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Developing and Translating a New Model for Teaching Empowerment Into Routine Chronic Care Management: An International Patient-Centered Project

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Abstract

Background: Health professional education has been criticized for not integrating patient expertise into professional curricula to develop professional skills in patient empowerment. **Objective:** To develop and translate a new expert patient-centered model for teaching empowerment into professional education about routine chronic care management. **Methods:** Eight Finnish patients (known as expert patients), 31 students, and 11 lecturers from 4 European countries participated in a new pilot intensive educational module. Thirteen focus groups, artefacts, and an online student evaluation were analyzed using a thematic analysis and triangulated using a meta-matrix. **Results:** A patient-centered pedagogical model is presented, which describes 3 phases of empowerment: (1) preliminary work, (2) the elements of empowerment, and (3) the expected outcomes. These 3 phases were bound by 2 cross-cutting themes "time" and "enabling resources." **Conclusion:** Patient expertise was embedded into the new module curriculum. Using an example of care planning, and Pentland and Feldman's theory of routine organization, the results are translated into a patient-centered educational model for teaching empowerment to health profession students.

Keywords

chronic care management, empowerment, patient centered, education, routine theory

Introduction

Practitioners may use patient empowerment to promote patient centeredness to effectively manage the increasing number of people living with chronic disease (1,2). Empowered individuals may adapt better to chronic illness, experience better quality of life/well-being and greater independence, and be more satisfied. This highlights the importance of clinician interpersonal skills, role expectation, and promoting patient autonomy in decision-making (3). However, health professional education has been criticized for not integrating patient expertise into professional curricula to develop professionals' patient empowerment skills (4,5).

There are 2 levels to empowerment—individual/self and community/social (1,6). Individual/self-empowerment looks to increase patient self-confidence and shift power between individual patients and professionals. Patients take ownership, control, and responsibility for their health, express choice (7,8), and change their lifestyle behaviors as they see fit (1,6,8). Community/social empowerment

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involves developing strategy, collective social actions, and processes, so groups/communities gain control, influence change, and develop and improve people's circumstances (7). Countries such as Australia have looked beyond individual clinician–patient relationships to include the "whole person" in the wider community in a rights-based, social justice approach (2).

Chronic diseases are defined by the World Health Organization (WHO) in 2017 as diseases that "*are not passed from person to person. They are of long duration and generally slow progression*" (9). There are 4 main types, cardiovascular, cancers, chronic respiratory, and diabetes. Based on the most recent data available on mortality rates published in 2014 by the WHO, chronic diseases contribute to over 68% of global deaths (10) and 88% of all Europeans (11). In the countries participating in this project, cardiovascular diseases accounted for 64% of total Bulgarian deaths in 2014, 40% in Finland, 31% in UK (including Wales), and 32% in Ireland (11). Major risk factors are obesity and tobacco use. World Health Organization Member States agreed a global action plan with 9 voluntary global targets to prevent and control these diseases by 2025 (12). The associated European Assessment Guide includes "population empowerment" as a fourth challenge. It calls for people to become "frontline workers" in managing their disease. In challenge 9, it questions the training and process of "integrating evidence into practice" (13). Governments have addressed this by developing guidance on personalized care planning (14–16). This is a clinical practice routine requiring "transformational change" by actively involving patients at its center, helping them to drive the care planning process (14). Patients' involvement in health and social care professional education is increasing, but little is known about how to integrate their expertise into curricula.This article describes how a new patient-centered model for teaching empowerment was developed and translated into routine chronic care management (CCM) using care planning as an example.

Methods

Project Setting

A pilot intensive educational module "Empowering Service Users through Support and Involvement in Chronic Care (ESSI)" was developed by an international team between 2013 and 2014 and undertaken in Finland. Its purpose was to enhance health and social care students' skills for patient empowerment and cultural sensitivity in CCM. Central to the module were face-to-face engagement sessions between expert patients and students and students working together to initiate a personal empowerment process through a "progressive inquiry" framework (17).

