Clinical pain research

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“No one wants you” – a qualitative study on the experiences of receiving rejection from tertiary care pain centres

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Abstract

Background and aims: Four out of 10 referrals to tertiary care pain centres in Norway are not granted pain centre treatment, confirming earlier research on that this group of patients struggle to access the highest standard of care. Still, no study investigating how people with chronic pain experience rejections from pain centres was found. The aim of the study was therefore to investigate how people with chronic pain experience receiving a rejection from tertiary care pain centres after being referred by their general practitioners (GPs).

Methods: This was a qualitative study with semi-structured individual interviews with 12 persons, seven men and five women, rejected from the four different pain centres in Norway. The data were analysed thematically using systematic text condensation.

Results: The pain centre rejection created strong reactions, partly because the rejection was perceived as a refusal from the health care system as a whole. This was especially so because the pain centre was regarded as the last remaining treatment option, and given the rejection, they were now declined help by the experts in the field. Even though some informants had received an explanation for why they had not been granted pain centre treatment, a prominent experience was that the informants found it difficult to understand why their referral had been

rejected given the severity of their pain. The incomprehensibility of the rejection together with a feeling of lack of future treatment options, increased the hopelessness and frustration of their situation and made it challenging to move on and search for help elsewhere.

Conclusions: The experiences with the pain centre rejections indicate that the rejection can have grave consequences for each individual in the following months. An improved system for how to handle expectations towards referrals, including prepare for the possibility of rejection and how to follow up a rejection, seems warranted.

Implications: Because a pain centre rejection most likely is received by persons in a vulnerable position, there should be available health care services to help them understand the rejections. And furthermore, help them to move from disappointment and hopelessness, towards an experience of empowerment and reorientation, by for instance planning further actions and interventions, and thereby, acknowledge their need for help.

Keywords: chronic pain; qualitative; pain centre; rejection.

1 Introduction

The complexity of chronic pain, including its impact on physical, psychological and social aspects of life, has led pain management towards a holistic treatment approach involving several care providers [1, 2]. The condition interferes for many individuals with both work life and social- and family life and has consequently a significant impact on their quality of life [3, 4]. The chronicity of the condition will for some individuals lead to a continuous search for treatments. This is reflected in studies showing that people with chronic pain are among the most frequent users of health care [5, 6].

Whereas most people with chronic pain are managed in primary care [2], some may need specialised pain treatment at the level of secondary or tertiary care [7, 8]. Still, persons with chronic pain describe difficulties with access

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to treatment [9, 10] and in specific, they struggle to access services that are considered to represent the highest standard of care for chronic pain treatment such as pain centres [8, 11, 12]. This was confirmed in a recent study which found that Norwegian pain centres declined four out of 10 referrals [13].

Previous research has investigated experienced barriers for access to pain care facilities. This includes how some interventions are perceived to be accessible only for those who have the skills and energy available to fight for them [14], inequality in accessing chronic pain rehabilitation, e.g. related to female gender and low education levels [15, 16] and a discrepancy between what patients want and what the health care system can offer [17], including staffs' misjudgement of what is important to patients [18]. However, we have not found any study investigating how persons with chronic pain experience rejections from pain care services. Related to other conditions, it has been found that persons with self-harm behaviour experiencing rejection may abstain from requesting future help [19], and that people suffering from diffuse symptoms and psychological distress perceived rejections as a sign of being a burden for others, which in turn prevented them from improving their health and to obtain adequate care [20]. Whether similar experiences and mechanisms are present when people with chronic pain is rejected access to specialised pain care, is unknown.

The aim of the study was therefore to investigate how people with chronic pain experience receiving a rejection from tertiary care pain centres after being referred by their general practitioners (GPs).

2 Methods

This was a qualitative study with semi-structured individual interviews. The interviews were conducted in November and December 2018.

2.1 Setting

The four Norwegian pain centres, situated at each of the Norwegian regional university hospitals as a tertiary care service, offer mainly outpatient services. They are staffed by a variety of health care professions with expertise in pain management, including physicians, nurses, mental health professionals and physical therapists, in line with the definition on pain centres by The International Association for the Study of Pain (IASP) [8, 21].

