

Original Research Article

# Mind the Gaps: A Qualitative Study Combining Patients' and Nurses' Reflections on Pain Care

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#### **Abstract**

Chronic noncancer pain is a serious health problem, one that is often associated with physical debility and emotional suffering. Although chronic noncancer pain is one of the primary reasons that people seek medical care, a significant body of evidence indicates that chronic pain is underdiagnosed and undertreated. There is a consensus among professional stakeholders in pain care that there is a need to strengthen quality, capacity, and competence in pain management at all levels of health care. Thus, there is a need for more in-depth knowledge of both the recipients and the providers of pain care, and qualitative studies can contribute to this. The aim is to explore and combine the perspectives of patients receiving pain care and registered nurses providing care at pain clinics. A multimethod design was based on two qualitative studies consisting of semistructured interviews with patients receiving pain care (N = 10) and nurses providing pain care at pain clinics (N = 10). Qualitative content analysis was applied to interpret and abstract their experiences. The themes developed from triangulation revealed significant gaps between ideal pain care and actual practice: "Dissonance in reflections on personalized care," "A corresponding need for improved information flow in all levels," and "A corresponding need for improved structure in pain care." We suggest a stronger commitment to efficient information flow and person-centered communication to facilitate the patient involvement and self-management. In addition, more resources, education, and training are necessary to enable nurses and other professionals to act upon guidelines and ensure effective pain care.

# **Keywords**

chronic illnesses, qualitative research, research, self-management

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# Introduction

Chronic noncancer pain is a debilitating condition that has a negative impact on relationship and work life, a significantly reduced quality of life, and increased rates of depression (Breivik, Eisenberg, & O'Brien, 2013). In addition, patients with chronic pain often face demanding encounters with a complex health system and in understanding and accepting their disease (Toye et al., 2013). Pain is usually an expected consequence of acute illness, injury, or surgery and is healed over time. Pain that persists or recurs for longer than 3 months is considered chronic (International Association for the Study of Pain, 2019). Thus, chronic pain severity is not correlated with amount of damage and is no longer a

symptom of another disease but a disease in itself (Treede et al., 2015; Turk, Wilson, & Cahana, 2011).

However, chronic pain does not occur in a vacuum; biopsychosocial factors are involved with persistent pain (Dezutter, Offenbaecher, Vanhooren, Thauvoye, & Toussaint, 2017; Gerrits, Van Marwijk, van Oppen, van der Horst, & Penninx, 2015). Acknowledging chronic noncancer pain as a multidimensional

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phenomenon and independent of tissue damage addresses the complexity of chronic pain care. Thus, a biopsychosocial approach is proven to be efficient in management of this condition (Gatchel, McGeary, McGeary, & Lippe, 2014; Hayes & Hodson, 2011). Treatment outcomes should therefore be measured in terms of pain intensity, psychological well-being, quality of life and functioning, and patients' satisfaction with their treatment (Elsesser & Cegla, 2017).

# Review of Literature

The evidence suggests that unimodal approaches to pain management produce limited benefit for a limited time (Gatchel et al., 2014). The available pharmaceutical, behavioral, rehabilitative, and complementary treatments provide only modest improvements in pain and minimal improvements in physical and emotional functioning (Turk et al., 2011). Hence, none of the many therapeutic interventions have been accepted as "the magic bullet" (Hylands-White, Duarte, & Raphael, 2017; Turk et al., 2011). Team-based care consisting of registered nurses (RNs), physicians, physiotherapists, and psychologists providing integrative and biopsychosocial care is the gold standard in pain care (Gatchel et al., 2014). The main goal in pain care is to stimulate patients ability to self-manage, which can be defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition" (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178).

An important consideration is the individual treatment response in pain care; one approach does not fit all (Turk et al., 2011). Thus, a crucial issue is to match treatment to each person's needs, preferences, and benefits while encouraging self-management (Nordin & Gard, 2017; Paul-Savoie, Bourgault, Gosselin, Potvin, & Lafrenaye, 2015). Person-centered practice is crucial in chronic pain care and has been emphasized both in recent research and by international health authorities as indispensable for efficient health care (Nordin & Gard, 2017; World Health Organization, 2013). The underpinning principles in person-centered practice are respect for personhood manifested through mutual respect, self-determination, and understanding (McCormack & McCance, 2017).

