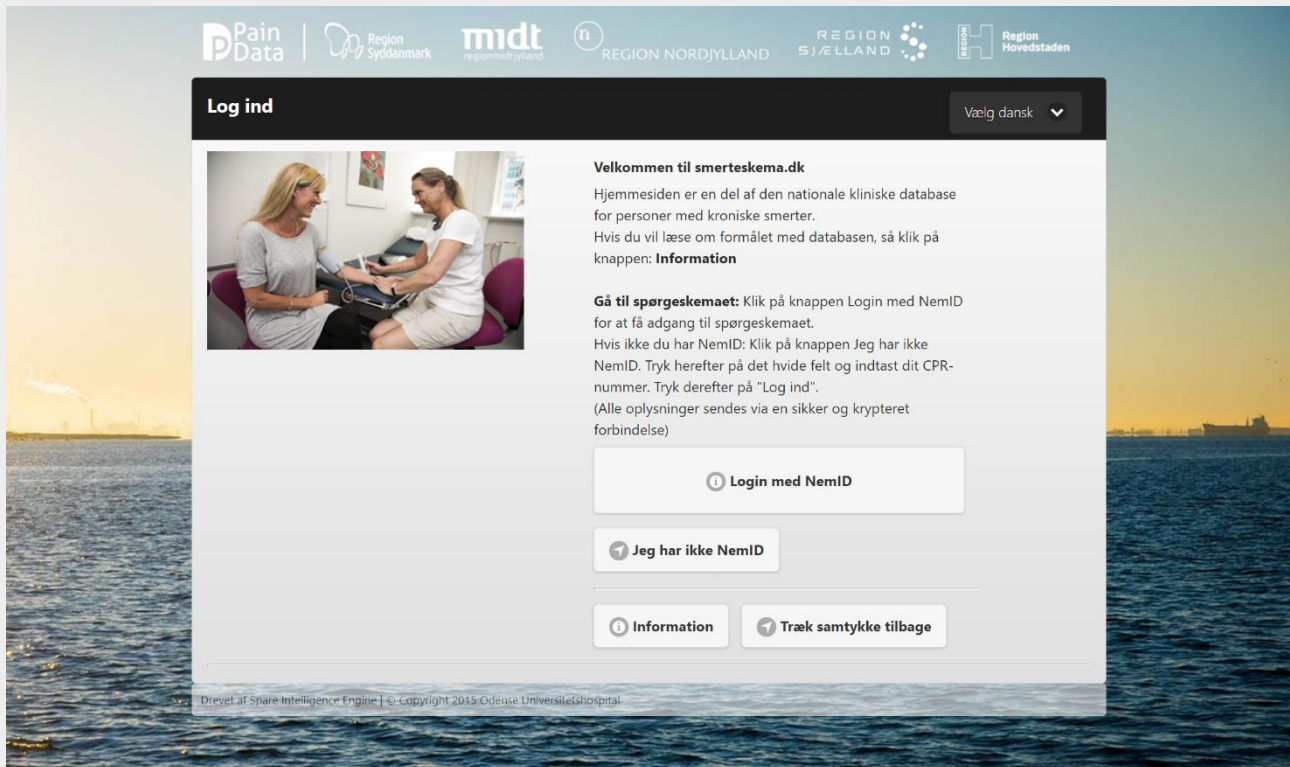


Chronic Pain

How do I explain?

How do I understand?



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Master Thesis

Summer 2022

Techno-Anthropology

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1 Abstact

Understanding the unspoken is the essential finding of this case study.

Twelve patients, referred to a multidisciplinary pain-center in the northern region of Denmark, have agreed to an explorative interview searching for signs of pain conceptualizations.

Inductive analysis has revealed that patients suffering chronic pain, who now can finally be given a diagnose 'primary chronic pain' if their pain also influences their psychological wellbeing or their social functioning. This definition is illustrative to the comorbidity and troubles that they suffer in connection to their pain. It also lays the ground for understanding why these patients do not bring forth reflected and well formulated explanations to their pain.

1.1 Table of appendixes

Appendix 1: Invitation for patients referred to the Pain-center to participate in this research

Appendix 2: Document for free and informed consent.

Appendix 3: Interview guide

2 Introduction

2.1 Inspirational and motivational considerations

An early impression of the citizen versus the healthcare system

In my first internship as a nurse student, I studied in an elderly home. One day I helped a nice old lady to the toilet. She did not walk well, so she needed the reassurance of accompaniment while walking to her apartment and assistance with her clothes. As she sat on the toilet and peed, she cried and moaned, and it took her forever to pea. When I asked her what the matter was, she answered, that it really heart, to pea. Afterwards I asked some of the caretakers, who with contempt in their voices and gestures answered, that they thought of her, that she was just moaning for no reason and that they hoped they would never behave like that, when growing old. I felt bad about this attitude and asked my supervisor, who responded that it needed examination. Later she told me that the old lady had had her bladder scoped finding a serious and chronic bladder infection and that she was now receiving adequate treatment.

Considerations upon early impressions

The pivotal elements of this narrative are a person suffering chronic pain, and the caretakers rejecting the message of pain as 'moaning for no reason'. It is as if the caretakers do not sense or catch on to the seriousness of the message.

Elaine Scarry (1985) uses philosophical narratives and considerations which may illustrate how this may be. Initially, she writes about pain as easily comprehended by the sufferer, but not

comprehensible to the person communicating with the sufferer, because there is no true way of proving the pain sensation. Scarry brings on the concepts of certainty and doubt as a narrative way of illustrating the different positions of communicating pain. Scarry has become an author often referred to, when wanting to describe the ways in which language becomes insufficient (or shattered as Scarry puts it), when a person needs to communicate his or her pain. She carries on and illustrates through narratives that the language of the sufferer is reduced to 'cries and moans' from the earliest stages of one's life.

Based on my experiences of being a mother and a grandmother, combined with the experiences of a nurse caring for many persons, suffering pain in different ways, I do object to this illustration. Babies cry and they cry with different intonations, but they do not moan. Moaning is an adult way of expression. Moaning, I believe, brings along a variety of emotions based on experiences from a lived life. By crying babies express their basic needs to their parents. Adults moaning, express suffering, and the appeal for care. Therefore, I will bring along Scarry's description of a '*shattered language*', but I will supplement it by emphasizing that the pain may influence an adult in a way that deprives the person the ability of speech and thereby the words to communicate the pain experienced. This is well illustrated by: William who had experienced such intense pain that he tells about curling up in foster position crying; and Laila who suffers difficulty remembering and concentrating her thoughts, leaving her in a position where she suffers from not understanding information given, difficulty in finding the answers, and a language profoundly changed, depriving her the ability of free and meaningful speech.

I return to the narrative above, carrying with me wonder as to why the caretakers expressed such contempt towards the nice old lady, while it could be expected, that they would be capable of understanding the basic nonverbal language of a human.

2.2 Understanding another person's pain

Giummarra et al. (2016), have examined human capability of sensing the pain of others, presented in the concept '*vicarious pain*'. They have performed language analysis to document qualitatively, '*vicarious pain*'. They find that those who experience '*vicarious pain*' seem to be more sensitive towards the emotions of others, who express their emotions towards threatening experiences (basically, pain is part of a bodily alarm system). I return to the narrative above, wondering whether the caretakers did not experience any kind of '*vicarious pain*', or they in fact had a subconscious unpleasant sensation of pain, and then being incapable of knowing how to act hereon, they expressed their contempt, giving themselves a reason to walk away.

My carrier of nursing has always been based on the wish, and maybe a sense of call, for taking care of others in need of such. Therefore, I find it easy to recognize myself in the concept of '*vicarious pain*'. Not that I consciously feel intense sensations, as those narrated by Giummarra et al. but I certainly react upon suffering and not only suffering pain. I, as a nurse understand that a person is suffering, but the cause may not be obvious, and the person may not display the symptoms and nonverbal language that I usually rely on. Even language seems to hold limitations as to explain pain. Therefore, I often use a learnt practice when asking a person about his or her pain. The Visual Analogue Scale (VAS) (often mixed with the Numeral Analogue Scale) is a widely used method for understanding pain intensity. Pain sensations are useful when addressing the possible cause to the

pain. Physiotherapists rely on this when identifying the tissue that might be causing the pain. Pain sensations could be stabbing, burning, throbbing, etcetera. However, suffering chronic pain myself, I have often tried to distinguish my pain intensity and pain sensation. This, I experience, is not an easy or natural thing to do. Therefore, I expect that these technologies of pain assessment are learnt.

2.3 Internship experiences and reflective considerations

To learn more about chronic pain and its treatment I have spent time of internship at a multidisciplinary pain-center in the northern region of Denmark. Here I became acquainted with patients, their situations, and their treatment. My focus was to understand the work of the team members, which also let me become acquainted with patient situations, morbidities, and comorbidities. Only patients suffering complex chronic pain are referred to multidisciplinary pain-centers.

What are the first encounters for patients referred to a pain-center

The first encounters of the pain-center have varied, due to the Corona situation. Normally the pain-center invites future patients and their relatives to an introductory meeting. This has not been possible before and while I spent time of internship at the pain-center. However, it was possible to find a video on the pain-center's homepage, alongside with other information about the center and its treatment. At the introductory meeting future patients were normally invited to log-on to PainData and assess their pain and associated troubles. According to the chief physician the number of patients doing so has plummeted to half, while the introductory meeting has been on standby.

The first meeting in the pain-center is the journal entry with one of the doctors. For this one and a half hour is scheduled. I have been granted access to observing journal entries and have thereby learned that the doctors invite the patients to elaborate their pain and other symptoms. The doctors ask in-depth questions and explain in detail causes and connections between what they have experienced until now and their pain condition. Plans for treatment are explained and the patients are invited to express their thoughts and needs towards treatment. Care is taken that the patient understands and agrees upon the chosen course of treatment.

