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ORIGINAL RESEARCH

Patients' and Family Members' Experiences of a Novel Nurse-Led Intervention Using Family Conversations Targeting Families Afflicted by Chronic Non-Cancer Pain

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Purpose: To explore patients' and family members' experiences of participating in an intervention using nurse-led family nursing conversations (NLFCs) targeting families affected by chronic non-cancer pain (CNCP), including the perceived impact of the intervention on the individual and the family. CNCP substantially impacts patients and families. Due to a lack of simple treatment solutions, the condition needs to be managed rather than cured. Family involvement seems a promising tool, but research evaluating specific approaches is limited. Interventions based on the family systems nursing framework by Wright and Leahey have been helpful in other populations. Nonetheless, the approach warrants further investigation and evaluation in patients with CNCP.

Patients and Methods: A phenomenological hermeneutical design was applied, and individual interviews were conducted with ten patients and ten family members who received the intervention. The analysis was inspired by Ricoeur's philosophy of text interpretation.

Findings: Three themes emerged during the analysis. "Taking part in the intervention while being affected by previous experiences" showed that patients and family members were affected by different experiences and burdens and therefore entered the intervention with varied starting points. "Being empowered through validation and understanding" showed that participants mainly viewed the intervention as beneficial, increasing patients' and family members' mutual understanding and underpinning acceptance of the chronic pain condition. "Being receptive to the intervention – mechanisms contributing to achieving benefit" identified contributing mechanisms influencing patients' and family members' experiences of the intervention. These mechanisms included confidence in the nurses' facilitation of the intervention, the timing of the intervention, the participant's level of acceptance, and readiness to engage in the intervention.

Conclusion and Relevance to Clinical Practice: The intervention was mainly experienced as helpful. Thus, healthcare settings treating CNCP should consider implementing NLFC in clinical practice with adjustments to meet the vulnerability of the CNCP population.

Keywords: family involvement, family systems nursing, qualitative, phenomenological hermeneutics, Ricoeur

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Introduction

Chronic non-cancer pain (CNCP) is a comprehensive healthcare problem leading to immense suffering for the affected person due to its far-reaching consequences on physical and mental health.[1–3] CNCP interferes with family life by worsening family functioning and increasing the burden on caregivers.[4,5] Children of parents with CNCP suffer due to its effects on family

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dynamics and have an increased risk of developing CNCP.[6] The 11th International Classification of Diseases (ICD-11)[7] recognizes CNCP as a disease rather than a symptom, ushering in a new paradigm for an illness clouded by years of stigma.[8] Despite the substantial disease burden associated with CNCP, people with CNCP are often faced with disbelief and lack of understanding and compassion from family members and healthcare providers, which may in turn cause social isolation.[9] Unfortunately, the ICD-11's acknowledgment of CNCP as a disease does not change the fact that the currently available treatment rarely resolves the condition;[10] therefore, the patient must manage the condition and come to terms with it as best as possible. The biopsychosocial treatment approach is the gold standard for ensuring healthcare professionals grasp the complexity of CNCP.[2,11] This approach considers CNCP the result of a dynamic interaction between biological, psychological, and social factors. Family involvement seems to be a prominent part of the social dimension of treatment, and existing research has shown that family involvement improves pain-related outcomes and supports the management of CNCP.[12–14] However, patients being treated for CNCP are usually not provided with intervention tailored to the family unit.[15] Wright and Leahey's family systems nursing framework is one approach to family involvement; it views the unit for care as the whole family and focuses on their interaction and reciprocity.[16–18] According to this framework, family should be broadly understood as "a group of individuals who are bound by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives".[16] They developed the framework from clinical nursing practice to help nurses facilitate therapeutic conversation to compassionately support patients and families in finding new ways to handle living with illness.[16,17,19] Interventions based on the family systems nursing framework could expand nurses' opportunity to practice the biopsychosocial approach and comply with the complex needs of patients suffering from CNCP. These interventions have been found helpful in other populations[20–22] but have never been tested on CNCP. Thus, it is necessary to assess its prospects as a part of multidisciplinary treatment. This paper presents a qualitative study evaluating a novel intervention with nurse-led family conversations (NLFCs) based on the family systems nursing framework and targeting families affected by CNCP. The study aims to explore patients' and family members' experiences of the intervention, including the perceived impact on the individual and the family.

Materials and Methods

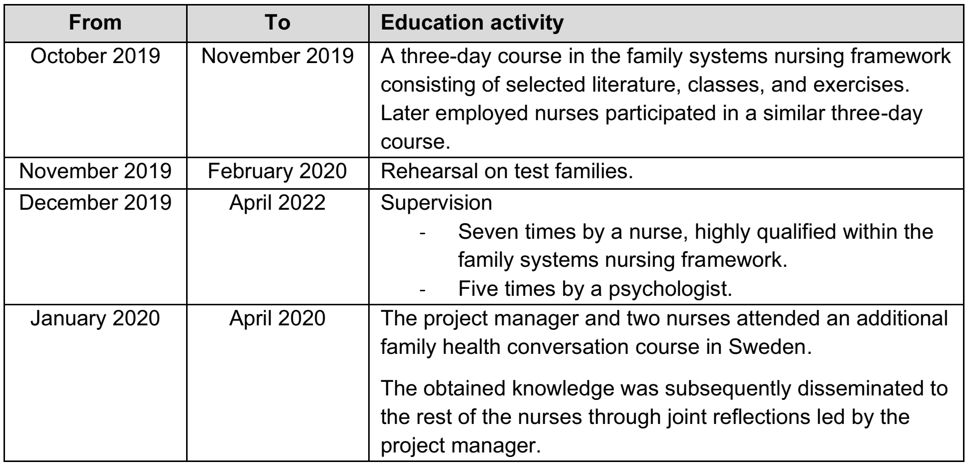
Design

The study applied a phenomenological hermeneutical design following Ricoeur's philosophy, where combining the phenomenological and the hermeneutical tradition allows people to make sense of their lifeworld through interpretation.[23–25] The design enabled the study to access the lifeworld of those patients and family members who participated in the NLFC intervention. Thus, it enabled a comprehensive understanding of their experiences, which gave an appropriate openness in the evaluation of an intervention never previously tested on a CNCP population.

