

“Keep trying”: a qualitative investigation into what patients with chronic pain gain from Project ECHO

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Abstract

Objective: The study aims to investigate the patient perspective on the pathway from healthcare practitioners' presentations of their cases at a Project ECHO (Extension for Community Healthcare Outcomes) tele-clinic to the management of those patients' chronic pain.

Introduction: Managing patients with chronic and complex pain constitutes a prevalent, stressful challenge in the primary care setting. Primary care physicians typically have received little training in treating such patients and, until recently, have relied heavily on opioid and other pharmaceutical therapies as part of their regimen. Project ECHO Ontario Chronic Pain and Opioid Stewardship is an interprofessional telementoring program connecting pain specialists to primary care practitioners with the aim of supporting them in managing their patients with chronic pain, although the patients concerned do not generally participate in the telementoring sessions. While a number of papers have described the benefits accruing to healthcare professionals through participating in Project ECHO, there has been little exploration concerning patients' perceptions of their care subsequent to case presentation.

Methods: Using data from in-depth interviews with 20 patients along with their associated case presentation forms and the recommendations following the presentation, we look at the alignment of patient and practitioner views and inquire about the patient's perceptions of how Project ECHO affects them.

Results: Results suggest that the impact on patients is indirect but positive: most respondents express pleasure in contributing to research around chronic pain management, though only two of them identified a direct impact on their own treatment. They also appreciated their practitioner's efforts to bring expert attention to the patient's situation.

Conclusions: Patients whose cases are presented to Project ECHO sessions experience positive emotions at being part of the process of research and quality improvement, regardless of changes in their own conditions. This study highlights the importance to patients of their practitioners' commitment to managing their chronic pain.

Keywords

Project ECHO, chronic pain, interprofessional education, primary care, patient experience

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Introduction

Chronic pain is one of the most prevalent problems that primary care practitioners are required to treat.^{1–3} Most primary care physicians receive little training in the management of patients with long-term and often multi-factorial pain.^{4–7} Such patients may bring with them emotional and mental health problems that are tightly bound to their pain symptoms.^{8,9} Interprofessional care is a powerful means of meeting the needs of patients with chronic pain, leveraging as it does expertise from multiple disciplines.^{10–12} For many healthcare professionals (HCPs), managing patients with chronic and

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complex pain conditions is stressful as, by definition, there is no “cure.” Added to the mix is the demand for careful stewardship of opioid prescription, which may prompt antagonism and distrust between patient and practitioner.^{13,14}

Project ECHO (Extension for Community Healthcare Outcomes) is a telementoring program that employs a hub-and-spoke model to connect an interprofessional team of healthcare experts (the “hub”) to a large number of primary care practitioners (the “spokes”) through weekly videoconferences.^{15,16} Project ECHO aims to leverage scarce healthcare resources, share best practices, democratize knowledge, reduce variation in access to high-quality care that occurs due to geographic and socioeconomic barriers, and foster the creation of a “community of practice.”^{17,18} Even before the COVID-19 pandemic inculcated the world into the virtues of distanced gathering, Project ECHO, since 2003, has relied on telecommunications technology to reach HCPs in remote and rural locations. The teleconferences typically last between 1 and 2 h and include a didactic presentation by an expert on a relevant topic along with a discussion of a current patient case presented by one of the spoke participants. With respect to these case presentations, Project ECHO fosters an “all teach, all learn” ethos, actively involving both spoke and hub participants in case discussions.

Project ECHO Ontario Chronic Pain and Opioid Stewardship launched in 2014 and has to date, involved 833 interprofessional HCPs, mostly practicing in primary care, as “spokes” connected to the central “hub” of interprofessional specialists. Participants describe numerous benefits of participating in Project ECHO for treating their chronic pain patients,^{19–21} reflecting findings from other incarnations of Project ECHO for chronic pain.^{22–25} These reports of beneficial outcomes and positive effects come from the target “spoke” participants: health practitioners in the primary care setting. Another related question arises concerning whether and how patients experience the impact of HCPs’ participation in ECHO and how such impact, if any, is mediated. In this study, we investigate the path from the presentation of the patient in an ECHO tele-clinic to the recommendations generated by the ECHO hub team to the patient’s perspective on how Project ECHO affects their case management. In addition to the interviews with patients, our data comprise HCPs’ case presentation notes and notes compiled about comments and recommendations made by the HCPs in the hub.