The healthcare system in general, the experiences that the patients carry along

When patients meet up with general practitioners (GP) in the search of help and pain relieve the story is different whilst GPs may have as little as ten minutes per patient.

In Denmark there is a long tradition for free and tax financed public health, which may be part of the expectations, that are present when meeting up with a doctor. As Danes, we expect to find help and understanding. We also trust doctors to be capable of identifying the diseases we may suffer and recommend curing treatment. Doctors are educated and trained in the use of a diagnostic system. A system that is based on international organization and clinical research. It is called International Classification of Diseases (ICD). The ICD-10, that has been adhered to until January 2022, did not have a diagnose for chronic pain. Pain was considered a symptom in connection to another disease. When a disease could not be found, doctors may have turned toward suspecting a

psychological cause to the pain. Therefore, the treatment has often consisted of pain-relieving medication and asking the patient to accept a life with chronic pain.

Chronic pain a significant health issue within the Danish population

The Danish healthcare system is free and equal for all citizens in Denmark. Even so the general health is not equal. Educational level and social status are influences that create distortion and skewness within population health. This is also significantly true for chronic pain sufferers, who mainly possess a lower educational level and therefore also lower income.

Patients referred to pain-centers suffer complex chronic pain, which means that their pain influences their psychological wellbeing or their social functioning. Information about the patients' situations, are obtained for statistical use, when the patients answer PainData. The first five-year report, based on these data, reveal that the main duration of suffering chronic pain before being referred to a pain-center is six years, and for 36% of the patients the duration of chronic pain is more than ten years. In this span of time the patients have needed help in different ways from the healthcare system, they may have been on sick leave, they may have been through job trial courses, and they may have retired early. Adding to the necessity of proper pain treatment is e.g., obesity which is a health issue of general concern, due to its influence upon many lifestyle diseases. Obesity may worsen the situation of suffering chronic pain, due to increased load on joints and muscle tissue. More than 60% of the patients are obese (Vægter et al, 2020). Chronic pain applies a major cost to society, increasing the need for research that may lay the grounds for interventions that may reduce these health issues and troubles of identifying suitable treatment for chronic pain.

Learnings given through internship

While observing doctors performing journal entry, I have found that the patients open up and elaborate upon their pain situation. This small exemplary part of a dialogue between patient and doctor illustrates the openness and mutual respect between the two parties.

Læge 3 Er i gode til at være kærlige overfor hinanden? Der kan være periode, hvor det ikke fungerer.

Læge 3 anerkender og fremhæver de ting de gør godt og, hvordan familien får det til at fungere.

Læge 3 anerkender patientens positive holdning og humor.

Parret kan godt finde på at tage gas på folk og indirekte konfrontere deres fordomme.

Hvad kan vi hjælpe dig med? Jeg vil gerne have den smertestillende til at fungere med færre bivirkninger.

Medicinen snakkes igennem (man kan godt tage på af Saroten).

Læge 3 der findes ikke noget smertestillende der er godt. Der er bivirkninger ved det hele.

Har du prøvet Transcutan Neuro Stimulation (TNS)?

Forklarer virkning og at det lindrer, det kan måske hjælpe med at falde i søvn.

Det er ikke sikkert at det hjælper eller lindrer hovedpine, men det kan være en mulighed. Man må bruge det så ofte man vil og det er forholdsvis let at betjene selv.

Reflections upon the differences between the healthcare system in general and the pain-center

The initiating narrative illustrated that the healthcare professionals did not understand the pain suffered by the nice old lady, they did not act upon her pain, and they expressed their contempt towards her appeal for help. The old lady cried and moaned which Elaine Scarry (1985) defines as a scattered language incapable of communicating pain. However, when asked she could define her pain by the sentence 'it really hurts to pea' thereby identifying the part of her body affected, so further examination could be applied. By using imaging technology, a diagnose was found, and treatment initiated, eventually her pain was relieved. Sadly, many persons suffer pain that has persisted for more than three months or the timespan of normal healing without finding a cause. Their pain is therefore considered chronic. Due to such an unpleasant situation the patient continuously contact the healthcare system in general, not always finding sufficient help. Their situation continues developing, giving them troubles, such as sleep deprivation, trouble remembering, concentrating, inactivity, and psychological problems such as stress and anxiety. This may lead GPs to consider psychological causes, which might seem appalling to the patient. There are several issues at play, within this situation. GPs and specialist work within tight time schedules not giving them much time to explore the situation of the patient's pain. I suspect that the communication between doctor and patient might be somewhat unequal due to differences in their levels of knowledge about diseases and pain. And whilst the patient suffers pain, their resources may not be as readily available as those of the doctor. Doctors are superior and should be capable of communicating about the needs of the patients in an explorative way. However, if Elaine Scarry, is right about the language of pain sufferers is shattered, then it may be very difficult for doctors to identify the patients' problems.

I therefore find it relevant to explore the ways in which patients conceptualize their pain.

2.4 Problem definition

How do persons suffering chronic pain conceptualize their pain and what is their pain perception? Which influences do different pain perceptions have in the meeting between patient and doctor?

3 Methodology

3.1 Case study

I am about to dig into the ways in which patients suffering chronic pain set words to their pain. Such conceptualization will be connected to a pain perception, which is carried along when meeting up with doctors. However, the doctors pain perception will be different from that of the patient, due to education and training. As mentioned in connection to healthcare in general the ICD-10 and now -11 are vital to doctors world-wide. The technology ICD is based on clinical research and organized in a rigorous and precise system giving no space to personal differences. To work with such a system, you must have technologies to help identify the symptoms and other information that may be vital in setting a diagnose. Such technologies could be questionnaires, visual imaging, or

palpation of the aching part of the patient's body. All these methods are based on quantitative research and clinical training.

The conceptualization within every single one of us is not developed in this way. Patients may have limited words and concepts, to explain their pain. And when meeting up with a doctor they may expect that the doctor will know what to do, if told where it hurts. However, as it has been presented, in connection to the significant health issues of chronic pain, this is not the case. Whereas patients suffer chronic pain for years before referred to a pain-center.

Clinical research will always be about organizing information into well documented categories or boxes, as lay people would phrase it. Working systematically when verifying and developing knowledge, is vital and impersonal at the same time. Therefore, to achieve insight to the patients' conceptualizations of pain and skills of communicating pain, qualitative method needs to be applied.

An ethnographic case study can provide detailed information about the communicative issues at stake when patients and doctors communicate about chronic pain. Case study of real-life situations may reveal details about the patients' pain perception and pain conceptualization. Case study may also reveal essential information, about the subtle ways in which pain and its connected troubles are communicated. The information found will be very concrete, and detailed, and the knowledge that can be developed will be related to that of practice (Flyvbjerg, 2006).

The initiating narrative of the crying and moaning old lady illustrated somewhat limited communicative skills. The exemplary dialogue, between patient and doctor in the pain-center, revealed that it is possible to empower the patient in a way, that opens to the concrete information of a patient's life lived with chronic pain.

Troubles such as tiredness, trouble remembering, and stressful thinking, etcetera, are readily available in patients who have suffered chronic pain for a span of time. These troubles oppose limitations to the patients and therefore offer information about pain impact and may be identifiable in a case study. Value towards understanding the impact of chronic pain may be found in these limitations. Whilst such signs and symptoms may be subtle and difficult to identify, in any patient suffering chronic pain, they may be more directly available in patients who suffer complex chronic pain and have been referred to a multidisciplinary pain-center. Therefore, choosing the extreme case may bring forth valuable information about the conceptualizations of pain and pain perceptions of the patients suffering chronic pain (Flyvbjerg, 2006). Such clear information may serve educational to health professionals and serve as a tool suitable for recognizing the necessity of intervention at an earlier stage.

By choosing case study, to understand how persons suffering chronic pain, conceptualize their pain in the extreme case of being referred to a multidisciplinary pain-center, it will be possible to identify subtle signs of pain impact. And by analyzing the ways in which pain perceptions influence the situations of the case, evidence may be found as to which pain perceptions open to dialogue and which do not. This information is essential to facilitating the diagnosing process and the following treatment (Flyvbjerg, 2006).

Successful identification and treatment of chronic pain will serve well to the patient as well as the economy of the society.

3.2 Emic positioning

Initially, I studied Clinical Science and Technology, thereby becoming acquainted with many technologies, developed to help people, who suffer chronic diseases, live free, independent, and happy lives. This study has trained my ability to comprehend and apply clinical science addressing chronic pain.

As it has already been mentioned, my background of nursing-experience lets me comprehend the settings of the Danish healthcare system and the multidisciplinary pain-center, of my internship. Years of nursing experience, in different settings, has given me an intuitive and therefore immediate understanding of the patients and their narrative. It has also given me a strong sense of overview, which is important when examining and talking to patients. This overview lets me know what to do and when to stop, and the sensitivity of a nursing overview lets me mirror patients in a natural and instinctive way. These skills are essential and useful when performing ethnographic interviews. The ethnographer, however, expands the research by letting me also identify and study the overall perspectives and conceptualizations, using qualitative method.

A beneficial position for ethnographic research, I believe.

Understanding the patients' conceptualization of their pain, necessitates research positioning resting within the emic position of the patient (Boas 1943, Spradley 1979). My background within public healthcare and further education will enable me to understand the information given by the informants. It will also enable me to create an interview guide suitable for this group of informants and while interviewing perform sensitivity towards their responses.

Harraway writes about knowledge that it must be developed through a conscious positioning and careful and critical analysis. She empathizes that knowledge must be situated and as such is also open to further development (Harraway 1988)

3.3 Choices towards informants

Having access

Based on my time spent in internship at a multidisciplinary pain-center in the northern region of Denmark, I have been granted access to interviewing patients. The informants will be invited to participate based on two criteria. They have been referred to the pain-center and they have assessed their pain situation, by answering PainData.