Study Setting

This study is the second in a comprehensive mixed-methods study, the FANCOC-PAIN study (FAmily Nursing COnversations Chronic non-cancer PAIN), hosted by a Danish multidisciplinary pain center (MPC) located in the Capital Region of Denmark. The MPC treats patients 18 years or older who are severely impaired by CNCP, taking a biopsychosocial approach to improving their health-related quality of life. The FANCOC-PAIN study also comprised a quasi-experimental trial, measuring and comparing the effect of NLFCs in an intervention group receiving NLFCs as an add-on to usual care and a control group receiving usual care (trial registration: ClinicalTrials.gov, NCT03981302, June 4th, 2019).[26] The intervention group included patients referred to the MPC within the past six months, and they were offered a series of up to four NLFCs at three-week intervals. Interested patients were asked to invite between one and three family members who met the family systems nursing framework's broad definition of family.[16] The patient and the selected family members constituted a family unit and could only be enrolled as such. The patients and family members had to be at least 18 years old. They were excluded if they could not consent or collaborate or if they participated in other family interventions. The nurses employed at the MPC conducted the intervention; they were previously unfamiliar with the framework but were educated on it through different activities facilitated by the first author, who served as the project manager for the FANCOC-PAIN study. Figure 1 provides an overview of the nurses' education activities.

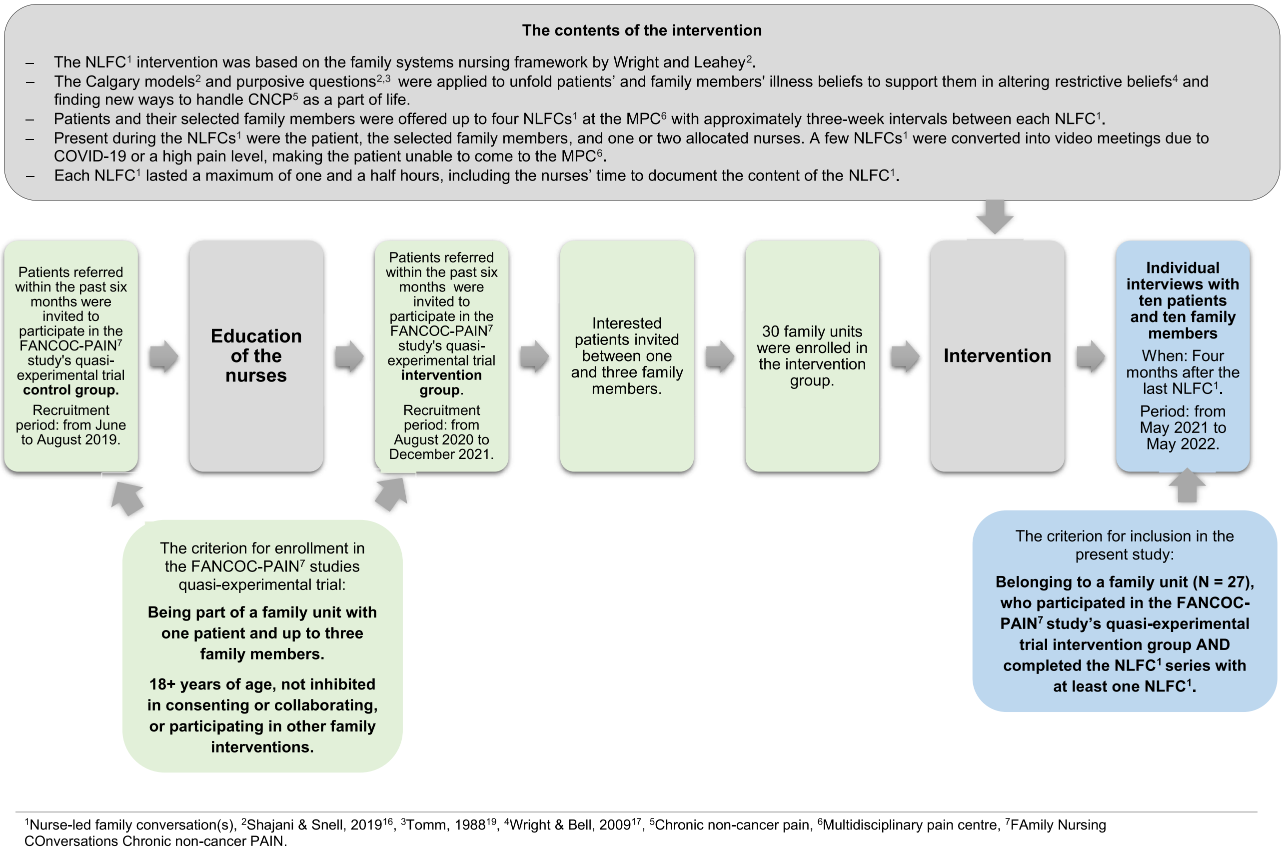
A third FANCOC-PAIN study investigated the nurses' process of acquiring the required skills.[27] Recruitment of patients and family members for the quasi-experimental trial's control group took place between June and August 2019.



From	To	Education activity
October 2019	November 2019	A three-day course in the family systems nursing framework consisting of selected literature, classes, and exercises. Later employed nurses participated in a similar three-day course.
November 2019	February 2020	Rehearsal on test families.
December 2019	April 2022	Supervision - Seven times by a nurse, highly qualified within the family systems nursing framework. - Five times by a psychologist.
January 2020	April 2020	The project manager and two nurses attended an additional family health conversation course in Sweden. The obtained knowledge was subsequently disseminated to the rest of the nurses through joint reflections led by the project manager.