The ESSI had 3 stages:

1. Student preparation in home countries—Production of individual student personal life story via photos and captions and developing group presentation of home country culture 4 months before the intensive teaching module.
2. Intensive 2-week course in Finland—Students were divided into 8 cross-cultural teams (3-4 students each) to work with a named expert patient living with a chronic disease who had knowledge of a relevant voluntary organization. Students and patients met face-to-face 2 to 3 times. Between meetings, there were lectures and seminars about empowerment tools, dialogical communication, caring ethics, and service design. Teams used the chronic care model for reference and tools such as empowering photography (photograph that represents the quality-of-life experience), storyboards, and mind mapping to capture experiences with patients. Each team presented the materials produced in a final exhibition to which patients were invited.
3. Reflection on returning home—Students produced an individual "letter of wisdom" based on their experiences for the next generation of students.

Participants

The 8 Finnish expert patients, 31 students, and 11 lecturers were from Finland, Ireland, Bulgaria, and Wales. The language of communication was English. Students represented nursing, occupational therapy, dental hygiene, social care, and health-care management. Lecturers represented nursing (adult, mental health, and child health), public health nursing, health and social care management, and medicine.

Project Design

This multimethods inductive (discovery) project (18) included 13 focus groups, artefacts, and an online student evaluation. Students were divided into 3 cross-cultural groups and interviewed at the beginning, middle, and end of the module. The single cross-cultural lecturer group was interviewed at the same 3 stages. One patient focus group was conducted at the end because of patients' personal, work, and lifestyle commitments.

The focus group method is a qualitative semistructured interview technique to collect data through group interaction (19). The focus groups were conducted in English, except for the patient focus group that used Finnish. Data were collected by designated lecturers. Artefacts produced by students, staff, and patients included a WordPress learning environment, closed Facebook page, student online evaluation questionnaire, photographs, Haiku poems, cultural observational notes, and letters of wisdom. These were gathered throughout the data gathering period.

Data Analysis

Data were transcribed and analyzed separately in 3 parts by 3 separate lecturers— artefacts (D.P.), student and teacher

Table 1. Six-Step Process of Inductive Thematic Analysis.

Step 1: Data familiarization	Data transcribed, read and reread. Initial ideas list generated from data
Step 2: Initial codes generated	Notes written on text, important patterns highlighted. Initial thematic map produced to conceptualize data patterns and interrelationships
Step 3: Data sorting	Relevant coded data extracts sorted into preliminary main themes and subthemes
Step 4: Themes reviewed	To see whether they worked in relation to data set. Confirmed thematic map generated
Step 5: Main themes and subthemes named	see Table 2
Step 6: Report produced	Data presented to provide an understanding of model as a whole (see Figure 2)

focus groups (C.W.), and patient focus group (L.K.). These were triangulated (C.W.) using a Meta matrix (20) to answer the question "What are the elements of empowerment in the expert patient–student team relationship?"

A 6-step process of inductive thematic analysis method was used to identify, analyze, and report patterns (themes; see Table 1) (21). Ethical approval was obtained via University of South Wales supported by each participating university's ethical boards. All participants provided written informed consent.

Results

Results are presented in a model that includes 3 phases of empowerment and 2 cross-cutting themes (see Table 2). Phase 1, "preliminary work"; phase 2, "elements of empowerment"; and phase 3, "expected outcomes." These 3 phases were bound by 2 cross-cutting themes—"time" and "enabling resources." Time in phase 1 was represented by having enough time to plan and reflect; phase 2, being patient and taking time to get to know patients; phase 3, taking time to reflect on expected outcomes. "Enabling resources" were personal characteristics and practical methods. Personal characteristics included confidence, being open-minded and flexible, inner strength or bravery to overcome fears of the unknown, and communication skills, for example, open-ended questioning. For many, using English on a daily basis and making arrangements for children or older family members were real obstacles. Participants who volunteered were considered by peers as adventurous for developing new skills.

Practical resources included the tools, artefacts, and meeting places, for example, patient's home, library, charity/leisure facilities that patients chose, described as "*safe gentle but persistent space[s]*" to build student–patient relationships.

Three phases of empowerment are:

1. *Preliminary work* includes subthemes: "preparation" and "student self-reflection."