Patients with chronic diseases, such as chronic pain, may encounter many different health-care professionals working across multiple clinical sites. Thus, patients and professionals alike consider continuity of care to be essential for high-quality care (Biringer, Hartveit, Sundfør, Ruud, & Borg, 2017; Haggerty, Roberge, Freeman, & Beaulieu, 2013). Continuity of care is a multidimensional and hierarchical concept ranging from the basic availability of information about the service to a complex interpersonal relationship between the

health professional and service user and is provided to each patient over time (Bahr & Weiss, 2018; Haggerty et al., 2003). Studies show that a high continuity of care combined with person-centered and integrative care is associated with better quality of care, better health, and lower societal costs (Kamper et al., 2014; Uijen, Schers, Schellevis, & van den Bosch, 2012).

A significant body of evidence indicates that chronic pain is underdiagnosed and undertreated (Dezutter et al., 2017; Geurts et al., 2016; Kress et al., 2015). Furthermore, with the increasing prevalence of chronic pain and often poor recovery, there is a great deal of concern among professional stakeholders in pain care about the quality (Kress et al., 2015; Turk et al., 2011). Thus, there is an international consensus that there is a need to improve the quality, capacity, and competence of pain care (Gatchel et al., 2014; Kress et al., 2015; The Norwegian Directorate of Health, 2015). The first step to improve pain care is a better understanding of the situation, and qualitative studies can contribute to this.

A deeper knowledge of patients' experiences with pain care and RNs' experiences with providing pain care at pain clinics can help make pain care more effective (Hibbard & Green, 2013; Kress et al., 2015; McCormack & McCance, 2017; Richards, Coulter, & Wicks, 2015). Patient experiences refer to the quality and value of all interactions covering the entire duration of the patient-provider relationship (Wolf, Niederhauser, Marshburn, & LaVela, 2014). The patient experience spans the continuum of care from the first phone call to a general practitioner (GP) to the final follow-up from the pain clinic. RNs' experiences also span the care continuum, as they usually have close contact with patients and other health-care professionals. At the same time, they coordinate responsibility for transferring their patients back to primary care settings or to active self-management (Gatchel et al., 2014; Kress et al., 2015). Given these considerations, the aim of the study was to explore and combine the perspectives of patients receiving pain care and RNs providing care at pain clinics. The following research question was formulated: What did patients and RNs describe as challenges and as areas needing improvement?

### **Methods**

# Study Context

Most people in Norway who have noncancer chronic pain are treated by GPs and the municipal health service. Most of these people are referred to the specialist health service where they are examined and treated by organ- or disease-specific units (The Norwegian Directorate of Health, 2015). Public interdisciplinary pain clinics are reserved for people whose chronic pain cannot be treated in the municipal or other specialist health services

(The Norwegian Directorate of Health, 2015). Treatment at the pain clinics is designed to facilitate and stimulate self-management throughout the treatment course. In addition, the interdisciplinary pain clinics should contribute to competence sharing for professionals such as primary care providers who treat people with chronic pain (The Norwegian Directorate of Health, 2015). A 2015 report by the Norwegian authorities notes that the development of interdisciplinary pain clinics in Norway has been slower than expected and cites problems such as difficulties with accessibility due to long waiting lists and lack of resources (The Norwegian Directorate of Health, 2015).

# Study Design

A multimethod design as described by Morse (2003) was used. The purpose is to explore several aspects of the same phenomenon, where different perspectives may enhance the description, understanding, and explanation of the phenomenon under investigation (Morse, 2003). We used a sequential *QUAL*—qual design where a qualitative project is followed by a second qualitative project, each conducted rigorously and complete in itself. The *QUAL* indicates that this is the base component of the study, and the "supplemental" qual component is planned to elaborate and to inform in greater detail about the phenomenon. In our project, where patients (QUAL) and RNs' (qual) perspectives were combined to illuminate the complexity of chronic pain care, this design was beneficial (see Figure 1 outline of the study design).

# **Participants**

Patients' experiences—The base component (QUAL). The base component—the experience of recipients of pain care—is obtained through interviews with patients. Purposive sampling was used to ensure that participants are experienced with the phenomenon of interest (Cresswell & Plano Clark, 2011). Therefore, people living with chronic pain were recruited in collaboration with a Norwegian patient organization. We published information about our study in the patient organization's website, on its Twitter feed, and placed a notice in its printed magazine. People who were willing to participate e-mailed a request, and the first author responded within 1 week by e-mail or telephone. The participants were then e-mailed extended information about the study along with an informed consent form. If they still wished to participate, the first author verified that all participants met the inclusion criteria:

- Age 18 to 67 years
- Noncancer pain > 6 months
- Referral to a pain clinic
- Living at home (outpatients).