Methods

Three sources of data contributed to this qualitative study: (1) in-depth interviews with patients, (2) the patients’ case presentation forms, and (3) the patients’ case recommendation forms following the presentations. While patients gave consent to their HCPs to present their (anonymized) information, no patients appeared for or joined in the teleconferences. For this study, HCPs who had presented patients were asked by email to request permission from presented patients to be contacted

by a researcher for the purpose of an interview concerning the patient’s attitude toward and experience of Project ECHO. Recruitment aimed to reflect the diversity of HCP professions and to reflect urban and rural participants in Project ECHO. Inclusion criteria for participation in this qualitative study were thus as follows: patients with chronic pain whose case was presented by their HCP during an ECHO session, patients managed primarily by presenting HCP and/or their team, and patients agreed to be contacted by researchers. Exclusion criteria for this study included any patient who did not have chronic pain, any patient who was not presented during ECHO sessions, any patient who was not being managed (immediately or long-term) by an HCP who attended ECHO sessions, and any patient who declined contact by researchers.

Patient contact was made by telephone after explicit permission had been granted. All HCP and patient participants provided written informed consent prior to the interviews, with the information reiterated to participants orally at the start of the interview and confirmed with participants’ oral, recorded responses. Both oral and written consent statements emphasized that participants could refuse before, during, or after the interview to share their responses. One potential participant did, in fact, refuse at the point of written consent and was not interviewed.¹

Patient interviews

All in-depth patient interviews were conducted by one member of the research team (DB), a PhD student who received training in in-depth interviewing. Interviews were conducted by telephone and lasted between 25 and 45 min. The research team collaboratively developed the semi-structured interview guide with content derived from previous investigations.^{18,20,21} Questions explored patients’ experiences and encounters with the medical system regarding their pain management, as well as their knowledge and understanding of Project ECHO (see Appendix 1).

The semi-structured interview guide was constructed by the research team and pilot-tested on 5% of the study population ($n=1$). (This interview was included in the final data sample because it did not differ substantively from subsequent interviews).²⁶ There were minor revisions to the original interview guide after the initial pilot test. Changes included editing the occurrence of multiple questions into separate ones and clarifying some probes.

All patient interviews were audio-recorded and securely professionally transcribed verbatim. Memo notes were made during the initial phone contact to collect informed consent and during the interviews themselves. All patients received a C\$20 honorarium for their time and participation.

Patient case presentation form

Structured patient case presentation forms completed by HCPs in preparation for the discussions at an ECHO session

provide de-identified clinical history and prompt HCPs to articulate their main queries regarding this patient (see Appendix 2).

Recommendation form

A patient case recommendation form generated after each case presentation provides a summary of the discussion and the suggestions provided by the hub. The recommendation forms are then faxed to each presenting HCP after the session (see Appendix 3).

Data analysis

A qualitative-descriptive lens, as outlined by Sandelowski^{27,28} provided a useful approach for analysis of the in-depth interviews.²⁹ Using a text matrix (constructed simply with word-processing software) allowed analysis of each participant by data source (interview, case presentation, hub recommendations) and of participants from one to another.³⁰ Themes were discussed and developed both across the rows for the patient interviews, case presentation forms, and recommendation forms (i.e., for each patient) as well as down the columns (i.e., for all the interviews separately, all the case presentation forms, and all the recommendations). Two researchers (JZ, LC) met regularly to discuss themes and to reach consensus regarding interpretation of responses. We ascertained that thematic saturation had been achieved when we no longer encountered novel or surprising topics (codes) in the data and when the themes relevant to our questions encompassed all the topics that we identified as relevant to our aims.^{31,32}

This study was approved by the University Health Network Research Ethics Board (#14-8606).

Results

At the time of recruitment, 243 patient cases had been presented as part of Project ECHO. Of those patients, 49 agreed to participate in Project ECHO patient research, and 20 consented to and were available for an in-depth interview. The interviews took place from December 2017 to February 2019. An average of 556 days passed between case presentation and interview (SD=283 days, range=147–952). The participating patients included an equal number of men and women, with an average age of 56.5 years. See Table 1 for patient participants' demographic details.

Main themes identified through close engagement with the data include (1) the importance to patients that HCPs recognize the social, structural, and familial as well as physical difficulties of managing chronic pain; (2) the generally good alignment between HCPs and their patients concerning the goals of pain management; (3) ongoing tension over the role of pharmaceuticals in managing chronic pain; (4) lack of clarity on the part of patients concerning how Project ECHO

works; and (5) the blend of hope, hopelessness, grace, and humor that characterize participants' self-presentations in the research interviews.

