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Original Article

Lived Experiences of Chronic Pain Patients Attending Follow-up Visits at a Pain Clinic During the COVID-19 Pandemic in Thailand

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ABSTRACT

Objective: The whole world stopped turning, for most countries, due to shutdowns during coronavirus pandemics, with the exception of chronic pain patients. More than 40 years of unprecedented service changes in the pain clinic, under the COVID-19 era, could cause major impacts on patients living with chronic pain. We conducted this in-depth interview to evaluate how COVID-19 affected pain in patients with chronic pain.

Material and Methods: Face-to-face, in-depth interviews with tape recordings were used to explore the informants' perspective, so as to capture their own words, thoughts, perceptions, feelings and experiences under the COVID-19 prevention and control measures. Field-notes and detailed memos were also recorded during the interview. The key informants consisted of 17 chronic pain patients, who came for follow-up visits at the pain clinic during the third and fourth waves of the COVID-19 pandemic. The qualitative content analysis method was employed to analyze the verbatim transcription of the interview recordings to identify themes and patterns.

Results: The findings revealed the key informants viewed COVID-19 as being closely tied with the perception of to what extent it impacted on maintaining their usual pain treatment and care as accessed. The key informants' feelings of fear and worry were not generated from the effects of COVID-19 on their physical health, but were from the healthcare services changes and restrictions they faced. The 'new normal'; as such social distancing, was viewed as similar and congruence with their long-lasting normal lifestyles. Talking about COVID-19 is a lot less interesting without talking about pain. The key informants preferred taking the risk of catching COVID-19, rather than coming back for untreated pain. The door-to-door pain medication delivery service provided a sense of uncertainty and could not replace the therapeutic feelings of a sense of heartwarming, care and safety generated while having face-to-face meetings with a doctor as well as acts of kindness and compassion from the pain clinic staff.

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Three themes emerged from the findings: 1) the COVID-19 pandemic poses a threat to perceived stability on pain control; 2) embracing the 'new normal' in the world of chronic pain patients; and 3) a silver lining in the midst of the COVID-19 pandemic.

Conclusion: The way patients experienced the COVID-19 pandemic well reflects individual differences in the subjective experience of pain and individual needs of chronic pain patients. Changing of healthcare services utilization at pain clinics during the COVID-19 pandemic should be therefore concerned not only with the continuum of pain treatments, but also congruent to the care needs of chronic pain patients.

Keywords: chronic pain; COVID-19; experiences; pain clinic; pandemic

INTRODUCTION

The outbreak of a novel global health crisis, COVID-19, has caused a dramatic, unprecedented disruption of changes to lives, livelihoods, education, and economics, with no exception to healthcare services worldwide[1,2]. Amidst the implications of the pandemic COVID-19 nationwide lockdown policy across the globe, healthcare service utilization is subject to changes and adjustment[3,4]. As a consequence, people with chronic conditions, or chronically ill patients requiring the care continuum were unintentionally faced with challenges from said changes[5,6].

To the best of the authors' knowledge, this is undeniable the first time of change from a conventional to a touchless service and care at the Songklanagarind pain clinic over the past 40 years. Doubtless, the pain clinical staff have been facing the effects of living under pressure with stress; in the same manner as other healthcare professionals around the world[6]. Regardless of personal safety and difficulty, healthcare practitioners are concerned about maintaining continuous pain treatments and care for chronic pain patients[7,8]. Striving to provide the best alternative to replace conventional services was initiated from the providers' or the hospital's lens, based on the best evidence available and opinions from experts. However, implementation of new services, adapted from strategies developed within the western context, as well as the preference of the local staff might be inappropriate or not meeting the particular needs of chronic pain patients visiting the pain clinic[9-12]. A previous qualitative study exploring lived experience of chronic pain patients called for more understanding from clinicians and for providing support that meets the actual needs of individual patients[13-15]. The evidence from previous studies described lived experiences of chronic pain patients under the era of the COVID-19 pandemic as presenting unique experences generated from each particular context[13-15,16-17]. Being subjective, experience of pain accompanying with this reason encouraged the researchers' enthusiasm for allocatin pain clinic services and realizing the importance of taking into account the needs of chronic pain patients living in a COVID-19 world. To date, in Thailand, there is a scarcity of information about how the COVID-19 pandemic affects patients with chronic pain in addition to the way they perceived the service changes as well as their needs. A clear understanding of these points of concern will help the providers to better appreciate and empathize the needs from the patients' point of view, which provide basis to design meaningful services and care to meets their needs[13,18].

