient's educational role is less active.

In exploring the varied reasons underlying patient participation (often volunteering) in health education programs, we hope to offer useful considerations for educators co-creating

programs in partnership with patients. We also hope to avoid oversimplifying or stereotyping diverse patient experiences, although any single study will have its own limitations in terms of representation. Thus, we intend this study to expand the conversation of how we, as educators and researchers, have the responsibility and opportunity to ensure we partner with patients in reciprocity within HPE. This effort must begin by acknowledging that patients may have experiences of dehumanization and may get involved in HPE in hopes of creating change.

It is important to define and situate two essential concepts of this study: empowerment and emancipation. In this paper we ground these concepts in how Tom Inglis (1997) distinguishes them: empowerment relating to "working within the system" and emancipation relating to "trying to change the system" (p. 4). By applying practices that increasingly recognize patients' agency and creating opportunities for patient emancipation, we believe stronger and more sustainable HPE and patient engagement/programmes will result. Moreover, we hope, this will lead to a better understanding of the pedagogical value of patient teachers and further opportunities to engage with educational experiences. This work is especially timely as health disparities, resulting from social inequities, have grown more visible during the COVID-19 global pandemic. The health field's reckoning with its own structural inequities has recently prompted multiple calls for change (Webb et al., 2020; Sharda et al., 2021; Coleman, 2020; Fadoju et al., 2021) and these calls extend into HPE. While healthcare and HPE are built on the well-established rhetoric of 'first do no harm', the potential of injustice inherent in the power imbalance between health professionals and patients can be harmful. Recognizing the power relationships at play in patient encounters is necessary to move towards a more equitable future of healthcare practice.

Theoretical framework

At the outset of this project, the concepts of oppression and emancipation rose to the surface quickly in initial data collection and analysis, and thus informed the work moving forward. Inglis (1997, p. 3) states that for us to be able to "understand the notion of empowerment and emancipation, we must begin with an analysis of power". In this section, this paper will be situated in a brief examination of how power has been seen enacting in healthcare. With this we hope to further elaborate on how a system that is based on a medical ethos of, "do no harm," can be unjust and oppressive.

Within most healthcare structures there is an inherent power imbalance between the healthcare provider/doctor and the patient. As Sharma (2018) notes, "in medical institutions, the permission to narrate, to decide what is said, when and how, and the authority to document and interpret, often lie with the physician. This grants the physician an astonishing degree of power" (p. 472). By situating this to Parsons (1951) theoretical analysis of the societal 'sick role', we can expand on the nature of this inherited power imbalance. According to Parsons, this power functions as a mechanism of social control of illness within a society; illness being considered as a form of social deviance potentially impairing the smooth functioning of society. To mitigate the societal disturbance an illness may cause, doctors and patients are assigned socially defined roles with rights and obligations. A patient fulfills a temporary *sick role* that exempts them from normal societal duties. However, the patient *must* seek help from a technically competent expert to legitimize the illness and return to health. This technically competent expert, the doctor, has the important role of 'gatekeeper' by legitimating and controlling the volume of

illness within a society. In this gatekeeper role, a doctor occupies a position of power relative to the patient and may exercise autonomy in performing their professional skills (Morgan, 2008).

While Parsons' theory sheds light on how the patient-doctor relationship is interlinked, it lacks symmetry. The doctor has "legitimate authority and expertise in matters of health and illness, gained through prolonged training and experience, and expressed through the special fiduciary responsibility for the care of the sick" (Williamson, 2008, p. 133–34) while the patient is expected to trust the doctor's expertise. It is here that dehumanization may take place. As Williamson (2010) states "patients are sometimes subject to various obvious or subtle, open or hidden, coercions and restrictions to their opportunities and abilities to act autonomously in accordance with their views of their interests" (p. 1). Although the healthcare practitioner intends no harm, the patient may be harmed simply because they are the weaker individual in this power dynamic, and this in turn can lead to coercion (Williamson, 2016).

Historical perspectives document increasingly oppressive practices within the healthcare system over time. Morgan (2008) describes the drastic changes experienced in the nineteenth century when practice and knowledge of medicine moved from bedside practice to *hospital medicine* (term coined by Jewson, 1976). During this era "the focus of medical knowledge moved away from the sick person as an individual, to the application of specific diagnostic procedures to identify general categories of disease" (p. 56). As hospitals became the centres for medical knowledge creation, the distance between the ill person, and the medical expert grew, granting doctors near total control. What Jewson called (1976) *laboratory medicine* "increasingly removed the patient from the medical professional's field of saliency" and "in particular led to reduced significance being given to understanding the patients' subjective perception of their illness and greater reliance on investigations and formal tests" (p. 57).

