



## Between three chairs

### Experiences of being a patient with chronic widespread pain in an intersectoral setting in Denmark

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*Published in:*  
Health Psychology Open

*DOI:*  
[10.1177/2055102919852500](https://doi.org/10.1177/2055102919852500)


*Publication date:*  
2019

*Document version*  
Publisher's PDF, also known as Version of record

*Document license:*  
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*Citation for published version (APA):*  
Schultz, R., Kousgaard, M. B., la Cour, P., & Davidsen, A. S. (2019). Between three chairs: Experiences of being a patient with chronic widespread pain in an intersectoral setting in Denmark. *Health Psychology Open*, 6(1), [2055102919852500]. <https://doi.org/10.1177/2055102919852500>

# Between three chairs: Experiences of being a patient with chronic widespread pain in an intersectoral setting in Denmark

Health Psychology Open  
January-June 2019: 1–10  
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DOI: 10.1177/2055102919852500  
journals.sagepub.com/home/hpo  


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## Abstract

This study explores how patients with chronic widespread pain experience their contacts with health and social services in Denmark, including general practice, hospitals, and municipality job centers. We analyzed interviews with 10 patients using interpretative phenomenological analysis and found the following four superordinate themes: meeting different attitudes, fragmentation of treatment, the importance of time, and feeling trapped. Findings show that when patients do not feel understood by professionals, they can resort to withdrawal strategies. On an organizational level, patients said that they needed sufficient time in meetings and better coordination of interventions in and between the health and social care sectors.

## Keywords

chronic illness, experience, health care systems, interpretative phenomenological analysis, pain

## Introduction

Patients with chronic widespread pain (CWP) experience a comprehensive burden of symptoms which cause a decrease in quality of life, in overall level of function, and in the ability to work (Burton, 2012; Creed et al., 2011). Consequently, these patients are in frequent contact with their general practitioners (GPs), social services in their local municipality job center, and they also attend specialized treatment at one or more hospital units. This makes assessment and treatment a lengthy process involving many different professionals who do not necessarily agree on how to understand and handle the patients' symptoms (Arnold et al., 2016; McBeth et al., 2015; On, 2016).

In Denmark, health care is tax financed and free of charge for patients. The GP is the first point of entry to health care and manages about 90% of all patient contacts without referral to other services. GPs can refer patients for specialist treatment in the secondary sector (Danish Health Authority, 2019). If people are unfit to work due to illness, they have the right to receive social benefits, for which they are obliged to

participate in meetings, work capability assessments, and activation programs in their municipality job center. Social workers in the municipality job center obtain health information from GPs or hospitals through agreed forms (The Danish Agency of Labor Market Recruitment, 2019). Apart from these requests for medical documentation, communication between health and social care professionals is sparse.

Research has shown that GPs find patients with CWP a communicative and therapeutic challenge that can cause frustration (Sowinska and Czachowski, 2018; Woivalin

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**Table 1.** Main questions in the interview guide.

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Tell me about your disease.
Which thoughts or explanations do you have about your disease?
Tell me about the assessment and treatment you went through.
How did you experience these efforts and the meetings with different professionals in hospitals, your GP and the municipality?
How did you experience the collaboration between professionals if any?
Which challenges do you experience in health care and the municipality in regard to CWP?
What would you wish could be different in the future in relation to your treatment and in the contact with different sectors?
Is there anything you wish to add that we have not talked about yet?

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CWP: chronic widespread pain; GP: general practitioner.

et al., 2004). When GPs run out of treatment options for patients, they feel inadequate and may experience their relationship with the patients as problematic (Burton, 2012; Hubley et al., 2016). Many patients with CWP, likewise, describe a troubled relationship with their GPs and experience that they have to repeat the same information and amplify or expand upon their descriptions of symptoms to be heard, which further complicates communication (Burton, 2012; Salmon, 2006).

Patients living with chronic pain are often met with skepticism or a lack of comprehension (Werner and Malterud, 2003). Women, in particular, have been found to struggle to gain credibility in meetings with physicians (Werner and Malterud, 2003). Research has found that patients with fibromyalgia often feel stigmatized, experiencing that professionals question their morality and veracity, and that physicians, especially, try to psychologize their symptoms (Åsbring and Närvänen, 2002). Acceptance of the illness from professionals is reported to be a very important issue for patients with CWP (Sim and Madden, 2008).

