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Moving Towards Design Justice Through Multivocal Design in Health Education

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Abstract

This paper examines how traditional forms of curricular design and content creation can reinforce oppressive knowledge hierarchies both in educational and clinical settings. We propose a reimagining of how knowledge content is created through a process called multivocal design, which draws on both design justice and knowledge justice frameworks. Multivocal design integrates and legitimises different types of knowledge and experience, thus establishing epistemic authority across a wider definition of expertise. We propose that this approach to curricular and content design has applications across education, but the design case presented here focuses specifically on understanding and addressing epistemic bias in medical education and practice.

Keywords: epistemic justice, co-design, design justice, interprofessional education, expertise, medical education

Introduction

In 2018, I (Dani Dilkes) slipped into the back of a lecture hall where a clinician was giving a lecture on multiple myeloma. I listened to a factual and detailed presentation of what multiple myeloma is (a blood cancer), how it presents, how it is treated, and the prognosis of patients. The presentation was full of statistics and diagrams of mutated cells. The lecturer was familiar to me, as she was one of my mother's team of doctors, a very knowledgeable and not unkind physician.

But what she missed on that day was the visceral experience of finding out that a loved one has a disease that you had never heard of before and didn't fully understand. The constant cycling between hope and hopeless of a barrage of experimental treatments. The exhaustion of living between home and the hospital. The anger felt towards a medical system that determined appropriate treatment based on a cost-prognosis analysis rather than the life of the patient. My experience as a family member was not captured in the expertise of the lecturer. My mom's experience as a patient was certainly not captured. The knowledge shared felt distant, alien, and not remotely reflective of our lives as my mom navigated a horrible disease, and we tried to support her. In medicine, "every case contains a human story of illness and a medical story of disease," and both stories are necessary to fully understanding the complexities of medical care (Cox, 2001, p. 862). The lecture that day did not convey the full story of multiple myeloma. It focused on a technical, objective understanding of the disease (the medical story), but lacked the emotional, subjective experience of it (the human story). Sitting in that lecture hall diminished and invalidated our lived knowledge of multiple myeloma, as though what we knew it to be was unreal, and biassed by our inexpert emotion, subjectivity, and humanness.

Epistemic Authority in Higher Education

This raised an important question about knowledge and experience in medicine and education at large: What is expertise? Who has it? And what makes them an expert?

Higher education is a social system very much invested in defining knowledge, legitimising ways of knowing, and establishing expertise. Course and program curricula define what is worth knowing, and institutional hiring processes and educational designs determine who has the expertise required to teach that knowledge. Here the term *epistemic authority* is a useful way of thinking about who is seen as a valid knowledge holder. Epistemic authority can be defined as the degree to which a source of information is perceived as legitimate and credible (Raviv et al., 1993). If we think of education as a design activity, drawing on design language, an educator with high epistemic authority would be considered a subject-matter expert (SME). Wikipedia defines a subject-matter expert as "a person who has accumulated great knowledge in a particular field or topic and this **level of knowledge is demonstrated by the person's degree, licensure, and/or through years of professional experience with the subject**" (Wikimedia Foundation, 2024, emphasis added). There is a certain irony to referencing Wikipedia to frame a conversation around the critique of institutionalized models of knowledge and expertise, but this definition mirrors legacy understandings of expertise in higher education where epistemic authority is determined through "university-mandated status" (Marginson, 2011, as cited in Lubbers & Ribeiro, 2015, p. 42) often tied to research production, credentials, and scholarly and professional experience. Notably absent from this definition of expertise is lived or personal experience.