The patients attending treatment in the pain-center suffer a variety of causes to their pain and different comorbidity. By disregarding a wish to unify the group of informants based on their pain situation I expect the group of informants to represent the population of patients that are referred to the pain-center in general. By also disregarding sex and age I expect the group of informants to represent the statistical knowledge, about patients referred to pain-centers and clinics (private and public) in Denmark. This means that there will be more females than males and their age will span from 18 to approximately 85 years. Other characteristics such as educational level, work situation etcetera will also be represented but these will not be questioned (Vægter 2020).

I invite the patients to participate in my investigation by creating an invitation where I present myself, with picture, explain my background and current education (Appendix 1).

To ensure the interests of the informants, documents for their volunteering and informed consent are developed. I create a document containing all relevant information enabling the patients understanding and volunteering consent (Appendix 2). The pain-center create a document informing the patients that they volunteer in my investigation and to do so the pain-center may pass on their name and telephone number to me.

Data safety GDPR

I have made an agreement with the pain-center that they will hold on to the documents of informed consent until July 1. 2022. This is based on their organization being better equipped for safe storage of personal data than I. I will store the informants' data on my computer using a code and a date only. The informants will be given their code as text, sent by SMS and informed that I will erase their names and numbers, so if they want to talk to me about their data, they must use the code. I have stated in the document of consent, that there is a date from when it will not be possible for me to erase their data from my report.

3.4 Explorative research

To understand how pain is conceptualized by patients and what their pain perception could be I choose to perform explorative interviews. My theoretical background is given by James Spradley (1979), who emphasizes the importance of acquiring the language, dialect, or way of speaking in a specific situation. He argues that this is important to truly understand the life world of the informant. By taking this stance he also argues for the emic perspective first introduced by Boas in 1943. Boas emphasizes that to truly understand a people's culture the ethnographic exploration must be based on the concepts of the informants or the people ethnographically explored. Neither Boas nor Spradley use the concept 'emic', instead they explain its meaning or use.

Spradley introduces important elements of normal conversation. Conversational rules that are unspoken but adhered to. He also describes how by twisting these rules they can work well when interviewing informants and encouraging them to elaborate upon the things they have already told.

Spradley will be the source of inspiration for creating an interview guide and performing the interview. I will lean on his three principles while interviewing. 1. Explain and repeat, 2. Repeat what the informant has told, 3. Focus on the use of a concept (Spradley 1979). And I will lean on his knowledge of language and conversation, when creating the interview guide. This means understanding the interview guide as a guide to build up the level of confidence and at the same time give space to change the order of questions in connection to what might be relevant at a given point. Importantly initiating the interview with explanations of the purpose followed by everyday questions that do not oppose any pressure or threat upon the informant. Such questions could be exploring the everyday life of an informant, which holds the privilege of tuning in on the melody of speech and choice of words.

3.5 Thematic inductive analysis

To have a wide and detailed understanding of the informants' conceptualization of pain, their pain perception, and the pain perceptions that they are met by, I choose to analyze my data inductively. Whilst this research aims at understanding the conceptualizations of pain, as they are represented by the informants, and choosing an emic positioning, it is not possible to know theoretically or based on existing knowledge, about pain, what to code deductively for. Therefore, the inductive approach is suitable. Through an intense and laborious process of performing the interviews, reading standard transcriptions, listening to the recordings repeatedly, transcribing phonetically (selected parts) and creating layers of notes and map-drawings, the themes and other findings will emerge from the data. (Braun and Clark 2006).

3.6 Situational analysis

Situation analysis based on Grounded Theory aims at mapping all influential parts of a situation. It may be anything from political influences on human actors and discourses. The purpose being understanding the relations between them (Clarke and Friese, 2007). Situation analysis and especially relational analysis I find suitable for understand the most widely accepted pain perceptions. These pain perceptions are represented by pain definitions agreed upon internationally. Relational analysis is chosen to understand differences and similarities between the presented pain perceptions and how they relate to each other. Relational analysis will also be chosen to understand the influences of a given pain perception.

3.7 Narrative analysis

I lean on Polkinghorne's (1995) text about narrative analysis, in my choices, as to how I can derive elements, from my interview data, that will appear useful in understanding, the patients' conceptualizations of pain and their pain perception. Polkinghorne presents two lines of narrative analysis, which he presents as originating from two types of cognition (paradigms) originally presented by Bruner.

The paradigmatic type aims at producing taxonomies and categories from the everyday stories of humankind.

The narrative type focuses on events and happenings, and aims at creating stories, that explain such phenomenon as patients' conceptualizations of pain and pain perceptions.

It is my choice to use the narrative type, as I wish to develop narrative knowledge, that may explain the level of conceptualization, characterizing the attempts of being understood by doctors, and receive sufficient treatment.

Inductive analysis involves close examination and comparison of the individual narratives. It will lead to finding categories of language that may represent pain conceptualizations and pain perceptions. The result will emerge from the reflection of the researcher, and it is normally presented using a plot that illustrates the logics and connections.

I have already positioned myself as ethnographic researcher with a specific background, I will rest in the acknowledgement, that this position will affect the informants in a positive manner, in connection to understanding their story. Therefore, I find it safe to write up my presentation of

results, using Dollard's seven criteria as they are presented by Polkinghorne, as my influence upon the data should be visible.

4 Method as it has been performed

4.1 Studying the case of understanding how pain is conceptualized and it's attached pain perception

This case study is composed by analyzing the emic perspective of patient referred to a multidisciplinary pain-center. By conducting patient interviews, using explorative interviewing method, thick description will be created. By analyzing the interview data using different methodology, the data will open to the deep understanding needed, to identify pain conceptualization and pain perception. The healthcare system in general and the pain-center work by structures, and as such these structures may be considered pain perceptions. By analyzing these pain perceptions, threads of cultural/ educational information may elicit ways in which patients create their pain conceptualizations and pain perceptions.

When referred to a pain-center, all patients are encouraged to log on to PainData and assess the pain, its connected troubles, and morbidities. This is a laborious process, through which reflective response may be expected. Considering PainData as an encounter it is relevant to analyze it both as an encounter and a pain perception.

4.2 Creating an interview guide

The interview guide is developed with the intension of creating thick description of lives lived with chronic pain, the experiences from public healthcare in general, and the multidisciplinary pain-center, including PainData, specifically. The interview guide (appendix 3) is structured by four research questions, that each are accompanied by many small guiding questions.

1. Understand and become acquainted with the informant's everyday lives lived with chronic pain.
2. Understand their experiences of meeting up with the healthcare system in general.
3. Understand their experiences of answering PainData.
4. Understanding their experiences of meeting up with a doctor at the pain-center and the influences PainData might have applied.

The intension is to invite the patient to elaborate freely upon their experiences from their every day, their experiences of meeting up with doctors and seeking treatment in the healthcare system in general, experiences of answering PainData, and experiences from their first meeting with a doctor in the pain-center.

4.3 Taking contact to the participants and planning ahead

After receiving names and telephone numbers I initiated a phase of contacting the participants by SMS. This worked very well for most of the participants, leading to agreements on when to perform the interviews. A few participants did not respond to my SMS, but they did respond to my phone call. There are twelve informants, three men and nine women in the age from 29 to 66.

4.4 Performing twelve interviews using an overt approach

While interviewing I draw upon my experiences in nursing and my experiences of interviewing, primarily learnt through studying techno-anthropology. Initially I ask if there is anything within their consent, they wish for me to explain. This was not the case for any of the informants. Then I move forward to explaining the purpose of my interview and how I have built the interview guide. I introduce my research questions and explain about my small inspirational questions. To ensure that the interview does not become unpleasant I ask of the informants that they let me know if they do not want to answer a specific question. This did not happen either. While interviewing, I confirm and encourage the informants, by giving them a new inspirational question or encouraging them to elaborate further on their answers.

As it turned out, it was difficult for the patients to answer my questions about PainData. They did not remember their specific experiences of answering PainData. Therefore, I adjusted asking questions informing about parts of PainData, making it more affordable for them to answer. I maintained the question ‘did any of the questions make a special impression in you?’ as some interesting answers had been given. Otherwise, I improvised.

I found that the informants answered in different ways e.g., that it was ok to answer these questions, some tried to remember what they had answered, and some associated freely upon my question. A few spoke of feeling assaulted by questions about sexual life, feeling that most questions were alike and that they were all about psychological issues, alcoholic-like, or that most questions were about having a depression.

To have as much information as possible I allowed the patients to jump around in their story making sure to recollect the missing parts. During the interview I maintain a sensitivity to not understanding a question or mere exhaustion.

The interviews were performed by telephone and recorded by an APP on my tablet.

4.5 Thematic inductive analysis

Getting acquainted with the interview data

I paid a company to transcribe the interviews, but as it turned out their version of a standard transcription drew out the essence of the interview, instead of transcribing the interviews with pauses, mistakes, repetitions, and other details. When I started reading the transcriptions, I was immediately frustrated but did not, at first, recognize the cause of my frustration. I then read through the transcription of the informant that spoke a profound Jutlandic dialect, which I had myself transcribed. I realized that the transcriptions were too perfect. I tested this assumption by listening to the sound file while comparing to the transcription. I then correcting one of the interview transcriptions coloring all my corrections. Through this process, I understood, that the speech of some of the informants, was clearly affected. I, therefore, decided that the transcriptions

were useless for performing thematic inductive analysis, and that the sound files held more valuable information. This was based on the recognition that I needed to dig deeper than the words spoken out. Something, in the informants' speech, was very different from any speech I had ever noticed while working as a nurse. This then became one route of examination, focusing on speech affection. The informants themselves gave information of trouble remembering and other troubles, letting a pattern emerge between their speech, their troubles, and how they described their pain.