No existing research deals with how patients with CWP experience their meetings with social workers in municipality job centers, although these meetings are often said to be demanding and stressful for patients, according to patient associations and pain clinics (Clinic for Functional Disorders, 2019; Healthtalk, 2019; Patient Association for Functional Disorders, 2019). While municipalities play a central role in intersectoral treatment of patients with CWP, it is important to qualify this assumption through research. These patients appear to face challenges both in health care systems and in municipality job centers, but not much is known about the patients' experience of being in this tension field. Therefore, the aim of this article is to explore how patients with CWP experience their contacts with health care and social services including general practice, hospitals, and municipality job centers.

## Methods

The study is qualitative with the data material consisting of interviews with patients. It is part of a larger project, which

also investigates professionals' perspectives on intersectoral coordination for patients with CWP and the understanding of CWP among social workers from municipality job centers.

## Procedure

Patients were recruited through a number of hospital units and municipalities. Health and social care professionals handed out flyers to patients with an invitation to take part in the project. Patients with CWP for more than 3 months who were in contact with their municipality job center and/or receiving hospital treatment were encouraged to contact the first author (R.S.). In some cases, professionals asked patients for permission to be contacted by the researcher by mail or telephone. Patients were recruited from February to November 2016 in the Capital Region of Denmark and sampled strategically to obtain variation in gender, socioeconomic status, and symptom duration. We stopped the recruitment when we considered that an adequate level of data saturation was reached and no new themes and codes occurred (Fusch and Ness, 2015).

## Interviews

R.S. interviewed patients individually and face-to-face using a semistructured format. The interviews lasted between 38 and 95 minutes (mean 59 minutes) and were conducted in the patients' homes, at the University of Copenhagen, or at the local municipality, depending on the patients' choice. We had developed an interview guide comprising the main questions shown in Table 1.

The interviews were audiorecorded and participants signed written consent to take part. Patients were assured that neither participation nor dropout would have consequences for ongoing or future treatment in social services or the health care system.

## Participants

The sample consisted of 10 patients with CWP who were unfit for work due to their pain and/or receiving specialist

treatment for pain. Patients were included according to the Danish Health Authority's definition of CWP: pain symptoms that had lasted more than 3 months and have a negative impact on quality of life and level of function. The pain could not be explained by a somatic or a psychiatric disorder (Danish Health Authority, 2015). Exclusion criteria were as follows: a severe psychiatric or somatic diagnosis and patients who were non-Danish speakers. No one in our sample was excluded or dropped out. Nine of the 10 participants were ethnic Danes, one was an immigrant from Turkey. Participant characteristics are shown in Table 2.

### Data analysis

R.S. or a student transcribed all interviews verbatim, and R.S. read them thoroughly. Analyses were conducted using interpretative phenomenological analysis (IPA), and we used NVivo 11 pro to assist the coding and analysis process.

IPA is an inductive analysis method developed within psychology research. The method is based on phenomenological and hermeneutic thinking, including key ideas from the philosophers Husserl, Heidegger, and Merleau-Ponty (Langdrige, 2007; Smith and Osborn, 2003). The method emphasizes interpretation as inherent in the participants' experiences. IPA aims to explore in detail the meanings of the participants' personal experiences and perceptions in a dynamic and so-called "double hermeneutic" process. It acknowledges the active role of the researcher and the influence of the researcher's own conceptions in the interpretative process (Davidsen, 2013). The authors have different professional backgrounds, possibly influencing their pre-understandings. R.S. and the third author (P.I.C.) are clinical psychologists; the last author (A.S.D.) is a GP with experience from psychiatry. R.S., P.I.C., and A.S.D. all have clinical experiences in the treatment of patients with CWP. The second author (M.B.K.) is a political scientist without clinical experience. The three authors with clinical experience in this field of practice had a presumption from their clinical work that the patients did not feel adequately understood and helped by the professionals and the system, but without any specific hypothesis on the mechanisms and causes for this. We all tried to put these pre-understandings aside during data collection and analysis.

We conducted the analysis ideographically: first, each interview was read thoroughly to get a sense of the text as a whole. Second, we performed open coding close to the original text. Third, the coding was specified and grouped into themes and subthemes for each interview. Fourth, we identified higher order "superordinate" themes that represented overriding themes from all interviews (Langdrige, 2004; Smith and Osborn, 2003).