An emphasis solely on degrees, licensure, and professional experience for establishing subject-matter expertise establishes epistemic boundaries that delegitimize somatic, affective, and lived experience expertise. The absence of these other ways of knowing a topic or discipline leaves significant gaps in the knowledge that is being constructed in educational settings. This single perspective expertise can be seen as a form of epistemic injustice: the devaluing of certain types and sources of knowledge based on a hierarchical bias (Fricker, 2007). Often, once epistemic authority has been established based on prestige, knowledge from other sources is disregarded and may be completely absent from educational content. This can be understood as an example of the *null curriculum*, which is the opinions, perspective, concepts, and skills that students are never granted access to, and thus that are likely to remain outside the scope of their knowledge (Eisner, 1985). The significance of the null curriculum is not just that it creates a knowledge void, but that it limits learners' ability to view, understand, and appreciate concepts from different perspectives.

Perceptions of expertise and epistemic authority have significant impact on educational design and experiences. In the classroom, an overemphasis on the epistemic authority of the instructor can result in what Freire (2000) called the banking model of education, where students are seen as empty vessels to be filled with the knowledge held by the teacher. The banking model of education reflects certain oppressive attitudes that exist in society as a whole, including, importantly to the idea of epistemic injustice, the belief that "the teacher knows everything and the students know nothing" and the way in which "the teacher confuses the authority of knowledge with his or her own professional authority, which she and he sets in opposition to the freedom of the students" (p. 73). The implications of conflating authority with knowledgeability need to be considered in any educational design activity in order to understand how epistemic design choices may reinforce existing power hierarchies of knowledge. Within this design case, we engaged with the possibility that those who hold the most power in an educational (or clinical) setting are not necessarily those who hold the most—or most important—knowledge.

The Singular "Expert" in Medicine

Narrow definitions of expertise can have a limiting effect on higher education curricula generally, but medical education provides a particularly rich example of how certain forms and sources of knowledge are often disregarded, and the potential impact this has on professional practice and medical care.

Different members of an interprofessional healthcare team hold different amounts of power in healthcare settings. An interprofessional team can be seen as all individuals involved in patient care, including all the healthcare providers but also the patient and their family members (Orchard, 2015). Power here can be understood as the degree of professional autonomy and the ability to make clinical decisions or influence other healthcare professionals' behaviours or decision-making (Stevens et al., 2021). Physicians often hold the most clinical and decision-making authority on interdisciplinary teams or in clinical settings (Janss et al., 2012; Oborn & Dawson, 2010). In clinical settings, clinical authority is often conflated with epistemic authority, echoing Freire's critique of oppressive knowledge practices in society where professional authority and authority of knowledge are treated as the same thing. Because physicians hold the most clinical authority, they are often viewed as privileged knowledge holders, and knowledge from other sources is often undervalued or ignored (Janns et al., 2012). Key perspectives that are often absent from medical education and practice are the knowledge and expertise of both other healthcare practitioners and the patients themselves.

Many studies have examined the power relationships that exist between healthcare professionals on medical teams and the impact that those power structures have on interprofessional competence and patient care (Stevens et al., 2021). Often, the expertise of non-physician members of the team is disregarded, even in cases when team members with lower institutional power have developed a greater expertise of a particular case or patient, such as nurses who typically interact with patients much more frequently than physicians (Liberati et al., 2016). In clinical practice, power dynamics can lead to poorer collaboration and communication across disciplinary boundaries (Oborn & Dawson, 2010), resulting in poorer patient outcomes. This can also impede the translation of tacit to explicit knowledge in clinical settings (Quinlan, 2009).