Analysis

The first careful examination of the interviews was done by both listening to the sound file and reading through the transcriptions. Soon my notes became messy and unmanageable. At this point I had already found some headline questions. Therefore, I drew up simple maps, on separate sheets of paper, and started collecting statements that answered the questions of my maps. This could be what are the patients telling; how are they describing their pain; what are their responses to PainData's questions addressing their sexuality; what do the patients tell about their social life; how is their speech affected, and more.

I created tables to have an overview of which statements or troubles were true for the individual informant.

The next step was to transform these maps and tables into a thematic inductive analysis. The headline questions were suitable themes and by carefully going through all subthemes, and notes clearly nurse observations, emerged. This process was performed on large sheets of paper.

A preliminary finding

Immediately a discovery needed careful consideration. Almost all the informants told about negative experiences from meeting the healthcare system in general, before the pain-center, and positive experiences of meeting a doctor at the pain-center. To understand causes that might be connected to the patients' conceptualizations about pain and their pain perception I decided to dig deeper.

Considerations in connection to the diversity of the informants' narratives.

The narratives of the informants were all different, leading to a real risk of concluding on the narratives of one or two informants. For instance, some of the informants suffer significant change to their speech, presumably caused by cognitive changes. It is important to recognize, that this can be, and that it will have a profound effect on the patient's capability of explaining his or her pain situation to a doctor, and that I will have to be careful, when analyzing these limited narratives. Likewise, it is important to notice that a few of the informants were overwhelmingly and intriguingly detailed in their narratives, however, the perspective could be that of reflection, and at times there were leaps and disconnections in the flux of words. Therefore, I decided to listen to all the interviews once more, this time making individual notes, to ensure that the information of every informant was considered.

Presenting the thematic inductive analysis

This presentation is a tricky one whilst a thematic inductive analysis ought to be presented as a narrative. However, the finding of my analysis has brought forth a combination of themes, subthemes, and findings of speech affection. Speech affection is not at theme which makes it difficult to narrate. However, understanding speech affection and other consequences may be crucial to finding information about how the informants conceptualize their pain and which pain perception they rely on.

Having chosen to work primarily with the sound files, it becomes difficult to bring over all information. Therefore, I will complement the transcribed sequences with descriptions of their speech and changes in their speech. At times the need to complement with information given by their narrative will be present. I will compliment when it brings information to changes in speech. The twelve informants bring over narratives of different pain situations, different troubles in connection to their pain, and different affection of their speech. If I were to bring all this information into one narrative, it would become chaotic and unrealistic. Therefore, I choose to present all informants, introducing their pain situation and then letting each informant present an affect to their speech. This is done to create a complete picture of findings that will help clarify, how persons suffering chronic pain conceptualize their pain, and what their pain perception may be.

4.6 Situation analysis of answering PainData and pain perceptions

Situational analysis PainData

To fully understand the scope of PainData I performed a situation analysis, drawing up all the questions, that the patients are asked to respond to. Even without having trouble remembering, concentrating, becoming exhausted, or not quite understanding the questions I find the task overwhelming. There are 54 pages with different questions, which take a considerable amount of thought and time to answer.

When the interviews were performed, I had a more direct focus on PainData. Through the different layers of analysis, I have learnt, that PainData represents an encounter. This encounter serves as a prism through which the patients are introduced, to the pain perceptions presented above.

Relational analysis

The relational analysis differs from the other analyses because I initiate by presenting the international associations and their definitions of pain (pain perception). The organizations considered are WHO (World Health Organization), ICD (International Classification of Diseases), and IASP (International Association for the Study of Pain). I find that PainData relates to these organizations, therefore it is taken into consideration. Other than that, I will relate the pain perceptions of these organizations to the findings of the thematic inductive analysis.

4.7 Narrative analysis

The narrative analysis works holistically searching for the influences towards developing pain conceptualizations and pain perspectives. Therefore, understanding the temporality of the informants' lives, lived with chronic pain, and the influences of sequential events, between the informants and the healthcare system in general, PainData, and the pain-center creates a basis for understanding their pain conceptualization and their pain perception.

5 Analysis

5.1 Introduction

The thematic inductive analysis will address two perspectives. Primarily the analysis will address conceptualizations of pain and pain perceptions as they may be represented by the informants. However, the solution to finding characteristics of conceptualizations of pain is not straight forward. Neither is pain perception. As it will be presented below, I find the evidence of conceptualizations and perceptions by addressing both occurrences, absences, changes in speech, choices of explanation, beliefs, and changes in normal ways of life. First, I will present changes to routines and structures of normal life. This is important because such routines and structures are essential to normal functioning (Gimler, 2019). Second, I will create a narrative illustrating the changes to speech that I have found. There will be no plot and no person presenting the plot. Instead, this will be narrated through all the informants, by presenting their pain situation, and speech affection, followed by exemplary interview answers.

The secondary perspective, that I find essential to understanding the informants' conceptualizations are some surprising answers to the question of being understood as a disease. This I find is a theme because it concerns the inner beliefs and personal needs for understanding. This will be presented by the comments of those informants, that have given a comment on this question, followed by my process of analysis.

The situation analysis will address pain perceptions that are significant within the Danish healthcare system and clinical research. This choice is based on the preliminary finding, that most of the informants have experienced lack of recognition of their pain situation, within the healthcare system in general, and recognition in the pain-center. This I find, may be caused by a clash between the pain perception that doctors work by, and the changes in speech represented by the informants. The situation analysis will also address the digital platform PainData, to find clues of the pain perception represented herein. This analysis will be presented by the structure of the questions of PainData (that is as I have grouped them in the interview guide). I will then let the most representative answers narrate the informants' experiences of answering PainData.

The relational analysis. To lay the grounds for understanding the pain perceptions that are adhered to by the healthcare system of Denmark as well as internationally I will present the organizations behind. Next, I will present the structure of ICD (International Classification of Diseases) and its influences upon understanding chronic pain and last, I will present the pain perceptions of ICD and IASP (International Association for the Study of Pain). In addition, I will present the pain perception adhered to by the pain-center, namely the Biopsychosocial model.

Based on this foundation I will analyze the relations between the pain perceptions of ICD, IASP and the Biopsychosocial Model. When this is done, I will relate to PainData and the findings of the thematic inductive analysis. The analysis will be presented as a working process.

The narrative analysis will address the changes within the lives of the informants. As such it will be presented in a character ‘Violet’ created for the plot. Violet will, with the help of the informants present a plotted illustration of the course of treatment and examination that these informants have been through. She will also illustrate the differences between the healthcare system in general and the pain-center. Differences that I believe are connected to, which pain perception the patient is met by.

For these presentations every participant has been given a fictive name and anonymizing caution performed by using general formulations, when presenting their individual situations. Information that would risk furthering recognition has been disguised with xxx.

I will cut out my own listeners comments using [yes, no, and humming] and if I have said something relevant to understanding the answer, it will be written within the [].

I will reduce the informants’ narratives by using () to emphasize their main messages.

5.2 Thematic inductive analysis of interview data

Primary (thematic), inductive analysis

I have noticed that the informants do not have much routine to their morning or their day. Many describe how their pain set the order of the day. However, they do not tell this in a structured and conscious way e.g., ‘I do not have morning routines because my pain sets the order of my day’. Therefore, it is worth examining a few extracts of the interview data which cast light upon what is said about routines.

Primary thematic analysis routines and habits

Cathy’s pain started out of the blue and persists. She already had the diagnosis PTSD (Post-Traumatic Stress Disorder), and she has suffered abuse. Her speech is monotonous, she speaks fast, and otherwise her speech is slightly affected.

I have just asked her to tell about her morning routines.

1.21 *Jamen altså den er sådan lidt øh den er meget præget af det altså der øh nogle dage er gode og andre dage de de knap så gode altså nogle gange kan jeg ikke rigtig noget efter at jeg fx har støvsuget eller noget øh stå og lave mad er også en udfordring [] øhm så det jo det det begrænset hvad jeg sådan ligesom altså jeg skal hele tiden planlægge min dag hvis nu jeg fx at jeg ved at i morgen skal jeg gøre rent jamen så skal jeg sætte en dag af til det og jeg skal også sætte næste dag af til at vide jamen så kan jeg heller ikk mere altså så vågner jeg op næste dag og så har jeg i sindssyge smerter [] øh så jeg skal ligesom hele tiden planlægge indad jamen skal jeg noget dagen efter så skal jeg nok ikke lige gøre sådan og sådan 2.03*

Cathy speaks fast without many pauses. However, her sentences seem disconnected leaping from one perspective to another.

Jamen altså den er sådan lidt øh den er meget præget af det altså der øh

She refers to her pain using pronouns without having anything to refer to. Then she leaps to an overall description of her days, and she leaps again to challenging activities.

Nogle dage er gode og andre de de knap så gode altså nogle gange kan jeg ikke rigtigt noget efter jeg fx har støvsuget eller noget øh stå og lave mad er også en udfordring

She stammers a little when referring to the not so good days and then she leaps into exemplifying causes.

Cathy does not seem to have routines for her mornings or her days. She leaves out the word pain when she speaks and then when using it, she emphasizes it heavily.

Amy has undergone simple surgery with subsequent serious complications. She has consequently developed PTSD, anxiety, and chronic pain. Her speech is affected to some degree, and she speaks of herself in third person. Amy uses clinical terms for pain sensations.

I have just asked Amy to tell about her weekday.