Foucault (1973) also examined the changes in the practice of medicine and medical knowledge creation at the end of the eighteenth century in *The Birth of the Clinic*, coining the term of the *medical gaze* (*Le regard medical*). This concept further elaborates on medicine's dehumanizing practice wherein a patient is 'abstracted' in order to objectify a person as a 'body', a separate container for an illness. Inspection and diagnosis of any given illness requires a penetrating medical gaze to allow manipulation of the human body as separate from the patient's identity. For Foucault, the socio-economic expression of power was tied to this medical gaze as it allowed a patient to be manipulated by the professional medical authority. As medical progress was made, the medical gaze evolved to be "refracted through computerised protocols and algorithms: first we check the template, then we listen to the patient. The screen has replaced the body as the emblem of contemporary medicine" (Gillam, 2016, p. 617). Patients subjected to the medical gaze are aware of this disembodiment (Gillam, 2016), and may experience it as dehumanizing.

Based on this brief "biopsy" of power we can see that there has been a movement throughout history that has further abstracted the patient within healthcare. It is perhaps the desire to reclaim the patient's autonomy which has led to contemporary calls for patient-centered care. Inglis (1997) explains that the difference between empowerment and emancipation can be situated in their larger function within any societal structure of power. Empowerment includes "people developing capacities to act successfully within the existing system and structures of power" whereas emancipation "concerns critically analyzing, resisting and challenging structures of power" (p. 4). While we have come far from the times of Parsons and Foucault into an era of information that has begun to balance the patient-doctor-relationship, we are still seeing

concerning coercion within healthcare. Arguably, patient-centered care is grounded in the idea of empowerment, while there is a craving for emancipation of patients within healthcare because the *system* needs change.

Methodology

"Phenomenography […] denotes a research approach aiming at describing the different ways a group of people understand a phenomenon" (Marton, 1981). It differs from phenomenology in both ontology and the analysis outcome. "In phenomenography, the outcome focus is on the variation in experiences of a given phenomenon. The result of a phenomenological analysis is the description of the essence of the lived experience of a given phenomenon" (Stenfors-Hayes et al., 2013, p. 262).

To illustrate phenomenography, we borrow and adapt the parable of the elephant in the dark room (Assarroudi & Heydari, 2016). Imagine a group of people who do not know what an elephant is and have never encountered or seen a picture of one before. This group is put into a dark room with an elephant, but can touch only a part of it (i.e. the side, tusk, trunk, ear). Not being able to "see" the elephant each person concludes that the part of the elephant they *experienced* personally must be the elephant's real and only form. This example showcases how tricky it can be to determine the "truth" of any given thing, or phenomenon, and demonstrates the varied ways of experiencing and making sense of reality. However, if this group of people came together and shared their experiences, they could co-create a more cohesive, collective understanding of the elephant. In a similar manner, phenomenography "identifies similarities and differences in the way we experience and understand phenomena in the world around us" (Barnard & Gerber, 1999, p. 212) and focuses on experience, conception and sense making of the world and a given phenomenon. In this parable, the interest is not on the elephant itself, rather the people making sense of the elephant—experiencing it. According to phenomenography "there is one existing phenomenon that is a collection of different yet related ways in which it can be understood and experienced" (Barnard & Gerber, 1999, p. 216).

The research outcomes (identification/description of various conceptions) are known in phenomenography as *categories of description* and the *outcome space*. The comparison of similarities and differences form specific categories of description which refer to a collective expression of the different ways the phenomenon can be understood. Once the categories of description have been determined, they form an *outcome space* which may reveal structural relations (potentially hierarchical) between the categories. The outcome space may be represented as a visual diagram when attempting to describe the qualitative variations of experiences and their potential hierarchical or logical relations (Larsson & Holmström, 2007).

Barnard and Gerber (1999) suggest that phenomenography may be a useful methodology across all areas of healthcare, and especially in research focused on education and the experiences of patients and healthcare practitioners. Stenfors-Hayes et al. (2013) also note the applicability of phenomenography in the field of healthcare and health education research, stating it "can contribute significantly to improving the quality of qualitative medical education research and establishing a more solid link between research and educational development and change" (p. 267).

Study context

This study examines how an HPE program involving patient teachers is experienced by participants. We examined this question in the context of a 'Patient as Teacher' (PAT) program launched at one of the University of Toronto's (UofT) teaching hospitals and later expanded to all UofT's teaching hospital sites. The program entitled "Humanism in Surgery: Patient as Teacher," is now required for all 3rd year UofT medical students who are completing their 8-week surgical rotation. Students attend 2h long sessions led by patient teachers who share their personal stories and experiences with the healthcare system, often focusing on how their illness has impacted them. Students have an uninterrupted time to listen, engage in dialogue, and reflect on the teachings patient teachers share. At the end of the rotation students discuss how the patient stories influenced their outlook during rotation by creating an art-based reflection piece.