Figure 1 Overview of education activities for nurses who facilitated the NLFCs[1] in the FANCOC-PAIN[2] project. Adapted from Rønne PF, Esbensen BA, Brødsgaard A, Rosenstrøm SM, Voltelen B, Hansen CA. Barriers and facilitators influencing nurses' confidence in managing family nursing conversations in the treatment of chronic noncancer pain: a Longitudinal Qualitative Study. *J Fam Nurs*. 2023;29(2):166–178.[27]

The nurses' education activities started in October 2019, and recruitment for the intervention group occurred between August 2020 and December 2021. Figure 2 presents an overview of the FANCOC-PAIN study and the intervention. A manual and a quick guide developed for the FANCOC-PAIN study are accessible as Supplementary Data.[28] A thorough description of the intervention was published elsewhere.[26]



The contents of the intervention

- The NLFC[1] intervention was based on the family systems nursing framework by Wright and Leahey[2].
- The Calgary models[2] and purposive questions[2,3] were applied to unfold patients' and family members' illness beliefs to support them in altering restrictive beliefs[4] and finding new ways to handle CNCP[5] as a part of life.
- Patients and their selected family members were offered up to four NLFCs[1] at the MPC[6] with approximately three-week intervals between each NLFC[1].
- Present during the NLFCs[1] were the patient, the selected family members, and one or two allocated nurses. A few NLFCs[1] were converted into video meetings due to COVID-19 or a high pain level, making the patient unable to come to the MPC[6].
- Each NLFC[1] lasted a maximum of one and a half hours, including the nurses' time to document the content of the NLFC[1].

Patients referred within the past six months were invited to participate in the FANCOC-PAIN[7] study's quasi-experimental trial **control group.**

Recruitment period: from June to August 2019.

Education of the nurses

Patients referred within the past six months were invited to participate in the FANCOC-PAIN[7] study's quasi-experimental trial **intervention group**.

Recruitment period: from August 2020 to December 2021.

Interested patients invited between one and three family members.

30 family units were enrolled in the intervention group.

Intervention

Individual interviews with ten patients and ten family members

When: Four months after the last NLFC[1].

Period: from May 2021 to May 2022.

The criterion for enrollment in the FANCOC-PAIN[7] studies quasi-experimental trial:

Being part of a family unit with one patient and up to three family members.

18+ years of age, not inhibited in consenting or collaborating, or participating in other family interventions.

The criterion for inclusion in the present study:

Belonging to a family unit (N = 27), who participated in the FANCOC-PAIN[7] study's quasi-experimental trial intervention group AND completed the NLFC[1] series with at least one NLFC[1].

[1]Nurse-led family conversation(s), [2]Shajani & Snell, 2019[16], [3]Tomm, 1988[19], [4]Wright & Bell, 2009[17], [5]Chronic non-cancer pain, [6]Multidisciplinary pain centre, [7]FAmily Nursing COnversations Chronic non-cancer PAIN.

Figure 2 Overview of the intervention and the recruitment of participants.

Participants

For the present study, a criterion sampling strategy[29] was applied to include the same patients and family members that were in the intervention group in the FANCOC-PAIN study's quasi-experimental trial. The criterion for inclusion was belonging to a family unit who terminated their NLFC series and completed at least one NLFC (N = 27; see Figure 2). Patients and family members were consecutively included as they finished the intervention.

Data Collection

Individual interviews with a narrative approach[24,30] were conducted between May 2021 and May 2022. Patients and family members were interviewed separately to build insights into their distinct experiences of the intervention. The interviews were conducted by the first author, who at the time was a Ph.D. student but was familiar with the discipline after conducting several previous interviews. As project manager for the FANCOC-PAIN study, the first author neither carried out the NLFCs nor held any clinical responsibility. During data collection, the first author was highly aware of ensuring the patients and family members were cared for and, if necessary, involved the responsible healthcare professionals. The interviews were held approximately four months after the family unit's last NLFC, when data collection in the quasi-experimental trial was completed.[26] The interviews were conducted in Danish and held at the MPC, the patient's, or a family member's homes, as they preferred. Due to the COVID-19 pandemic, a few interviews were conducted online (face-to-face) or by telephone. The interviews were guided by a semi-structured interview guide[31] developed by the first author and the research group. Due to a tight schedule in the wake of the pandemic, the interview guide was not pilot-tested on patients and family members. Still, it was suitable to create rich data, which may be due to its open approach. The interview began by asking the interviewee to generally tell about their experiences with the NLFC intervention. The following questions were optional and were only asked if they could meaningfully expose the interviewees' narratives. The questions concerned the intervention's influence on perceived self-efficacy, family function, and well-being, the experience of the nurses' facilitation, and proposals for changes in the intervention. The interviews were audio recorded and immediately transferred to a logged file that was only accessible to members of the research group.

Analysis

Ricoeur's philosophy of text interpretation guided the analysis. Central to Ricoeur's approach is the process of distanciation,[25] starting with converting speech to writing. The verbatim transcribed interviews thus created a written text that, in line with Ricoeur, had a meaning on its own, which should be subject to interpretation.[25,30] According to Ricoeur, the analysis of the text consists of three steps: a "naïve reading", a "structural analysis", and a "critical interpretation". In the naïve reading, all the interviews were read and re-read to grasp the initial meaning of the text as a whole.[30] The structural analysis followed the text's movement from "what was said" by the interviewees in the quotations to "what was talked about" between the lines. This movement was a circular dialectical process, shifting back and forth between the parts and the whole, understanding, explanation, and comprehension to validate and adjust the naïve reading.[23] In the first part of the structural analysis, NVivo helped to manage the extensive interview text (445 regular pages) and sort data into interim explanations based on the narrations from the naïve reading.[23,30] The final part was conducted manually to enable a more comprehensive understanding of the subtext. The comprehensive understanding unfolded "in front of the text", what Ricoeur refers to as a "being-in-The-world", capturing how patients and family members experienced their participation in the NLFC intervention. The themes emerged by condensing the comprehensive understanding.[23,25,30] Finally, the structural analysis continued in the discussion section as a critical interpretation of the extant research.[23,24]

Findings

Twenty individual interviews (range: 46–124 minutes, mean: 65 minutes) were conducted with ten patients and ten family members (twelve women and eight men, age range 18–75 years, mean age 44 years). The family members' affiliations with the patients were the following: spouse, cohabitant, ex-wife, boyfriend, mother, father, and daughter.