To improve reliability, a number of transcriptions and initial codes made by R.S. were discussed with A.S.D. who had read most of the interviews. To improve respondent

validation, codes and themes were discussed with informants and local experts at an early stage. Quotations from the interviews were closely translated from Danish. To ensure data anonymity, all patients are referred to as *she*, as only two were men. To simplify descriptions, the term *patient* is used throughout the article, although in municipality settings the participants are referred to as *citizens*.

### Ethics approval

The study was presented to the regional research ethics committee, which (4 February 2016) stated that this qualitative project should not be evaluated according to *health scientific research projects section 14, sub-section 2*. The study was notified to the Danish Data Protection Agency (reference no.: 514-0284/19-3000).

### Context of findings

In the Danish health and social care systems, patients with CWP are encountered by professionals in three different sectors with different goals. Both patients and professionals are subject to different rules and legislations in health care and in the social sector.

In general practice, the core task is to make an assessment of the patient's symptoms and decide who can be treated within general practice and who needs further examination or treatment in secondary care. This often takes place over a time span, and GPs usually know their patients for a long time and have knowledge of the patient's life story.

In the municipality job centers, the social worker's main role is to guide and inform patients about their opportunities, rights, and duties according to social and employment laws and to ensure that conditions are met by both the patient and the municipality. If people do not comply with demands within the employment law, they can be financially sanctioned. The social workers do not necessarily have training in communication or knowledge of health issues and health care.

In hospitals, the primary focus is to offer specialized treatment for patients with CWP to improve their quality of life and reduce or cure their symptoms. Patients are discharged to their GP when they have ended treatment.

### Findings

We identified four main themes during the analysis comprising the patients' experience: meeting different attitudes, fragmentation of treatment, the importance of time, and feeling trapped.

#### Meeting different attitudes

*Empathic, understanding attitudes.* In the majority of meetings with social workers, GPs, physicians, and other health

**Table 2.** Participant characteristics.

Alias <sup>a</sup>	Primary symptoms	Symptom duration (years) Mean 10.4	Age (years) Mean 47.4	Marital status	Ongoing contacts with health and social services	Status of employment	Level of education	Interview setting
P1	Pain and cognitive difficulties	5	58	Divorced	Municipality and GP	Clarification process in municipality	Bachelor or more	Municipality
P2	Pain	14	55	Married	Municipality and GP	Unemployed from reduced-hour job	Bachelor or more	Home
P3	Pain, fatigue, and cognitive difficulties	25	43	Married	Municipality, GP, and physiotherapy	Workability test in municipality	Vocational training	Municipality
P4	Pain, fatigue, and cognitive difficulties	3	28	Single	GP, pain clinic, and liaison psychiatry	Part-time education	Ongoing Middle-range education	Home
P5	Pain and severe fatigue	13	52	Married	Municipality, GP, and pain clinic	Sick leave	Unskilled	Home
P6	Pain, dizziness, and fatigue	9	28	Cohabiting	Liaison psychiatry and GP	Part-time education	Ongoing higher education	University
P7	Pain	6	57	Married	Municipality, GP, and physiotherapy	Sick leave	Bachelor or more	Home
P8	Pain and fatigue	8	46	Single	Municipality, GP, and liaison psychiatry	Rehabilitation program	Middle-range education	University
P9	Pain and fatigue	12	60	Married	Municipality and GP	Unemployed from reduced-hour job	Middle-range education	Municipality
P10	Pain, dizziness, and fatigue	2	55	Married	Municipality and GP	Clarification process in municipality	Bachelor or more	Home

GP: general practitioner.

<sup>a</sup>Two of the 10 participants are men. To ensure anonymity all participants are referred to as females.

care staff, patients experienced, and expected, an empathic, understanding attitude and they mostly felt “met and acknowledged in their situation” (Patient (P) 2). Patients described professionals who recognized their symptoms and their suffering, showed an open awareness during meetings, listened actively, and responded properly on somatic and emotional cues from the patient. In these situations, patients said that they developed trust in the professionals. This promoted an alliance between patient and professional where patients dared to speak honestly about their pain and worries.

However, patients accentuated experiences where the professionals did not have an understanding attitude. The patients described two types of “non-understanding” attitudes from professionals: (1) put-on understanding and (2) disrespectful non-understanding.