Participants

The surgical clerkship students, patient teachers, and PAT session facilitators who were a part of the 1st year program edition were invited to take part in our study. All patient teacher participants had been diagnosed with breast cancer and ranged from 20–60 years of age. 8 out of the 10 patient teacher participants self-identified as white women who had either been born and raised in Canada (4) or had immigrated (6) to Canada at some point. The over-representation of white women within the PAT program was well acknowledged by all study participants, and was often highlighted as problematic.
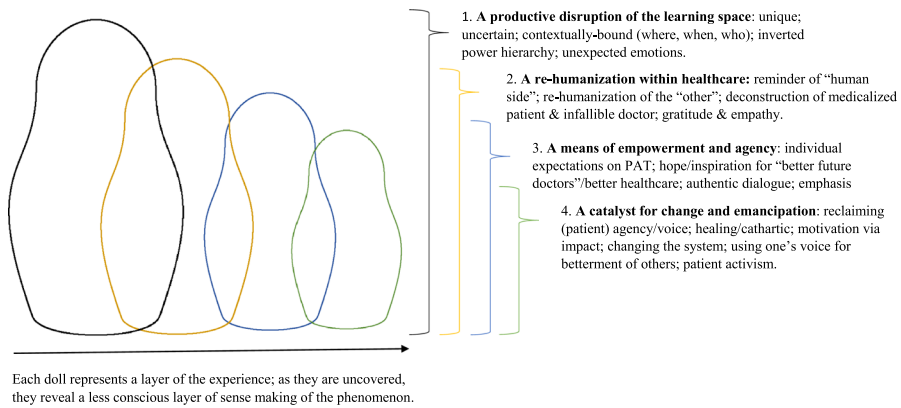
Data collection

We conducted 24 semi-structured interviews in total between April–October of 2019 with patient teachers ($N=10$), medical students ($N=10$) and program facilitators ($N=4$) who participated in the PAT program to investigate the qualitatively different ways the program (the phenomenon) was experienced. The 60–90 min interviews focused on each participant's description of the PAT program based on their experiences, conceptions, and understanding of it.

Data analysis

The one-on-one interviews were digitally recorded and the audio was transcribed verbatim for analysis. NVivo (QSR International Pty Ltd. Version 11, 2010) was used as data management and analysis software. The raw data was first analysed using an iterative process of constant comparison combining of content and thematic analysis. As more interviews were conducted, certain clues and themes kept emerging from participants that helped refine the questions asked of participants. This was followed by a more focused phenomenographic analysis and re-reading during which we began to cluster codes based on similarities and differences. At this point, the team also started exploring theoretical framing that would help explain the emergent themes. The comparison of similarities and differences started forming the specific construction of the categories of description that finally comprised the

Table 1 The outcome space: layers of experiencing a PAT program

1. **A productive disruption of the learning space**: unique; uncertain; contextually-bound (where, when, who); inverted power hierarchy; unexpected emotions.

2. **A re-humanization within healthcare:** reminder of "human side"; re-humanization of the "other"; deconstruction of medicalized patient & infallible doctor; gratitude & empathy.

3. **A means of empowerment and agency**: individual expectations on PAT; hope/inspiration for "better future doctors"/better healthcare; authentic dialogue; emphasis

4. **A catalyst for change and emancipation**: reclaiming (patient) agency/voice; healing/cathartic; motivation via impact; changing the system; using one's voice for betterment of others; patient activism.

Each doll represents a layer of the experience; as they are uncovered, they reveal a less conscious layer of sense making of the phenomenon.

findings of our research. The final step of the analysis phase was to structure the findings into a meaningful visual representation that reflected, the outcome space of the study. The Matryoshka doll found in Table 1 was chosen to visually best depict this.

Findings

Our findings resulted in 4 *layers* representing the qualitatively different ways in which participants experienced/perceived and conceptualized the various aspects of their experience with the PAT program. To visually illustrate the *outcome space* of the results, a nesting (Matryoshka) doll was chosen. This image captures the 4 layers, while also representing an uncovering of less conscious layers of sense making of the phenomenon (see Table 1). As each doll is opened to reveal the smaller one inside, we begin to determine the guiding principles, beliefs, feelings, and sometimes hidden motivations that influence the practices of the PAT participants. While this paper focuses on the emancipatory potential of PAT programs for patients, all participants' viewpoints are included to form the collective understanding of how the program was experienced. Though the differing experiences might appear contradicting, this is part of the phenomenographic process, aka the 'elephant in the dark room'. Each descriptive quote is coded depending on the participant: 'F' for facilitator participant; 'S' for student participant; and 'P' for patient teacher participant.

1st layer: a productive disruption of the learning space.

