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Expert patients leading activities on social justice: towards patient-centered education

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Abstract

Background: Social justice is recognized by reputable international organizations as a professional nursing value. However, there are serious doubts as to whether it is embodied in Catalan nursing education.
Objectives: To explore what nursing students take away from two teaching activities led by expert patients (one presentation and three expert patient illness narratives) on the topics of social justice, patient rights, and person-centered care.
Research design: Qualitative study using a content analysis approach. The research plan included (1) think-pair-share activities (additional faculty-assisted presentation and three faculty-assisted, semi-structured scripted narratives); (2) paired reflections; (3) focus groups; and (4) content analysis of paired reflections and focus groups.

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Data Availability Statement included at the end of the article

Participants and research context: Fourth-year nursing degree students at the Autonomous University of Barcelona (UAB), Spain. Convenience sampling was used.
Ethical considerations: The UAB Research Ethics Committee did not deem it necessary to apply any specific measures. We fully explained to patients that they could decide what medical information they would share with the students that was relevant to their learning, and we provided students with guidelines about patient confidentiality, dignity, and respect.
Findings/results: The students engaged in reflection about their education (recognizing that it had been centered on the professional and not the patient) and their relationship with the patient, in which they reproduced low-involvement patient care by modeling behaviors of their nurse educator. Moreover, they valued a person-centered care model with an emphasis on the emotional part but left out decision-making as an individual right of people.
Conclusions: The think-pair-share activities were useful to spark self-reflection among students, who identified aspects to change in their own practice, and reflected about their own education process, both of which promote change.

Keywords
Expert patient, nursing education, patient participation, person-centered care, social justice

Introduction

Social justice has been identified as a professional nursing value by reputable associations such as the International Council of Nurses (ICN), the Canadian Nurses Association, and the American Nurses Association (ANA), among others.[1] However, there is serious doubt as to whether this truly is a value upheld by nurses since their practice has not always adequately embodied it.[2] Developing social justice as a professional value is an ongoing process that begins with professional nursing education and continues throughout the years of nursing practice.[2] It is rarely included in the nursing curriculum,[3] which focuses more on clinical issues and/or illness-based care than on professional values and/or the social determinants of health.[2] There have been plans to address this deficiency[2,4] by modifying both the curriculum and educational approaches.[5] There is little research on the development and evaluation of teaching strategies to foster students' understanding of social justice.[6]

Background

The 2023 Sustainable Development Goals (SDGs) aim to eradicate poverty, reduce social inequalities, promote health and well-being, and establish peace, justice, and solid institutions. Most countries have taken notice of the SDGs and developed plans to reach them at all levels.[7] However, the COVID-19 pandemic represented a setback and exacerbated inequalities and discrimination, especially in healthcare.[8,9] These health inequalities, conditioned by structural inequalities in opportunities and resources, benefit some individuals and limit or discriminate against others based on sex, age, race, and socioeconomic conditions.[10,11] The literature shows a social justice perspective of patient rights only in cases in which there is clear discrimination, such as transgender people,[12] people with disabilities,[13] and those living in poverty.[14] Along these same lines, social justice programs in nursing focus on content related to marginalized communities due to race or gender as the main social determinants of health, while personal rights to self-determination are not included.[15,16]

The goal of social justice education is to help students become more aware of social injustices, examine and be critical of them, and recognize their own position (privileged or not) in systems of oppression to motivate action toward social change.[17] However, it is not clear what it refers to in practice. The content of social justice education tends to comprise concepts such as diversity, racism, antiracism, social determinants, social awareness, social justice, and poverty.[6] Emphasis is often place on global actions to achieve a more just society but health professionals feel the need for justice on a more personal level.[18] Therefore, focusing on the nurse-patient relationship, we organized a teaching activity on social justice and person-centered care (PCC), including the principles of equity, participation in healthcare decision-making, and patient rights. It should be noted that patient-centered care and person-centered care are two separate terms used in the literature that go by the same acronym (PCC) despite being quite different. Patient-centered care means treating patients as partners, involving them in planning their healthcare, and encouraging them to take responsibility for their own health.[19,20] Alternatively, person-centered care focuses on the whole person (not just their medical conditions). Each person is recognized as a unique individual with distinct goals, needs, and preferences, which is very important in providing long-term services and supporting the healthcare system.[20] A synthesis of reviews revealed that the goal of person-centered care is a meaningful life while the goal of patient-centered care is a functional life.[21] However, patient-centered care is a highly complex phenomenon that is challenging to implement given its murky definition.[22] From the nursing perspective, patient-centered care is defined as a complex phenomenon involving interactions of the patient, the nurse, and the environment and in which sharing decisions and individualizing care based on patient preferences, values, and needs are two important defining characteristics.[23] In this article, we use PCC interchangeably since our research falls under the person-centered care model, but we also use concepts from patient-centered care at the analytical level—caring (understood as tending to the emotional needs of the patient) and sharing (desire for information and to be part of decision-making)—because they assist in using the quantitative content analysis as a tool.