Table 1 Overview of Interviews with Patients and Family Members

	Patients (n = 10)	Family Members (n = 10)
Affiliation with the patient (family members only)		
Spouse		1
Cohabitant		1
Boyfriend		1
Ex-wife		1
Mother		4
Father		1
Daughter		1
Gender, no.		
Male	4	4
Female	6	6
Age, years		
Range	18–56	29–75
Mean	37	51
Duration of self-reportedCNCP[a] for the patients, years		
< 2	3	2
2–5	5	3
6–10		5
> 10	2	
Number of NLFCs[b], no.		
One	1	2
Two	4	5
Three	5	3
Location of NLFCs[b], no.		
The MPC[c]	9	9
The MPC[c] and video meeting	1	1
Location of the interview		
The patient's home	3	1
The family member's home	1	5
The MPC[c]	2	2
Online (face-to-face)	3	1
Telephone	1	1
Duration of the interview, minutes		
Range	46–124	52–100
Mean	64	66

Notes: [a]Chronic non-cancer pain, [b]Nurse-led family conversation(s), [c]Multidisciplinary pain centre.

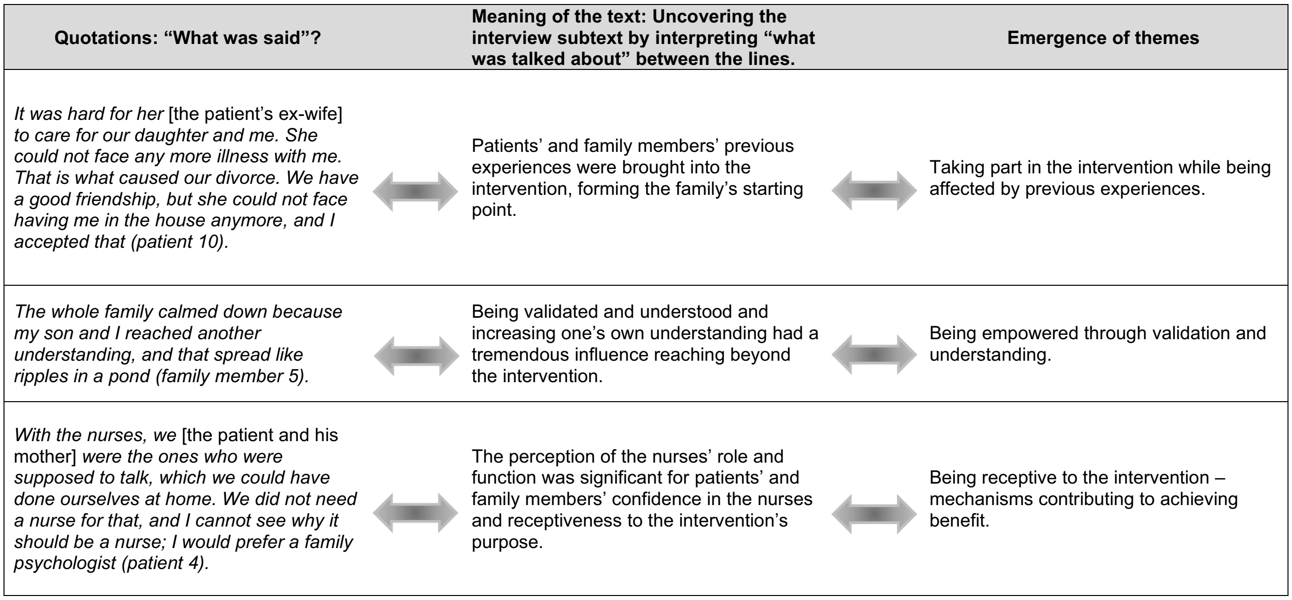
Table 1 provides an overview. After the 20 interviews, the research group had obtained a richness of information, further perspectives thinned out, and information power, as described by Malterud, was, therefore, considered reached.[32] One patient and one family member declined the request for an interview. All others accepted.

The naïve reading uncovered that narrating the experience of the intervention was inseparable from narrating the experience of living with CNCP in the family and shed light on it as a varied but comprehensive burden. The intervention was perceived as a mainly positive experience, with different impacts related to the perceived burden. In some cases, the intervention was of minor importance, albeit not harmful. The timing of the intervention, level of acceptance, and readiness to participate were perceived as essential for benefitting from the intervention. The nurses were generally perceived as suitable facilitators, but patients and family members discussed wanting nurses to ask more in-depth questions. The subsequent structural analysis developed three themes. The first theme, "Taking part in the intervention while being affected by previous experiences", revealed that patients and family members entered the intervention burdened by previous experiences that should be considered during the NLFCs. The second theme, "Being empowered through validation and understanding", signaled that participating in the intervention was a multifaceted experience for patients and family members, comprising increased understanding of their own and others' perspectives. The third theme, "Being receptive to the intervention – mechanisms contributing to achieving benefit", illuminated the contributing mechanisms influencing patients' and family members' experience of the interventions. Figure 3 provides an illustration of the structural analysis.

Taking Part in the Intervention While Being Affected by Previous Experiences

The patients and family members entered the intervention burdened by previous experiences. Interviewees viewed CNCP in the family as onerous and as profoundly affecting patients and family members. The patients struggled with complex illness-related problems deriving from their CNCP, frequently complicated by parallel comorbidities. CNCP had consequences for patients, family members, and the roles and interactions within the family. The experienced burden varied, as the load on each family member differed depending on the affiliation between patients and family members, who therefore entered the intervention with varied starting points. Parents of younger patients experienced a high level of concern and alertness, which induced an urge to monitor their adolescent or young adult child. They expressed difficulties in balancing the parent's role while respecting the young person's need for independence. Watching the young person's plans disintegrate produced a feeling of powerlessness and pushed the parents to find a solution. This was described as follows by a mother:

> We tried to determine what we could do: Could we try some other treatments? We tried various therapies, acupuncture, yoga, and pilates. We thought about searching for a second opinion in a foreign country (…) when she is that young, we will try anything that may have an effect. (Family member 7)



Quotations: "What was said"?		Meaning of the text: Uncovering the interview subtext by interpreting "what was talked about" between the lines.		Emergence of themes
It was hard for her [the patient's ex-wife] *to care for our daughter and me. She could not face any more illness with me. That is what caused our divorce. We have a good friendship, but she could not face having me in the house anymore, and I accepted that (patient 10).*	⟺	Patients' and family members' previous experiences were brought into the intervention, forming the family's starting point.	⟺	Taking part in the intervention while being affected by previous experiences.
The whole family calmed down because my son and I reached another understanding, and that spread like ripples in a pond (family member 5).	⟺	Being validated and understood and increasing one's own understanding had a tremendous influence reaching beyond the intervention.	⟺	Being empowered through validation and understanding.
With the nurses, we [the patient and his mother] *were the ones who were supposed to talk, which we could have done ourselves at home. We did not need a nurse for that, and I cannot see why it should be a nurse; I would prefer a family psychologist (patient 4).*	⟺	The perception of the nurses' role and function was significant for patients' and family members' confidence in the nurses and receptiveness to the intervention's purpose.	⟺	Being receptive to the intervention – mechanisms contributing to achieving benefit.