In this layer, the participants perceive their experience of the program as being unique, uncertain and contextually-bound in the sense that the experience was defined by where, when and with whom the experience took place. Each session was different, something which was highlighted by the program facilitators, who had the unique perspective of taking part in multiple sessions.

> The dynamic is different depending on the paired teachers [at] that time, and depending where the stories go on that day. I would say they were different every time and

it depended on the dynamic between the two teachers and the stories that they tell. (F01)

The space had an impact on the experience as well, from the room location to the layout of furniture. In particular, the patient teachers who moved between different hospital sites spoke of the impact it had on their experience, specifically relating to their sense of being appreciated and valued. Entering a room that is in disarray, dark, and hard to find versus having clear directions and someone welcoming you to a ready room made a difference. One patient participant explained the impact it made to how she perceived her experience with the program. One of her sessions being "very disrespectful" due to a lack of preparation and guidance, whereas another session "was amazing" because she knew what to expect and how to prepare. This highlights the significance of knowing what the expectations are for each stakeholder that takes part in the program (e.g. students being late due to not finding the room), and how these expectations can impact the experience.

Another defining factor of this layer is the temporal disruption of the "regular" form of learning in HPE because a patient was the teacher. This inverted power hierarchy of who is sharing their expertise within the space impacted the program experiences in a pronounced way. Not only who is teaching, but also the type of knowledge being shared was "irregular" from what is conventional in HPE and thus added a layer of uncertainty and productive discomfort within the program. The PAT program is structured around patient teachers sharing stories that often include intimate personal experiences. Unexpected feelings, emotions, or reactions to these stories make the experience less controlled and this can cause discomfort that may act as a catalyst for learning.

> Yes, absolutely, absolutely it makes them uncomfortable because you're standing in the room there and I'm looking right at them. I'm sure it's uncomfortable for them because despite it being many years it's still a personal story and you get to some of the nitty-gritty stuff and there's a tension in the room and you can tell they're like oh. You can just read the people's faces and body language and maybe they're worried that I'll get emotional or start crying and not being able to [handle] an uncomfortable situation. (P06)

The nature of sharing a difficult personal story/experience can be hard and is not commonly a part of HPE. Yet, suffering comes with the practice of medicine/health and acknowledging what it can teach us within HPE should not be avoided. There are educational benefits to this challenging experiential knowledge.

> It's upsetting to hear but I think it's really important. I liked having these sessions and when you hear these stories, I think it really… puts things in perspective. It takes us out of our day-to-day and kind of that business, […] I think they are valuable for us to hear. (S01)

2nd layer: a re-humanization within healthcare

The second layer is defined by experiences of re-humanization. The program is understood to be a reminder of the human side of medicine. The experience is "real" because patient teachers and students are face-to-face, sharing and experiencing from each other, instead of reading a textbook or having a case example. As one student participant phrased: "it's just that common thread of humanity which weaves together all of medicine and the human experience". Perceptions of an 'us' versus 'them' dichotomy within medicine were

challenged and instead the program offered a way of experiencing re-humanization of the "other". This experience was multi-directional.

> So, it's kind of like seeing the human of both sides of it, not just seeing the patient as a human but also seeing the healthcare professional [as a human]. (P10)
>
> I guess, at times, truly it's just the patients' stories made me feel sad, and I wished that I could connect on almost like a closer level, not physician/patient or a medical student/patient, but just be a bit more real and human so just go, oh my god, I'm so sorry, that sucks. (S02)

The program was experienced as a space for deconstructing the 'medicalization' of patients to instead focus on their individuality, simultaneously deconstructing the idealization of an infallible doctor. Participants were reminded of the common humanity in each given medical encounter. Within this layer, all participants perceived the program as fostering empathy and gratitude towards the 'other'. Students were grateful for patient teachers sharing their personal stories, patient teachers were grateful for the opportunity and space to speak about their experiences, and facilitators felt grateful to be able to hold the space for learners and patient teachers, while also learning themselves.

> I feel very grateful to have had those experiences, in particular with the patient teachers, because they have shared amazing insights and stories that, no doubt, have impacted me as a person, and as a clinician, as a teacher. (F01)

3rd layer: a means of empowerment and agency

The 3rd layer of experiences of the program begins peeling back the underlying factors that give us a better understanding of the driving forces behind *why* do patients take part in these programs. Many participants experienced the program as empowering, particularly for the patient teachers.

> You get the validation. That is really important. And, I think it could be very empowering, both for the students and also for the patient teacher. (F04)
>
> The end portion of them [students] going back around and thanking me or saying what they got from it, helped affirm that, yes, you are strong for sharing this, yes, we appreciate all that you've been through and, yes, it means something because there will be a change. Thank you for coming and being here and we will do something about it. It is meaningful. We are listening to you now. (P10)
>
> I think that it is not only a chance to feel empowered but actually be empowered to share their story which then informs... I don't think it's just lip service, I think it is actually meaningful. (S04)

Many of the patient teachers also experienced a sense of healing due to taking part in the program. Some even described the program as being "therapeutic".