PCC could be considered a right rather than a service value.[24] In the context of intellectual disabilities, rights-based and person-centered approaches are neither identical nor in true conflict with each other; rather, they are two extremes of one of the many dialectics encountered when working with people.[25] In line with what Glicksman et al.[25] defend, we will consider the rights-based and person-centered approaches as two equally valid and related poles on a dialectical continuum, regardless of the care scenario and/or group the patients belong to (marginalized, racialized, mental disorders, immigrants, etc.). Social justice is based on a belief that all people are entitled to equitable treatment, support for their human rights, and a fair allocation of social resources.[26]

Cognitive learning approaches, such as lecturing, for teaching principles and concepts have proven to be ineffective when it comes to embedding social justice in nursing degrees.[27] On the other hand, digital storytelling promotes understanding.[2,28] The narratives or ethnographies of personal experiences of lived injustice offer a vision of how injustice manifests in people's daily lives and encourage reflection on what social justice means.[29] Voices of experience often compel and move readers differently than abstract concepts such as theories or arguments in favor of social justice because they increase understanding of personal experience related to differences and discrimination.[29] These approaches have been described as affective learning as they improve students' understanding and use of ethical values,[30] demonstrating greater benefits and effectiveness than cognitive approaches.[27]

There is little research on the development and evaluation of teaching strategies to foster students' understanding of social justice.[6] Therefore, we propose to examine the effect of two activities taught by expert patients, following the concept of "experts by experience."[31] The aim is to explore what nursing students take away from two teaching activities led by expert patients: one presentation and three expert patient illness narratives (EPINs) related to the areas of social justice, patient rights, and PCC.

Methods

Design

Qualitative study using a content analysis of paired reflections and transcriptions of subsequent focus groups.

Setting and participants

The study was carried out at the Nursing Department of the Faculty of Medicine of the Autonomous University of Barcelona (UAB). Fourth-year nursing students who were enrolled in the course Nursing and Anthropology of Medicine in the 2018-19 academic year ($N = 65$) were invited to participate. Participation was voluntary since students could opt in as an alternative to another assessable assignment. Convenience sampling was used, by which the students who agreed to participate were invited to the learning experience assessment.

Think-pair-share activities

The intervention consisted of think-pair-share activities: one presentation and three EPINs. The frequency was one think-pair-share activity per week between February and March 2019 (see Figure 1). The cognitive activity was the faculty-assisted presentation led by a woman living with HIV. The topic was social justice focused on sexual and reproductive rights of women living with HIV. Basic concepts of social justice were first described and then exemplified with the results of a study conducted by and for women living with HIV. The fact that rights are discussed by sharing community experience brings a sense of tangible reality that contributes to a better understanding by the students. The affective activities were the EPINs, which were faculty-assisted, semi-structured scripted narratives. We opted for oral narratives because the PI has over 6 years of experience working with them and they have proven results similar to those of affective learning.[32,33]

Date	Participants	Task
January 2019	Expert patients and researchers	Collaboration session to create an EPIN, faculty-assisted, semi-structured scripted narratives based on patient-centered care + rights (right to information, etc.)
February-March 2019	Expert patients	Think-pair-share activities: 1) Cognitive activity : faculty-assisted presentation given by expert patient on global justice/social justice focused on sexual and reproductive rights of women living with HIV. 2) Affective activity: EPIN 1 (living with HIV), EPIN 2 (living with cancer), EPIN 3 (living with multiple pathologies: HBP, HIV, fibromyalgia; hypertriglyceridemia)
February-March 2019	Students	Paired reflection: guided reflection to write knowledge pearl after EPIN & presentation
April 2019	Students and expert patients	Feedback from students for expert patients
May 2019	Students and researchers	2 focus groups with nursing students
June 2019	Patients and researchers	1 focus group with patients to assess the implementation of the EPIN script

Figure 1. Project outline.

To focus the narratives within a PCC framework, a faculty-assisted, semi-structured script was prepared in collaboration with the expert patients to guide the EPINs. The script was organized into four main areas: diagnosis, treatment, follow-up, and overall summary of the experience. Each area was structured into an experiential description (how it impacted or was integrated into daily life) and a description of the relationship with the nursing professional from a person-centered perspective, specifically regarding the concepts of sharing (listening, informing, and involving patients in their care) and caring (considering the patient's expectations, emotions, and life circumstances). The purpose was to delve into the positive and negative experiences associated with the principles of the PCC model and patient rights (participation in decision-making, respect for patient autonomy, right to information, etc.).