Each year, in total 4,000–5,000 referrals are received by the Norwegian pain centres [22]. The referrals are reviewed by multidisciplinary teams at the pain centres according to the national guidelines [23, 24]. The legal right to health care at a pain centre is granted if the patient is expected to benefit from the health care provided and the expected costs are reasonably proportionate with the outcome of the intervention. In addition, all other available primary and secondary care services should have been tried prior to a pain centre referral [23].

2.2 Informants and recruitment

The study's inclusion criteria were persons who had been referred by a GP to one of the four Norwegian pain centres and that a rejection was registered by the designated pain centre. The exclusion criteria were having received treatment at a pain centre during the last 3 years and not being able to participate in an interview without interpreter. The aim was to have variation in the pain centres rejected from (three to four informants from each pain centre), in addition to variation among the informants in age, gender and lengths of pain duration.

To recruit informants, the first 10–15 persons identified by each of the pain centre's staff to meet the inclusion criteria were sent an invitation that included information on the intentions of the study, a consent form and a prepaid envelope. When a signed consent was returned to the pain centre, the staff passed on name and phone number to the first author who contacted the respondents to make an appointment. The inclusion criteria were then checked and appointments for interviews were made.

Recruitment continued until 12 informants were interviewed. At this point we considered to have sufficient data to answer the research question.

2.3 Data collection and interview guide

The first author conducted all interviews by telephone. The interviews lasted between 22 and 81 min (mean duration 39 min) and were audio recorded. Reflections were written down immediately after each interview.

The interview guide was semi-structured with open-ended questions to allow the informants to speak freely. The guide was developed from the research question, previous studies and discussions among the authors who have experiences from similar studies. To check if the interview guide needed alterations, the first and last

author read the transcripts from the first two interviews, but no changes were made.

The main question in the interview guide was “*Can you tell about your thoughts when you received the rejection letter from the pain centre?*”. If the informants did not talk about it themselves, the following topics were also introduced; what their expectations had been when the referral had been sent, and how they looked upon their future.

2.4 Data analysis

All interviews were repeatedly listened to by the first author who took notes and transcribed the most important parts for use during the analysis process. The data were analysed using systematic text condensation, a descriptive thematic cross-case analysis strategy involving an iterative four-step procedure [25]. In the first step, the authors worked to gain an overall impression of the data and identified seven preliminary themes, including previous history, lost hope and uncertainty about the future. In the second step, the first author systematically reviewed all the interviews to identify meaning units relevant for the research question. The meaning units were coded, and the preliminary themes were used for sorting these into code groups initially before the themes were adjusted based on the discussions in an iterative process.

In the third step, the first author performed a systematic abstraction of meaning units within each of the themes, reducing the content into a condensate that maintained the informants’ sayings. The authors had discussions on the condensates resulting in further adjustments and renaming of the themes. In the final fourth step, the content of the condensates was synthesised into generalised descriptions and concepts, while ensuring that the result still reflected the original context. The first author identified illustrative citations, which were translated by the first author and validated by the co-authors. The mind mapping tool MindManager [26] was used as systematization tool during the analyses.

To expose the data for different views and perspectives, preliminary results were discussed several times with a research group on patient education and participation at the university.

3 Results

A total of 13 persons responded positively to the study invitation and 12 persons, seven men and five women, within the age of 34–71 years (median 52 years), were interviewed

Table 1: Characteristics of the informants

Characteristics	Number
Gender	
Female	5
Male	7
Age	
≤45 years	2
46–55 years	6
56 years or more	4
Working status	
Working part or full time	3
Sick leave/disability pension/retired	9
Pain duration	
1–5 years	3
6–9 years	2
10 years or more	7
Main reason for pain	
Musculoskeletal pain	5
Back and neck pain	7
Time since received the pain centre rejection	
1–2 months	8
3–6 months	4

(Table 1). The informants had lived with pain from 2 to 36 years (median 11 years) in which a majority experienced back and neck pain. The informants had extensive experiences of using different health care services due to pain, such as physical therapy, rehabilitation centres, chiropractor clinics and different medical specialists at the hospital. The reasons for why their GPs had referred them to the pain centre were said to be due to a worsening in their pain, that their treatment needs were perceived to only could be handled by a pain centre, the pain centre was the only treatment option they had left to try, and some said they did not know the reason for why they had been referred. The time between the interview and the time of receiving the letter containing the pain centre rejection varied from one to 6 months, with a mean of approximately 2½ months.