There are also frequent reports of how medical professionals undervalue patients as sources of health knowledge—often referred to as *medical gaslighting*. Medical gaslighting is a term used to describe instances when patients' own accounts of their experiences or clinical concerns are discounted in favour of clinical expertise due to physician ignorance, implicit bias, or medical paternalism (Ng et al., 2024). Medical gaslighting results in poorer health outcomes and a reluctance of patients to engage in healthcare-seeking behaviour. It also disproportionately affects vulnerable or marginalized groups. A common example of medical gaslighting is the underdiagnosis of endometriosis, a chronic health condition that impacts women and presents as pelvic pain and irregular menstrual cycles. Women report that their concerns are often dismissed or ignored by physicians, resulting in a prolonged time between the onset of symptoms to diagnosis (Koufopoulou, 2022). Another example is the wide occurrence of psychiatric patients' concerns and requests being ignored, which was so pervasive in the UK that it resulted in new legislation being passed to protect these patients by establishing a patient advocacy program in the early 2000s (Kidd & Carel, 2019). Medical gaslighting can be seen as a form of testimonial injustice (Fricker, 2007), where patients' lived experience is believed to lack credibility and not viewed as a valuable form of knowledge. Kidd and Carel (2019) suggested that one of the root causes of this pervasive dismissal of patients in the clinician-patient relationship is the privileging of biomedical knowledge in healthcare disciplines: because patients lack the knowledge and language to describe their experiences through a scientific, objective, biomedical lens, their accounts are dismissed as subjective and unscientific.

Epistemic Bias as Null Curriculum

The issues of power imbalances in clinical care are embedded in the culture and structure of healthcare institutions. However, as educators, we considered how this epistemic bias, and the defining characteristics of epistemic authority in healthcare, are established long before clinicians enter health practice or institutions: they start in health education. Curriculum that favours a single perspective teaches a narrow understanding of healthcare practice and implicitly teaches medical students' which type and sources of knowledge should be valued and, thus, which can be ignored. Effectively, in situations where the only epistemic authority is a clinical educator, students are being taught to discount other sources of knowledge through the very fact that they are absent in the curriculum and course content. Although these students may develop technical proficiency, the absence of other sources of knowledge can result in a lack of narrative competency, or the ability to listen to and form connections with patients (Charon, 2006). Narrative competency contributes to clinical effectiveness, as it allows healthcare professionals to translate stories of illness to medical practice.

Curriculum design processes can be seen to reinforce this epistemic hierarchy. In traditional instructional design projects, a common model is for a single subject-matter expert (SME) to provide content knowledge to an instructional designer (ID) who converts that knowledge into course content. The expertise of the single SME may be based on training, professional experience, credentials, or other revered forms of knowledge merit. The resulting content often has one perspective, one voice, and quite often fails to acknowledge the inherent bias of a single perspective. Thus, the hidden, or perhaps not so hidden, curriculum of most medical education programs is that physicians hold the greatest epistemic authority because theirs is the dominant voice that students encounter in the curriculum.

The co-leads for this project interestingly do represent the roles found in a traditional instructional design project. Dani Dilkes is an educational developer with no formal education or professional experience in healthcare or medicine who worked for many years in medical education and health professions education. She offered design and curricular expertise, as well as co-design facilitation knowledge. Courtney Casserly is a practicing neurologist and clinical educator who works in both undergraduate and graduate medical education. She offered professional and clinical expertise. We initially came together on a collaboration focused on increasing diverse representation of patients and practitioners in health education media. Within this earlier collaboration, our roles became blurred as we learned from each other. We found that our distinct experiences complemented each other and helped us each challenge our own assumptions about healthcare and health education, which became a foundation of our approach to this project.

A Design Justice Approach to Curricular Design

If students were being taught to privilege certain sources of knowledge and devalue certain types of expertise through the design of their curriculum, we believed that we could address the problem by changing what and how students were taught. We developed a learning module which explicitly teaches interprofessional competency and does so in a way that legitimises different professional knowledges and the lived experiences of patients.

For both the content and our design process, we drew heavily upon the Canadian Interprofessional Health Collaborative (CIHC) National Interprofessional Competency Framework, which defines six competency domains: role clarification, team functioning, patient/client/family/community-centred care, collaborative leadership, interprofessional communication, and interprofessional conflict resolution (Canadian Interprofessional Health Collaborative, 2010). Based on the professional expertise of the neurologist, we focused on an interprofessional stroke case. Treatment of stroke is a particularly complex and multifaceted process, which allowed us to showcase the myriad healthcare professionals involved in stroke care and examine three of the interprofessional competencies in depth: role clarification, patient/client/family/community-centred care, and interprofessional communication.