A qualitative descriptive approach was employed to obtain a broad insight of the study phenomenon from the patients' perspectives.

MATERIAL AND METHODS

Study design

A qualitative descriptive approach was conducted from 1-16 March 2021, with 17 semi-structured interviews

and audio recordings using a smart phone. Formal, open-ended interviews using the interview guide unwraps and elicits an accurate and meaningful data from the participant's ideas, thoughts, world views and experiences[19-21]. The interview questions and sequences were modified to sharpen the initial questions, after talking with the informants to gain more meaningful understanding.

The key informants were recruited from the outpatient pain clinic, using purposeful sampling techniques. In total 17 adults, who attended in-person follow-up visits with regard to chronic pain problems, were willing to participated voluntarily and gave informed consent were included for formal interviews.

Sufficient data, gaining insight of the study phenomenon, generating themes or data saturation, was reached with 9 informants; however, a further six interviews were conducted to increase the trustworthiness and transferability of this study

The strategies used to conduct the interviews were based on the following: 1) greeting and building rapport; 2) giving the explicit explanation the project, questions, recording; using the Thai native language; 3) asking interview questions; 4) repeating instead of repetition; 5) encouraging expansion on what the informants say; 6) incorporating informants' terms; 7) creating hypothetical situations; 8) asking friendly questions; and 9) taking leave[22-26]. During the interview, the interviewer tried to relax the informant and listen attentively to their major ideas, themes, patterns and statements in response to each area of inquiry. Tape recording of the interviews and spot checks on specific responses to ideas that were not clear were conducted during the interviews, after obtaining permission to ensure accuracy of data collection[19-21].

Unlike previous extensive qualitative research experiences pertaining to face-to-face in-depth interviews of the researcher, this time these were proceeded with the utmost extreme caution against COVID-19. In this study, smart phones or zoom interviews were not possible, as all informants were more comfortable as well as preferring in-person talks; regardless of the risks of contracting COVID-19[27,28].

With respect to risk of getting infected from long periods of time spent together in closed areas, the time set aside for the interview was 20 to 30 minutes in length. However, the extended time was spent on individual interviews, for which were irrelevant to the interview questions; as the researchers had no need to ask about their pain story, due to all informants continually and tirelessly talking about their pain. Here, the authors had no chance of balancing the benefits of listening to patients and the risks of COVID-19 infection and transmission[27,28]. Importantly, the interviews were conducted and continued based on convenient times of the informants.

Iterative data analysis was conducted to bring out meaning of the data that generated a deep and nuanced understanding of the participants' descriptions of their experiences. Themes and patterns were determined using the following sequential steps: 1) become familiar with the data, 2) generate initial codes, 3) search for themes, 4) review themes, 5) define themes, and 6) write-up[22-26].

This study was ethically reviewed and approved by the office of human research ethics committee (HREC), Faculty of Medicine, Prince of Songkla University (REC.63-359-8-1). It also registered with the ClinicalTrials.gov (NCT04715815). Ethical principles in conducting research concerning considering informants first, safeguarding informants' rights and privacy were employed in every steps of the study. Particular attention was given to informed consent and confidentiality. Voluntary informed consent was obtained from each participant, and for each particular method of data collection (tape recording, interview, and field jotting) in an open and honest manner without coercion. The consent forms were kept in a secure place, until they were subsequently destroyed. All information was kept confidential and was not disclosed, unless for the study purposes. A pseudonym was used for each informant and information that could identify individuals was removed.

RESULTS

The participants comprised of 6 males and 11 females, having a median age of 55.5 years. The average experience with pain was 5.2 years, with the average duration in attending the pain clinic being 4 years. As to the causes of chronic pain conditions these included: trigeminal neuralgia, meralgia paresthetica, phantom limb pain, entrapment syndrome, peripheral nerve injury, spinal cord injury, arachnoiditis, peripheral arterial disease, flexor tenosynovitis and second degree burns.