When describing their immediate response to the received rejection letter, the informants used terms like “*upset*”, “*sad*”, “*frustrated*” and “*angry*”, in addition to referring to the rejection as “*a slap in the face*” and as “*a punch in the gut*”. After having received the pain centre rejection, some even spoke about having suicidal thoughts as without access to those they perceived to be the pain experts, they saw no end to their struggles.

“*One just has to continue taking pain medication and wait. Wait until you reach heaven*” (male, 71–75 years).

The informants’ experiences of receiving the rejection were categorised into the themes “Refusal from the health

care system as a whole”, “Trying to understand why” and “What to do next?”.

3.1 Refusal from the health care system as a whole

The strong reactions created by the pain centre rejection were partly because it was perceived not solely as a rejection to pain centre treatment but also as a refusal from the health care system as a whole. Although few had specific expectations on the outcomes of a pain centre treatment, they had hoped for receiving help from pain experts that would positively impact their everyday life. Some informants said they had been concerned about their own functioning at the time of the referral, for instance if they in the future would manage to work, to carry out everyday activities and to participate in family life activities. After the pain centre rejection, these worries had increased.

“I just thought, that there, at the pain centre, there they might be able to help me. But when you cannot even get help there, you, well, you get quite depressed” (male, 55–60 years).

The feeling of receiving a refusal from the health care system as a whole was mainly said to be due to their previous experiences of rejections and not finding adequate help for their pain even from specialists in secondary care services. Moreover, experiencing that referrals were forwarded from one health care service to another was said to put an extra burden to their struggles. When they were referred to the pain centre, some of them spoke of it as playing out their final card by reaching out to those they considered able to help them when no one else could. For those who saw the pain centre as their best treatment option, and sometimes their last resort, the pain centre rejection was experienced as more dramatic than previous rejections, as it was interpreted to mean that there was no help to be found anywhere. Therefore, the pain centre rejection was by some said to be “*the nail in the coffin*” and that they might as well just “*give up*”, because now, there was no remaining treatment options to look for.

One example was a woman with a long history of being sent from one specialist to the other. She had perceived the pain centre with its multidisciplinary approach to be an appropriate service as she there would meet different specialists at the same place. When she had received the pain centre rejection, she said that for her this represented a final rejection from the whole healthcare system. She elaborated by saying that if the pain centre did not want to help her, no one else would either. She had spoken to her

GP about her concerns regarding her struggles of finding appropriate and available help, to which the GP had said to her:

“No one wants you” (female, 45–50 years).

3.2 Trying to understand why

Most informants said they did not understand why the pain centre would not grant them treatment, given the severity of their pain. They wondered which criteria had been used when deciding on who to provide or not to provide treatment, and said it was difficult to reconcile with the rejection when they did not understand it. Some said they thought it might be there actually was nothing anyone could do about their situation and that this gave them a feeling of hopelessness. Others said they had tried to rationalize the reason for the rejection to prevent themselves from being trapped in despair, and their most common explanation was that others had it worse and thus needed the pain centre treatment more than them.

For some, not being provided with the opportunity to talk to the pain centre staff made it especially difficult to come to terms with the rejection. They said that if they had been provided with a chance to talk to the staff, they thought the staff would view their treatment requests differently and consequently, would understand that they really needed their help.

“At least, I had hoped to get to talk to them. That I maybe would get some advice on what to do or something. But no, it was nothing. It [the rejection letter] just said that there was nothing to be done about my situation” (female, 55–60 years).