Twenty-five people made contact; six were excluded due to age and because they had been diagnosed with a malignant pain condition, and one withdrew before the interview for an unknown reason. Eight were excluded due to lack of referral and thus experience from pain clinics. This left us with 10 patients (8 women and 2 men, aged 22–65 years) with wide-ranging experience with pain care. The patients are presented in Table 1.

RNs' experiences—The supplemental component (qual). The supplemental component—the experience of pain care providers—is obtained through interviews with RNs working at public pain clinics. The supplementary is strategically different from the base component and is used to extend the investigation (Morse, 2003). Therefore, RNs' experiences in public pain clinics were of interest. We planned for a total population sampling, as we invited all 16 public pain clinics in Norway to join the study. The managers at the pain clinics were contacted by telephone and given basic information about the study. Extended information with a formal invitation to participate in the study was sent by e-mail shortly after the phone call. An appointment for individual interviews was scheduled with RNs who wanted to participate and who fulfilled the following inclusion criteria:

- Working with outpatients with noncancer chronic pain
- A minimum of 2 years of training.

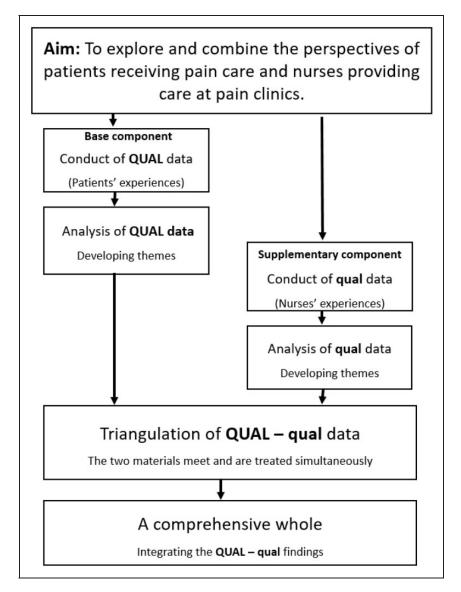
One pain clinic did not meet the inclusion criteria (its RNs did not work with outpatients), one did not want to participate for unknown reasons, and four answered neither our e-mailed request nor the reminder. Thus, 10 different pain clinics were included. The RNs are presented in Table 2.

### Data Collection

A total of 20 semistructured interviews (10 patients + 10 RNs) were conducted and lasted 50 to 75 minutes. The researcher provided some structure based on the interview guide but allowed room for the participants to offer more spontaneous descriptions. Each participant could choose to have the interview at home or somewhere else. Five patients were interviewed at home, three in a hotel conference room, and two interviews in a conference room at the first author's workplace. All interviews with the RNs were conducted at their workplace.

# Data Analysis

We analyzed the data materials (QUAL-qual) independently using qualitative content analysis as presented by



**Figure 1.** Overview over multimethod design where the left pathway illustrates the base component (QUAL) and the right pathway illustrates the supplemental (qual) component of the study. The components were conducted and analyzed independently. *Triangulation* is the position where the components meet and are treated simultaneously. *A comprehensive whole* refers to the integration of patients' and RNs' experiences.

Graneheim and Lundman (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). Qualitative content analysis focuses on subject and context and emphasizes variation, such as similarities and differences between parts of the text (Graneheim et al., 2017). Consistent with a hermeneutic phenomenological point of view, we sought to be close and connected to the study participants in order to elicit meaning from the data using various degrees of interpretation. The codes were systematically organized and placed in categories, representing the manifest content. Then, the latent content, or the underlying meaning, was interpreted and presented in the themes. The results were then triangulated, which refers to the position where the two components

meet and are treated simultaneously (Figure 1). This process led us to what Morse (2003) refers to as a comprehensive whole, which is a combination of the results to provide a fuller picture and deeper understanding than either study could do alone. The findings are presented in Table 3.