1.01 *jamen altså for mig er det jo jeg har tre børn øhm og øh så for mig er mit hovedfokus og have energi til dem når de kommer hjem fra fra skole og vuggestue [] øh så så for mig er det meget meget varierende hvordan min hverdag fungerer*

for er jeg træt så bliver jeg nødt til at slappe af når de er afsted [] øh har jeg energien til det så kan jeg godt give det et skud men det giver bagslag i sidste ende [] øh så så det er meget at føle efter hvad hvad hvad min krop signalerer hvis man kan sige det sådan 1.41

jamen altså for mig er det jo jeg har tre børn øhm og øh så for mig er mit hovedfokus og have energi til dem når de kommer hjem fra fra skole og vuggestue

Amy pauses and searches for her answer. She then leaps to exemplifying how she chooses to focus on her children. She leaves out the word pain.

Cathy and Amy, who both suffer PTSD represent the most extreme cases of efforts done to be in control. However, it seems it may be the other way around. The other informants speak of habits and routines that aim at mitigating their pain to a level, where they can go ahead with daily chores or other activity.

Primary thematic analysis of pain conceptualization and pain perception

I have just asked Amy how she described her pain.

10.04 *“jamen det jo det jo øhm åh me jamen hvordan skal man forklare dem jamen altså det det det varierer igen af hvor smerterne ligger henne øh det kan være brændende det kan være stikkende det kan være trykkende [] øh det det det er altså øh det er ts øh øh murrende øhm som ligger i overfladen øh øh ja jeg ved ikke lige hvordan jeg kan beskrive dem anderledes” 10.27*

det kan være brændende det kan være stikkende det kan være trykkende [] øh det det det er altså øh det er ts øh øh murrende øhm som ligger i overfladen

Amy refers to pain sensations and connects a sensation to a level rather than a body part such as her skin. However, her explanation is fragmented.

Laila suffers sequela from a violent accident where she was diagnosed. Recently, she was also diagnosed Fibromyalgia (an autoimmune disease). Laila has trouble remembering, concentrating, and understanding. She gets tired and is easily over stimulated. Her speech is severely affected. Laila's social activity has changed, she has lost her job and work ability, changing her social status.

I have just asked Laila to explain how she told about her pain, when they began.

11.08 *“jamen allerførst det var da jeg kom ind på xxx sygehus efter ulykken så sagde jeg bare at jeg havde hovedpine og jeg havde kvalme og og jeg havde fået hold i nakken i løbet af en time [] det det tror jeg det var det [] øhm og så nu her efter så jeg bare begyndt med og så sige det det gør altså bare ondt over det hele nu der” 11.41*

I have just asked her how the doctor reacted to her explanation.

11.45 *”jamen øh jamen han jeg synes faktisk han var meget sån altså forstående og hvordan at han vidste lige nøjagtig altså han var hurtig til at sige at øh at du har fået xxx og xxx og da jeg kom sån kom til lægen også sagde det der med ved du hvad nu er det altså simpelthen begyndt så sagde han med det samme ved du hvad jeg får*

dig altså til en neurolog fordi at øh det tyder på at det er Fibromyalgi der har sat sig nu” 12.10

bare at jeg havde hovedpine og jeg havde kvalme og og jeg havde fået hold i nakken i løbet af en time [] det det tror jeg det var det [] øhm og så nu her efter så jeg bare begyndt med og så sige det det gør altså bare ondt over det hele nu der

Laila refers to symptoms and pain all over. She pauses many times as if searching for the words.

Alice suffers osteo-arthritis and migraine. She has trouble remembering and concentrating. Her speech is affected to some degree, and at times she speaks of herself in third person.

Alice is detailed in her narrative. However, she does not quite succeed in being coherent and rigorous. Her narrative is fragmented, she searches for the words, she pauses and repeats words as if she stammers, and some sentences end unfinished. This seems to be connected to emotion whilst she speaks fluently when the content lets her distance herself from her emotion.

I have just asked Alice to tell about how she explains her pain and her tiredness to health professionals.

30.17 “ja jamen altså jeg forklarede jo bare at øh at jeg har den her vedvarende øh når jeg fortæller om min tommelfinger så er det sådan meget ligesom om at der sidder en og trykker på det hele tiden øh ligesom om man har sådan et blå mærke øh der bliver trykket på hele tiden [] øh og så knæene jamen det kan være hvor jeg oplever at det giver nogen knæk eller det knager eller det skurrer øh ft og hofterne det kan være sådan at at man er påvirket nå man går og og igen den her ligesom om der sidder en og trykker en finger ind [] øhm det er jo svært og forklare også fordi at nogen dage så er det meget markant og andre dage så det så mærker man dem næsten ikke fordi man måske også vænner sig lidt til de er der øhm [] øhm så det øh det er mere den der med lige at prøve at sætte en finger på [] at der er noget der ikke er som det skal være” 31.19

når jeg fortæller om min tommelfinger så er det sådan meget ligesom om at der sidder en og trykker på det hele tiden øh ligesom om man har sådan et blå mærke øh der bliver trykket på hele tiden

Alice explains her pain using the metaphor of somebody, outside of her body, creating pain by pressure upon her.

øh og så knæene jamen det kan være hvor jeg oplever at det giver nogen knæk eller det knager eller det skurrer øh ft og hofterne det kan være sådan at at man er påvirket nå man går

She also explains her pains by sound and her walking being affected. In this way she seems to rely on impressions that could be audible or visible to others.

det er jo svært og forklare også fordi at nogen dage så er det meget markant og andre dage så det så mærker man dem næsten ikke fordi man måske også vænner sig lidt til de er der

Alice continues referring to her pain by using pronouns agreeing for her difficulty explaining by telling about shifts of intensity and habituation.

at sætte en finger på [] at der er noget der ikke er som det skal være

And she finishes her explanation with ways of speech

Lucas has not yet been diagnosed but being referred to the pain-center so directly, indicates that a specific disease could be indicated. Though having suffered pain significantly shorter time than the rest of the informants, he is severely affected. He suffers trouble remembering, his speech, physical activity, and social activity are affected. Note should be taken that he is an elderly north-west Jutlandian, which gives a significant character of few words, and a significant Jutlandic dialect.

5.56 "Jamen det er jo simpelthen bare at a hånd er en stor nerve" 5.59

9.15 "Jamen jeg har ondt i e hånd a kan æt bruge hånden til noget" 9.18

12.12 " jamen jeg har ingenting nu [] for jeg deltager ikke i nogen ting for jeg kan ikke [] lige så snart pulsen stiger så får simpelthen som et søm [] ja bare ved at gå på stedet når jeg er ude at gå så dunker det jo så det er jeg har både cyklet og løbet og [] jeg har løbet en halvmaraton og [] øh ja og vældig aktiv med fodbold [] og spinning men øh alt er væk øh" 13.04

at a hånd er en stor nerve

By using a physical term 'nerve' he describes how sensitive he experiences his hand to be.

Jamen jeg har ondt i e hånd a kan æt bruge hånden til noget

In this sentence he both uses a simple phrase 'I feel pain' and refers to limitations.

lige så snart pulsen stiger så får simpelthen som et søm [] ja bare ved at gå på stedet når jeg er ude at gå så dunker det jo

In this fragmented sentence he explains what activates the pain, the immediacy of pain and a pain sensation.

Throughout the interview Lucas speaks fragmented, make grammatical mistakes, speaks with little nuance and swears.

Phillip has suffered an accident and then later, he was diagnosed with a constricted nerve. He suffers trouble concentrating and remembering, as a side effect to medication. His speech is minutely affected. Phillip speaks slowly and emphasizes words by expressing them as if they were almost in two parts. He seems to swear when he emphasizes emotions, he may have due to his pain. He suffers affected activity level and sexual life.

2.57 "øh og de smerter forplanter sig også så det er ikke kun oppe i lår ene så er det nede i hvad hedder det læg muskler og og det kommer længere ned også i under fødderne [] som om at man går på blå mærker hele tiden [] og øh fts det bliver sådan jeg får føler mer og mer der sidder en kniv og stikker mig ind i lænden hele tiden" 3.25

øh og de smerter forplanter sig også så det er ikke kun oppe i lår ene så er det nede i hvad hedder det læg muskler og og det kommer længere ned også i under fødderne

Phillip refers to the radiation of pain by naming the affected body parts.

Audrey has suffered an autoimmune disease for many years, without having a diagnosis. Her memory and speech are not affected. She expresses determination not to let her pain control her life.

She is so determinate that she believes, her mother, sister, and husband are the only persons that can tell when she is in pain. Audrey is physically and socially active.

I have asked Audrey to describe her pain.

0.18 *smerter i knæene [] øhm og blev undersøgt for gigt indtil flere gange [] stille og roligt begyndte de og brede sig til øh hofter albuer skuldre [] øhm og så kom muskelsmerter med ind også* 0.45

Audrey describes her pain by location and tissue.

And when asked how her body feels in the morning, she uses properties which may also be used about things. She emphasizes by referring to the timespan of this condition.

2.07 *den føles ret stiv og den føles tung 'sukker' og det varer en i hvert halv en halv time til en time inden jeg sådan begynder og ka fungere* 2.19

Sophia suffers an autoimmune disease and an accident. Her memory and speech are affected. She has grown up not being very attentive to the unnatural nature of her bodily needs. In early childhood she suffered extreme pain due to growth, and in her teens, one arm needed the support of a pillow.

Sophia tells about a pain situation.

29.03 “ () og jeg ku ikke forstå at den skulle gøre så ondt den der nakke [] efter faldet men deet er ikke rigtig blevet mødt med jow jeg ku tage nogle flere piller fik jeg og vide jeg kunne tage nogle flere hovedpinepille og så Ipren [] blandet sammen og så skulle jeg spise det også øh så der er jeg egentlig bare blevet mødt med piller når jeg så kom hjem og sagde jeg skal flere piller og så sagde til min kæreste det gør jeg jo ikke [] og han ved jo også godt at det gør jeg ikke” 30.08

jeg ku ikke forstå at den skulle gøre så ondt den der nakke

Sophia only uses the word pain and its position. However, she tends to pause when talking of her neck pain and she refers to her pain in a distance creating way, as if it is not her neck.