Participation of expert patients

We invited three expert patients to participate. Expert patients were patients with expertise on their condition, had extensive experience in dealing with the healthcare system, and the ability to communicate and articulate their experience.[34] As explained in recent research, we used the term "expert patients" based on the term "experts by experience," which recognizes the extensive work and knowledge involved in living with and managing chronic disease.[31] The funds required to carry out the project, including compensation for the participation of expert patients, came from a grant (see Funding).

Data collection

Data collection for the think-pair-share activities was performed in two phases. The students submitted their paired reflections via Moodle after each think-pair-share activity (presentation or EPIN) from February to March 2019 (see Figure 1). The second phase consisted of two focus groups with students in May–June 2019.

The paired reflection was guided by four statements/questions. The script was as follows: (1) Answer the question "What is your takeaway from the teaching activities led by expert patients?" We call these answers "knowledge pearls" because students had to condense what they had learned after listening to each of the four think-pair-share activities. Students were asked to use the following sentence structure: *When we [nursing professionals] do xx, the impact [usually on the patient] is xx*. It was specified that the knowledge pearl should be a single sentence about (a) patient rights, (b) social justice, or (c) the PCC model; (2) justification of the knowledge pearl in the form of a written paragraph in which the student explains what they heard in the narrative that led them to that knowledge pearl; (3) justification of the pearl based on their own experience (whether as a patient, companion, family member, or student during clinical practices); and (4) keywords (two to three). Keywords were not requested for the knowledge pearls elicited after the presentation because it contained explicitly theoretical content (social justice and rights). The EPINs, however, offered no explicit theoretical content but rather a narrative to listen to.

The second phase consisted of two focus groups with students. We used a script with semi-structured questions based on the presentation and EPINs that focused on: (1) general learning; (2) understanding and appreciation of the PCC model; (3) differences/similarities between the learning that occurred in the presentation vs. the EPINs (cognitive vs. affective); and (4) implications/actions for change in their clinical practice now and in the future. Focus groups were audio recorded and verbatim transcribed.

Analysis

For the knowledge pearls and keywords, quantitative content analysis was performed, focusing on overt content. For the focus groups, only qualitative content analysis was performed.[35] The knowledge pearls were coded by the first author using the three a priori categories: PCC, rights, and social justice. The objective review of the responses resulted in the identification of two additional categories: humanization and nursing

care. The knowledge pearl content was coded using all five categories. The keywords were also initially coded using the a priori terms PCC, rights, and social justice. While coding, four additional terms were identified: humanization, nursing care, communication, and patient experience; keyword content was coded using all seven keywords. The additional categories were discussed and consensus was reached with two other researchers, both experts in qualitative methodology. The frequencies were recorded for each category associated with the knowledge pearls and keywords.

The content analysis of the focus groups was carried out by two authors (MF and RG). They coded the first group together and then independently analyzed the second. They then worked together again to classify the codes into different categories and subcategories by comparing differences and similarities and identifying the final categories. A consensus was reached for any differences that arose. Moreover, two expert researchers (AAM and MFC) reviewed both the coding process and the conclusions.

Ethical considerations

The Research Ethics Committee of the University did not deem it necessary to apply specific measures to the students participating in the study. Still, the study was clearly explained, emphasizing the importance of confidentiality when dealing with the patient's personal experiences. Students were also informed that they could withdraw at any time with no need to offer explanations and no academic consequences. Confidentiality and anonymity of the qualitative data were guaranteed. All nursing students gave their verbal permission to be audio recorded in the focus groups.

As consent and confidentiality might represent major concerns for patients, we fully explained to them that they could decide what medical information they would share with the students that was relevant to their learning.

Results

A total of 44 fourth-year nursing students enrolled in the course Nursing and Anthropology of Medicine participated in the study. 184 keywords and 92 knowledge pearls were collected. Of these, 11 keywords and 7 knowledge pearls were eliminated because they did not meet the criteria established in the exercise, leaving a final count of 85 knowledge pearls and 173 keywords for analysis.

The keywords associated with the EPINs were grouped into seven categories (see Table 1). Humanization was the most common category while justice and rights were the least prevalent. There were slight differences in each EPIN: in EPIN 1 the keywords refer to humanization (19/62) and nursing care (16/62); in EPIN 2, to humanization (20/59) and communication (16/59); and in EPIN 3, to humanization (14/52). As for the meaning of the knowledge pearls, that is, the expected result (see Table 2), in EPIN 1, it focused on the emotional care of the patient (14/20); in EPIN 2, on humanization (7/21) and understanding the patient (6/21); and in EPIN 3, on the humanization of the professional (8/19). The main category of the knowledge pearls from the justice and sexual rights presentation was fairer nursing care without prejudices (7/23) and patient rights (6/23), as would be expected following theoretical content. Of the total of 85 pearls, 15 were focused on the professional. Overall, the knowledge pearls emphasize the PCC model (34/85) and humanization (27/85), while the keywords focus on humanization (50/173) and nursing care (30/173). In the category of PCC, emotional care, which falls under caring, is the central theme (23/34). In the category of humanization, considerable importance is given to the humanization of the professional (8/27).