Area of residence included: Songkhla, Phatthalung, Nakhon Si Thammarat, Satun, Yala, Pattani and Narathiwat provinces; all provinces are located in the lower part of southern Thailand. The majority of informants were married, with a few as single and widowed. Seven of them had a bachelor's degree, while the rest had an education level of grade 4, 6, 9 and 12.

COVID-19 pandemic poses a threat to perceived stability on pain control

Participants were asked to describe their life and experiences during the COVID-19 pandemic. However, silence was the answer until they were asked about their pain. Putting pain at the center of attention throughout the interview was the key to success in conducting the interviews with all participants. Due to this, asking and continually asking about pain was the gateway question in building a good rapport with the participants as well as to illicit the answers for every question of interest; as witnessed in the interview extract below:

What's also relief is sitting and talking with someone listening to my pain. I have a hard time to overcome the distress of my pain. What's more distressful is the responses of people as annoying, their ignorance or it's not a big deal. Indeed, I want everybody to talk to me about pain and give the highest priority to my pain, always.
(Interview – Chaba)

Perceived severity of COVID-19 was compared to their pain experiences and the extent to which it affected their pain control. From the key informants' point of view, the effects of COVID-19 on physical health and other impacts surrounding it had not called for attention from the majority of the study participants. Rather, COVID-19 harm perception was noticed by all study participants stemming from the health care service changes and perceived, uncertain possibility of their regular pain medication and treatment and care received.

I know COVID-19 is more dangerous. I saw the doctor spray alcohol on her handbag, chairs, and around and I understand that she was scared of getting COVID-19 from her patients [low voice]. For me, I strictly adhere to the instructions and I am confident that I will not contact COVID-19. But when I received a call from the pain clinic staff informing me that the upcoming follow-up visit was cancelled, because of COVID-19, and that they will send the pain medication to me at home; you know that's the first time COVID-19 frightened me. COVID-19 is actually less bad than my intractable pain, but it made me unable to visit the doctor as needed. I don't trust the door-to-door medicine delivery, in that I'll get the medication in hand on time. I fear that my pain will go back to out-of-control levels, as previously.
(Interview – Mali)

Instead, the perceived seriousness of COVID-19 was attributed to the existence of their pain experience. The study participants expressed their suffering experiences of struggling with seeking the right pain treatments for a long journey. Thus, uncertainty in getting pain treatments made them afraid of returning to previous pain or of it getting worse:

I've been living with pain for more than a decade. Previously, no night was a good night for me. It hurt so much when my friends my family didn't believe in my pain. Even the doctor, he sent me to the psychiatrist. The only thing I do was trying every recipe; such as cannabis,

to relieve my pain. Commencing treatment at the pain clinic made me feel like rebirthing. So, when I received a call from the staff that my coming follow-up appointment was cancelled I felt shocked. Indeed, I prefer dying than enduring intractable pain as previously.
(Interview – Kularb)

Embracing the 'new normal' in the world of chronic pain patients

Living with chronic pain, accompanied with chronic disease required the study participants with chronic pain to adjust with some limitations to stay healthy. While the majority attempted to adjust with the nationwide lockdown and social distancing policy owing to the COVID-19 pandemic, which people deemed as 'the new normal', this was not uncommon in everyday life for them:

What people deem as 'the new normal' is: 'old-wine-in-a-new-bottle'. I only leave my home for going to the hospital since I've been diagnosed with cancer. Other people might feel large changes for their everyday life due to social distancing. But, I was more likely to wear a face mask, stay home, and avoid crowded areas before the COVID-19 outbreak to prevent getting infection from others.
(Interview – Zonklin)

Besides, from the study participants' viewpoint; 'the new normal' is defined for converting in-person follow-up visits to telemedicine visits, with door-to-door medicine delivery. Certainly, they needed to adapt to 'new normal' health services, regardless of their own preferences:

I do understand the significance of changing the service system to decrease the risks of getting infected. But I strongly believe that I can stay safe and healthy to go to the hospital as usual. Telemedicine is good, but I'm feeling like it's not real or I'm not a part of conversation. I don't know whether or not the doctor will hear me clearly. Also, I'm feeling like I lost my privacy since everybody can hear my voice. Sending the pain medicine to my house is good, but I'm not quite sure somebody can take them or they will send to the wrong address. Most of all, I did not have time to prepare for this. I wish I could go back to the hospital as usual.
(Interview – Moke)