William has suffered an accident several years ago in combination with xxx disease, which was not connected to his pain until recently, during acute and serious hospitalization. He suffers affected speech, changes to his social life and work ability, he has had thoughts of escaping. His narrative is a little mixed up.

13.12 ”jamen altså det var jo i starten var det jo svært og finde ud af hvorfor har du ondt og så det var en ting der virkelig fyldte fordi jeg forstod ikke hvorfor jeg havde ondt når lægerne sagde at jeg ikke fejlede noget ()også var det først her da jeg begyndte og få ondt og jeg begyndte og kaste op og jeg virkelig virkelig fik ondt [] og de sagde jamen der er ikke noget der du du fejler ikke noget men du ligger stadigvæk med smerter og du ligger og vrider og drejer dig” 13.54
*også var det først her da jeg begyndte og få ondt og jeg begyndte og kaste op og jeg virkelig virkelig fik ondt ()
men du ligger stadigvæk med smerter og du ligger og vrider og drejer dig*

William refers to feeling pain. However, when he speaks about his pain he pauses and emphasizes words. He may e.g., emphasize every word when slowly expressing the question ‘hvorfor har du

ondt?’ and by using second person he distances the pain from himself.

Evelyn has suffered an accident. She suffers affected speech, sleep, and trouble remembering. She is physically active, with caution, and she want to participate in social activity. Evelyn finds it hard to accept her pain.

When asked about her first impressions of meeting up with the healthcare system in general she gives a long description of her course.

7.57 ”() øh men jeg ved at hun har skullet skubbe rigtig rigtig meget til for vi bare ku få en lille smule af det og finde ud af hvad der ligesom var helt galt med mig og ja få en anerkendelse [] meget har været meget svært og få en anerkendelse [] at jeg faktisk har smerter [] og jeg har tit fået kastet i hovedet at øh af læger generelt har man bare fået kastet i hovedet at man har angst og [svært at høre] problemer eller et eller andet selvom det er virkelig virkelig tydeligt at der er noget galt () jeg har haft jeg har simpelthen brugt så meget tid og krudt på at få banket ind i hovederne på dem at der faktisk har været noget galt 9.55

og finde ud af hvad der ligesom var helt galt med mig () at jeg faktisk har smerter () selvom det er virkelig virkelig tydeligt at der er noget galt

Evelyn uses strong phrases to explain her pain expressing the expectation that something serious is the matter. There is a development in her narrative, she shifts from being emotional to being angry. When emotional, her speech is disconnected and then, when she speaks of insinuations of a psychological cause to her pain, she speaks more coherently and uses strong expressions such as ‘at få banket ind i hovederne på dem’.

Rose suffers an autoimmune disease, which was not diagnosed for a long time. She suffers affected work ability, activity level and sexual life. Rose is detailed when describing the difficulties of explaining about her pain.

23.43 “øhm jamen så har det været meget sådan noget altså jeg synes det er enormt svært og fortælle om fordi at at du ved når det ikk er nogle smerter som alle kender [] så er smert smerter meget diffuse og forklare for andre fordi det er jo sådan ligesom hvis vi to taler sammen nu eller hvis jeg siger til dig ’åh jeg har også ondt i hovedet’ så vil du jo relatere det til en hovedpine du kender [] fordi det sådan vi gør som mennesker det er den måde vi forstår hinanden på og prøver og sætte os ind i noget ()” 25.15

jeg synes det er enormt svært og fortælle om fordi at at du ved når det ikk er nogle smerter som alle kender [] så er smert smerter meget diffuse og forklare

Rose has a lot on her mind and explains with examples. However she does seem to stammer due to emotion.

Eliza suffers an autoimmune disease, in combination with other diseases. Her memory, endurance, sexual life, and speech are affected.

0.16 ”en dag lige op til sommerferien der vågnede jeg op og havde sån lidt stive fingre
() jeg havde simpelthen ondt i samtlige led i kroppen” 0.37

0.38 ”fordi at je jeg kun simpelthen havde så ondt jeg kunne ingenting jeg kunne
ikke engang når jeg havde samlet vasketøj jeg kun ikke engang lægge strømper
sammen så ondt havde jeg” 0.50

2.06 ”Jeg har simpelthen så ondt jeg kan ikk sove om natten og jeg kan ikk bevæge
mig om dagen altså jeg var virkelig virkelig i en pine uden lige” 2.15

Eliza explains that her joints hurt, that she cannot do anything and that she feels tormented.

Phillip has suffered an accident and then later, he was diagnosed with a constricted nerve. He suffers trouble concentrating and remembering as a side effect to medication. His speech is minutely affected. Phillip speaks slowly and emphasizes words by expressing them as if they were almost in two parts. He seems to swear when he emphasizes emotions, he may have due to his pain. He suffers affected activity level and sexual life.

2.57 ”øh og de smerter forplanter sig også så det er ikke kun oppe i lår ene så er det
nede i hvad hedder det læg muskler og og det kommer længere ned også i under
fødderne [] som om at man går på blå mærker hele tiden [] og øh fts det bliver
sådan jeg får føler mer og mer der sidder en kniv og stikker mig ind i lænden hele
tiden” 3.25

øh og de smerter forplanter sig også så det er ikke kun oppe i lår ene så er det nede
i hvad hedder det læg muskler og og det kommer længere ned også i under
fødderne

Phillip explains his pain by descibing how it radiates downwards in his leg.

Secondary thematic, inductive analysis

Did you feel you were met as a disease?

Sophia: 19.55 ” øh ja det blev jeg da osse fordi han var øh altså meget inde omkring min
sygdom og vidste hvad den indebar og alt sån noget syns jeg da [hvordan oplever du det] at han
øh ja altså jeg oplevede det på den måde hvis det sån du tænker det at han forstod min sygdom []
og han forstod hvad det var den gjorde ved min hverdag [] når den var allerværst og det som han
siger at vi skal have skubbet de der hvor at jeg ligesom begynder og kan rumme nogen ting igen
og komme lidt ud igen og i steden for sige det kan jeg ikk så så han var meget omkring når du
færdig her xxx så så er du kommet langt [] ja”20.41

Eliza: 20.19 ”hm nej jeg er blevet mødt med et menneske der har eller ja et mennesker der har
behov for hjælp til og og komme af med nogen smerter jeg synes ikke at det er en sygdom altså
det synes han snakket mere om at med forståelsen og acce accepten af det hele jeg synes virkelig
at øh ja det var ikk så meget sygdom eller hvordan skal man sige vi snakkede [] det var mere
løsninger” 20.55

William: 21.01 ”det synes jeg ikke jeg jeg synes de har været gode til og vise mig at jeg den
menneske jeg er [] jeg har jeg har bare en kronisk sygdom der gør at jeg har nogle barrikader

som skal skånes så jeg synes ikke at jeg er blevet set som en syg person [] der har jeg fået jeg er blevet set som en der der har nogle forhindringer som skal have hjælp [] ja” 21.29

Lucas:14.40 ”*ja det tror jeg ja det giver ja ja [og hvad ligger der i det når du synes du er blevet mødt som en sygdom] jamen øh de spurgte da ind til tingene [ja i forhold til din tilstand] Lige nøjagtig ja” 15.01*

Amy: 8.57 “*nej jeg er blevet mødt som en hypokonder” 9.01*

Rose: 21.00 ”*ja det har jeg [] den den overlæge som øhm som jeg var tilknyttet der på xxx sygehus som sån lavede de her xxx nogen gange hvor jeg skulle have lavet de her indgreb (xxx) men men med ham øhm altså ham har jeg haft meget at gøre med gennem årene () det var også ham der diagnosticerede mig i sin tid altså han var sikkert dygtig og sådan noget men det var meget der der følt jeg mig der var jeg ingenting der var jeg blevet [kan ikke høre] patienten altså der var ikk noget hvor vi ligesom snakkede om andet” 22.21*

The surprising and interesting elements of these answers are that I as a nurse have a preconception of negativity in connection to meeting patients as a disease. Somewhat like the way Rose explains it, only she has had to accept this situation as the doctor was the specialist who knew about her disease and could treat it.

From the nurse perspective it would mean that one was only caring for a specific part of the patient in front of you leaving out the identity of the patient.

The core of these statements I believe is the effect that pain has on a person’s identity. I will return to this perspective when tying the analyses together in the process of developing an understanding of the case.

5.3 Situation analysis PainData

Introduction

To fully understand the technology PainData I will present the background for its development, and the team behind it. To understand the purpose and importance of PainData I will present some common comorbidities and troubles. This distinguishment is done based on the assumption that, comorbidities are actual diagnoses and troubles are problems that occur in connection to chronic pain e.g., sleep deprivation. As such PainData is considered Patient Reported Outcome (PRO) which is an often used, method when wanting to understand the ways in which patients experience their situation of disease. Much research has already gone into developing questionnaires for the understanding of chronic pain, its comorbidities, and troubles. Therefore, as Henrik Bjarke Vægter answered, in an interview performed, while I spent time of internship. ‘Caution is taken to use well documented questionnaires and their translations, into Danish, when possible’.

Finally, I will present a narrative consisting of informant answers creating a running thread, based on questions answered.