> It's a brilliant programme and as I said, I say it's symbiotic. I think it can be healing for us [patient teachers] and it's educational for them [medical students], so it's a win/win. (P03)

Additionally, participants experienced the program as inspirational because it demonstrated a shift in how HPE can be taught with incorporating patient's point of views. And as one student participant stated "to see everything from the patient's side […] to become a better doctor". In general, the hope for "better doctors" was linked to majority of

participants feeling that healthcare currently treats patients as a "number"/"chart"/"disease" or "slab of meat," instead of a unique person/human with emotions, and someone always deserving kindness, regardless of who they are.

> I think the purpose is to make for a more well-rounded medical professional and to make sure that they are seeing the patient as a person and not as a chart, or as the disease. (P08)

Issues within healthcare are commonly seen as part of a larger systemic structural problem and may prompt feelings of lacking agency on an individual level. One's actions may seem meaningless against the macro structural barriers. This was often reflected in students' comments and concerns about making meaningful connections with their patients when they have so little time with each of them. When faced with structural barriers impacting each patient encounter, knowing that each encounter can be dehumanizing or re-humanizing can be empowering. It demonstrates that individuals have agency within each patient encounter.

> It really just makes you realize there's a huge disparity in not necessarily the surgical skills of physicians, but just that bedside manner piece. And what a big difference that can make especially when it is patients who are coming from more marginalized or vulnerable backgrounds… It's also just physician specific. Some doctors are just warmer or have better bedside manner or seem to have better communication skills and that can make a really big… that can make a really big difference, especially for the patients. (S08)

4th layer: a catalyst for change and emancipation

Although each participant had individual expectations of the program, a collective hope for change was present across all experiences. Participants recognized that patient teachers occupy a role within the program that isn't commonly seen. In healthcare, we typically do not associate patients as being teachers, as givers of knowledge, but as someone needing aid/care. Within HPE, patients are often seen as tools for teaching. As such, PAT programs in themselves are offering a platform for patients to act as agents of change.

Despite the program being embedded in surgery clerkship, the overarching concept of change is relevant across all healthcare and allied healthcare professions. Essentially, PAT programs have a potential to be seen as a catalyst for change.

> If you have been a patient and have had a horrible experience, you're hoping that you volunteering your time and telling your story informs how people decide to change their practice and open up their mindset to think a little bit differently, through a patient's perspective and a patient's journey. (F04)

Experiencing a PAT program as empowering, healing or even cathartic is something that takes place on a personal level but participating in it as a patient teacher in hopes of invoking change is happening in a collective level. The element of the 4th layer reflecting potential emancipation stems from the attempt of driving for change in a system, in this case how patients are treated and how to teach about patient experiences within HPE. This is rooted in experiences of dehumanization within healthcare that leave a patient feeling powerless and without agency, due to being treated as a number rather than a person. Although the majority of the patient teachers' health journeys were ultimately "good" in regards to survival and general health outcomes, the moment(s) where

things went wrong had a deep impact on them. These were the moments that motivated patients (and facilitators) to take part in the PAT program: I don't want this to happen to anyone else. (P01).

> I've been a patient myself and I know what my experience was like. And 12 years later, it's still there with me. I'm thinking of the negative parts of my experience as a patient. […] And I'm thinking, that is not how you're supposed to behave. That stayed with me for 12 years. (F02)

In addition to hoping for patient dehumanization to stop, patient teachers experienced the program as emancipatory by reclaiming control over their negative healthcare experiences. The opportunity to share their stories in an educational setting provided patient teachers with a space where they were allowed to reclaim agency over the experiences of dehumanization. In a way, the PAT program created a means for personal *retroactive emancipation* for the patient teachers, by giving the opportunity of taking back control.

> I've been not at the wheel, this past going on almost a year in a couple weeks. So yeah, that wheel kind of disappeared. I want it back. Maybe this is the way for me to get it… so, the wheel is starting to reappear on my car. And yeah, kind of me taking back control. (P08)

The potential of emancipation expands beyond reclaiming one's own agency to a wider emancipatory movement for disrupting an oppressive healthcare system. Patient teachers hoped that by sharing their stories in the program they are helping to implement more comprehensive change in how patients are treated. Thus, the PAT program can also be seen as a platform for patient activism.