Another disadvantage narrated by the study participants is the negative feeling and perception generated from 'the new normal' healthcare service. From the participants' perspective, in-person doctor visits provide the senses of heartwarming, caring and trust as well as acts of kindness and compassion from the pain clinic staff. Here, they valued that nothing else could replace the typical follow-up visit and care. They shared their willingness and happiness to take the risk of catching COVID-19 when visiting the doctor at the hospital. As expressed, they appreciated the changes and attempts made during the COVID-19 pandemic, but had more concern in that their needs and feelings should receive more attention:

Because of the COVID-19 pandemic, I experienced postponed and cancelled follow-up appointments with the doctor, which I really needed. I prepared my concerns and questions about my symptoms, and expected to tell the doctor during my visit to receive more treatments. The doctor doesn't know what's wrong with me without doing physical examinations or blood sample testing. It's too bad that nobody seems to know the exact answer when the pain clinic service will return back to normal. Doctors and all staff have the best intent, but they might forget about listening to patients. Good attentions were not enough without recognizing patients' greatest needs.
(Interview – Bua)

The unexpected disadvantage, derived from the study participants, was generated from the door-to-door pain medication delivery service. From their side, pain medication delivery provides a sense of receiving little to no attention being paid by the doctor:

I know the doctor tried to decrease the risk of getting COVID-19 by sending pain medication to my home. But

my deep feelings are badly negative. Indeed, I felt the doctor paid no attention to me, or they did not worry or were concerned about me anymore. They just routinely sent me the medication or they did not want me to come to the hospital. Actually, I do prefer getting pain medication from the hospital.
(Interview – Dokkaew)

A silver lining in the midst of the COVID-19 pandemic

This final theme is generated from one extreme or deviant study participant. Unlike other participants, this case has struggled to come to the hospital for follow-up visits; thus far. Cancellation of in-person visits in combination with home medication delivery is viewed as the miracle that surprisingly made my dreams come true:

I feel worthless whenever I reach the follow-up visit schedule. My mother and I have to ask the neighbors to do us a favor by driving me to the hospital. You know, I have to spend the whole day in limitless waiting for their available. Of course, I am exhausted and suffering more pain and need 2-3 days to return back to normal. So, when the service changes dramatically happened because of COVID-19 I'm had the feeling as if I had won the lottery.
(Interview – Sai)

DISCUSSION

This study is not global, novel research; regarding chronic pain patients' experiences during the COVID-19 pandemic. On the contrary, this study's findings reflect the unique participants' experience of in what way they interpreted and attributed meaning to their existence. These findings support the value of a qualitative approach in proving contextual insight and seeing the room for improvements to meet person-centered care[18].

The finding on their concern about stability of pain control is congruent with the experiences of chronic pain patients in Canada[18]. The first and foremost healthcare service change emerged during the COVID-19 pandemic made chronic pain patients feel uncertain regarding their pain and its management. Formerly suffering from chronic pain, and its impacts made required people to maintain the power of stability to keep their pain under control[29-32].

The silver lining, which emerged from this study, is that less to no adjustment to 'the new normal' is required for people living with chronic pain. Healthy people may have experienced social isolation for the first time in their lives. However, chronic pain patients are familiar with the consistent struggle to perform many of the normal daily activities; for which the majority take for granted as well as to adhere to social isolation or stay away from crowds, in general.

This study's finding on the participants' perception regarding the new healthcare service system well reflects the significance of patient-centered care and contextual difference. Rapid utilization of new interventions could provide gaps for some groups of patients, because of individual and cultural differences[33,34]. Aside from this, healthcare service changes have to be focused and respect the preferences, needs and values of individual patients[34].

CONCLUSION

Understanding the experiences of chronic pain patients in the context of particular pain clinic provides deep understanding and accurate feedback on their needs; in particular pain management services and the appropriateness of changes provided during the pandemic. Successful implementation of new interventions; such as, telemedicine and drug delivery globally needs to be modified for effective use in particular within the Thai context. Beyond expectation, the nature of a qualitative research approach provided huge support to the study participants, as it provided them a chance for somebody to listen to their pain story.

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