Presentation the team behind PainData

In 2015 SDU (Southern Danish University) announced the Professorship of Physiotherapy and Pain Treatment, which was given to Henrik Bjarke Vægter. This is based on the acknowledgement that patients who suffer complex chronic pain also suffer reduced functionality and quality of life. Henrik Bjarke Vægter will work within a strong multidisciplinary environment to develop and implement PRO (Patient Reported Outcome) databases. PainData is such a database developed to serve three purposes one of which is to facilitate the dialogue between health professionals and patients. The overall purpose is to obtain and develop better understanding and treatment. Henrik Bjarke Vægter also aims at furthering collaboration between research and clinical practice. ([New professor at SDU, Vægter et al. 2017](#))

Presentation PainData

PainData is a digital platform consisting of questionnaires. The setup is pleasant, and the questionnaires are all presented in Danish. The questionnaires are not presented as such, and their titles are more inviting and trustworthy than e.g., Pain-catastrophizing scale. The language is simple and accessible offering extra information. The answering options are presented as either choices or scales. The answering options are explained in an easily accessible language. The questionnaires address a variety of morbidities and troubles, that may be present in connection to chronic pain. Patients referred to any pain-center or clinic in Denmark are encouraged to log-on PainData and answer the questionnaires.

PainData is based on fourteen questionnaires

They are:

- Brief Pain Inventory
- Pain Disability Index
- Karolinska Sleep Questionnaire
- PROMIS Health
- Internationals Trauma Questionnaire
- Pain Catastrophizing Scale
- Perceived Stress Scale
- Tampa Scale of Kinesiophobia
- Patient Health Questionnaire
- Generalized Anxiety Disorder
- Spørgsmål om dine værdier/ ønsker for behandlingen
- Demografiske faktorer
- Spørgsmål om medicin, tidligere behandling, rygning, alkohol og stoffer

([Information about PainData, Jensen 2021](#))

Chronic pain and its possible comorbidity

During internship I have learnt about several comorbidities which I will present briefly.

Anxiety may come in different forms. An influential form is kinesiophobia, which will worsen the pain condition due to letting the body become weaker and less flexible. Kinesiophobia lets the sufferer believe that something dangerous will happen to the body if it is moved in a specific way or situation. Fear of movement is a milder form, having the same influence.

Depression will keep the sufferer in a state of mind, where every thought is negative to a point of exhaustion and loss of hope, thoughts of suicide may occur.

Fibromyalgia is a condition, where all bodily tissue is highly sensitive to touch.

Post-Traumatic Stress Disorder (PTSD) may be a result of abuse, violent accident, or other events that were out of the sufferer's influence. PTSD includes an alarm system always on high alert.

Sensitization means that the nerve system reports pain without a prior harmful event. Central and peripheral forms may be distinguished.

Trouble in connection to chronic pain

Loneliness and isolation.

Loss of job and social status. This is often connected to a course of finding new job possibilities lead by the municipality.

Loss of friends and social activities.

Low level of life quality.

Low level of concentration causes difficulties in solving even small tasks, or understanding information, or even communicating about the pain suffered. Loss of cognitive skills such as e.g., planning events.

Trouble remembering causes difficulties similar those connected to low level of concentration and these problems are often connected.

Sleep deprivation is caused in different ways. It may be difficult to find rest and fall asleep or one may wake up too early, unable to sleep anymore. It can also be waking up during the night and having trouble falling asleep again.

Statistical findings in connection to chronic pain

More women than men suffer chronic pain, and their pain situation initiates at a lower age.

More men than women commit suicide due to chronic pain. The cause is often intoxication which is connected to men more often medicating their illness with alcohol.

More men and women, suffering chronic pain, possess low level of education, than high level of education.

(Vægter et al. 2020, Sundhedsstyrelsen 2015)

5.4 The narrative of answering PainData

The questions will be the running thread letting an informant answer each question.

What do you feel about making a pain-drawing?

Evelyn 22.03 *"altså øh også at de kan se hvor det er man har ondt henne og man egentlig også lige selv at det egentlig lige selv går op for sig hvor mange steder man egentlig går og har ondt"* 21.11

Describe your pain by intensity, over time and in connection to activity.

Cathy 13.49 *"jeg synes det er lidt svært altså fordi det det der med at nogle dage der er de træls og andre dage der er de sådan nogenlunde til og leve med [] øh og det der med jeg tror man skulle svare på hvordan de havde været den sidste uge eller sådan noget jamen jeg synes det var sådan lidt det synes jeg var lidt svært"* 14.11

Medication.

William 6.52 *jeg synes faktisk det var nemt øh og få øh få sin medicin ind fordi meget af det som jeg egentlig fik det stod derinde [] så så det var meget af det gængsede medicin man egentlig får øh der der står inde på på det skema der var derinde [] så det synes jeg det var faktisk det nemmeste af af hele spørgeskemaet"* 7.17

Previous treatment.

Cathy 14.36 *"det har været det det har været fint nok altså igen det der med altså det det har været en helhed i det altså det der med at de så ligesom ved hvad man kommer fra man har været igennem nogen ting altså sån"* 14.54

Sleep, digestion, and restless legs.

Audrey 16.43 *"det kan osse være et jeg gerne ville have haft en kommentar til [] fordi jeg kan godt ha en periode hvor jeg sover godt men så kan jeg ha en periode hvor jeg øh faktisk ikk sover om natten pga smerter"* 16.56

Family life, leisure activity and social activity.

Phillip 20.10 *"jamen det har da forberedt mig på den måde at øh jeg ku se at der var eller blev ops blev opmærksom på at der var flere ting eller mange andre ting man øh sku*

ind og snak om end end bare hvad man følt af smerter [] ikk at det både var jamen øh søvnproblemer jamen øh samvær med andre øh øh soci ja socialt samvær øh jamen det sexuelle osse øh () øh så er jeg osse forberedt på jamen det det vi skal ind og snak om [] det er mange af de ting vi skal ind og snak om selvfølgelig og det har da samlet set en øh gør at han bedre kan vurdere øh hvordan jeg har det () det her påvirker øh alle andre sanser i kroppen osse ikk” 22.28

Life quality.

Rose 1.10.53 ”det nok der hvor jeg synes det bliver mega mega trist og sidde og lave [] at der meget osse fordi jeg lige nu er et sted hvor jeg er enormt ramt på den del altså virkelig meget [] øh så det synes jeg er super hårdt [] så hårdt og skulle side og beskrive en ting er at skulle tale med andre om det men noget andet og skulle sidde sån og krydse af og ved beskrive og [det bliver meget konkret] ja ja det syns jeg er hårdt [] men oss altså igen er det nødvendigt det osse en del af det og sku på smertecenter” 1.11.41

Eliza 15.23 ”altså det jo lidt en øjenåbner [] men hvor meget smerter egentlig gør ved en og får ja altså man altså jeg vil sige at livskvaliteten den blir den blir dårligere når man har smerter [] og det syns jeg faktisk altså det ikk noget man tænker over når man er i det men når man så skal reflektere over det så er der sån nogle spørgsmål jeg syns faktisk det er noget af en øjenåbner” 15.57

Civil status, height, weight, and education.

Rose 1.11.52 ”ja det tænker jeg bare det sådan er standartagtigt” 1.12.00

Habits in connection to smoking, alcohol and drugs.

William 11.49 12.23 ”ja jeg mener øh [] ja så jeg synes øh altså jeg lægger ikk øh skjul på at på de svar jeg har og deet ja som sagt jeg er meget ærlig og meget åben overfor hvad det er jeg fejler hvordan jeg har det og [] og jeg syns sku ikk at deet det noget altså der er jo ikk noget personligt personligt på den måde altså i i spørgeskemaer for det meste [] det er jo det er jo meget relateret til det som du fejler og ikke øh hvad kan man sige personlige [] ting såå” 13.10

Violent event.

Cathy Voldsom begivenhed 17.06 ”ja den synes jeg ikke var så rar ha ts [] øhm men det gav måske lidt mere mening da jeg så kom derind på smertecentret altså [] men det var mere det der med med at man ligesom fandt ud af at det måske kunne stamme fra noget af det hvor hvis ikke jeg havde haft svaret på det jamen så vidste de jo ikke hvad man kom fra [] øh og hvad man havde været igennem så på den måde så var det jo egentlig fint nok da jeg kom derind men jeg synes jeg forstod det ikke helt dengang da jeg skulle udfylde det” 17.39

Audrey 18.21 ”den ville jeg meget gerne have haft en kommentar til [] øhm ja og det det vil jeg fordi at øh (private nature) så det har været et stressende år det sidste år” 19.16

Physical activity and exercising

Rose 1.18.16 ”det sy det har jeg ikk sån det synes jeg var fint [] men igen altså det hele er jo bygget op omkring altså skemaet er bygget op omkring helhed har man ligesom bygget op omkring at man er kronisk syg ikk oss og det er klart at alle alle spørgsmålene kommer jo i en eller anden sammenhæng ikk oss altså () det klart så kommer der oss en reminder på at jeg laver jo ikke de ting jeg gerne ville altså men man må så der nogle andre ting jeg gør det sætter mange tanker i gang det sætter mange følelser i gang sån et skema” 1.18.58

Physical activity in connection to pain

Rose 1.19.18 ”sukker jamen det tror jeg det ligger så bob øh fordi det har det har en påvirkning for mig og det gør jo at jeg ikk laver voldsom meget og det gør jo at jeg hele mit liv er jo tilrettelagt sådan at jeg holder pauser øh imellem hver ting jeg laver [] hvis jeg kan for når jeg ikk kan det så det alt for øh så går det galt ikk oss [] øhm så igen det bliver jo også bare det tydeliggør hvo hvor lidt jeg laver samtidig med egentlig laver jeg jo mange ting fordi jeg holder jo stort hus og jeg går tur op til tre gange om dagen og jeg har tre børn og de er til sport og dem og køre og så det jo ikk fordi jeg bare sidder og ser Netflix hele dagen med mig selv og min kat du ved det jo ikk sån det er vel men jeg kan godt føle at når jeg skal beskrive det at jeg alligevel bliver lidt småt på en eller anden måde jeg ved ikk ja” 1.20.26