Preparation: Preparing for ESSI and patient meetings was important for maximizing the empowerment process. Staff and students respected its importance in increasing and sharing their knowledge of disease, the chronic care model, changing health and social care systems in each country, understanding new tools such as empowering photography, and raising awareness of patients' circumstances.

Shared information also alleviated fears about their new working context, the Finnish culture, and personal and university expectations. Patients acknowledged an awareness of this preparation in the quality of student engagement.

Student self-reflection: Using and sharing personal individual and family lifespan photographs before engaging with patients was key to self-reflection. Initially, students thought about their own lives through photographs in isolation and then later collectively in cross-cultural groups as they developed their final exhibition. They appreciated the difficulty of sharing personal moments with strangers. Students later recognized some empowering aspects of their own reflected in patients' life stories (eg, overcoming personal difficulties and finding comfort in looking at an experience through another person's eyes).

2. *Elements of empowerment:* Patients and students nurtured elements of empowerment through 4 subthemes: expressing their "life story," "compassionate care," "expert identity," and "learning through action" (Figure 1 and Table 2).

Life story: Expert patients were empowered by telling their personal life stories to student teams. Just like the students had previously prepared themselves, each expert patient reflected on personal memories during the student group meetings and told their own life story in different ways. This was healing and therapeutic for them all. Patients connected with students by using their life stories and inviting them to locations that were important in helping them "*pull through*" their chronic illness or condition.

There are 4 empowering elements within the life stories: (a) patients and students recognized individual positive aspects of their lives, (b) they noticed how they had pulled through bad times, (c) they enjoyed positive feedback from each other, and (d) they saw their own lives with "outsider" eyes.

Table 2. The Model Themes and Participant Statements.

Model	Subthemes	Participant Statements and Poems
Cross-cutting themes	Time and enabling resources	"need to be in a positive way curious, be brave and move on your discomfort area."
		"The first meeting was in my home . . . I happened to have pictures on my computer and started from the wedding picture of my mother and father. I was there as a little child and then later sick in a wheelchair. I showed pictures from my entire life span. They were very interested in me and my home. We spoke about the legislation and aid facilities. Then we sat around the kitchen table and had coffee and tea . . . They were interested in my confectionery . . . The discussion was as if we were old friends . . . There was a social work student in the team and she brought up to conversation about disability services, personal assistants and transport services."
		"being aware-in the moment."
Phase 1: The preliminary work	Preparation	"Because of this preliminary work we understood our clients a bit better."
		"I noticed that they had done a lot of work in advance in preparing themselves into the meeting."
	Student self-reflection	"Sometimes thinking about our lives and our past isn't easy thing to do and when you have to talk about those things to a stranger that's more difficult."
		"When I meet people from other countries I can try to look at things through their eyes. It's quite comforting."
		"Past is part of you Things that create your future What is truly you"
Phase 2: Elements of empowerment	Life story	"We went through my whole life span and sickness history. In the second meeting they asked me what I would do if I had one healthy day. Whether there is something I have missed and would like to do? . . . In this point I had a very strong feeling that I have pulled through so many bad things and will survive in the future."
		"We went through my life and were looking for its empowering elements. It was a very positive process. The entire day I felt that I had been in my past and I was amazed how many good things we had found from there. And in the everyday life you fight with those small negative things. . . . In fact, the meetings were very empowering because I had to speak out the things that empower me."
	Compassionate care	"I was astonished by the fact that we did not know each other in advance and were total strangers without any earlier care contact. We started from an empty table. First I tried to tell them about the organization. But they said they are interested in me and my story. Well, I had plenty of material from my life that I had worked and they were extraordinarily interested in it. I had pictures and a written story through the pictures. And the students were asking: tell more about this. . . . Goodness, it was a powerful experience to me and also the students. In such a short period something grew up that cannot be explained in words. It was a deep consensus; we understood the message of the meetings, although we did not plan it in advance."
		"The basic for all is in a human encounter . . . I think us all (service users) and (students) reached this. Although we came from different cultures we found the core, the humanity. We all want to become heard and acknowledged. If professionals dare to throw themselves into this kind of encounter as these students did. . . . This constructs both parties . . . is this genuine love or care or sympathy?"
		"There was a warm climate in the meetings and we got to know each other very fast. The atmosphere was caring. They were interested in me and empathetic."
	Expert identity (by experience)	"I got a strong feeling to increase this type of work, if I will have healthy days left. . . . This is what empowers me. After all I did not die from the cancer although I have had it so many times. Every time I have been telling my life story to others I have received positive feedback. Actually I should do it more often and empower others."
		"It was a good idea to arrange one meeting in the space on the cancer society as we spoke much about the patient organizations and they were interested in these. They noticed that I am involved in many of these things. We spoke how much joy and benefit I have had from it (patient organization) and hopefully the other way round. They also had concrete information from there. . . . For instance the Bulgarian student was very impressed."
		"We also discussed about the peer support, its importance already in the diagnostic crisis phase. . . . A person must learn to recognize the situation and thus accept and adjust with the situation. And a strong push ahead."
		"I have normally supported spinal injury patients in face-to-face meetings . . . group conversation (like we did in this project) makes the support much stronger as the conversation starts meandering around. And the stories we tell will survive. It is what touches people; that there is a human being behind the story."