Figure 3 Depiction of the structural analysis. The arrows illustrate the dialectical movement back and forth between parts and the whole and between understanding, explanation, and comprehension.

Furthermore, patients and family members shared that the healthcare system often failed to provide help. Indeed, the search for the proper treatment to end the pain had exposed them to disrespectful encounters with health professionals who displayed disbelief and indifference to the patient's suffering. Such experiences further burdened patients and family members and made them feel let down by the healthcare system, in some cases to a traumatizing extent. Another example of a family member's burden came from an adult daughter, who was very uncomfortable with her mother's CNCP and had struggled to reconcile herself with the influence that CNCP was having on their communal life:

> It has been difficult to grasp that my mother is ill. I tended to think, no, you cannot be ill; you must not be ill. It is a long process for me, that I am still in, to understand and embrace her. (Family member 2)

Having an ill mother created feelings of uneasiness and existential uncertainty in the daughter. In response, the daughter had avoided discussing CNCP with her mother, who avoided raising the subject as part of an unsaid agreement. The lack of vocabulary was a pervasive issue for many interviewees, leaving patients and family members unable to recognize and describe what was at stake when the patient had limited energy, failed concentration, or emotional outbursts due to CNCP. For partners living together, the increased domestic workload further affected the family members, giving rise to conflicts. For example, the relationship balance had tipped over for one patient whose CNCP was part of an exhausting illness trajectory:

> It was hard for her [the patient's ex-wife] to care for our daughter and me. She could not face any more illness with me. That is what caused our divorce. We have a good friendship, but she could no longer face having me in the house, and I accepted that. (Patient 10)

This patient only participated in one NLFC. Though perceiving the intervention as helpful in narrating his story, he did not believe that further NLFCs would change anything. He entered the intervention with his ex-wife, who had felt compelled to terminate their marriage to avoid significant repercussions for herself. This situation indicates the influence of the caregiver's burden on family members' physical and mental health. Conversely, being aware that they were burdening their family members triggered a feeling of guilt in the patient, which further increased their burden. A patient described this:

> I guess I rapidly had this lousy conscience about knowing people would be uncomfortable. It was such a guilty conscience that my physical pain would cause other people mental pain or heartache. They would feel sorry for me, and the good mood would be ruined. (Patient 9)

Thus, the common theme that living with CNCP was burdensome for the family unit had many forms and expressions. Regardless of the form, the participants were unaccustomed to talking about the impact of CNCP in the context of the family. Furthermore, feeling unable to engage in conversations about CNCP was not limited to families who were inexperienced in communicating with each other. Patients and family members who perceived that they had elaborate communication practices in their family were equally uncertain about entering into vulnerable CNCP-related conversations.

Being Empowered Through Validation and Understanding

Patients and family members mainly stated that NLFCs positively impacted living with CNCP, alleviating the family's burden. In addition, participating in the NLFC intervention changed how they communicated and provided them with a vocabulary that enabled them to converse about the impact of CNCP on each of them and their entire family instead of assuming the other's point of view. Voicing concerns during the NLFCs was relieving but could also be difficult, as described by a young patient who participated with her parents:

> The best part was the honest conversations it started in our family (…) It was a little hard to realize that they [the parents] were sad and, indeed, very concerned. Still, by putting it into words, we could talk about it, and I knew how they handled it and what we could do to make us all feel better. (Patient 7)

The uneasiness that this patient experienced when listening to her parents' worries was counterbalanced by the gratefulness towards the new awareness of how to take care and be gentle when confronted with each other's feelings. The intervention established a platform for continued conversations within the family unit. Moreover, discussing vulnerable issues in a safe context boosted patients' and family members' self-confidence and encouraged them to be open about CNCP-related problems beyond the family unit. The experience of being understood and validated during the NLFCs was significant for patients' and family members' self-perception and contributed to their well-being. When patients invited their family members to participate in the intervention, they acknowledged their suffering. Furthermore, being embraced by understanding nurses had a healing effect on traumas arising from previous experiences of disbelief in the healthcare system. The opportunity to discuss frustrations was relieving. However, in some cases, this was perceived as little more than addressing only the surface of the problems. Accordingly, participants experienced the positive influence of NLFCs differently. For some, the NLFCs were life-changing. This was the case for a mother whose son besides CNCP had a disabling co-diagnosis and therefore required her help. The mother would, at times, trigger his pain and emotional outbursts, which would in turn increase her alertness, creating a vicious circle. The intervention helped them establish a more appropriate pattern and downscale their tensions:

> The whole family calmed down because my son and I reached another understanding, and that spread like ripples in a pond. (Family member 5)

The change was apparent and had important ramifications for the rest of the family members, even though they did not directly participate in the NLFCs. This also applied to other interviewees, who stated that the intervention motivated the family to cooperate. The insight into each other's perspectives and the presence of nurses helped the participants. The nurses could provide family members with knowledge about CNCP in a way that the patients could not do themselves, rendering CNCP visible and legitimizing their suffering. The family members' enhanced understanding created a space for CNCP in the family and motivated family members to resist their urge to push for quick-fix solutions. Furthermore, the family members who embraced CNCP as an inherent part of life supported the patients' coping process. For one patient, knowing that her family members would help her despite her CNCP-related disability had been essential for her process of acceptance:

> I kind of started to accept it because my family verbalized that they accepted it. They know this is how we live, and they don't leave me, even though things may get tough. (Patient 8)

For this patient, two NLFCs confirmed that she could count on her family members' care and support, which allowed her to believe that she could deal with the consequences of CNCP. Furthermore, the intervention also created a space for the family to talk about issues unrelated to CNCP, balancing the space given to CNCP and ensuring it did not take over the family dynamics completely. Seeing each other in a new light and embracing each other's perspectives made room for vulnerability. The honest and nuanced conversations allowed the participants to gain insights into each other's burdens. Patients and family members began to learn more about each other's emotional landscape and were supported to change inappropriate interaction patterns. However, some participants did experience the intervention as unimportant. One patient, who faced the issue of finding a way for him and his girlfriend to communicate when his pain peaked, had a disappointing experience:

> I would have preferred that they [the nurses] returned the next time with some professional advice instead of trying to give us their own best advice (…) I wished that they could give us another angle on the problem, somehow giving us some advice on how others in the same situation handled the issues. (Patient 2)

This patient hoped the intervention could help them find a more suitable pattern for managing his pain as a couple. However, he found that the facilitating nurses failed to move beyond delivering shallow recommendations. While some participants did not experience any benefits, no participants expressed experiencing any adverse consequences of the intervention. The experience of participating in the NLFC intervention was thus multi-faceted, yielding a broad spectrum of impacts depending on the burden to each patient and family member. For those who benefitted, the validation and mutual understanding that unfolded during the NLFCs seemed to empower them, as being a family team seemed to ease their specific burdens.

Being Receptive to the Intervention – Mechanisms Contributing to Achieving Benefit

The intervention was embedded in a multidisciplinary context, making it challenging to discern precisely what influenced each member and the family as a whole. However, various contributing mechanisms had a distinct relevance to the participants' experience of the intervention. A significant contributing mechanism was the nurses' conduct during the NLFCs. Patients and family members generally viewed the nurses' facilitation of the process favorably. They perceived the nurses as obliging and listening, but, in some cases, they stated that the nurses abstained from following up on emotional subjects that came up during the NLFCs, which left the participants with a sense of unfulfillment. However, patients' and family members' beliefs about the nurse's role turned out to be significant for buying into the NLFC concept, as described by this patient:

> With the nurses, we [the patient and his mother] were the ones who were supposed to talk, which we could have done ourselves at home. We did not need a nurse for that, and I cannot see why it should be a nurse; I would prefer a family psychologist. (Patient 4)

This patient had entered the intervention believing he would have time with a coordinating nurse who would help him navigate the system. He thought of nurses as competent coordinators but did not envision them as facilitators of family conversations, a belief which was confirmed by his experience with the intervention. Others trusted the nurses deeply, underlining their humanity, empathic approach, and knowledge of CNCP as essential qualifications for successfully facilitating the process. Thus, confidence in the nurses' ability to meet their specific needs seemed vital to ensure the intervention was impactful. Another crucial mechanism was the timing of the intervention. An issue that came up often was ensuring that the intervention was offered at the right time. Some believed the intervention came at the best time. Others stated that it would have helped to receive the intervention earlier to ease the burden of CNCP on the family. They had already been forced to struggle with the challenges on their own. For some, the consequences of waiting too long were changed or dissolved relationships. Others had somehow adapted to the changes brought on by CNCP independently, but they still believed that the NLFCs were beneficial. One family member who participated with his daughter stated the following:

> Of course, having lived with chronic pain for quite a long time is necessary to gain some experiences from which you can build upon. (Family member 8)

This quotation conveyed that the families needed to have some experience in living with CNCP to benefit from the intervention. The interviews also uncovered different levels of coping with CNCP, ranging from striving for easy and quick solutions to recognizing the need for other strategies to ensure CNCP did not dominate life and family life. It seemed that some level of acceptance was necessary for the NLFCs to be experienced as beneficial. However, some patients and family members whose narratives did not indicate acceptance did find that the NLFCs were helpful because they allowed them to talk about traumatizing experiences with nurses who believed them. In addition to appropriateness of timing, readiness to enter an NLFC intervention also seemed to be beneficial, as participants had to be comfortable with being vulnerable and sharing emotions. Several participants could think of family members who would not do the intervention. One family member thought that the intervention gave rise to an inappropriate focus on CNCP. She perceived the intervention as more relevant for couples or families afflicted by malignant diagnoses, indicating that readiness is also associated with CNCP-related illness beliefs. Additionally, circumstances and willingness to prioritize the intervention were other aspects of readiness:

> It requires an effort from you. You need to set time aside for it [the NLFCs] and be motivated to work with yourself and your patterns and be motivated to change. It requires some energy and openness from you. But I would definitely recommend it to everyone. (Patient 6)

Thus, the experience of participating in the NLFC intervention was related to patients' and family members' starting points and burdens and how they ascribed meaning to the intervention. The considerable variety of contributing mechanisms presented a complex puzzle of experiences. However, as the above quotation shows, the intervention was considered worthy of becoming a substantial and permanent part of the multidisciplinary treatment service regardless of the revealed variation. Still, it seems that the patients and their families did not realize the advantages of the intervention before they started participating in it. One family member, who had participated with his wife because he had the desire to support research, had realized that the interventions benefited his family and stated the following:

> You should have made me recognize how important it [the intervention] was. We participated in your research to give something in return for the help we received from the healthcare system, but this was more important for me than I had realized. (Family member 1)

This patient requested that efforts be made to increase patients' and family members' awareness of the importance of sharing CNCP experiences within the family. He believed that either the intervention should be mandatory, or nurses should use their position to promote participation.