> I have the stories to share. I get to be around people who can do something to ease that. It's not going to actually directly benefit me […] but it benefits our society and our community. I consider that we live in a community and we want to just help everyone rise together. (P09)
>
> My goal since day one was to help others going through that or prevent others from having the negative experiences that I had. (P10)
>
> I want to use my voice and my experience to help people see the patient's side. To help people understand the patient experience as lived, in something that is acute. (P03)
>
> It's exhausting to try to fight the system […] There should be some other way to address it. […] And so to kind of disrupt what the system is like now, like talking to them and saying **I'm speaking for myself but I'm speaking for so many other survivors.** A lot of us are going through this and then is that kind of just snowballing into being like yeah, no this is actually valid. (P09)

The drive for emancipation may be originating in patient teachers and their personal experiences of dehumanization within healthcare, but other participants (facilitators and students) also experienced the potential of emancipation.

> I can definitely attest to when you create space where patients get the opportunity to be a part of something, in a way where it's meaningful, where they're valued, where they're included, it can empower them. It just really depends on how it's done. (F04)
>
> I feel it's a kind of mindset that can work to adjust this power dynamic that we do have in medicine, especially the physicians have where they kind of hold all the

power and the patients hold none of it. So thinking of patients as our teachers and remembering that we're not the only one who's bringing something to the interaction I think is an important mindset to have. (S08)

Discussion

"We're back in control of the story and we're not letting anyone take that away from us." (P08)

The above quote highlights the meaning a program like PAT can hold for patient participants. It speaks to the power of personal storytelling to reclaim control when the narrator has experienced a loss of agency. It also reflects the collective drive for a change with the wording of *we* (the patients) are back in control, implying that although their story is extremely personal, it reflects a shared experience amongst fellow patients. The findings of our study suggest that patients who get involved in HPE often do so with an emancipatory agenda (conscious or unconscious), aiming for changes in healthcare. With this finding, our paper also responds to concerns of the structure of the healthcare system being potentially oppressive for the patients it purports to care for. Considering the potential of oppressive structures at play in healthcare and the drive for patient emancipation requires us to pay utmost care and attention, to ensure further harm will not be perpetuated towards patient participants. This discussion expands on the emancipatory potential of PAT programs, considers what pedagogical conditions/framing is required to enact emancipation in HPE, and examines the need for continued reflexivity when engaging in education partnerships with patients.

In the last three decades, studies have started examining PAT programs, and other programs actively engaging patients, more closely and with increased attention to systemic social inequities. A recently published meta-narrative review by Rowland et al. (2019) for example critically examines the different ways patient involvement in HPE is conceptualized across academic disciplines and research traditions. Sharma (2018) notes that the healthcare system, at its core, is structured around colonial practices in which "physicians have the sovereign power to decide which questions are asked and when, how the answers provided are truncated or expanded, and how they are recorded" (p. 475). Acknowledging healthcare as potentially oppressive is an important first step towards more inclusive coproduction/collaboration between health providers and patients. This view of healthcare – a system that is built on "first do not harm" – can appear contradictory and cause confusion. However, as Williamson (2019) states "seeing oppression as a consequence of structural factors in wider society, as well as within the medical profession itself, liberates doctors from guilt for the oppressive policies and practices they inherit" (p. 151). A critical examination of the structural factors at play averts misunderstanding of why and what patients wish to change in healthcare practices. By recognizing and acknowledging the inherent power dimensions at play, we can start to move towards what Sharma (2018) calls a "true dialogue with patient experts" (p. 476).

Implications for HPE

The first and especially the second layer of our findings display how a program like PAT can moderate the power hierarchy at play in health systems and HPE. For example, by 1) disrupting the familiar learning space and placing value on experiential knowledge that

patient teachers bring, 2) highlighting common humanity between patients and healthcare practitioners 3) and by demonstrating a way of re-humanizing a relationship (patient/doctor) and interaction that is often dehumanizing. HPE is deeply rooted in the traditions of positivist/post-positivist thinking and aligned pedagogical paradigms. Within these paradigms, conceiving of a patient as an expert with relevant teachable knowledge can be challenging. Sharma (2018) talks about how we educate future doctors reflects what knowledge is valued, and what is not. Quoting Swartz (2005) she writes "clinicians hear what their training enables them to hear" (p. 476) and within this training patient voices are often not foregrounded. Truly seeing the role and value of patient knowledge and experience is paramount to a PAT approach. However, we must be wary of "paradigmatic misalignment" (Baker et al., 2019) in educational programs and emphasize the importance of paradigmatic origins of any educational practices. Without considering these, we run the risk of failing to realize the original purpose of the practice and the intended impact.