**Put-on understanding attitudes.** Some patients described situations where professionals from health and social services were apparently polite, but where the patients perceived that their understanding was not genuine and that the professionals did not fully understand the implications of the symptoms presented. For example, a patient recounted an episode with a social worker who said that she understood the patient, but then suggested an activity which showed that she did not understand how disabling the patient’s pain was:

The social workers were nice. I didn’t experience anything unpleasant about them. But I thought it was uncomfortable that they didn’t meet me in my limitations. They did not acknowledge that I was in pain. (P7)

This attitude made the patients feel as if they were under suspicion and they did not know whether they could trust the professionals and see them as supporting coplayers or as opponents. As a result, the patients withheld information from professionals: “Nobody really understands this diagnosis. So, I say as little as possible” (P3).

**Disrespectful non-understanding attitudes.** All patients reported having experienced undisguised negative attitudes from professionals where they did not feel respected as a person: “I am tired of being treated badly. I think the respect has been very limited, in some places” (P10). In these situations, the patients perceived that the professionals did not make an effort to comprehend the patients’ symptoms and their situation. Although the disrespectful experiences were reported to be few, the patients said that these episodes had a high impact on their subjective well-being and the experience of their overall treatment because they created distrust in the professionals and negative expectations for future meetings.

Patients said that most experiences of a disrespectful approach were caused by offensive remarks from social workers as, for example: “Just pull yourself together” (P8).

Comments like this resulted in strong emotional reactions in the patients. They interpreted the statements as humiliating and as a devaluation of them as a person, and this could lead to resentment:

I am very peaceful, but I can assure you that I do understand why somebody slaps them (the social workers) when they are as rude as I experienced. We are worth less than the social workers. The citizens should not believe that they are anything. That is what I experienced. (P1)

Only one patient had experienced a disrespectful, non-understanding attitude in consultations with GPs, while most had experienced a disrespectful attitude in meetings with hospital physicians. Most of these episodes were described as inappropriate emotional responses with a lack of awareness and understanding of the patient’s situation: “When I told him about my suffering, he (the doctor) just laughed at me” (P10). However, a patient also described being verbally assaulted by a hospital physician:

I was simply scolded by the doctor who had been operating on me. I was completely knocked over. I did not understand anything. (P7)

Some of the patients described that the experience of not being understood and met with respect created a negative emotional reaction and anxiety:

It didn’t do anything *for* me—It did something *to* me. It has made me anxious about the system, about getting caught in this hamster wheel. Anxious that I don’t make myself clear, and anxious that they will misunderstand me. (P9)

Such experiences made the patients withhold information and step back from developing a trustful relationship with the professionals.

One patient tried to imagine why it might be difficult for other people to understand the nature of the illness by comparing it to depression where it could also be difficult to enter into the other person’s experience: “If you do not have it yourself, you cannot understand what it is like” (P8). For this patient, CWP was similarly difficult to understand, which could lead to others not taking it seriously.

### **Fragmentation of treatment**

All patients experienced fragmentation in their treatment trajectories across and within the different health and social care sectors.

Patients explained that it was difficult to navigate through the increasingly specialized health care system, where both assessment and treatment were carried out according to well-defined areas of expertise that did not necessarily fit the patients’ symptoms and problems. Patients were often examined by several different medical

specialists, where each physician saw one symptom, organ, or piece of the puzzle at a time without connecting the dots:

You are sent from one department to the other in the hospitals. You have one test after the other. (P2)

Patients experienced this as frustrating and they felt that nobody was assessing the whole problem. As a result, patients reported that they had to face many different people in the system and tell their stories over and over again. This could be quite exhausting for them and it was hard to remember where they had been and who they had seen during assessment and treatment in the secondary sector:

I think that it has been depressingly hard to navigate in (the health care system). I really missed a coordinator. So, if you somehow find a solution for this problem, it would be fantastic. I really think it has been the most chaotic thing ever and I still find it stressful. (P4)

Most of the patients also described fragmentation in the municipality job center when social workers changed, which happened quite often. Sometimes social workers changed jobs, or patients were transferred to another department based on the type of social benefit they received at a given point of time:

Then you are in too good health to be in one group but too sick to be in the other group. It is a jungle and your social worker changes all the time and then you have to start all over again. (P8)

This made the course of rehabilitation incoherent and difficult to navigate for patients. It also challenged the relationship between the patient and the social worker, because the patient did not always have the energy to start all over again.