### Ethical Considerations

The study was approved by the Regional Committees for Medical and Health Research Ethics, Norway (Project number 2014/2165). Every participant provided informed written consent ahead of the interview. The participants received written and verbal assurance that

**Table 1.** Sample Characteristics Patients (N = 10).

Participants	Age	Pain area	Received health care
Male	47	Low back pain	GP, pain clinic, rehabilitation stay,
Male	42	Low back pain	GP, pain clinic
Female	38	Neck/shoulders	GP, pain clinic, Rehabilitation stay
Female	61	Muscular pain	GP, pain clinic, Rehabilitation stay,
Female	65	Muscular pain	GP, pain clinic, Rehabilitation stay
Female	22	Low back pain	GP, pain clinic
Female	37	Neck/shoulder	GP, pain clinic
Female	42	Pelvic pain	GP, pain clinic, Rehabilitation stay
Female	50	Neck/shoulders	GP, pain clinic, Rehabilitation stay
Female	52	Muscular pain	GP, pain clinic
Mean age	43		

Note. GP = general practitioner.

**Table 2.** Sample Characteristics Registered Nurses (N = 10).

Characteristics of participating nurses	N = 10
Sex	
Female	10
Male	0
Clinical experience means <sup>a</sup>	9.4
Education	
Registered nurse	10
Specialty	
Anesthesia	4
Intensive care	I
Psychiatry	1
Other relevant courses <sup>b</sup>	4

<sup>&</sup>lt;sup>a</sup>Range 2 to 19 years.

they had the right to withdraw at any time and were assured that their participation was anonymous.

### **Results**

The following presentation of findings was developed from triangulation and constitutes our comprehensive whole: "Dissonance in reflections on personalized care," "A corresponding need for improved information flow," and "A corresponding need for improved structure in pain care." The findings are presented in accordance with the themes, and quotations are included to give the participants a voice.

# Dissonance in Reflections on Personalized Pain Care

All RNs insisted that a comprehensive approach to patient involvement was the key to ensure that care

was responsive to patients' needs. The patients' values, preferences, and context were of great interest; therefore, on their first visit to the pain clinic, they were invited to describe their pain, pain trajectory, and life situation.

We know that many factors affect the pain experience, and it is therefore important to get an understanding of the patient's perception of his life and his pain. It's about mapping past pain history, life story, and how the life situation is now, as well as the patients' description of the pain. (RN #2)

At the pain clinic, the patients noted that nurses had asked for their pain narrative and taken it seriously. Nonetheless, the patients claimed that the treatment goal(s) had often already been set and were limited to improving their overall functionality. This was often in contrast to the patients' own goals, which, in addition to decreased pain, were often deeply personal, such as becoming a better parent, becoming a better partner, increasing or maintaining employment, or as essential as finding that their lives were worth living.

They [healthcare professionals] just want me to get back to work. To me, it is first and foremost important to increase my quality of life. To have something in my everyday life that makes me think life is worth living. (Patient #7)

The patients suggested that there should be a variety of opportunities where patients themselves could choose what treatment options that accommodated their lifestyle. Some patients were parents of small children and therefore did not want long-term rehabilitation stays. Others, who lived hours away from the hospital,

<sup>&</sup>lt;sup>b</sup>Cognitive therapy, pain, and palliative care.

Table 3. Overview Abstraction Process From Separate Themes to a comprehensive whole.

Themes Patients experiences	A comprehensive whole <sup>a</sup>	Themes RNs experiences	
Experiencing a need for more tailored care and involvement	Dissonance in reflections on personalized care	Experiencing patient centered care as important but challenging	
Experiencing a need for improved information flow	A corresponding need for improved communication in all levels	Experiencing a need for improved information flow	
Experiencing a need for improved structure	A corresponding need for improved structure in pain care	Experiences a need for clearer structure	

Note. RN = registered nurses.

preferred rehabilitation stays since traveling so far just for short outpatient appointments was exhausting.

I wish I did not have to find out on my own about the offers that are available to me, but that there was a set of offers for pain patients where you could choose what best suits you and your life situation. Then you can continue trying until you find something that fits. (Patient #4)

The RNs recognized the patients' need for flexibility and tried their best to accommodate them. However, it was not always easy to offer personalized and flexible health care.

Ideally, they [the patients] know what to expect and what is offered [at the pain clinic], but often, we have to look together to find it [an optimal treatment] and what we can offer and what the patient wants does not always fit like a glove. (RN #4)

# A Corresponding Need for Improved Information Flow in All Levels

The patients expressed a need for more relevant information on available health-care services earlier in their pain trajectory in order to obtain help in a more timely manner. They described the GPs as lacking knowledge about comprehensive health care.

I am on the fifth year [with chronic pain], so now I'm getting to know which people I can ask. But in the first few years I did not know anything. I had to find all the information myself. Maybe it has to be this way, but I think it would be very nice if the doctor had known what healthcare offers were available, since he is the focal point of information for the patients. (Patient #1)

Likewise, the RNs noted that some primary health-care providers lacked competence in pain care and treatment. The RNs mentioned several factors that could enhance

the knowledge of available treatment, such as providing more information to health-care providers in primary care about the kinds of assistance and competence the pain clinic could offer.