One informant had in the rejection letter been told that his situation could be solved by trying physiotherapy. He said he found it strange that such a suggestion could be made without anyone having seen or talked to him. Another informant said the recommendation in the rejection letter on how he should stop using some of his pain medication, was useless if he did not receive any other treatment. There were also informants who interpreted the rejection as a sort of guidance, like the informant who interpreted the rejection to mean that the pain centre wanted him just to proceed using strong pain medications and that there were no other options for him.

Some informants had asked the pain centre for an explanation. Two of them said they had been explained that the pain centre did not have the finances to treat them due to limited resources which meant that they had

to do strict prioritisation on whom to provide treatment. Another informant was told that the requested treatment was only given to participants in a trial the informant did not fulfil the criteria to participate in.

3.3 What to do next?

After learning about the pain centre rejection, some had talked to their GPs to get more information about the content of the rejection; however, there were informants who said the rejection had not been talked about at all when they had been in contact with their GPs afterwards. One informant said that for her, the pain centre rejection was like an isolated episode which never was discussed with anyone.

“There has been no follow-up afterwards, more than that the GP has put me on sick leave” (female, 55–60 years).

Among those discussing the rejection with their GPs, one of the things they had talked about was what to do now that the pain centre was not an available treatment option. Some informants had been encouraged by their GPs to look for treatment options outside the public healthcare system. One example was an informant who now regularly attended a private neurologist who she partly paid for herself and partly was financed by her employer’s healthcare insurance. On the other hand, other informants said they did not have the finances to make the use of private services.

There were informants who talked about how they and their GPs at the time of the referral had planned for what to do if the pain centre would not treat them. Even though their main reaction to the rejection was negative, they said that having decided at the time of the referral on where to turn to next, prevented them from falling apart. With a plan it was easier to remain a hope of that at the end, they would find some help that would improve their situation.

“My GP said we will take it step-by-step and we will get you into the NN [name treatment service] and then we take you to the NN. I thought that was a good plan and I have high hopes, I have, really” (male, 55–60 years).

4 Discussion

The pain centre rejection created strong reactions. This was partly due to that the rejection was perceived as a refusal from the health care system as a whole. Furthermore, it

was related to that the pain centre was regarded their last remaining treatment option, and given the rejection, they were declined help by the experts in the field. Even though some informants had received an explanation for why they had not been granted pain centre treatment, a prominent experience was that the informants found it difficult to understand why their pain centre referral had been rejected given the severity of their pain. The incomprehensibility of the rejection together with a feeling of lack of future treatment options, increased the hopelessness and frustration of their situation and made it challenging to move on and search for help elsewhere.

4.1 A total rejection

The informants’ perception of the pain centre rejection as a refusal from the health care system as a whole is understandable given their long history of searching for treatment options without finding any solution to their complaints. This finding adds to previous reports of that persons with chronic pain have difficulties accessing health care [10, 11, 27] and to the literature on experienced injustice among chronic pain patients [28]. For instance, studies have found that this group of patients have experienced refused access to treatments because healthcare providers assumed they would not benefit from them [29], and that persons with neuropathic pain found interacting with the healthcare system as a struggle [17].

Compared to these previous studies, the current study adds an important element regarding the experience of being rejected from a tertiary care service such as a pain centre. The current rejection was perceived as something more than rejections from other services as it implied being denied help from the experts in the field. This is understandable as the pain centre is a highly specialised care facility [8] to which one of the criteria for being admitted is that all other available primary and secondary care services are tried [23]. Thus, a pain centre rejection implies a rejection from the service at the top of a treatment services hierarchy, in which a rejection can be interpreted to also represent rejections from services situated at lower care levels.

4.2 Moving between hope, small expectations and hopelessness

Even though only a few informants had specific expectations to pain centre treatment at the time of the referral, most had a hope of receiving something that would

improve their situation. Hope has been described as a driving force towards searching for available treatment options [30], but in the current study the informants also spoke of having few or none expectations to actually finding efficient treatment. In a systematic review on the subject of patient expectations for chronic pain management, it was emphasised that patients express different types of expectations [31]. Relevant to the finding in the current study, the review reports that patients can hope for a full cure but still predict to gain little or nothing from the treatment, and that one reason for the discrepancy between ideal or predicted expectations can be negative experiences from trying different treatments in the past [31].