Two categories emerged from the analysis of the focus groups: breaking the mold of professional-centered education, and self-reflection on justice and rights in care. In turn, this helped them to reflect about the

Table 1. Absolute frequencies of keywords categorized by topic.

Topic			Total	EPIN 1	EPIN 2	EPIN 3
Humanization (empathy, listening, humanization, holism, etc.)			53	19	20	14
Nursing care (self-care, accompaniment, and chronicity)			30	16	5	9
Patient experience (illness, lived experience, and expert patient)			16	0	8	8
Communication (healthcare relationship, communication, trusting relationship, etc.)			27	6	16	5
Patient-centered care*	Sharing (co-responsibility, patient decision, participation, and active patient role)		17	8	7	2
	Caring (various emotions, or the word "emotion")	Emotional care	7	0	1	6
		Emotional sphere/ emotions	10	7	2	1
Justice (equity and prejudice)			6	6	0	0
Rights** (autonomy and rights)			7	0	0	7
Total			173	62	59	52

The words that are most frequently used as keywords are in parentheses.
*"Patient-centered care" only appeared once as a keyword. **The rights to which they were referring were not specified.

theoretical/practical education they had been receiving in their degree and on justice and rights in the care they provide as students.

Breaking the mold of professional-centered education

The students recognized that their entire education, both theoretical and practical, had been focused on the professional and not on the patient. All the education they had received had been taught by professionals, based on the biomedical model and on how they should act as professionals. The nurse educator presents a health problem and suggests the appropriate management thereof as a nurse. They had been taught the experience of the professional, not that of the patient. The experience of expert patients gave them real and personal examples of how they manage their health and illness to guide them in more humanized care. Through a process of introspection, they recovered an understanding of the patient as a person, a human being with feelings, beliefs, and expectations.

> I think there is sort of a gap between everything we're taught and the patient's experience. And they prioritize teaching us the perspective of the professional (GF2).

> If a professional explains it to you, that's fine and good, but when the patient explains it, that's when you really know what you have to do and how you should approach it (GF2).

Students were not aware of reproducing a mostly non-participatory model focused on the professional. They point out that, throughout the practicum, they must model the behaviors of the nurse educator, in whatever and however they do things because their grade depends on it. In this way, students believed they had been reproducing paternalistic and dehumanizing behaviors since it was the nurse who decided how to manage the health problem, overlooking the patient's perspective.

Table 2. Absolute frequencies of knowledge pearls categorized by topic*.

				Total	Justice lecture	EPIN 1	EPIN 2	EPIN 3
Patient-centered	34	Caring (23)	Emotional care patient *When we focus on the needs and experiences of the patient and not just on the diagnosis and treatment, then the patient feels heard and, therefore, cared for*	23	3	14	1	5
		Sharing (8)	Patient participation *When the nurse plans the treatment with the patient, the patient can express any needs that are not covered*	1		1		
			Shared decisions *When the health professional provides information on all the existing treatment alternatives, the patient is involved in making informed decisions about their health*	5	1	4		
			Inform/educate the patient *Giving the patient information on how to manage their disease and helping them understand it encourages good self-care*	1				1
			Knowledge exchange *Active listening generates a relationship of trust and results in an exchange of the healthcare professional's knowledge and the patient's experience, helping to develop new knowledge applicable to other patients*	1			1	
		Co-responsibility for care *Health professionals must ditch paternalistic attitudes and promote patient-professional co-responsibility so that the patient has all the options and can make decisions with the professional team. P18EPIN1*		1			1	
		Patient-centered *When health professionals include the self-care alternatives of the expert chronic patient, their autonomy and adherence to treatment are promoted*		2			1	1
Humanization	27	Humanization of care *When health professionals are able to listen to the patient and not judge them regarding their illness or lifestyle, that's when they are really capable of caring for and treating this person, because this allows them to build a relationship of trust between them*		13	1	1	7	4
		Understand the patient *When the professional-patient relationship is based on understanding the patient's decision and accompaniment, the patient feels that they can share their doubts and feelings about their health process. P2EPIN2*		6			6	
		Humanization of the professional *When health professionals become aware of their prejudiced attitudes and avoid them, then they can provide more humanized care that is focused on the needs of the patient*		8				8
Social justice	11	Non-paternalistic relationship When as health professionals we offer the means, resources, and options for personal decision-making, we help put an end to the paternalistic pattern		1			1	
		Fairer nursing care without prejudices When nurses reflect on our prejudices, we protect people's right to equality and to be cared for by health institutions without discrimination		7	7			
		Equity *When each person is given what they need, equity is promoted*		1	1			
		Justice *When all people, no matter where they come from, have access to all the available health resources, we will be offering equitable, fair, and egalitarian healthcare*		2	1	1		