Discussion

The present study aimed to explore patients' and family members' experiences of participating in an NLFC intervention targeting families affected by CNCP, including the perceived impact of the intervention on the individual and the family. The chosen open approach uncovered that families viewed living with CNCP as burdensome, as illuminated in the first theme. The perceived burden to the family aligned with the existing literature on living with CNCP and chronic illness in general.[4,5,33] However, the present study reported a significant magnitude of the burden, emphasizing its impact. The experience of the intervention and the experience of living with CNCP were deeply intertwined. Thus, the study illustrated that patients' and family members' experiences of participating in the intervention were inseparable from the perceived burdens, which should be considered in future nursing interventions targeting patients and family members afflicted by CNCP. There was considerable heterogeneity throughout the themes, starting with the variation in the experienced burden. Every patient and every family member are unique, but the variation also mirrors the inherent complexity of CNCP. The ICD-11 definition of chronic pain as persistent or recurrent pain that lasts for more than three months[7] comprises several primary and secondary chronic pain syndromes, characterizing a diverse population.

The second theme illuminated that patients and family members mainly viewed the intervention as positive. It gave them a vocabulary for an invisible illness that is usually challenging to grasp.[34] This enabled them to address CNCP-related issues and continue communicating about CNCP outside the NLFC context. Sharing experiences of CNCP allowed the patients and their family members to build a stronger mutual understanding of the topic. This understanding brought upon changes in inappropriate patterns and created space to address CNCP and its effects on family life. The benefits of participating in this NLFC intervention adds to a mounting body of research that stresses the significance of interventions based on the family systems nursing framework.[20,35,36] The study found that nurses' validation of patients' and family members' previous experiences was of great value. Validating, acknowledging, and normalizing emotional responses are important elements in the Calgary Family Intervention Model.[16] According to Duhamel, legitimization through validation is powerful as it conveys that "everyone's 'reality' matters".[37] The patients' repeated experiences of other people disbelieving their bodily symptoms led them to doubt their perception of reality, a well-known phenomenon.[9,34] Therefore, validation was a significant component for our study population, as it valued their perception of CNCP and helped them comprehend the nature of CNCP in the context of the family. Participating in the intervention also seemed to make patients and family members better at coping with CNCP and viewing it as a part of life, which may be considered very important for an illness that current treatment options cannot adequately resolve.[10] As unfolded in the third theme, some level of prior acceptance of CNCP seemed to help the participants benefit from the intervention. This finding may be tied to the patients' and family members' core beliefs. Årestedt et al found that families living with chronic illness hold two core beliefs about the illness as either a part of life or a threat to life.[38] When holding the core belief that CNCP is a threat to existence, it may be counterintuitive to abandon the search for a rapid-fix solution. Patients who experienced that the intervention was unimportant may have lacked the readiness to perceive CNCP as an inherent part of life. However, a lack of framing and misalignment of expectations probably also contributed to the perception that the intervention was meaningless. Lack of framing is known as one of the causes that interventions based on the family systems nursing framework are inefficient.[16] Some participants had the impression that the intervention would have a different purpose and content than family involvement in CNCP. This may have occurred because they desired something different and hoped the intervention would meet their expectations. The lack of clarity about what to expect may be ascribed to the ambiguous perception of what family involvement implies for patients with CNCP, as reflected in Rønne et al.[15] In our study, the nurses' conduct was crucial for patients' and family members' experience of the intervention. Broekema et al,[39] Gervais et al,[40] and Östlund et al[41] also discussed the significance of the nurses' conduct but they only covered its positive aspects. Though patients and family members in the present study appreciated the nurses, they also experienced unfulfilled moments due to the nurses' reluctance to engage further with emotional issues. The intervention nurses had received education on the intervention beforehand. Still, they were novices as facilitators of NLFCs, which was thoroughly discussed in the paper that reported the findings from the third FANCOC-PAIN study.[27] Since NLFCs takes hours to learn,[42] the participants' experience of unfulfilled moments has to be interpreted within the picture of the nurses' lack of experience. Furthermore, patients' and family members' views on nurses' roles also seemed to affect their experience of unfulfilled moments. The lack of public acknowledgment of nurses' competence, autonomy, and independence is not a local phenomenon. The nursing profession is described as invisible and unknown, with a perception of nurses as "doers" who are subordinate to physicians.[43–45] From this perspective, confidence in nurses' ability to take on a therapeutic role and facilitate NLFCs should first be established. Timing was another important contributing mechanism to the experience of the intervention. Many participants in the study expressed that they wished the intervention had occurred earlier, a finding also found by Benzein et al in their study.[46] An earlier intervention would mean involving the healthcare settings that patients had gone to before being referred to the MPC. The wish for earlier family involvement indicates that healthcare settings should ensure they take care of the entire family. However, early interventions could paradoxically interfere with patients' and family members' level of acceptance. Given the broad heterogeneity that characterized the experience of participating in the intervention, it may not be possible to time such an intervention in a manner that is suitable to all participants. The relevance of the intervention was supported by the common suggestion that the intervention should be offered as a permanent service, even though it had left some participants indifferent. A similar desire to make family conversations a permanent service was demonstrated by Ahlberg et al.[36] To extend the benefits to more participants, there should be increased expectations alignment and adjustments to the standardized intervention. The patients who completed the intervention with at least one NLFC with their selected family members accounted for approximately 21% of patients eligible for the FANCOC-PAIN intervention. Refusal to participate was due to, among others, lack of relevant family members, difficult life situations, and lack of energy to participate in a research project. The interviewees in the present study found that answering the questionnaire for the quasi-experimental FANCOC-PAIN study was an extra burden they needed to carry. However, the questionnaire also was an eye-opener for some participants. Fundamentally, a high level of vulnerability among the population seemed to limit family involvement. More research is necessary to uncover the specific needs and preferences of those who declined to participate in the intervention. Nonetheless, the findings indicate that an effort to align expectations and motivate patients and family members to participate in NLFCs could be a fruitful endeavor in the multidisciplinary treatment of CNCP. Supporting potential participants to perceive CNCP as a part of life rather than a threat would be a separate effort contributing to the overall CNCP treatment. However, coming to terms with chronic illness is a complex process.[47] The present study illuminated that there were various aspects of the positive influence of the intervention and that the participants had different perceptions of its benefits, which may confuse how to start. A suitable first step may be to embrace the family and its members where they are, with their own experiences and burdens, thus creating a context for small but significant steps toward perceiving CNCP as a part of life.