(continued)

Table 2. (continued)

Model	Subthemes	Participant Statements and Poems
	Learning through action	"dynamic programme, a river responding to an amount of rain and things around it 'It's language sensitivity I suppose, and coming across well in you know, not just with your peers and your colleagues but also with a diverse range of service users." "I actually think some of the pictures didn't need the words because the pictures told the story themselves." "I have the same feeling than others. Before this I have not realized how important certain things in my life are. During the meetings these were repeated and were also summarized in students' displays in the final exhibition. . . . I have been wondering, how we came to such a common understanding as we spoke different languages." "You are going to a foreign country is almost like going into a hospital and not knowing and not understanding the language and that is a very good way of putting it." "They put significant efforts to crush the barrier "lecturer–student". It was example for management with delegation of rights and responsibilities to us. It reflects my idea for cooperating and for me it was pleasure to be part of such work-model." "Yes, they were very skilled. They ensconced themselves at the situation of a faint-hearted 8 years old child when I told my story. It was kind of a drama that we created and wrote together. This type of experience does not take place even in any good therapy . . . their competences for working were on that level." "I am trying to work in a way that we all bring something to the table to help, because we all have something that we can bring to the table" "What I have learned . . . is that people are just people, where as we express things in our own language in different words, but the feelings are the same. We all feel love and pain and we are afraid, we have the need for belonging and friendship. So I think we all need the same things.
Phase 3: The expected outcomes	Patient in control	"As well it makes you focus less on the actual illness the person has . . . there's a lot more in the equation than just this sick person, this is their illness, this is their symptoms." "Come and walk with me See the change in yourself Let me walk with you"
	The changed student	"it has made me want to push myself to achieve high levels of education but to also always make time for family and friends and to treasure these moments and to constantly create new memories. It also made me to reflect on my life so far and I believe I have been truly blessed in life so far." "Now I see everything in different way and am grateful for every moment there. In the future I will use every method and every word to be more helpful to the patients." "I am trying to work in a way that we all bring something to the table to help, because we all have something that we can bring to the table" "I think from talking to the clients is that level of awareness and that insight you get from their lives, that it's definitely going to affect the way you talk to people. It's like when you look at a photo, it's just so much history behind it, it's the same with people you'd see every day passing by. There's just so much history there. You can never make assumptions about anything. I think that's definitely already a change that I see in myself."

Compassionate care: Patients felt empowered by the compassionate care (Figure 2) they experienced during the student meetings and the ESSI final exhibition. Students were described as being mature, genuinely interested in the patients, and wanting to learn from them. Most student teams were interprofessional, which broadened the meeting dialogue content. Four empowering elements were identified in compassionate care: (a) empathy and interest toward service users, (b) experience of mutual understanding, (c) sense of warm atmosphere, and (d) expressed professionalism.