(continued)

Table 2. (continued)

			Total	Justice lecture	EPIN 1	EPIN 2	EPIN 3
Rights	6	Right to decide *When health professionals inform the patient and respect the decisions that they make regarding their health, the [patient's] right to decide about their health and treatment is guaranteed*	3	3			
		Right to health *When health professionals treat the patient as a person beyond their diagnosis, we respect their right to health*	1	1			
		Patient rights *When nurses recognize their [own] prejudices and ignore pre-established social patterns, they take the first step to stop violating people's rights*	1	1			
		Respect patient rights *A process of introspection by health professionals contributes to the beginning of respect for the human rights of patients*	1	1			
Nursing care	7	Nursing care *When nurses bear in mind all the dimensions that make up human beings, they will receive comprehensive intervention that has a positive impact on their physical and psychological recovery and on their social well-being*	7	3	1	3	
		Total	85	23	22	21	19

One example of a knowledge pearl is included for each topic.

> I would have said participatory (…) Because at that time I thought you did that (…) but from the EPIN I realized that you didn't. But in the moment you think you are doing it right, you're not aware. (GF1)

> You grow with this perspective (…) from the first year, they explain the whole biomedical model, what you have to do (…), they focus more on your concerns as a professional and that you must comply with, but not the person's concerns (GF1)

> I didn't usually introduce myself because no one else introduced themselves (…) Now, even when I'm alone, I always introduce myself; it's one of the things I've changed. (GF2)

Listening to expert patients not only fueled this reflection about what their education was like but also led them to contemplate and make changes in their practice as students. They reported feeling more prepared to communicate with the patient and to handle the healthcare relationship on their own without the supervision of their nurse educator because they felt capable of understanding the patient.

> I personally feel more, like more communicative with the patient (…) I now see myself as having more tools to talk with the patient. (GF1)

> Because I now ask what [the patient] needs a lot more, and not so much what I have to do… (GF1)

Self-reflection on justice and rights in care

Students said that they were able to detect the most obvious injustices such as racist and/or discriminatory attitudes and comments, and treating a patient differently based on their social class or type of illness. They sensed there were other injustices, such as those pertaining to everyday life, but were unable to label them. Following the intervention, they were able to describe them in terms of social injustice or violation of the patient's rights. To some extent, they recovered the language of justice and rights, as well as their meaning and importance in care. They become aware of two basic patient rights: the right to privacy and information.

> I noticed it after the EPINs. I saw that it [lack of information in the ICU] was bad during the practicum and later I thought: they [the family] have every right in the world to know, to be updated on the status, and receive information and not just… "Well, the doctors will be by soon". (GF1).

> Privacy, especially physical privacy, and privacy related to information, because sometimes during checkups things are shouted, like "Patient so-and-so has X-Y-Z…" (GF2).

Speaking of social justice and PCC was difficult. During the focus groups, the right to privacy and the right to information were particularly relevant, but nothing else. It was when students spoke about the knowledge pearls exercise and justice and sexual rights presentation that the patient's right to make their own decision came up very briefly.

> We used to tell them ["We are going to do an IV in"] but you did not expect them to possibly say no. But now you're aware that they can say no (…) You didn't even consider that they had the right to say "No, I don't want to." (GF2).

Discussion

This study incorporated the concept of social justice and patient rights in the education of nursing students using think-pair-share activities (EPINs and a presentation). EPINs helped students break out of the mold of a nurse-centered education through reflection. The quantitative content analysis of the knowledge pearls and keywords shows that when the content of think-pair-share activities explains concepts of social justice first and then exemplifies them, as with the justice and sexual rights presentation, the takeaway (knowledge pearls and keywords) was mostly related to the specific concept. On the other hand, following an illness narrative such as an EPIN, the takeaway was essentially focused on humanization and caring. Keywords such as PCC and the patient rights involved in sharing (such as the right to information and the right to make decisions about one's health) were not used.