Although teaching interprofessional competency was a key objective of the learning module, we wanted to ensure that this module didn't just teach about interprofessional teams but rather authentically reflected the distributed expertise of an interprofessional team. Through the design process, we attempted to redefine "expertise" by centring the voices of everyone involved in stroke care. To do so, we moved away from the traditional SME-ID relationship which, in medical education, centres on the expertise of a physician. Instead, we took a design justice approach, which challenges these institutionalised concepts of expertise by centring the voices of those most affected by the final design and recognizes that "everyone is an expert based on their own lived experience, and that we all have unique and brilliant contributions to bring to a design process" (Allied Media Projects, 2018).

The design justice framework is the result of a collaboration between designers, artists, technologists, and community in an attempt to move beyond good intentions to truly liberatory design practices (Costanza-Chock, 2020). Design justice acknowledges that those most affected by designs are often left out of design processes. It can be applied to the design of technologies, physical spaces, visual media, or any design project. In this case, we adapted the design justice framework to the design of knowledge. A design justice approach allows anyone to examine epistemic authority and take steps to empower communities most impacted by health knowledge.

The website of the Design Justice Network (Allied Media Projects, 2018) shows the 10 collective principles of design justice that members commit to embodying and practicing. The emphasis is found in the source document:

1. We use design to **sustain, heal, and empower** our communities, as well as to seek liberation from exploitative and oppressive systems.
2. We **center the voices of those who are directly impacted** by the outcomes of the design process.
3. We **prioritize design's impact on the community** over the intentions of the designer.
4. We view **change as emergent from an accountable, accessible, and collaborative process**, rather than as a point at the end of a process.
5. We see the role of the **designer as a facilitator rather than an expert.**
6. We believe that **everyone is an expert based on their own lived experience**, and that we all have unique and brilliant contributions to bring to a design process.
7. We **share design knowledge and tools** with our communities.
8. We work towards **sustainable, community-led and -controlled** outcomes.
9. We work towards **non-exploitative solutions** that reconnect us to the earth and to each other.
10. Before seeking new design solutions, **we look for what is already working** at the community level. We honor and uplift traditional, indigenous, and local knowledge and practices.

In this project, we aspired to achieve a more equitable design process by engaging with most of the design justice principles to varying degrees. We attempted to subvert existing power structures through vertical collaborations (principle 1) and by empowering different members of the interprofessional team, including the patients, to share their stories (principle 2). Although we had a rough design concept for the case, we made iterative ongoing changes based on the input of all collaborators (principles 3 and 4). We also positioned ourselves as facilitators of the process rather than experts (principle 5), though this change in role needed to be more intentional for the physician co-lead, as will be discussed in the design process below. We invited collaborator feedback on the final case materials, and all of the materials that we developed are shared under a Creative Commons Attribution-NonCommercial-ShareAlike (principle 7) licence. Principle 6 (valuing the expertise of everyone) was the most clearly embodied in the design process, though our approach and understanding of expertise continually evolved as new perspectives were shared and as we challenged our own assumptions about expertise and knowledge.

Patients as Experts

As a starting place for this project, we invited stroke patients and their families to share their experience of stroke care. Patients can be seen as lived experience experts (LEEs), important sources of knowledge to inform and improve healthcare practice and education (Vázquez et al., 2023). They are experts in their own experiences of illness and of the healthcare system—an expertise that, from a systems perspective, is as important as traditional professional expertise in understanding healthcare experiences.

We interviewed five stroke patients, and through their stories, we were able to reconstruct the journey of stroke from a patient perspective and to identify the different healthcare professionals who needed to be involved in the project. The stories shared by our patient partners were used as the basis of a fictitious stroke case but were also integrated into the learning module as an additional source of knowledge. You can hear the story of one of our lived experience experts, Nicole, by clicking on the image in Figure 1 or visiting the URL shown in the note.