This furthermore relates to previous descriptions of hope as a paradox for people suffering from chronic pain, in which hope often involves balancing between hoping enough to carry on and at the same time keeping hopes in check to avoid the ever-present possibility of despair [32]. From other areas it is known that when experiencing a chronic condition there is a value in knowing where to turn to for help [19], and furthermore, that when health professionals are experienced as not available, this can lead to hopelessness [33]. The resignation and the despair the informants spoke of in the current study, can be seen as a movement from a hope of finally finding help towards a hopelessness when yet another treatment option turned out to be unavailable. What the current study thus can add to previous studies, is that those informants who had a plan for what to do if the pain centre would not grant them treatment, said the plan helped them to move on from the disappointment and to keep hoping that in the end, they would find something that could help them.

4.3 Desiring a chance to be heard and seen

The finding that informants experienced the rejection as an extra burden to their struggles resonates with previous studies' findings on experiences of distrust, disbelief and pain invalidation in chronic pain patients' consultations within the health care system [34, 35]. These experiences have been linked to powerlessness and mistrust [29], to which the informants reports in the current study of resignation, frustration, sadness and anger can be added.

What some of the informants wished for in the current study, was the opportunity to talk to those acknowledged as the experts at the pain centre. A study of chronic pain patients' experiences with healthcare services in Norway, found that healthcare services were perceived to acknowledge the individuals as persons when listening to them and

addressing their health-related problems in an appropriate way [36]. Thus, the informants request for telling their story to the pain centre staff can be seen as a desire for being acknowledged for their struggles in managing their pain. This is important since having a feeling of not being believed, in addition to experiencing a lack of compassion and understanding, have been related to consequences such as threats to self-image, loss of identity and isolation [34], as well as affecting future help-seeking behaviour [37]. Thus, similar experiences and mechanisms described in studies of persons with self-harm behaviour [19] and people suffering from diffuse symptoms and psychological distress [20] are present among persons with chronic pain rejected access to tertiary pain care.

4.4 Strengths and limitations

A strength of the study is the novelty in exploration of experiences of persons receiving a rejection after being referred to a tertiary care pain centre by their GPs. However, there are some noteworthy limitations. The sampling strategy could have led to a biased sample as the informants were initially identified by the pain centre staff. Nevertheless, our sample showed variation, including informants of both genders at different ages, with different lengths of pain duration and with various experiences of being rejected by a pain centre. To minimize potential biases during the analysis, preliminary results were discussed with an extended research group to expose the data for different views and perspectives.

5 Conclusion

This present study on experiences with receiving a pain centre rejection indicates that the rejection can have grave consequences for each individual in the following months. An improved system for how to handle expectations towards referrals, including prepare for the possibility of rejection and how to follow up a rejection, seems warranted.

6 Implications

Health care providers caring for people with chronic pain should be aware of that individuals may link their responses to treatment requests to prior experiences of rejections and treatments from other services. Because a

pain centre rejection most likely is received by persons in a vulnerable position, there should be available health care services to help them understand the rejection. And furthermore, help them to move from disappointment and hopelessness, towards an experience of empowerment and reorientation, by for instance planning further actions and interventions, and thereby, acknowledge their need for help.

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Authors' statements

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Conflict of interest: The authors state no conflict of interest.

Informed consent: Written informed consent has been obtained from all individuals included in the study.

Ethical approval: The research complies with all the relevant national regulations, institutional policies and was performed in accordance with the tenets of the Helsinki Declaration. The study was submitted to The Regional Committee for Medical and Health Research Ethics in Central Norway, which assessed that no formal ethics approval was required (2018/309 REK Midt). Approval for the study was obtained from the data protection officer, the Norwegian Social Science Data Services, NSD (60619).

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