Expert identity (*by experience*)*:* The patient–student relationship brought out the "expert identity" of patients based on their experiences of their individual chronic disease, which they found to be empowering. When meeting student teams, expert patients were poised between being a patient and a peer supporter. In their minds, meetings with students reminded them of their expert (by experience) role in their patient organizations. They supported students' learning in the way they worked with newly diagnosed individuals in their peer supporter role. They recognized the value of the work they were doing.

Three empowering elements were identified within expert identity (by experience): (a) sharing knowledge and experiences with students, (b) reflecting on the important contribution they made to students' learning and to patient

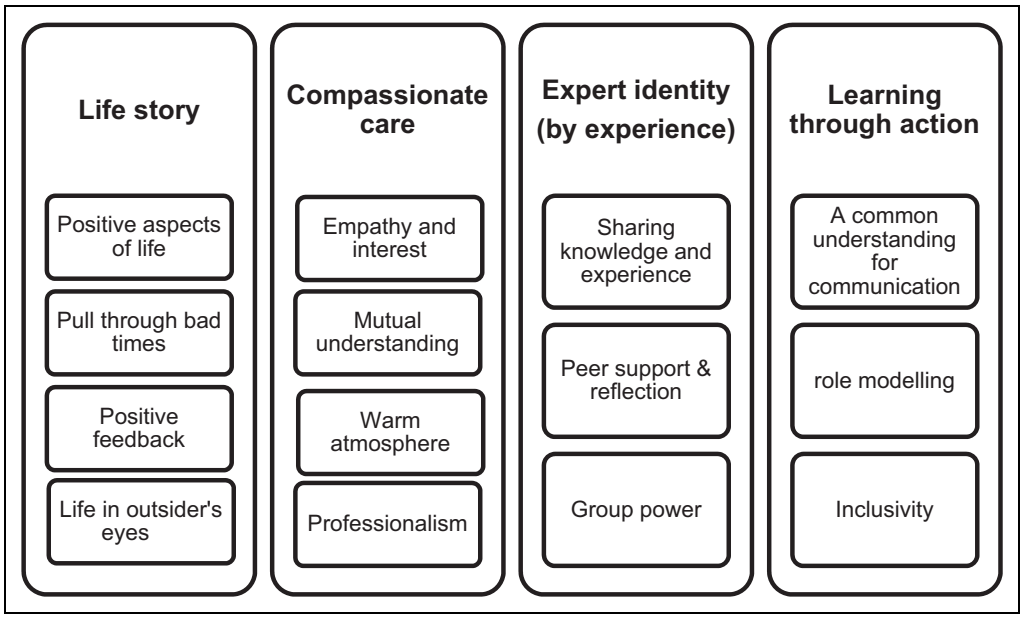


Figure 1. The elements of empowerment.