The results indicate that think-pair-share activities helped students break out of the mold of professional-centered education and adopt a reflective attitude toward the education they had received throughout their degree. The professional-focused model revolves around the issue of managing the patient and their non-compliance, overlooking their perspective and offering solutions and adequate management only from the perspective of the professional.[36] While it is true that the teaching discourse includes PCC theory, the teaching activities employed do not manage to include the value of the patient as an agent of their own health rather than the object of care. When students reported that before completing the think-pair-share activities they had never self-defined the care they provided as mostly non-participatory, it is because they're operating under a process-centered communication model. The students in the focus groups reported that after listening to expert patients they felt more prepared to communicate with patients and handle the healthcare relationship on their own without the supervision of their nurse educator. The students made a switch, understanding the need to move from process-centered communication to PCC. The type of communication that is taught and observed in their clinical practices presents nurses who ask questions of patients/caretakers to understand the conditions of their care but who do not encourage them to convey their ideas about their care needs.[37] Patients/caretakers are recognized as people with unique care needs but not with the capacity to influence in the care process[37] despite the PCC theory content. Asking the patient what's important to them rather than what's wrong with them is a simple and subtle change that empowers and enables them to contribute their own care needs.[38] The think-pair-share activities led to changes in their practice, thus meeting one of the objectives of social justice: action that promotes social change. We cannot venture to say that this is a structural change, but we can confirm that for the students in the focus groups, it was the trigger of change. A small, localized, personal change, but a change nonetheless.

As reported in other studies, affective learning strategies yield better results than cognitive strategies by reinforcing the integration of knowledge with emotions, attitudes, and personal beliefs.[27,32,33] Improving students' capacity for reflection is one of the basic learning outcomes for which EPINs have proven effective.[32,33] Through reflection, one can review experiences, develop new perspectives, work their cognitive understanding, improve their affective abilities,[39] and integrate the affective aspects of their learning. Participating in activities that provide a change in perspective, focusing on others, instead of activities focused on oneself, improve acquisition of affective learning.[39] The EPINs allowed students to connect with patients on a personal level; they observed injustices in the healthcare relationship and their consequences from the perspective of real patients.[29] Affective strategies help students reflect because they learn to identify and consider their own experiences in relation to the narratives. They can connect the experience of patients with their own experiences as students. The narratives provide rich, contextual examples of situations they might face as future nurses, some of them negative and serving as a warning of what avoid.[29]

The results clearly point to the EPIN as a strategy that helps students to value a PCC model, with greater reference to caring (understood as tending to the emotional needs of the patient) than to sharing (desire for information and to be part of decision-making) and the need to humanize the care provided. The presentation did not have a clear impact on this aspect, but it did influence students' understanding of the concepts of justice and rights. The EPINs also made them aware of another reality: that of their clinical practicums, where they did not observe PCC, despite more theory-based education and intentionality in the matter. A model of care that they demand due to its importance and in which humanization is fundamental. Various care initiatives have emerged in recent years promoting PCC and the humanization of care. Professionals also recognize the need to incorporate humanized care into daily work.[40] However, it is not easy to implement or maintain[41] due to relational, organizational, and structural barriers.[40,42] Despite all this, the students did not fully perceive PCC, which is evidence that the tendency toward the biomedical approach rather than humanized nursing care still exists in health institutions and nursing education and practice.[43] The results of this study emphasize the current gap between the expectations of the actors involved in the care process (patients, caregivers, and healthcare providers) and routine clinical practice.[42] Both aspects are important given that a misalignment between the dominant values of the biomedical model and those of professionals can result in emotional responses when they recognize this and feel stuck between what they know they should be doing and what they do.[44] While we do not know if the students have developed such emotional responses, they have become aware of the misalignment.

Moreover, our results show that since talking and thinking about a PCC model is done from a perspective focused on caring (the more emotional part of care), sharing (the part linked to shared decision-making) does not appear so clearly in either the knowledge pearls or focus groups. As reported in the literature, one of the obstacles to the implementation of the PCC model is the lack of a clear definition.[22] In some definitions, PCC is care that is respectful and responsive to the wishes of patients.[45] According to the Institute of Medicine, it refers to respectful care that includes attention to the patient's unique values, beliefs, needs, circumstances, and shared decision-making. Shared decision-making as part of PCC[46] is considered the pinnacle of PCC,[47] the cornerstone of PCC.[48] Despite this, the use of PCC in clinical practice is suboptimal, focusing mainly on treatment options rather than collaboration between the patient and professional in all aspects of clinical care.[49] In accordance with the literature, our results show that while the first aspect seems integrated at a theoretical level, the fact that students are not aware of patients' right to make decisions about their own health confirms that one of the greatest challenges continues to be routinely involving patients in decision-making.[47] Social justice refers not only to the protection of marginalized groups but also to the ability to seize opportunities and exercise rights.[50]

Conclusions

The faculty-assisted presentation and EPINs led by expert patients as think-pair-share activities were useful to provoke self-reflection among students, who identified aspects to change in their own practice, as well as deep

reflection about the education they had received during their degree, both of which promote change. Both think-pair-share activities have had an impact on the value placed on the PCC model, although they demonstrate the challenges of transferring it to care practice. The students underscore the emotional part, forgetting the part related to decision-making as an individual right of people.