There are all these other tasks we should have addressed, in addition to running the pain clinic, such as building primary healthcare expertise throughout the region, working with them, holding courses and offering follow-up to the GPs and others who are in contact with these patients. Possibly, also certain units at the hospitals and in nursing homes, which are so neglected. (RN #7)

The RNs expressed a need for greater collaboration with primary care professionals, and some pain clinics had hired a GP to solve this problem.

The doctors at the pain clinic write notes to the GPs, but we want a more committed cooperation. Now we have employed a GP at the pain clinic, he is working to improve the transfer loop [between specialist care and primary care]. (RN #2)

The patients also stressed the need for improved information flow between health-care professionals to better connect the health-care services from primary care and specialist care. This would facilitate more seamless and continuous health care.

Professionals at different levels providing healthcare services must be able to exchange information more efficiently. The patient must be spared this coordinator role. (Patient #8)

# A Corresponding Need for Improved Structure

The need for improved structure in pain care was related to lack of clear care pathways for people living with chronic pain. The patients suggested a coordinator in a neutral position to solve this problem, serving as a

<sup>&</sup>lt;sup>a</sup>A comprehensive whole integrating patients and nurses experiences with pain care.

liaison between primary care, specialist care, and the patient.

We [the patients] need a coordinator who has information about available healthcare services and who also ensures efficient information flow between the various healthcare professionals. This coordinator should also have information about our rights. (Patient #2)

Some of the patients described the health care they received as fragmented. The patients suggested care plans to improve continuity and follow-up.

I think there is something missing, from something as basic as a medication plan. What should we do now? When should we evaluate this? (Patient #7)

The RNs acknowledged the importance of making a plan including both medication and other relevant information. They were currently working to include individual treatment plans at the pain clinics.

We think it is important to make a plan. We make a plan for what we can help with, what should we do? We have to have a longer perspective on [pain care]. (RN #4)

The RNs emphasized that they needed more resources to perform all of their required tasks, such as providing genuine interdisciplinary pain care and being a competence center for other health-care professionals treating patients with chronic pain.

All regions should have a pain clinic in accordance with the guidelines, but it does not say anything specific about the type of healthcare we [the pain clinic] should provide, so it is up to each one (hospital) what they want to offer. We [the pain clinic] get a small amount of resources, so our services are limited in proportion to the needs out there. (RN #10)

### **Discussion**

The aim of this study was to explore and combine the perspectives of patients receiving pain care and RNs providing care at pain clinics. Our findings revealed that patients and RNs experienced what can be understood as significant gaps between ideal pain care and actual practice. We will now discuss these findings.

Our findings revealed dissonance in experiences with personalized pain care between patients and RNs. The patients reported a lack of flexibility and personalized treatment as well as personal treatment goals that were not acted upon. Living with chronic pain often requires a revision of one's life goals and expectations and can trigger an existential search for meaning in life (Dezutter et al., 2017). It has been shown that patients with chronic pain often wonder how their lives can be meaningful when they are cut of from work life, social participation, or raising their children, things that give meaning to their lives (Dezutter et al., 2017). RNs and other professionals must therefore ensure they understand what matters most to their patients and reach an agreement on the central goal of each patient's pain care (Dezutter et al., 2017; Joseph-Williams, Edwards, & Elwyn, 2014). This builds on earlier research, emphasizing that health-care providers should elicit and promote the each patient's life goals; this is where chronic pain management must begin (Paul-Savoie et al., 2015).

The RNs in this study insisted that a comprehensive approach to patient involvement was the key to ensure that care was responsive to patients' needs but also noted that the patients often did not understand what the pain clinic could actually offer. A mutual understanding between patients and health-care professionals is fundamental for exchanging information to determining the optimal choice of treatment and facilitate patient involvement (Fu, McNichol, & Marczewski, 2015). Patients' involvement in their own health care increases when the health-care professional uses the patients' values, preferences, and lifestyle to develop specific treatment for different health needs and individualized selfmanagement strategies (Fu et al., 2015; Geurts et al., 2016). Nurses and other health-care professionals can thus play a critical role in supporting and enabling patients to manage their chronic pain (Devan, Hale, Hempel, Saipe, & Perry, 2018). Previous findings show promising results in patients' self-management after their health-care providers received person-centered training in communication and strategies (Geurts et al., 2016). Therefore, we want to underline the importance of person-centered pain care to achieve each person's treatment goals.