To engage in PAT programs that are more epistemologically inclusive, we should consider transformative paradigms of education, which are aligned with social change, and disrupt the traditional teacher-learner hierarchy. This paradigm supports Freire's (1970) view of seeing education as means for freedom. It thus establishes the patient as having epistemic access and/or capital – expertise in something of value. Here again we return to the parable of the elephant in a dark room: sharing power and valuing diverse voices does not mean that all people bring the same degree of expertise on all topics. Rather, different perspectives and knowledge can collectively provide a broader and fuller understanding of complex situations. For example, patients may not always know the full details of their condition at a physiological level, but they will know the lived experience of that condition. To truly invite this experiential knowledge into conversation with the objectified, scientific rendering of it requires critical pedagogical approaches, such as dialogue. Hooks (1994) notes, "to engage in dialogue is one of the simplest ways we can begin as teachers, scholars, and critical thinkers to cross boundaries, the barriers that may or may not be erected by race, gender, class, professional standing, and a host of other differences" (p. 130). Our finding reflects this with PAT program being seen as highlighting common humanity and by demonstrating a way of re-humanizing a relationship (patient/doctor) within a structure that may dehumanize patients. Hooks (1994) continues by explaining how "sharing experiences and confessional narratives in the classroom helps establish communal commitment to learning" and thus has the potential of disrupting common assumptions and perspectives we can share (p. 186). Our student participants spoke to this by commenting on the "realness" the PAT session had due to being face to face with patient teachers who shared their personal experiences with them. Kumagai and Naidu (2015) have distinguished dialogue from discussion in the following manner: dialogue foregrounds affect and experience and striving for understanding of another to raise new questions and broaden ways of seeing, whereas discussions foreground articulating perspectives and information to reach decisions and a sense of closure. The facilitators of the PAT program spoke about how their role was specifically for facilitating dialogue between the patient teachers and students, and prompting reflections.

However, it is important to be aware of how questioning and disrupting commonly felt beliefs in education may result in resistance and discomfort. The discomfort of unsettling the status quo and power structures common in HPE is often overlooked; education does not traditionally aim to produce discomfort (Boler, 1999). PAT programs are however very likely to make people uncomfortable. Soklaridis et al. (2020) note that co-producing with patients who are directly impacted by health services "aims to unsettle the status quo" and "engaging authentically in this work means feeling uncomfortable in it" (p. 164). Sharma

(2018) also alludes to discomfort, by expressing how health professionals may be confronted by views that challenge their beliefs and may even feel their own expertise is being devalued. This in turn may result in resistance that makes co-producing educational programmes with patients even harder. It is crucial to be aware of this potential resistance and the discomfort and it is essential to eliminate barriers to patient engagement, including physician hierarchy and skepticism about the value of patient engagement (Szumacher, 2019).

Implications for potential patient emancipation

Building on Charlotte Williamson's work on patient movements and patient emancipation (Williamson, 2008, 2010, 2016, 2018a, 2018b, 2019) we argue that HPE programs that are co-produced with patients and actively involve patients as teachers have the potential to be emancipatory. The collective hope for changing the system that can dehumanize patients was shared between the PAT participants who took part in this study. Williamson (2010) notes that patient activists and movements are built on the motive to improve healthcare for other patients rather than denigrating healthcare professionals' skills, knowledge, or "wish to do good" (p. 151). Similarly, our findings indicate that patients who become involved with PAT programs do so in hopes of improving healthcare, out of a desire to share power with health professionals and make healthcare better for both professionals and patients. While the hope for systemic change was shared between patient teachers, facilitators and medical students, it is the patient teachers who are the active agents of change. Our findings indicate that patient teachers can experience so called retroactive emancipation on a personal level by regaining agency over their experiences of dehumanization. But the hope of challenging and disrupting an oppressive healthcare system was what motivated them to take part in the PAT in the first place.

While patient teachers reported feeling empowered and even experienced a sense of healing from their experiences, they still knew that even when they have control over their narratives, they do not necessarily hold significant power. Indeed, the patient teachers who took part in our study hinted at reluctance to share elements of their journey that did not fit with what was "acceptable" to be shared. For example, one patient teacher mentioned how they had to appear "professional enough" to be viewed as worth listening to. This was not something that was told to them explicitly, rather patient teachers knew to be careful not to rock the boat too much, assuming this would diminish their credibility as an expert. It is important to emphasize this since it demonstrates that the inherent power imbalance between the healthcare provider and the patient is still present, even though the setting is not clinical. The patient teachers were expecting to be challenged or questioned. They acknowledged that speaking from a "patient perspective" to health professionals meant certain narrative formats were to be followed.

While observing how differently physicians, patients and caregivers tell illness stories Moniz et al. (2021) conclude that, "a worrisome gap exists between patient and family caregiver perspectives and the perspectives of physicians on their respective experiences of healthcare and illness" (p. 1). This gap might further explain why discomfort may arise in PAT programs and why certain stories/narratives are viewed as more "acceptable" in HPE and healthcare more broadly. Recognizing that we may be expecting to hear certain narratives from patients may aid us to see that we simultaneously – either consciously or unconsciously – silence other narratives, ones that we are not used to hearing, or don't want to hear. Frank (1995) argues that the dominant and socially accepted illness story of

medicine is one of a "restitution narrative", a story of an ill patient who is restored back to health because of modern medicine, i.e. "by an agent outside the body" (p. 88) (the health-care provider). Such restitution narratives continually perpetuate the ideal patient-provider encounter, one in which a patient is restored to health by the healthcare provider. This can make it difficult to hear narratives that do not reinforce the status quo ideal, such as patients experiencing dehumanization.