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Conflict of Interest Statement

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author [AAM], upon reasonable request.

References

1. Mitchell PH. Nursing ethics and social justice. *Int Nurs Rev* 2016; 63: 1–2.
2. Habibzadeh H, Jasemi M and Hosseinzadegan F. Social justice in health system; a neglected component of academic nursing education: a qualitative study. *BMC Nurs* 2021; 20. Epub ahead of print 1 December 2021. DOI: 10.1186/s12912-021-00534-1.
3. Kpandemoi Abu V. Let us be unequivocal about social justice in nursing. *Nurse Educ Pract* 2020; 47: 102849.
4. Einhellig K, Gryskiewicz C and Hummel F. Social justice in nursing education: leap into action. *J Nurs Care* 2016; 5: 1–7.
5. Rozendo CA, Santos Salas A and Cameron B. A critical review of social and health inequalities in the nursing curriculum. *Nurse Educ Today* 2017; 50: 62–71.
6. Shahzad S, Younas A and Ali P. Social justice education in nursing: an integrative review of teaching and learning approaches and students' and educators' experiences. *Nurse Educ Today* 2022; 110. Epub ahead of print 1 March 2022. DOI: 10.1016/j.nedt.2022.105272.
7. United Nation Development Programme. The SDGS in action 2023. Available at: https://www.undp.org/es/sustainable-development-goals 2023 (accessed 11 July 2023).

8. Khazanchi R, Evans CT and Marcelin JR. Racism, not race, drives inequity across the COVID-19 continuum. *JAMA Netw Open* 2020; 3: e2019933.
9. Pagel C. There is a real danger that covid-19 will become entrenched as a disease of poverty. *BMJ* 2021; 373: n986.
10. American Association of Colleges of Nursing. *Social determinants of health concept*, 2023; Available at: https://www.aacnnursing.org/essentials/tool-kit/domains-concepts/social-determinants-of-health (accessed 12 July 2023).
11. Marmot M and Bell R. The sustainable development goals and health equity. *Epidemiology* 2018; 29: 5–7.
12. Padrón KM and Pederson C. Using a social justice lens in nursing: intersectionalizing person-centered care with transgender and non-binary patients. *Creativ Nurs* 2022; 28: 261–265.
13. Gergel T. The 'Mental Health and Justice Project': using interdisciplinarity to move beyond impasse in disability rights. *Int J Law Psychiatr* 2020; 71. Epub ahead of print 2020. DOI: 10.1016/j.ijlp.2020.101570.
14. Hellman AN, Cass C, Cathey H, et al. Understanding poverty: teaching social justice in undergraduate nursing education. *J Forensic Nurs* 2018; 14: 11–17.
15. Roy K, Hunt K, Sakai K, et al. Social justice in nursing education: a way forward. *J Nurs Educ* 2022; 61: 447–454.
16. Houston D, Rzayeva R, Holmes M, et al. Implementing diversity and social justice curriculum for prelicensure nursing students. *Nurse Educ Today* 2023; 120: 105660.
17. Adams M. Social justice education. *The Encyclopedia of Peace Psychology* 2011; Epub ahead of print 13 November 2011. DOI: 10.1002/9780470672532.WBEPP258.
18. Igoumenidis M, Kiekkas P and Papastavrou E. The gap between macroeconomic and microeconomic health resources allocation decisions: the case of nurses. *Nurs Philos* 2020; 21: e12283.
19. Greene SM, Tuzzio L and Cherkin D. A framework for making patient-centered care front and center. *Perm J* 2012; 16: 49–53.
20. Kumar R and Chattu V. What is in the name? Understanding terminologies of patient-centered, person-centered, and patient-directed care! *J Fam Med Prim Care* 2018; 7: 487–488.
21. Håkansson Eklund J, Holmström IK, Kumlin T, et al. "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Educ Counsel* 2019; 102: 3–11.
22. Robinson JH, Callister LC, Berry JA, et al. Patient-centered care and adherence: definitions and applications to improve outcomes. *J Am Acad Nurse Pract* 2008; 20: 600–607.
23. Lusk JM and Fater K. A concept analysis of patient-centered care. *Nurs Forum* 2013; 48: 89–98.
24. Manthorpe J and Samsi K. Person-centered dementia care: current perspectives. *Clin Interv Aging* 2016; 11: 1733.
25. Glicksman S, Goldberg C, Hamel C, et al. Rights-based and person-centered approaches to supporting people with intellectual disability: a dialectical model. *Intellect Dev Disabil* 2017; 55: 181–191.
26. Lee CC. *Social justice: a moral imperative for counselors.* Alexandria: ACAPCD-07, 2007.
27. Einhellig K, Hummel F and Gryskiewicz C. The power of affective learning strategies on social justice development in nursing education. *J Nurs Educ Pract* 2014; 5. Epub ahead of print 10 November 2014. DOI: 10.5430/jnep.v5n1p121.
28. LeBlanc RG. Digital story telling in social justice nursing education. *Publ Health Nurs* 2017; 34: 395–400.
29. Hytten K and Bettez SC. Understanding education for social justice. *Educ Found* 2011; 25: 7–24.
30. Neumann JA and Forsyth D. Teaching in the affective domain for institutional values. *J Cont Educ Nurs* 2008; 39: 248–252.
31. Towle A, Brown H, Hofley C, et al. The expert patient as teacher: an interprofessional Health Mentors programme. *Clin Teach* 2014; 11: 301–306.
32. Feijoo-Cid M, Moriña D, Gïménez-Ibáñez R, et al. Expert patient illness narratives as a teaching methodology: a mixed method study of student nurses satisfaction. *Nurse Educ Today* 2017; 50: 1–7.
33. Feijoo-Cid M, García-Sierra R, García García R, et al. Transformative learning experience among nursing students with patients acting as teachers: mixed methods, non-randomized, single-arm study. *J Adv Nurs* 2022; Epub ahead of print 16 July 2022. DOI: 10.1111/JAN.15364.