In their interviews, patients describe complex histories of pain, mental and emotional suffering and, in most cases, complicated histories of care. Many describe the burden of family involvement in their conditions, both in the sense of needing extra care and of inability to be an adequate caregiver to other family members. Patients are knowledgeable about what ails them and how it is treated. Evident throughout the interviews are examples of participants displaying humor and self-deprecation or describing examples of their own strength and resiliency with regard to their chronic pain, even while they talk about hopelessness and despondency in the same interview.

Our sample of HCP presenters at the ECHO teleclinics include representatives from seven different healthcare professions. Their presentations vary in structure and focus. The organizers asked participants to present their most troubling and difficult patients. Recruiting presenters can be a difficult task because compiling the information required is non-trivial and time-consuming. Almost all describe their patients' issues beyond physical ailments and pain and demonstrate these practitioners' knowledge of economic stressors, psychological or psychiatric complications, social and family issues, and histories of trauma. In most cases, the presenters' descriptions of their patients align well with the patients' self-descriptions. Most presenters are interested in how to reduce opioids and streamline the sheer number of medications prescribed. Some ask explicitly for non-pharmaceutical pain management strategies. Some incorporate "patient goals" into their presentation.

The expert hub is represented by specialists from approximately 12 clinical disciplines, depending on the week. The feedback they offer to the presenters varies in its physical appearance, sometimes neatly typed and signed, sometimes messy and handwritten.² There is diversity in the quantity of feedback: sometimes up to 20 different recommendations are made, and between 2 and 15 suggestions of differential diagnoses appear. There is a wide variation in type of feedback, ranging from the highly medicalized and pharmaceutical (e.g., specific guidelines about use of suboxone and structured pharmaceutical dispensing) to the complementary or alternative domain (e.g., water tai chi and reading a book about elimination diets).

Table 2 provides a summary of each patient case, including basic pain complaint, the patient's comments in the interview concerning their pain and its management, the presenter's description of the patient's pain complaints and their own main concerns, the gist of the hub's response, and the patient's comments on having been presented at an ECHO session.

Patients' and presenters' accounts in general accord with one another although there are notable exceptions. In one case, ID14 does not see themselves as a "chronic pain

Table 1. Patient and presenter summary demographics.

Presenter characteristics	n (%)
Profession	
Pharmacist	6 (30)
Physician	5 (25)
Nurse practitioner	3 (15)
Occupational therapist	3 (15)
Physician assistant	1 (5)
Registered nurse	1 (5)
Social worker	1 (5)
Practice type	
Family health team	14 (70)
Community mental health and addictions service	3 (15)
Community health center	2 (10)
Fee for service, solo practice	1 (5)
Patient characteristics	
Sex	
Female	10 (50)
Male	10 (50)
Age	
	Mean = 56.5 years (range = 35–81)
Education	
<High school	1 (5)
High school	7 (35)
College (further education)	7 (35)
University	2 (10)
Missing	3 (15)
Rurality Index of Ontario (RIO) score*	27.8 (range = 0–93)

*The Rurality Index of Ontario (RIO) score is a composite score developed by the Ontario Medical Association that ranges from 0 to 100, where 0 refers to an urban center and 100 refers to a very rural and Northern community. The RIO score is “a measure of rurality that ensures funding is specifically targeted to northern and very rural communities.” The RIO score is composed of three factors: (1) population (count and density), (2) travel time to a basic referral center, and (3) travel time to an advanced referral center. RIO scores are assigned to Statistics Canada census subdivisions (CSDs).³³

patient” at all, saying to the interviewer, “that’s my boyfriend.” The hub responses vary in the directness with which they address the presenters’ questions, their stated concerns, and limitations volunteered (e.g., lack of access to physical therapy). In the case of ID07, for instance, the presenter’s aim to taper or alter the patient’s pain medication regime is at odds with the patient’s self-description as someone well able to manage their opioids and, in fact, would like more but is scared to ask. For ID11, the patient’s self-description is rich in household and family factors affecting their pain management, whereas the presenter’s description focuses on the medical and pharmaceutical approaches to management. The hub’s responses vary in the directness with which they address the presenters’ questions, their stated concerns, and limitations volunteered (e.g., lack of access to physical therapy).