Moving toward more epistemologically inclusive patient engagement in HPE will require us to recognize the diversity of patient experiences and positionality. With transformative paradigms of education, we are better equipped to hear more diverse narratives from patients and may be less resistant to stories that are shared with the motivation of changing how we treat patients within healthcare. We are, however, still left with the dilemma of representation. In their paper, Rowland et al. (2018) explore the nuances of this issue and recognize how it is not only a practical or technical problem, but a deeply ethical and moral one. The two patient participants of this study who did not identify as white, were younger, and very conscious of their "role" and responsibility as a representative of diversity. Yet, this responsibility gave them the opportunity to share their views and instigate change. As HPE researchers, it is our responsibility to keep being reflexive and to continually ask hard questions: emancipation for whom? Who is being included and excluded? How might we be more inclusive? Attending to these questions in partnership with patients will, as a patient participant (P09) stated, "*help everyone rise together*".

Conclusion

PAT programs have been a part of HPE for decades, and we still strive to realize their full potential. HPE must navigate the risks of essentializing complex experiences or perpetuating inequities and oppression by privileging particular patients and particular stories. Our study contributes to this aim through an exploration of patients' reasons for participating in PAT programs. We uncovered an understanding that PAT programs can be, though are not guaranteed to be, emancipatory experiences. By intentionally supporting this potential, we may create more ethical, sustainable and paradigmatically aligned HPE programs in solidarity with patients. We must first, however, confront health sciences' oppressive structure and its impact on patients. This approach is necessarily disruptive and uncomfortable. Examining how the *medical gaze* can influence healthcare systems, patients and even the narratives we expect to hear from patients can also be difficult. One way to begin deconstructing oppressive power structures is to rethink how health professions are taught. Supporting patient emancipation within HPE and the health system through a reflexive, equitable, and transformative approach, we are better positioned to shape a more inclusive and epistemologically diverse healthcare system.

Limitations

As authors of this paper, it is relevant to acknowledge and admit that by writing for an academic audience about patient emancipation without a patient co-writer, or member checking with a patient participant, we ourselves are running the risk of perpetuating the same power dynamics we criticize by "speaking for" the "patient". Co-producing education and research with patients is challenging on a multitude of levels. There are distinct challenges

and obstacles within our systems to do it in a way that is thoughtful and minimally harmful, which speaks to how much work is still needed to enable patients to meaningfully take part in HPE. In regards to why member checking is not included in our study, in addition to privacy concerns and institutional ethics considerations that determine how it would even be possible, the main reason is the design and purpose of the study. Phenomenographical inquiry results in a collective expression of the different ways a given phenomenon can be understood. It is not interested in the elephant itself, rather the interpretation of the elephant through different points of view.

For this study, we hope to have emphasized the value and importance of so-called lay knowledge and expertise, even though the authors themselves work within the system. While we are a part of the system, we also brought our own personal patient lens into the analysis process. The practical challenges and restrictions involved in co-producing are real and multi-layered. Reflecting on them is relevant, and including these reflections in the academic literature will hopefully push us to continue dismantling the barriers of true collaboration and co-production with patients.

Positionality and reflexivity statement

Emilia Kangasjarvi conceived the research and questions, designed the study, collected and analysed data and was the main contributor to the writing of the manuscript. She is an immigrant to Canada and her background is in social psychology and anthropology. Her research in Health Professions Education often reflects on experiences of navigating multiple different health systems as a patient of chronic health concerns.

Jacqueline Forsey assisted with data analyses, framing data interpretation and contributed the writing of the manuscript. She is a PhD student at the University of Toronto in the department of Rehabilitation Sciences studying the way we teach communication skills to Health Professionals. Her work in the field of Health Professions Education draws on and is inspired by her experiences as a patient and as the parent of a critically ill child.

Jory Simpson is a General Surgeon and Director of undergraduate education at the University of Toronto. He is the creator and the clinical director of the PAT program. He assisted with the design of the study and contributed to the writing of the manuscript. His research focuses on Humanism in Surgery and Surgical Education.

Stella Ng contributed to the study design, conceptualization and methodology, interpretation of data, pedagogical framing and was the senior contributor of the manuscript writing. She came to health professions education research after practicing with children and families at the intersection of public schools and health and rehabilitation clinics and institutions. At this interface, she witnessed and enacted the structural and systemic challenges to compassionate, collaborative, equitable care that she has now come to study and address through critical health research, education, and leadership.

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