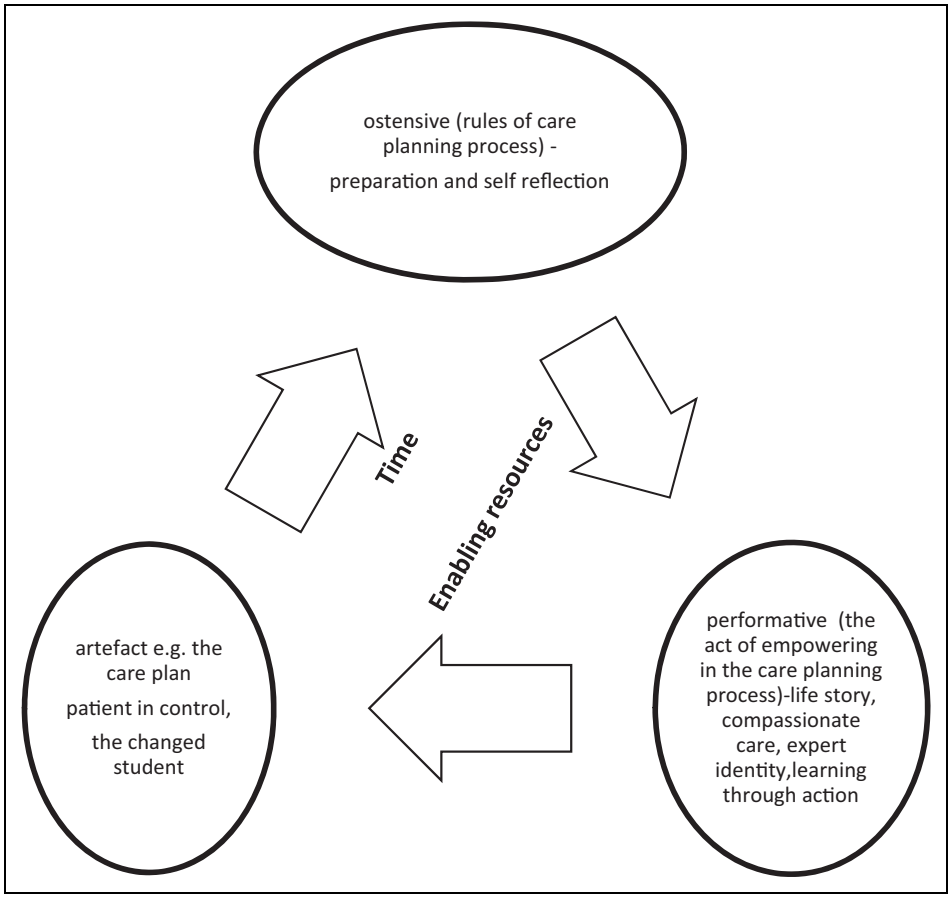


Figure 2. The new pedagogical model of empowerment using care planning as an example.

groups in their peer supporter role, and (c) valuing group power and wanting to transfer this model into their expert by experience work.

Learning through action: Bringing expert patients and students together within the learning process acted as a catalyst enabling participants to learn about

empowerment together and compare their experiences of the unknown to that of a patient admission to hospital. Students felt empowered, as they were able to "*put a face to the information.*"

Three empowering elements were identified within "learning through action": (a) common understanding for communication, (b) role modeling, and (c) inclusivity. The act of talking and listening about experiences enabled patients and students to find ways to overcome barriers and gain "*common understanding for communication.*" Patients and students spoke different languages, were from different professional groups, and had different life experiences. Nevertheless, they were sensitive to language and cultural differences. Both patients and students used different levels and methods of communication, for example, simple signs and storyboards.

The classroom role modeling exercise mirrored the empowering behaviors students saw in the expert patients. Lecturers removed barriers through delegation, demonstrating flexibility of time and action, acknowledging personal perspectives, being prepared but not over prepared so that it controlled the engagement, and managing the student–teacher relationship through motivation to cocreate via reflection on patients' stories rather than authority. Key to this was acknowledging that everyone had a contribution to make within the relationship through promoting inclusivity and working together.

3. *Expected outcomes:* This phase comprised of 2 themes–"patient in control" and "changed student."

Patient in control: Patients were recognized as being in control because it was their lived experience. They offered advice on what they saw as key principles of the process. Students were encouraged to be patient, flexible, and responsive. Acknowledging that patients had different experiences of their ill health was important, and time was needed to get to know them as people and not to "*push*" patients into expressing themselves too soon. It was important to get the balance right of giving and taking in the relationship and accepting that things don't have to be perfect.

Changed student: Students realized they had grown personally and professionally: appreciating life, changing their ideas and understanding about the importance of relationship, human need, and how the learning process may influence their future patient care. They saw patients in a different way from when the process started. Using the resources helped them make observations they would have previously missed, for example, patient and student body language.

It gave them a new sense of appreciation of the positive aspects of their own services and an understanding of what needed to change in order to empower people. They learned to appreciate and respect one another, especially patients whom they saw as activists, trying to empower people to gain better experiences of their CCM.