One patient (ID10) comments that the suggestion of a long-acting opioid prescription (Kadian) has been a “major step forward.” Another patient, ID11, also noticed changed, improved pharmacological regime for her pain that included cannabis and anti-depressants. The majority of patients indicate that they perceive little to no direct effect of “being presented” on their case management. Patients had varying understandings of how Project ECHO worked. One participant, for instance, believed that having her case presented at the clinic would enable her to receive “off-label” medication for her pain (ID03). Another patient expressed the hope that by speaking to the interviewer, he would be conveying to his doctor the message that he, the patient, is “not an addict” (ID07). Almost all respondents express pleasure and appreciation at having been presented by their clinician and at being part of a research project, mentioning the importance of (a) helping other patients with chronic pain, (b) adding to scholarly knowledge, and (c) continuing to “try” to resolve the problem of chronic pain. This idea of being able to voice one’s experience of chronic pain in order to influence research and practice is not one that stemmed from any particular interview question; it arises “inductively,” to use the terminology of Hennink et al.³²

Discussion

While not all patients interviewed clearly understand the nature of Project ECHO or what it involved, over half of the respondents expressed positive feelings about participating in ECHO ($n=12/20$): they described ECHO as a “good thing” due to its efforts to help patients with their pain or to instruct practitioners in how to manage their patients’ pain. In only two of the 20 cases explored here were we able to draw a direct line from case presentation to hub response to patient-perceived improvement in pain management.

Prior research, however, shows that the HCPs who participate in Project ECHO very much appreciate and value their involvement.^{18,19,24} Focus group discussions with HCPs who have presented cases at ECHO sessions describe benefiting from the experience (unpublished; data available upon request). These findings lead us to ask, “who is Project ECHO for?” or more specifically, “who is Project ECHO Chronic Pain and Opioid Management for?” Chronic conditions by their very definition do not follow the medical model of treatment leading to cure. What then are medical practitioners to do for, and say to, their patients? The hopelessness and frustration experienced by patients with chronic pain are evident in our interview data as well as in the relevant literature.^{14,34,35} HCPs also experience frustration. The default prescription of opioids as a long-term solution has been shown for the nightmare that it is. Fanning Madden et al.³⁶ describe the difficulties faced by HCPs in engaging complex patients—a category in which patients with chronic pain may belong—in their healthcare; such struggles are structural in nature and not easy to surmount. The burden on

Table 2. Summary of each ECHO pain patient case.

ID	Gender	Age (years)	Pain condition	Patient says	Presenter says	ECHO recommends	Patient comments on ECHO involvement
01	F	81	Long-ago MVA (motor vehicle accident) and subsequent fibromyalgia	“[O]pioids are not the answer” and describes several non-pharmacological treatments she would like, including massage and hydrotherapy	RN: Struggles to reduce opioids while managing the patient’s pain OT: Concerned about balancing opioid dosing with pain control and being aware of the patient’s “low mood” and depression	Assistance from community care organization, urine drug screening, non-opioid medications, and a possible psychiatric diagnosis (borderline personality) Consultation with a rheumatologist, “focused PT,” urine drug screening, and working on “goal-focused behavior.”	ECHO is “a wonderful way” for patients’ voices to be heard; she speaks highly of both physicians and RNs in her care team ECHO is “great” because being presented “opened it up so that somebody like me on a fixed income or inability to have a lot of access to transportation and stuff” She expected Project ECHO to help her gain access to “off-label” medications that might help her cope with pain. She has not noticed any change in her treatment since her presentation Project ECHO is a good program because it might help patients try something new; he is open and motivated to attempt new treatments. He has not noticed any change in his treatment following the presentation of his case
02	M	58	Residual pain from long-ago winter sports accident; also depressed and grieving the loss of his wife	“[W]hether it [treatment] works or not doesn’t matter, it’s when you stop trying”		Modification of existing medications; in addition, get a pet, a warm pool, light therapy, and mindfulness	
03	F	45	Motor vehicle accident (MVA) and fibromyalgia	Lack of funds is a problem; she has “tried everything.” is frustrated, and feels that she is a “difficult” patient. She deploys humor during interview	Pharm: “[D]aily generalized pain and stiffness for many years; fibromyalgia diagnosed 12–13 years ago and treated at pain clinic”; other problems include “dysfunctional family” FP: The patient’s goals are to sleep through the night, be able to help with housework, and use his garage workshop		
04	M	41	Diabetic neuropathy and history of “a broken back”	Found palliative care professionals were comfortable prescribing the amount of pain medications he needed. He has been on many medications and fears medication shortages and what will happen to his pain in that case. Willing to try suboxone. Recognizes that he will always have pain and that he will live with it		List of 14 possible diagnoses, plus four investigations or treatments, including BMD scan, a sleep study, new prosthesis fitting, and measuring testosterone levels; additionally, the team offers ideas on tapering opioids and adding cannabinoids	
05	F	75	Back problems plus long-ago back surgery. Chronic burning sensation in her foot	Does not like taking opioids but has come to accept both the pain and the opioids; uses also costly alternative therapies. “Acceptance” improves quality of life	NP: wants to explore more non-pharmacological strategies and hopes to remove opioids from the patient’s regimen	Suggests trying cannabinoids, rotating opioid medications, increasing aerobic exercise, “core flexion exercises,” and a goal of gradually returning and to interests such as gardening and volunteering	Project ECHO “helped” but also comments that nothing in her pain management changed as a result of it
06	M	35	Pain in back, knee, and hip; multiple psychiatric issues including depression and anxiety; obesity; history of trauma	Found “the study” to be “overbearing.” Likes and trusts his family physician and the team pharmacist (= presenter). Does not trust specialists. Willing to try new therapies other than exercise	Pharm: Patient “inherited” from another practice; fearful of making changes in his pain management because of complexity. Presenter would like a “trial of cannabis”	Nine possible diagnoses mentioned, numerous psychiatric or psychological screening tools suggested, plus multiple specialist referrals, including a weight loss clinic. Instead of cannabis trial, propose trial of nabilone, with a caveat to be “cautious with psychotropic effects on anxiety and depression”	Happy about recent changes to medication and speaks positively about ECHO, but does not attribute those changes to his case being presented at ECHO