Finally, patients perceived fragmentation between sectors. Social workers needed health information to progress social care, and, in some cases, patients felt responsible for handing over information between departments and sectors to create a more coherent understanding of their symptoms and to access the right treatment. Although most patients knew that their social worker had collected health information from their GP or a hospital department, they had the impression that the actors from the different sectors rarely coordinated or discussed their treatment with each other:

To my knowledge, there hasn't been any contact between the municipality, my GP or the pain clinic. And usually they have to ask me first. (P8)

However, a few patients had attended a meeting between their GP and their social worker to discuss the most appropriate course of action. Such meetings had been perceived as helpful by the patients and reduced fragmentation in their trajectory.

### *The importance of time*

The patients experienced time as a crucial factor in meetings with professionals in all three sectors. However, time was important in different ways depending on the situation.

*Time in consultations.* When patients met with professionals, they experienced time as an important precondition for creating a good working alliance. The patients explained that it was important to have enough time in each meeting to talk about their problems, to develop trust and to plan the appropriate intervention. The importance of time was especially evident in the relationship between patients and social workers in the municipality job center, as trust in each other could develop over time in a longitudinal relationship.

*Time between interventions.* When a treatment program was completed (e.g. cognitive behavioral therapy, graded exercise in a hospital setting, or a rehabilitation program in the municipality), the patients reported that it was essential for them to have time to reflect upon what they had learned. Time was crucial for them both to capture the full meaning of the content of a given treatment and to benefit from the intervention. Treatment for CWP relies a great deal on self-management strategies which take time to integrate. One of the patients said: "I cannot tell when the penny dropped, it came after a while" (P9). Many of the patients explained that it was important for them to have time to reorganize their daily lives in accordance with their pain condition in order to get the full benefit of an intervention:

There are no miracles. What has helped me is to gain more stability in life and to plan my life in a way that makes it possible to feel bad without any pressure on my shoulders. (P6)

Hence, the patients considered it important not to rush into the next program of treatment or rehabilitation. When patients felt they had the time they needed in between programs, they perceived it as helpful: "When I got quiet periods, then it got better." (P8)

*Waiting time for treatment and administrative decisions.* On the contrary, patients experienced that long waiting times to attend specialized treatment programs in hospitals had a negative impact on their pain and caused a setback in their recovery process:

The waiting time has worked against my recovery because it has hindered the right treatment from getting started. Instead, I have been left to my own devices during these periods of waiting. (P10)

Patients also mentioned long periods of waiting for administrative decisions in the municipality due to lengthy case management processes:

After a month had passed, I thought: Now something should have happened. Then I call the municipality and they just say: “We haven’t started yet.” (P10)

Such long waiting times were experienced as problematic and could result in some very prolonged courses of interaction with the social system.

*Time as a deadline.* In interactions with the municipality job center, time was also described in terms of the deadlines set in relation to social benefits and social and employment legislation. Patients experienced that these deadlines could cause emotional stress that worsened their health condition:

Well, then there are no more sickness benefits and you have to consider if you want to receive “real” unemployment benefits and be reported fit to return to work or if you will receive cash benefits. And I couldn’t afford to get my income reduced as I am alone with a little boy. But I couldn’t go back to my former profession either, so because of that I’m highly stressed. (P8)

### *Feeling trapped*

The patients said that when they became sick and took on the role of a patient, they experienced a shift from feeling independent to being dependent on the system and on different professionals within that system:

I have always been able to take care of myself and suddenly you are dependent on a system, dependent on others to make an assessment of you in regards to the municipality and I need letters and documentation for everything. (P8)

Most patients described this as emotionally difficult: “I feel trapped in my body with symptoms I cannot get rid of and I feel trapped in the system, where nobody is able to do anything” (P6).