Discussion

This project aimed to identify the elements of empowerment in the expert patient–student team relationships.The model consists of 3 phases: preliminary work, elements of empowerment, and expected outcomes, bounded by time and enabling resources. Elements of empowerment are organized into 4 subthemes, "life stories," "compassionate care," "expert identity (by experience)," and "learning through action." These elements of empowerment do not occur in isolation but need to be planned, as both patient and student will be changed as a consequence. Although student–patient relationships have been studied previously (22), learning with patients, rather than just learning about them, is important (23). Bravo et al (1) have recently introduced a novel conceptual map of patient empowerment and identitied 5 key components: underpinning ethos, moderators, interventions, indicators, and outcomes. This conceptual map provides a wide framework for clinicians and researchers who are designing and evaluating interventions to promote patient empowerment at personal and social levels. They suggest that training health-care providers may be effective in promoting patient empowerment. Our model takes this a step further by intergrating patient expertise (by experience) into the module curriculum core. In this project, patients and students learned together to coproduce a common ground of understanding. This approach is essential if professionals are to learn to enable patients to routinely use resources such as care planning to self-manage (1,14).

Translating such a model into CCM is possible through using care planning as a practical example of a routine, that is, repetetive recognized pattern of interdependent actions (24,25). Care plans (a fundamental principle of CCM (2)) are formed by translating information from assessment into diagnosis and planning (26). Patients need to be active participants, and professionals need to identify and influence the level of patient "activation" in managing their own care and becoming expert (27).

To aid the translation of our findings into a practical model, we used Pentland and Feldman's theory of routine (24,25). This theory explains that organizational routines are dynamic systems that form patterns when people interact. Recognizing these patterns helps us to understand how our model can fit into a professional routine such as care planning and its potential for change (Figure 2). According to Pentland and Feldman, a routine has 3 distinct parts, the artefact, the ostensive rules, and the performative behavior (24). These are interrelated and create the repetitive care planning routine. This routine evolves as each part influences the next. Therefore, the artefact (or product of this routine clinical practice) is the care plan document and an outcome of a care planning routine resulting in a "patient in control" with a "changed student."

The ostensive rules of care planning routines are set by national, local, and professional guidance on how care plans should be completed. They often consist of more than 1 view about what should happen, but their purpose is to reinforce the routine's identity and pattern (25). These ostensive rules are influenced by "preparation" and "self-reflection" in our empowerment model. This assumes that if student professionals are prepared to understand patient-centered contexts, it will influence the performative part of care planning routines.

Not all professionals participating in care planning routines will understand each other's actions, but together they become a "collective performance" of the whole care plan. Therefore, there is opportunity for each professional involved in the performance to interpret it in their own way. The performative aspect of the routine is influenced by individual behavior and how and when the routine is undertaken. It often becomes a tacit behavior that is rarely verbalized. The 4 themes of empowerment elements (Figure 1) may influence the delivery of the "collective performance." This in turn influences the outcome of the artefact and perhaps the ostensive. Our 3-phase model of empowerment embedded within this care planning routine (Figure 2) provides a practical example demonstration for student professionals of how theory can be translated into research-based practice. When this routine is repeated by numerous student practitioners, then new patterns of care plan delivery may emerge which influence patient level of activation and empowerment, thus influencing the "transformational change" required (14).

Conclusions

Patient expertise was embedded into a new module curriculum. Using an example of care planning, and Pentland and Feldman's theory of routine organization, the results are translated into a patient-centered educational model for teaching empowerment to health and social care profession students.

There are practical challenges of reproducing this study. These are centered on establishing a sustainable core group of patients with experience to work with students, understanding multiprofessional student contexts and their learning needs, and recognizing that the role of the educator is to role model by facilitating inclusivity and working together. Nevertheless, this project provided students with experiences and enabling resources that initiated a process of personal empowerment that may not be easily achieved by traditional approaches to learning in the classroom or clinical settings. Eight expert patients with a chronic illness were at the center as participants who gave students a unique opportunity to learn about empowerment and enabled the development and translation of a patient-centered educational model for teaching empowerment.

Limitations and Strengths

Expert patients were representatives of their respective patient organizations and had experience as peer supporters and as experts by experience. This level of expertise and experience is likely to have positioned the patients as being already empowered. However, if this were the case, the findings indicate that they were further empowered through their relationship with interprofessional student teams.

Finally, the researchers were familiar with the research context in their role as ESSI project lecturers, and familiarity can weaken a project's trustworthiness (28). To ensure data trustworthiness, the researchers collaboratively reflected on their decisions throughout the project.

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