Figure 1

A Stroke of Genius: Interview With Nicole, a Stroke Patient

Note. From *A Stroke of Genius: Interview With Nicole, a Stroke Patient* [Video], by Health Education Media Library, 2023 (https://vimeo.com/821716270). CC BY-NC-ND 3.0.

Notably, we experienced friction between our approach to engaging patients in the process and traditional methods of data collection from patients, which emphasise aggregation and anonymity rather than highlighting individual experiences. We had to work closely with the privacy offices at our partner institutions to develop a consent process that fit into their policies while allowing us the freedom to work with patients as individuals with unique experiences.

In working with patients as lived experience experts, we realised that the very different nature of the biomedical knowledge of clinicians and the experiential knowledge of the patient changed the way knowledge was shared and the relationship between the knowledge holder and the knowledge receiver. Patient expertise is affective, personal, and subjective, which is simultaneously why it’s a powerful and important form of knowledge, but also why it requires a different type of relationship-building in a design project. Asking patients to recount their experience of healthcare can be re-traumatizing and invites a level of vulnerability not expected of other types of experts. At the start of this project, we were underprepared for supporting this element of lived-experience knowledge sharing, but it is something we worked to develop our understanding of and approach to throughout this and subsequent projects. A design justice approach emphasises the need to develop knowledge with those most impacted by the outcome of the design through open dialogue and empathy (Costanza-Chock, 2020, p. 230). We started with an idea of the information we needed to build the case but realised that in order to truly centre the voices of our collaborators, they needed to direct the narrative. Although the interviews had guiding questions, the interview process was open, allowing for participants to focus on the parts of their stories they felt were most significant. When working with patients, and even at times healthcare providers, it was important to acknowledge the affective nature of their experiences and create a safe environment, encouraging them to pause or stop when needed. Interviewing collaborators about their experiences also requires narrative humility, which means recognizing our own power in relation to those from who we are eliciting stories and being open to the nuances and particularities of each individual story even if they contradict our expectations (DasGupta, 2017). To help offset power imbalances, the patient interviews were conducted by a collaborator who had no pre-existing clinical relationship with the patients.

Although we strived to embody design justice principles, there were limitations on how fully we could enact them. There were restrictions on how involved patients could be in the design process due to time demands. In this project, the outcomes were patient and partner informed, but not controlled. We did share the final videos with patient partners and asked for further feedback, but they were collaborators rather than leaders on the project. This is in the nature of the existing power dynamics of the institution, as a patient-initiated project on medical education would struggle to achieve the same levels of access and authority that a physician-led project was able to.

A Shifting Understanding of Interdisciplinary Expertise

In our initial design plan, we felt it was essential to invite real healthcare practitioners to participate in the case to ensure their roles and expertise were accurately portrayed. However, our design process was still quite biassed by traditional forms of expertise. Early in the project, the neurologist, who can be seen as our traditional subject-matter expert, scripted the interaction between emergency medical technicians (EMTs) and the patient based on her understanding of what an EMT does and what they are responsible for. As a primary member of the stroke team, she was confident in her understanding of the roles of different team members. However, our EMT consultant noted with bemusement that the scripted scenario did not accurately reflect their role, expertise, or the typical course of events when responding to a suspected stroke. Figure 2 is an image from the first scene of the case, showing EMTs bringing Holly Black, our fictionalized stroke patient, into the emergency department.

Figure 2

Holly Black Arriving at the Emergency Department

Note. From *A Stroke of Genius: An Interprofessional Stroke Case* [Video], by Health Education Media Library, 2023a (https://vimeo.com/820624326). CC BY-NC-ND 3.0.