34. Towle A and Godolphin W. Patients as teachers: promoting their authentic and autonomous voices. *Clin Teach* 2015; 12: 149–154.
35. Hsieh H-F and Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; 15: 1277–1288.
36. Poskiparta M, Liimatainen L, Kettunen T, et al. From nurse-centered health counseling to empowermental health counseling. *Patient Educ Counsel* 2001; 45: 69–79.
37. Kwame A and Petrucka PM. A literature-based study of patient-centered care and communication in nurse-patient interactions: barriers, facilitators, and the way forward. *BMC Nurs* 2021; 20. Epub ahead of print 1 December 2021. DOI: 10.1186/S12912-021-00684-2.
38. Mastors P. What do patients want, need, and have the right to expect? *Nurs Adm Q* 2018; 42: 192–198.
39. Donlan P. Developing affective domain learning in health professions education. *J Allied Health* 2018; 47: 289–295.
40. Meneses-La-Riva ME, Suyo-Vega JA and Fernández-Bedoya VH. Humanized care from the nurse–patient perspective in a hospital setting: a systematic review of experiences disclosed in Spanish and Portuguese scientific articles. *Front Public Health* 2021; 9. Epub ahead of print 3 December 2021. DOI: 10.3389/fpubh.2021.737506.
41. Ortiz MR. Best practices in patient-centered care: nursing theory reflections. *Nurs Sci Q* 2021; 34: 322–327.
42. Busch IM, Moretti F, Travaini G, et al. Humanization of care: key elements identified by patients, caregivers, and healthcare providers. A systematic review. *The Patient - Patient-Centered Outcomes Research* 2019; 12: 461–474.
43. Díaz-Rodríguez M, Alcántara Rubio L, Aguilar García D, et al. Orientaciones formativas para un cuidado humanizado en enfermería: una revisión integrativa de la literatura. *Enfermería Glob* 2020; 19: 640–672.
44. Marcellus L, Pauly B, Martin W, et al. Navigating conflicting value systems: a grounded theory of the process of public health equity work in the context of mental health promotion and prevention of harms of substance use. *BMC Publ Health* 2022; 22. Epub ahead of print 1 December 2022. DOI: 10.1186/S12889-022-12627-W.
45. Brickley B, Williams LT, Morgan M, et al. Patient-centred care delivered by general practitioners: a qualitative investigation of the experiences and perceptions of patients and providers. *BMJ Qual Saf* 2022; 31: 191–198.
46. Kuosmanen L, Hupli M, Ahtiluoto S, et al. Patient participation in shared decision-making in palliative care – an integrative review. *J Clin Nurs* 2021; 30: 3415–3428.
47. Barry MJ and Edgman-Levitan S. Shared decision making — the pinnacle of patient-centered care. *N Engl J Med* 2012; 366: 780–781.
48. Finderup J. Shared decision making—the cornerstone in person-centred care. *J Ren Care* 2021; 47: 144–145.
49. Tonelli MR and Sullivan MD. Person-centred shared decision making. *J Eval Clin Pract* 2019; 25: 1057–1062.
50. Ornstein AC. Social justice: history, purpose and meaning. *Society* 2017; 54: 541–548.