(Continued)

Table 2. (Continued)

ID	Gender	Age (years)	Pain condition	Patient says	Presenter says	ECHO recommends	Patient comments on ECHO involvement
07	M	41	History of traumatic blunt-force injury 20+ years ago, resulting in amputation of (part or all of) his foot; history of sexual abuse, alcohol misuse, illegal and prescription drug abuse	Friendly and forthcoming, patient stated that he is not an addict and that the prescribed opioids are essential to him; he is sole family breadwinner and works full time.	Pharm: main question is whether this patient can be managed in primary care. Further questions included use of suboxone and topical medications to manage pain. He is currently on 160 MED. ³	Yes, this patient can be managed in primary care; however, they also included suggestions for referrals to a mental health professional and to a pain clinic	The recommendations from case presentation did not help; the tapering of medication left him in pain, and he did not see a psychologist. He hoped participating in this interview study would convey to his doctor that he was not an addict
08	F	59	Guillain-Barre syndrome (GBS), severe chronic pain following an MVA	Feels she takes too many medications, including opioids; blames GBS on a flu vaccine	FP: Wonders about genetic components of pain; also links between GBS and fibromyalgia, and what else to offer this suffering patient, who has a history of "taking more [opioids] than prescribed"	Notes handwritten and difficult to decipher but include notes of support, acknowledging both the patient's and the practitioner's suffering. Suggestions include PT referral, reducing opioids, goal-setting, and prescribing exercise and "water Tai Chi"	No longer sees this FP, but has positive feelings about her case being presented at ECHO. Even though she did not get helpful advice from the experts, she likes the idea of her situation contributing to learning among professionals and increasing education about chronic pain, and in particular, helping her own family doctor. "I feel like nobody really knows what to do with me," she says
09	M	54	Chronic neck and back pain	Pain is from "botched" surgery 20+ years ago. His situation is bleak. He calls himself "a hermit", forced to stay at home because of his pain. Expense of treatment is a problem due to WSIB limitations.	PA: Wants advice on managing the patient's opioid dosing and improving pain control. Previous trials of non-opioid therapies include facet injection, PT, and acupuncture. Limited funds are a problem. Pharm: concerned about current regimen of "Hydromorphone Contin plus short-acting oxycodone, but non-opioids (Nabilone, NSAIDs) have caused problems. The patient rates his pain as 3/10 with opioids and 10/10 without	Hub provides three separate documents, one "official" and signed, the other two unsigned, one going into great detail about possible differential diagnoses. They all suggest exercise; two recommend a referral to physiatry, and one mentioned the possibility of retraining for work. Sparse; difficult to decipher; suggests Kadian (long-acting opioid, dose= 1x/day)	Frustrated; willing to try anything; post-ECHO presentation, his FP has given him the message that there is no point in coming to see them, but that he should maintain his current medication regimen. Pleased with the Kadian idea, "a major step forward." Hopes his primary care team will "keep trying"
10	M	71	Chronic pain from arthritis	Arthritis runs in his family, giving him first-hand awareness of the harm it can do. Does not sleep well; has tried Nabilone and other medications; they are unhelpful or harmful. Inpatient during interview: "Why ask me? I'm just the patient." Likes his primary care team			