Even though patients experienced a loss of self-determination when they entered the health care system, they experienced a more severe loss of self-determination in the municipality, where they felt they did not have the opportunity to make their own decisions about fundamentals, such as whether they should work, attend education, or take sick leave. Often somebody else made these decisions, and they just had to follow:

He (the social worker) said that I should go through rehabilitation. I thought: Education at my age? I surely can’t go back to school. But I started education and according to the papers it should take about 1–1½ years. It turned out that I couldn’t handle it. (P9)

Patients said they followed the social workers’ decisions because they had fears or worries about the consequences if they did not comply:

I do not want to be pushed into something, but you also know that it has an economic consequence, if you do not do the things you are required to do. (P8)

## **Discussion**

The study showed that some patients experienced some interpersonal discomfort when they did not feel understood and acknowledged by professionals in health and social services. This made the patients use withdrawal strategies during meetings with professionals. The patients also experienced organizational challenges in the system with a lack of coherence within and between sectors, which was perceived as stressful. Furthermore, the patients felt trapped by the system with limited opportunities to get what was considered the right help. They found that time was an important factor, both to develop trust in the professionals and to benefit from treatment. While these problems were perceived to be present across the sectors, they were predominantly related to interactions with the municipality job centers.

Existing qualitative research shows that patients with CWP experience negative attitudes in both professional and personal relationships. In previous studies, negative attitudes are described in terms such as stigma or prejudice, and the phenomena identified in our work seem to be alike. Åsbring and Närvänen (2002) found that patients with fibromyalgia and chronic fatigue syndrome experienced stigma in relation to their illness. This was described mainly in contacts with physicians, when patients felt that their veracity and morality were being questioned when presenting their symptoms. A study by Nettleton et al. (2006) showed that patients struggled to find acknowledgment of their symptoms and that the attitude and manner of the doctor were the main reasons for evaluating the doctor as “good” or “bad.” Similarly, in Houwen et al.’s (2017) study, patients with medically unexplained symptoms experienced prejudice from GPs as a main problem in consultations. Unlike existing research, our data did not point to a particular problem with negative attitudes from GPs, but rather from hospital physicians and social workers. However, our findings emphasize the importance of the professionals’ attitude across sectors. Åsbring and Närvänen (2002) found that patients’ ways of coping with stigma comprised both withdrawal and approach strategies, depending on the circumstances and goals of the patients. Our findings only revealed withdrawal strategies, which could be both cognitive (when patients withheld information and knowledge from the professional) and emotional (when patients withdrew or disengaged from the relationship with the professional). This is in contrast to clinical literature which highlights that patients tend to expand or amplify their descriptions of symptoms when they do not feel adequately understood (Burton, 2012).



Our analysis showed that patients experienced meetings as productive when professionals listened actively and responded to somatic symptoms and emotional cues in consultations. This is in line with research showing that patients are willing to talk about emotional, psychological, and social factors in relation to their illness, but that GPs often miss these cues or do not take them sufficiently into account (Salmon et al., 2004).

The patients' distinctive experience of not being understood in meetings with professionals can be elucidated by the theory of mentalization developed by Fonagy and colleagues. Mentalization is a general social capacity for understanding other people and, therefore, understanding interactions between patients and professionals (Allen et al., 2008; Davidsen and Fogtmann, 2016). Mentalization is defined as the capacity to see the other person from the inside and yourself from the outside and hence to reflect upon the other's and one's own state of mind (Allen et al., 2009). The understanding of others helps us to communicate in an adequate cognitive and emotional way (Davidsen and Fogtmann, 2016). When patients do not experience a genuine understanding, it seems that professionals have failed to mentalize. To make a proper mentalization, the professionals must reflect upon the patient's state of mind by keeping an open, curious, and not-knowing stance. This requires time and effort. Both GPs and social workers are known to experience high workloads and the social workers' actions may be restricted by the legal-administrative frame of their role (Shier and Graham, 2013). These conditions may affect their capacity to mentalize negatively and create learned behaviors such as the put-on understanding attitude described in this study, where professionals behaved politely, but did not seem to understand the lifeworld of the patients.

Our findings highlight the importance of the professionals' approach to meeting patients with CWP. The findings suggest that proper mentalization from the professionals may improve the patients' experience of interactions and prevent or reduce the tendencies of patients to withdraw and thereby improve conditions for producing relevant information about the patients. To strengthen the professionals' capacity to mentalize in professional relationships, proficiency training in this area should have an increased focus in the education of both GPs and social workers, because research has shown that mentalization training of professionals can improve this capacity significantly (Ensink et al., 2013).