The present study has both strengths and limitations. The intervention was a novel practice for the nurses involved, and the interview data were taken from patients and family members in the initial intervention phase, when the nurses were least experienced. More time for the nurses to practice could have given another picture of patients' and family members' experiences. A strength was that several steps were taken to ensure trustworthiness.[48,49] The credibility, that is, the truth of the findings,[48,49] was achieved in various ways. During the preceding quasi-experimental trial, the first author had repeated contact with the participants, which ensured a prolonged engagement that contributed to a trustful environment in which the interviewee could share their narratives about the intervention, thus creating rich data. Patients and family members were interviewed approximately four months after their last NLFC to avoid contamination of data collected in the quasi-experimental trial of the FANCOC-PAIN studies. The waiting time caused some loss of detail but also the study to collect patients' and family members' long-term impressions of the intervention. Persistent observation was achieved by the semi-structured interview guide, which contributed to adhering to the study aim. Furthermore, through the repeated reading of the interview text and the movement back and forth between "what was said", "what was talked about", and the creation of the final themes. The first author led the data analysis, but researcher triangulation was used throughout the process, in which continuous discussions within the research group about the analysis and interpretation helped achieve what Ricoeur describes as a probable interpretation of the text.[23] Before the interviews, the first author was interviewed herself to foster reflexivity upon her position on the research subject and enlighten her beliefs about the population, the intervention, and the influence of private experiences as a family member to close relatives with chronic illness, although from other illness areas.[48,49] The research group had continuous awareness of the first author's private experiences, which were regularly discussed. Doing member checks to confirm the analysis and interpretation would be incompatible with the Ricoeur approach, as the distanciation implies that the interview transcripts are divorced from the interviewees' intention.[25] To comply with the lack of member checks, the findings discussed varied and minor cases, including all negative cases. Dependability and confirmability[48] were ensured through deliberate transparency throughout the research process. Copies of the temporary working files were continuously saved, and the research group had unlimited access to data and working files.

One limitation was that the intervention was carried out during the COVID-19 pandemic and a Danish nursing strike (June 19th to August 28th, 2021), which forced the planned intervals between the NLFCs to be extended. Moreover, due to organizational obstacles, the intervention period coincided with a reduced intake of new patients at the MPC. To ensure data collection within the available timeframe, the study setting was broadened to comprise a specialized clinic for patients suffering from complex regional pain syndrome (CRPS), a specific chronic pain condition.[7] The CRPS clinic is part of the MPC and uses its nurses and other health professionals in cooperation with specialized neurologists, physiotherapists, and occupational therapists. The study initially planned to apply a purposive sampling strategy to ensure the representation of various perspectives.[29] However, due to the constraints, it used a criterion sampling strategy,[29] inviting patients and family members to be interviewed once they finished the intervention. On reflection, this prevented us from unintentionally filtering out patients and family members with a critical view of the intervention, which may be viewed as a strength. As Table 1 shows, the study did manage to collect data from a diverse study population. It may be a limitation that some of the interviews were conducted online or by telephone due to Covid-19 restrictions, which limited the collection of the interviewees' non-verbal communication. Nonetheless, as the interviewer, the first author did get the impression that an intimate space was created in all interviews. Collecting data in different contexts may be viewed as increasing credibility,[48] and thus, the unintended data collection triangulation could have even promoted credibility. The reporting of the findings attempted to provide thick descriptions and enlighten all aspects of the research process to create transferability[48,49] and allow readers to decide if the findings may resonate in their practice.[48,49] Generally, the findings should be applied, considering the consequences of conducting research on families during an exceptional historical period.

Conclusion and Relevance to Clinical Practice

Noticeable heterogeneity characterized our findings. This applied to previous experiences, burdens, and patients' and family members' experiences of the intervention and its impact. Across this heterogeneity, the intervention was mainly experienced as beneficial, somehow relieving the burden of living with CNCP in the family. The intervention had a wide-ranging impact, and the participants perceived its benefits differently. Patients' and family members' experiences with the intervention were shaped by their perception of the nurses' role, the timing of the intervention, their level of acceptance, and their readiness to participate. Despite varied opinions, the NLFCs were perceived as worthy of becoming a permanent multidisciplinary treatment service. Thus, our study concludes that it could be relevant to implement NLFCs as a part of the multidisciplinary treatment of patients with CNCP. However, further tailoring to comply with the specific family's needs would be necessary to increase the access to more families. The population's vulnerability should be considered to prevent the exclusion of the most vulnerable families, and further research should attempt to include patients and family members with limited resources. Furthermore, nurses' role in caring for families in a multidisciplinary setting should be elaborated.

Abbreviations

CNCP, Chronic non-cancer pain; CRPS, Complex regional pain syndrome; FANCOC-PAIN, FAmily Nursing COnversations Chronic non-cancer PAIN; NLFC, Nurse-led family nursing conversation; ICD-11, The 11th International Classification of Diseases; MPC, Multidisciplinary pain center.

Data Sharing Statement

Data are not publicly available due to the General Data Protection Regulations. Requests may be directed to the corresponding author.

Ethical Approval and Informed Consent

The study complied with the ethical guidelines of the Declaration of Helsinki.[50] The Danish Committee on Health Research Ethics waived the requirement for notification of the study, which was registered with record no: H-19016896. The Danish Data Protection Agency registered the study with record no. P-2019-508. Eligible patients who consented were contacted by the first author face-to-face or by telephone. Patients and family members interested in participating in the NLFC intervention received written and oral information about the quasi-experimental trial and the present study. The verbal information about the present study was repeated to those who were enrolled after the completion of the last NLFC with an invitation to participate in an interview. Patients and family members were informed that their participation was voluntary and that they could withdraw their consent anytime without explanation or treatment consequences. The interview data were anonymized during transcription, analysis, and reporting of the results. Oral and written consent was obtained. The informed consent included the publication of anonymized responses. The reporting followed the consolidated criteria for reporting qualitative research.[51]

Consent for Publication

Written consents are available.

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Author Contributions

All authors made a significant contribution to the work reported, whether in the conception, study design, execution, acquisition of data, analysis, and interpretation, or in all these areas; took part in drafting, revising, or critically reviewing the article; gave final approval of the version to be published; agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of the work.

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Disclosure

The authors have no conflicts of interest in this work.

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