(Continued)

Table 2. (Continued)

ID	Gender	Age (years)	Pain condition	Patient says	Presenter says	ECHO recommends	Patient comments on ECHO involvement
11	F	55	Back and knee pain residual from a motor vehicle accident a decade earlier	Says she is depressed. Appreciates her primary care team, dislikes all but one of the numerous specialists to which she has been referred. Also complains about difficulty in obtaining referrals for back pain. Chatty describes a recent trip to Mexico to counter seasonal depression after her mother's death. Recently, her sister attempted suicide	NP: says patient is benefiting from Cymbalta, saying that "colors have gotten better" and her marriage has improved. Enquires whether patient would benefit from surgery, from a long-acting opioid, or non-pharmaceutical strategies	Includes 20 different action points including new prescriptions, deprescribing, and a series of investigations, handwritten and difficult to read. One recommendation—the presenter's question about non-pharmacologic management	Speaks highly of Project ECHO and her experience of being "presented." She saw changes in her pharmacologic management to include cannabidiol and anti-depressants; she was referred to a pain management program and believes her existing referral to neurosurgery was "reinforced" via ECHO. She sees herself as moving forward, but perhaps too quickly
12	M	63	Pain started with traumatic injury while working as a firefighter, necessitating amputation of his lower arm. Later, he had nerve transplant surgery, to which he attributes his current intermittently severe pain	"It's good that it's intermittent," he says. He does not like to take opioids as they make him feel unwell "in himself," so takes a variety of other medications and is hoping to have his surgery reversed, but has been denied at two clinics. He speaks well of his healthcare team	Pharm: 6 typed pages, 3 specific questions: (1) would opioids be beneficial?; (2) "How else can we treat/manage this patient?" and (3) how to address the patient's belief that the "intermittent I/O/I0" pain is due to the nerve transplant?	Addresses the questions with 12 separate suggestions, including returning to opioids, trying acupuncture and exercise such as 'one-handed golfing and hunting', and referring patient to surgeon who performed the nerve transplant. Notes are handwritten and difficult to decipher	No opinion regarding ECHO per se; satisfied with his healthcare team and would like to be in touch with others in his situation to share stories and advice. He is still seeking the "right answer."
13	M	41	Ongoing joint pain from leukemia treatment two decades earlier	Comes across in his interview as knowledgeable and engaged. Uses prescribed opioids plus strategies such as mindfulness and physical therapy	Pharm: comments on the patient's obesity, mentions that he is white, has a partner, and has had issues with addiction in the past; concerned about patient's opioid use because his mother has edema of the heart. No specific question is listed	Myriad suggestions including six referrals (e.g., psychiatry, orthopedic surgery for hip replacement; peer support groups); trying long-acting opioids; non-pharmaceutical strategies (physical therapy, cognitive behavioral therapy, TENS); investigations for muscle atrophy and B12 levels; and patient management approaches such as UDS and reviewing SMART goals	Expresses enthusiasm about being presented at ECHO and wished he could have attended his case discussion. Rejects the idea of long-acting opioids out of fear for their effect on his heart, given his mother's condition
14	F	45	None specified by patient	Patient wonders whether she is a good candidate for interview as she has balance and mobility issues due to "spastic hemiplegia," rather than chronic pain (contrasts herself to her boyfriend: "he's hips and knees")	OT: patient suffers from chronic pain managed by Tylenol 3, as well as from other ailments, and has a history of trauma	Minimal response; propose two possible alternative diagnoses; expresses concerns for the woman's family relationships	"ECHO" told her doctor to try "magnesium oxide" supplements to manage stomach spasms, which "seems to have helped some"

(Continued)

Table 2. (Continued)