We quickly realised that it wasn't enough to have real healthcare professionals star in the case, but that if we really wanted to tell the authentic story of stroke care, we needed every member of the team to script their own roles and tell their own stories. This resulted in what we are calling multivocal design, which meant redistributing power and allowing each individual to bring their own expertise to the design process. Each team member also provided a detailed overview of their understanding of interprofessional practice and the scope of practice for their role. Interestingly, many emphasised the diversity of expertise as a fundamental benefit of interprofessional practice. Katie Cameron, a social worker who collaborated on the project, explained this succinctly when she described interprofessional practice as "taking everybody's expertise and pulling it together for the best interest of the patient. So having the patient at the centre of everything that we do and hearing from all of the different people involved of how this medical event has impacted them … working together to help them through it in whatever way that looks like." (Health Education Media Library, 2023b, 1:02–1:21).

You can watch a snippet of the interviews by clicking on the image in Figure 3 or accessing the URL shown in the figure note.

Figure 3

A Stroke of Genius: Interprofessional Care Video

Note. From A Stroke of Genius: Interprofessional Care [Video], by Health Education Media Library, 2023b (https://vimeo.com/820618352). CC BY-NC-ND 3.0.

Our multivocal design approach to constructing this learning module was emergent. As we talked to and learned from each participant, we uncovered new nuances of stroke care and identified new healthcare professionals who were integral to the process but overlooked by our traditional experts and even the patients themselves. Each new perspective reshaped the story, which evolved into a complex, multi-scene case. The development process really emphasised the importance of multivocal storytelling and highlighted the knowledge gaps that occur when not all perspectives are considered. The evolving storyboard for the project is shown in Figure 4.

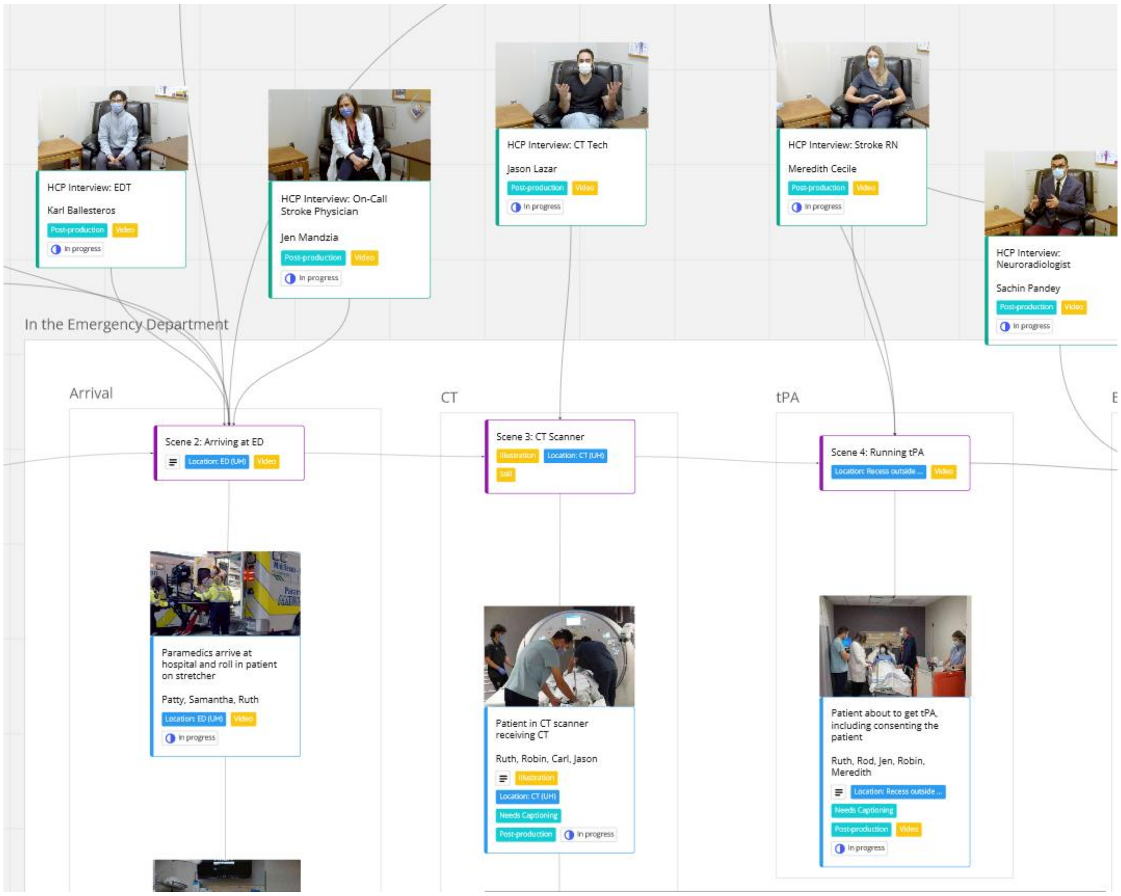
Our approach to this project helped us overcome some of the inherent knowledge bias in medical education by not centring a single voice of authority in the learning module, but rather by acknowledging the expertise of 22 healthcare professionals and five patients in the design and content of a teaching module on interprofessional care. Patients' own experiences of stroke care were elevated as a valid source of experiential knowledge. Healthcare professionals were recognized for their unique professional expertise and knowledge, thus allowing us to separate epistemic authority from professional authority. The resulting module, now embedded in the required curriculum for undergraduate medical students at Western University, allows for new forms of expertise to be acknowledged in medical education and by the next generation of physicians. It has also created a modified design justice framework for patient-centred design that we continue to evolve and apply to other design projects, allowing us to draw on diverse sources of knowledge to teach and ultimately improve healthcare practice.