On an organizational level, patients experienced fragmentation of their trajectories in hospital and municipality settings and across sectors. The lack of coherence and coordination made it difficult for patients to navigate the health and social care systems, and they felt that they carried most of the responsibility for delivering information to the other actors in the system. The same experience of responsibility for organizing their own care and bringing information to different professionals has also been described by patients in a Danish cancer treatment setting (Dalsted et al., 2012).

These patients assumed responsibility for preventing delays and interruptions in treatment. The patients with CWP in our study mainly tried to ensure a flow of information to establish a coherent understanding of their symptoms which would help them to get referred to appropriate treatment units. Similarly, a study from Denmark among children with functional disorders showed that their parents experienced fragmentation in hospital treatment, where a change between departments could result in different explanations for the symptoms and different treatment suggestions. The parents felt that they had to keep track of the overall illness trajectory and become experts of their children's needs and symptoms when interacting with professionals from different sectors (Hulgaard, 2018).

Patients experienced that having sufficient time to talk with professionals during meetings and having time to develop trust in professionals had a positive influence on recovery. Qualitative studies of GPs' perspective on psychological interventions in general practice have shown that time is similarly important, both in the longitudinal perspective and in each consultation, when dealing with emotional problems and common mental disorders (Davidsen and Reventlow, 2010). Our finding that patients also experienced time as an important factor in relation to meetings with social workers is, to our knowledge, a new contribution. On the contrary, long waiting times for investigations and administrative decisions were counterproductive for recovery. The negative influence of waiting time was also found in a systematic review showing that patients with chronic pain experienced a significant deterioration in psychological well-being and health-related quality of life while waiting for treatment. It is unknown at what point in time the negative impact begins, but the review states that waiting times of more than 6 months are medically unacceptable (Lynch et al., 2008).

The patients often felt trapped by a system that could not help them sufficiently. This experience is echoed by studies from other settings. Patients with medically unexplained symptoms in Poland did not expect that the health care system could help them and they preferred to attend therapy in the private sector (Sowinska and Czachowski, 2018). Other studies have shown that up to 79% of the patients with chronic non-cancer pain believe that their pain is inadequately treated (Bekkering et al., 2011; Geurts et al., 2017). This indicates that the problem of patients being dissatisfied with the help they get is a phenomenon that exists across pain populations and not only among patients with CWP.

## Limitations

The study has some limitations. The sample is small, and findings only reflect the patients' perceptions in one region in Denmark. Only two men were included in the data material. However, the distribution between men and women represents the reported distribution of patients with CWP, where more women than men are affected (Andrews et al.,

2017). Only one non-ethnic Dane was included, but because it was an interview study, the informants had to be able to speak Danish. This may have limited the number of non-ethnic Danes, although it mirrors the number in the Danish population. In addition, the analysis did not show any differences between genders or ethnicities. Due to the limitations, the results may be difficult to transfer to other settings, although some of the results correspond well with findings from other studies. In line with the authors' pre-understandings, findings showed that the patients did not always feel adequately understood and helped in their meetings with professionals and the system. Our educational and clinical backgrounds may have played a role in the analysis and discussion of findings, as we unavoidably have used the concepts and experiences from within our profession as psychologists or GP to interpret the data. However, the analysis was critically discussed with the non-clinical researcher, which could make the results less influenced by our pre-conceptions. Further research is needed, encompassing the health professionals' and the social workers' understandings of the mechanisms behind and explanations of CWP, to investigate the underlying motives of the described phenomena.

## Conclusion

Although patients with CWP were met with understanding attitudes in the majority of their encounters with professionals from health and social services, they nevertheless highlighted several examples of problematic encounters and described how these had negatively influenced their well-being, their trust in the professionals and the system, and their rehabilitation. These findings suggest that professionals working with these patients must be conscious of their approach and use their communication skills to create positive working alliances. On an organizational level, it is important to prioritize sufficient time for meetings and coordination of interventions between different sectors to overcome some of the problems experienced by patients. Further research is needed to establish how pervasive the experienced problems are and how they can be relieved.

## Acknowledgements

We would like to thank all the participants for sharing their stories. We would also like to thank the professionals who helped to recruit patients and the municipalities which cooperated with us on this project.

## 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.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this

article: The study is funded by the Intersectoral Fund for Health Service Research in the Capital Region of Denmark; The Health Foundation (grant number 17-B-0035); The Danish Rheumatism Association (grant number R150-A4431); and The Research Council for the Practice Sector in the Capital Region of Denmark.

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