Both patients and RNs reported some discontinuity in the information flow. These experiences are inconsistent with the aim of informational continuity, which is the use of information to link previous treatment to the present and the future and to connect providers to each other (Bahr & Weiss, 2018; Haggerty et al., 2003). Informational continuity is crucial in complex conditions such as chronic pain, where patients often encounter several professionals within and across all levels of health care (Agarwal & Crooks, 2008; Haggerty et al., 2013). In addition, chronic pain often varies in intensity, meaning that there will be many encounters in different levels of health care (Landmark et al., 2018). Thus, health-care professionals must offer personalized communication in addition to bridging single care interventions (Dekel, Varani, Dekel, Di Nino, & Melotti, 2014). Therefore, we emphasize the need for a greater commitment to

information flow to facilitate continuity and quality in pain care.

The patients in our study reported unclear structure in pain care when requiring more comprehensive care and claimed that the GPs often lacked essential knowledge of available treatment options. RNs acknowledged difficulties in providing timely and integrative pain care. This is consistent with the previous findings, showing that only about half of the physicians are confident in their ability to manage their patients' care and are unsure what to do when a patient complains about pain over an extended period of time (European Pain Federation EFIC, 2010). Thus, unclear structure in current care and lack of training can create potential for confusion where the GPs do not know when to refer or introduce a more comprehensive approach. Ensuring timely health care is crucial because patients with chronic pain waiting for treatment may experience a deterioration in their quality of life, their psychological well-being, and an increase in depression (Elsesser & Cegla, 2017). We suggest that enhanced competence in chronic pain care and in competence sharing will facilitate more efficient care pathways and more timely pain care.

# Strengths and Limitations

We integrated a research strategy offered by a multimethod design that enabled us to investigate different aspects of the phenomenon (chronic pain care) and comprehensively answer our research question (Morse, 2003). To strengthen the study's credibility and transferability (Lincoln & Guba, 1985), examples of the abstraction process are provided in Table 3. To ensure consistency and confirmability, the initial findings are based on individual analysis followed by discussion with research fellows to reach agreement. The transferability of the findings to similar conditions can be considered because the study was based on international knowledge and research. Therefore, we believe that our results and suggestions are relevant to health-care professionals interested in chronic pain care. However, we acknowledge the following limitations. All patients were recruited from a patient organization and thereby represent those who are willing and able to join such associations. In addition, the sample of patients consisted of eight women but only two men. It is uncertain whether men are less willing to talk about pain or less likely to seek health care for pain. Finally, the inclusion of RNs only from the interdisciplinary team at the pain clinics may have affected the findings, despite their key role in comprehensive patient contact and collaboration with other health-care professionals. Future research should include other members of the team to provide a more comprehensive picture of the kind of pain care provided at pain clinics.

# Implications for Practice

The findings of this study suggest a stronger commitment to information flow and person-centered communication to increase patient involvement and self-management. Furthermore, there is a need for additional education and training among professionals who treat people suffering from chronic pain to ensure efficient care pathways and more timely pain care. Our findings might also create a basis for improving quality and continuity of pain care when provided by multiple professionals across the health-care system. More resources to enable health professionals to adhere to clinical guidelines and to share competence seem obvious.

### **Conclusion**

Our findings revealed several gaps between aspects of person-centered care and continuity that are essential for efficient pain management and experiences with actual practice. To bridge these gaps, we suggest a greater commitment to efficient information flow and person-centered communication to facilitate patient involvement and self-management. In addition, more resources and additional education and training seem necessary to enable nurses and other professionals to act upon available guidelines and accomplish competence sharing. We hope that this will ensure more efficient and timely pain care in primary care and at pain clinics.

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# **Authors' Contribution**

Gjesdal, Dysvik, and Furnes designed the study. Gjesdal conducted and transcribed all interviews. Gjesdal, Dysvik, and Furnes analyzed the data and Gjesdal drafted the manuscript. All authors contributed to editing of the final manuscript, revised it critically for scientific content, and read and approved the final version.

# **Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

# **Ethical Considerations**

The study was approved by the Regional Committees for Medical and Health Research Ethics, Norway (project number 2014/2165). Every participant provided informed written consent ahead of the interview. The participants received written and verbal assurance that they had the right to withdraw at any time and were assured that their participation was anonymous.

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