Instructional Designers as Knowledge Brokers

One of the challenges that we encountered in this project was that the collaborations were situated within the same power hierarchies that we were attempting to reveal and challenge. The professional authority of the physician co-lead was present in all interactions with the interprofessional team and with patient partners. Thus, the role of the educational developer co-lead, here taking on the tasks of an instructional designer, was key to facilitating the multivocal design process across existing power relations. Since instructional designers practice at the periphery of multiple communities of practice, they have the ability to coordinate multi-disciplinary projects through knowledge brokering (Keppell, 2007).

Figure 4

A Stroke of Genius Project Story Board



Note. The project storyboard was a living document that we continuously updated as the story of stroke care evolved. Access the full storyboard here (https://miro.com/app/board/uXjVPQzrrpM=/).

Multivocal Design as a Step Towards Design Justice

Multivocal design allows more voices and perspectives to be present in curricular content and is a starting point for a design justice approach to curriculum and content development. By collaborating with a large team of healthcare professionals and stroke patients, we were able to challenge existing ideas of expertise and knowledge. The resulting learning modules centred more diverse voices, particularly those most impacted by healthcare practices: the patients. This module provides multidisciplinary knowledge that transcends boundaries of professional practice and offers balance between different types of expertise: stories of illness and stories of medicine.

By critically examining whose voices are present in the curriculum, and thus who is established as an epistemic authority on the topic or in the field, we can start to change oppressive epistemic structures in clinical and educational settings. By expanding our definition of expertise to include more diverse sources with different types of knowledge, learners will simultaneously have a more fulsome understanding of the topic or content and will also learn implicitly that different sources and types of knowledge hold value.

This case demonstrates the potential for multivocal design as a design justice approach to curricular and content design for overcoming epistemic bias and redistributing epistemic authority.

Authors' Contributions

Dani Dilkes was the primary author of this work and a project co-lead. Courtney Casserly was the project lead and initiator.

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Ethics Statement

All participants completed a standard consent form, which explained the nature of open licensing on media projects. This consent process was developed in collaboration with the privacy office at the London Health Sciences Centre. REB approval was obtained for a student review of the finished teaching module, which involved individual student and resident feedback and a series of focus groups. This feedback was used to further refine the teaching module.

Conflict of Interest

The authors do not declare any conflict of interest.

Data Availability Statement

Not applicable.

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