ID	Gender	Age (years)	Pain condition	Patient says	Presenter says	ECHO recommends	Patient comments on ECHO involvement
15	F	54	Fibromyalgia	Articulate about her pain and feelings of hopelessness. Has used oxycocet for 16 years ("only five a day" now); has also tried acupuncture, "lidocaine and ketamine infusion," liquid marijuana, and hydromorphone. Family checks on her but knows "there isn't anything that they can do for me." Has told doctor that she prays at night not to wake up in the morning	FP: patient is "well-groomed"; very upset by the family estrangement and feels like "a throwaway." Seeking to manage fibromyalgia with a less "risky" medication regime; currently on seven different prescriptions and has tried up to thirteen in the past	Suggestion for tapering of medications and for lifestyle alterations	Patient says she was "excited" to be presented at ECHO session: "I think it's wonderful." Perhaps FP chose her case because she is so depressed about her pain. Thinks ECHO recommended CBT (cognitive behavioral therapy), which she does through her work at a mental health charity
16	F	35	Pain from motor vehicle accident some 2 decades previous	Has tried many different medications; dislikes the feeling: "I'd rather have the pain and have all my head." She has 3 young children. Has tried naturopathy and also physical therapy, but they are expensive, difficult to access given her rural location, and not long-lasting: "the pain came back"	FP: asks about pharmacological trials, especially regarding headache prophylaxis, and about prescribing opioids. Alternatively, about mindfulness or exercise. The patient has generalized pain, has experienced "adverse life effects," cannot work and relies on others for help, suffers from social anxiety, depression, and disordered sleep	Suggestions include Urine Drug Screen, trial of Lyrica but avoidance of opioids, some micronutrient supplements, social worker involvement, postural exercises, a sleep study, a PTSD screen, and breathing exercises	Has a vague memory of her case being presented. May have joined a pain management support group as a result of ECHO suggestions, but it was not helpful. Recalls no other changes in managing her pain.
17	M	56	Pain is worst in his legs; also has gastrointestinal (GI) pain	Difficult interviewee; reserved; low education level, living in a group home. Describes working with OT to create an exercise regime	OT: conveyed the distress and difficulty of working with this patient, who also has schizophrenia, social anxiety (GI) complaints, and phobia of exercise-induced pain. Has had a good relationship with patients for 10+ years	Suggestions focus almost entirely on the GI issues offering ideas both for diagnosis and management. Offers congratulations on "a very good presentation"	Believes his OT told him that the ECHO hub suggested more exercise to "keep his legs strong." The pain in his legs has lessened, but he does not link it to ECHO nor to the increase in exercise

(Continued)

Table 2. (Continued)

ID	Gender	Age (years)	Pain condition	Patient says	Presenter says	ECHO recommends	Patient comments on ECHO involvement
18	F	81	Severe back pain affecting both mood and sleep	Does not like admitting to debility. Fit and active until 5 years ago. Believes pain stems from a car trip on rough roads 20 years ago in a vehicle with poor cushioning. Praises her nurse practitioner. Mentions MRI 5 years ago	NP: patient is "delightful" and socially active. concerned about diminishing independence and increasing "stoop." The NP describes the car ride incident as a recent event, the diagnostic image as CT, and says the patient's sleep is "very good." She also mentions a diagnosis of Parkinson's Disease	More than twenty suggestions listed, mainly forms of physical exercise or therapy, including foam rollers, pool therapy, hot packs	Patient had no mention of treatment changes following ECHO presentation; no comment about ECHO at all. Comments on good relationship with the "wonderful" NP who delivers exercise classes and acupuncture treatments
19	M	67	Osteoarthritis (OA) has caused "40 years of pain"; also, diabetes and diabetic neuropathy	Father and brother also have OA. Worked in security, was active, lots of walking in spite of pain. Has tried opioid and non-opioid medications but nothing works, including cortisone injections which are "pure garbage." Helped by pain management sessions suggested by SW, which "trick the brain" and exercise. "You learn to live with it"	SW: seeks advice managing the patient's painful hand and leg cramps. Presenter also describes patient's difficult relationship with his wife, who is a substance abuser, his attachment to an aging dog, and "unsupportive" family	Offers several differential diagnoses and suggests relevant investigations, as well as suggestions for non-pharmaceutical management. References to two articles on cramps are included, and, from the hub psychologist, ideas about helping the patient with respect to the aging dog and difficult wife	Little comment on case presentation at ECHO, deflecting questions about it, though recalls the SW asking his permission to present. Feels happy "if somebody can learn out of that." He wishes he could "kill" the pain, but meanwhile, continues to be physically active: "I guess I'm pig-headed or some darn thing." Relies on "helpful" and "concerned" health care team which helps him manage his stress and anxiety. By the time of the interview the SW had left the practice, but he had a satisfying relationship with the FP; his dog had died
20	F	78	Peripheral neuropathy, scoliosis, and headaches	A former entertainer, both patient and spouse participate in interviews, teasing and bickering. Both agree that opioid dependence is a problem	FP: confirms same pain causes and history as patient describes. Opioid dependence is problematic; seeks strategies to reduce dosage	Suggestions range from MRI to confirm diagnoses to inpatient treatment for substance abuse	Offers enthusiastic praise for Project ECHO and for her physician; also says, "My case has been presented twice without improvement"

FP: family physician; NP: nurse practitioner; Pharm: pharmacist; OT: occupational therapist; RN: registered nurse; PA: physician assistant; SW: social worker; UDS: urine drug screening; WSIB: workplace safety and insurance board (of Ontario).

practitioners can lead to burnout.³⁶ For people trained in “the healing arts,” chronic pain presents a conundrum.^{37,38}

Each patient who participated in the interviews shared deeply personal material and provided rich context to the presentations, as discussed in the ECHO sessions. For the most part, the patients’ presentations of self matched the HCPs’ presentations of their patients suggesting good communication between patient and provider. Some discrepancies appeared, but overall, patients and their HCPs seemed very much in tune with one another. Most of the patients had words of high praise and warm feelings for the presenting HCP and, more generally, for other practitioners in their primary care “home.”

Some criticism regarding the effectiveness of Project ECHO in terms of direct patient benefit has been expressed.³⁹ Our analysis suggests that benefits to ECHO patients with chronic pain are diffuse and indirect but nonetheless positive and important. The growth of a community of practice⁴⁰ that spans miles and professions allows HCPs to gain knowledge and also to share it, as well as share their uncertainties, their frustrations, their hopes, and their ideas, and to return to their patients, if not with a cure, then with confidence that they are doing the very best they can in their professional and personal capacities.¹⁸

Conclusions

Patients whose cases are presented to Project ECHO sessions experience positive emotions at being part of the process of research and quality improvement, regardless of improvement in their own conditions, which, for many of the patients interviewed, continue to be difficult and dire. The benefit of Project ECHO for chronic pain is most directly found in the support it provides to HCPs, who can share with their patients the confidence and strength gained from the ECHO community. Project ECHO for chronic pain (and perhaps other chronic conditions) is a very particular form of CME (Continuing Medical Education), one which aims to support HCPs in their efforts to manage their patients with chronic pain in their primary care homes. Patients express appreciation for the effort and investment of HCPs in managing their pain. Support for these practitioners is critical to the health of the healthcare system. By fostering a communal “all teach, all learn” ethos, as well as providing pain management expertise, ECHO contributes to the effective management of chronic pain where patients feel most content: in primary care.

Future research aims to expand our inquiry into the impact of Project ECHO on chronic pain management beyond Ontario to across Canada.

Limitations of the study

The original aim of the study was only to explore the patient experience; the ability to link the patient cases to their

interviews and recommendations occurred post hoc. Ideally, we would have interviewed presenters as well as patients. The patients who participated in the study likely differ from the larger population of patients with chronic pain in Ontario, and also from the smaller population of patients with chronic pain rostered to those practitioners involved in Project ECHO. The individuals in this study are patients whose relationship with their HCP is such that the practitioner selected them to be considered for participation. There may have been some loss of information due to the length of time between case presentation and patient interview, due to logistics around enrollment and scheduling. Finally, the information about case presentation and hub recommendations are in the form of written documentation. Recordings of live, weekly videoconference sessions exist and may provide deeper, more granular information regarding interactions during the session. Analysis on this level may be the subject of future research.

Author contribution statements

Leslie Carlin and Q Jane Zhao conceived and wrote the main body of the paper and conducted the bulk of the data analysis. Dominika Bhatia, Paul Taenzer, John Flannery, and Andrea D Furlan assisted in constructing the interview guide and commenting on the paper’s development. Paul Taenzer contributed to the summary table construction. Dominika Bhatia conducted the interviews and provided commentary on the analysis.

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Ethics approval

Ethical approval for this study was obtained from the University Health Network (Toronto, ON, Canada) Research Ethics Board (#14-8606).

Informed consent

Written informed consent was obtained from all subjects before the study. Informed consent was obtained a second time, orally, at the start of each interview.

Trial registration

Not applicable.

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Supplemental material

Supplemental material for this article is available online.

Notes

1. The data on which this paper is based, including interviews, case presentations, and summary notes, are as per our reviewed ethics agreement securely stored at the University of Toronto and University Health Network. Should researchers wish to request access to these materials, please contact the corresponding author.
2. More recently, all feedback returned to presenters is in typescript.
3. Morphine equivalents per day.

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