Audrey 20.17 ”jamen det mener jeg også det var nemt nok [] øh jeg er øh faktisk ret god til og og vælge hvor meget hvor meget jeg kan og hvor meget jeg ikk kan [] og begrænse det hvis det er sån jeg kan mærke i dag det en dårlig dag [] så går jeg jo ikk fem km med hundene [] jamen så bliver det måske kun det halve eller en km eller et eller andet [] så det jeg egentlig ret god til og styre selv [] ” 20.47

Wishes and personal values in connection to treatment

Rose 1.21.25 ” jamen det synes jeg det synes jeg er en rigtig god ting fordi det gør jo netop at man bliver reflekteret inden man starter altså så man ikk bare ruller ind i smertecentret det kan jo godt være at man altså jeg tænker når man bliver henvist dertil så det jo på baggrund af af en problemstilling som ens læge eller man selv oplever har brug for og få taget hånd om og for rigtig mange så tror jeg så kan det enten være noget smertehåndtering eller også aktuelt skal ha lavet om i sin medicin som det er for mig og øhm men jeg synes det er godt og ha de der spørgsmål fordi man næsten bliver tvunget til lige og tænk igennem hvad hvad egentlig jeg ku bruge altså hvad er det hvor er jeg henne hvad har jeg brug for” 1.22.09

5.5 Relational analysis pain perceptions

Presentation World Health Organization (WHO)

WHO is an organization founded in 1948. To ensure developing research relevant to all countries, and regions, it was stated in 1949, that it should be conducted within a collaborative network of already existing institutions. The goals of research are to ensure better health to everybody, everywhere. Amongst the obligations are “*standardization of terminology and nomenclature, of technology, of diagnostic, therapeutic and prophylactic substances, and of methods and procedures*” (WHO).

Presentation the International Classification of Diseases (ICD)

The ICD is a system of diagnoses agreed upon internationally. Initially the purpose of ICD was to diagnose the reason of death. However, development and adaptation are ongoing international processes, influenced significantly by WHO and IASP.

ICD is a rigid system of careful clarification of diseases. The diseases are organized by the origin of diseases, using a numeral system, sorting them into groups of related diseases. In every group of diseases diagnoses are presented and sorted into more and more specialized diagnoses. Within the group of chronic pain sorting under non-malign pain, diagnoses such as Fibromyalgia and Complex Regional Pain Syndrome (CRPS) can be found.

How does ICD influence upon the understanding of chronic pain?

Within ICD-9, which was still working in 2014, chronic pain was considered a symptom to a disease or the code 338.2 ‘other chronic pain’.

In 2015, ICD-10 entered into force, offering more options for diagnosing chronic pain.

January 2022, ICD-11 enters into force. ICD-11 is based on significant amounts of research and international cooperation. Dr. Med. Rolf Detlef Treede chaired the taskforce for research and data collection, in cooperation with Prof. Dr. Winfried Rief.

The differences between ICD-10 and ICD-11 are substantial, towards understanding chronic pain. ICD-10 differentiated chronic pain as a symptom connected to another disease, whereas ICD-11 opens the possibility of distinguishing chronic primary pain as a disease (Treede et al, 2015; Nicholasa et al, 2018; sundhedsstyrelsen.dk; Zimboonyahgoona et al., 2021; [ICD-11](#); [IASP](#)).

If digging into the different possible diagnoses within the three latest editions of ICD, there is a profound difference, as to the possibilities of finding understanding for a situation of chronic pain, and which treatment would be offered. If one ended in the ICD-9 category ‘other pain’ then the pain may have been recognized and treated using pain relieving medication, which would then give significant side effects; habituation and addiction, leading to low quality of life. There would be little understanding for the troubles and comorbidities, to the situation of pain. ICD-10 introduced some diagnoses that would cause chronic pain (ST.Jude Medical, 2015). However, when examining statistics such as the Global Burden of Diseases (2016) and Sygdomsbyrden I Danmark (2015) note should be taken, that when assessing neck pain and low back pain it is distinguished as pain, not chronic pain, which disrupts the possibility of knowing how many suffer chronic pain. It is also interesting to note that WHO initiated the process of developing the ICD-11 in 2015, for it to become ready for testing and later, international adoption at the World Health Assembly. Some

interesting threads to notice are developments such as: the [spring meeting of IRF 2017](#) (under the Danish Health and Medicines Authority) focusing on alternative treatments of pain; [the Danish Health and Medicines Authority's clinical guideline addressing treatment of non-malign pain using opioids 2018](#) and later the same authority's announcement that the [long term use of opioids is reduced in 2020](#). These actions illustrate that the Danish health organizations are adjusting towards the ICD-11 and that they work. Now that the ICD-11 has entered into force the significant diagnostic is that pain must “*persists or recurs for longer than 3 months*” and be “*associated with significant emotional distress or significant functional disability*” (ICD-11) to be considered primary chronic pain. This relates well to the Biopsychosocial Model of understanding and treating chronic pain.

While doing this research I was happy to find that the Danish Health and Medicines Authority initiated a [campaign of information about chronic pain](#) in 2020, which is a positive development towards braking taboos and misunderstandings about chronic pain.

Presentation The International Association for the Study of Pain

In 1973 the IASP was founded and has expanded from Seattle (America) to 133 countries throughout the world. IASP is ubiquitous to scientific work on pain conditions. Has a strong organizational structure and cooperates with other worldwide organizations such as WHO.

It seems clear that there are connections between the scientific knowledge available and the agreements acknowledged by international associations such as ICD, WHO and IASP. Meaning that existing clinical research is built upon the agreements of these associations. Therefore, clinical knowledge will be based on the ICD system valid at the time of completion, and the culture of trusting the latest and best validated research will continue. Therefore, the definitions of chronic pain, as they are defined by these organizations, are relevant in the understanding of the pain perceptions that patients are met by, when consulting the healthcare system. This means that many of the informants of this research have been met by the ICD-10 and therefore they have not had their pain recognized if another diagnose could not be found.

Chronic pain defined by ICD-11

The system of diagnoses is a significant part of the structure that doctors work by.

Within the pain-center the health professionals, at times spoke of now having an actual diagnose for chronic pain. It is named chronic primary pain.

Chronic primary pain is defined:

“Chronic primary pain is pain in 1 or more anatomic regions that persists or recurs for longer than 3 months and is associated with significant emotional distress or significant functional disability (interference with activities of daily life and participation in social roles) and that cannot be better explained by another chronic pain condition.” (Treede et al., 2015, (p 1004))

Chronic pain defined by IASP

The pain definition as it is presented by IASP does not only concern chronic pain or only humans. Their definition addresses the sensory perspective of pain and connects it to a more ethical perspective by attaching six key notes to the definition.

According to IASP pain is defined:

“An unpleasant sensory and emotional experience associated with, or resembling that associated with, potential or actual tissue damage”

The key notes are:

- *Pain is always a personal experience that is influenced by varying degrees of biological, psychological, and social factors.*
- *Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.*
- *Through their life experiences, individuals learn the concept of pain.*
- *A person's report of an experience as pain should be respected.*
- *Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.*
- *Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or nonhuman animal experiences pain.*

(IASP)

The key notes one and two address perspectives shared with ICD-11. However, they strongly emphasize that pain cannot be reduced to something biological. In the third keynote they address a cultural perspective to pain. In the fourth they address an ethical perspective clarifying the subjectivity of pain experience, and not measurable nature of pain, and that it needs respect on this ground. The fifth keynote refers to the diagnosis, primary chronic pain of ICD-11, addressing the impact that pain may have on a person's wellbeing. And sixth addresses the situation that it may be difficult to communicate pain verbally and that changed behaviors may be equivalently as important when communicating about pain (in this keynote animals are included).

In Denmark pain-centers and clinics are part of the public healthcare system alongside with private pain clinics. The multidisciplinary pain-center of the northern region, who have given me access to internship and this emic research, adhere to the Biopsychosocial pain model. Therefore, a presentation is relevant.

The Biopsychosocial Model of chronic pain, a theoretic perspective

Kelley Bevers et al. (2016) review and discuss the historical background for the development of the Biopsychosocial model for pain. They describe the biopsychosocial model for pain, by presenting the vulnerabilities of the physical, psychological, and socio-cultural aspect of life.

- Physically a person may be disposed to injury and loss of fitness. The progress of such problems is closely connected to the level of psychological responses such as fear-avoidance, kinesiphobia, and pain-catastrophizing.
The biological side of these problems has to do with the transmitter substances/ biochemicals: Cortisol, adrenaline, serotonin, and norepinephrine which are biochemicals of normal functioning, and a vital part of normal functioning out of balance.
- Psychological vulnerabilities may lead to reduced mental functioning. This may be expressed in behaviors such as learnt helplessness anxiety disorder, abuse, and depression.
- Social and cultural vulnerabilities are connected to basic income, which is connected to educational level, employment, and housing.

In Denmark access to healthcare does not have the same limitations and consequences as presented by Bevers et al. However, prejudice and stigmatization may be a result of not finding a diagnostic cause to chronic pain.

Cultural background may influence whether pain sufferers ask for help or even realize the need of help which could be the case with stoicism.

Bevers et al. argue that by including the genetic predispositions the composition of treatment may become more efficient.

Learnings of the situational analysis of PainData

Besides understanding the structure and purpose of PainData the narrative gives an insight to the patient perspective of answering PainData. An insight that reveals a level of reflection, emotional reaction, and satisfaction that they bring over valuable information to the doctor.

PainData relates to ICD through the questionnaires, that are based on clinical research. It relates to the pain perception of IASP through the set up and the ways in which the questionnaires are presented. As the informants have found that by answering PainData, they have reflected upon some of the questions, they feel somewhat prepared to meet the doctor at the pain-center, and they express a sense of relief that they have ensured, their knowledge of their pain situation, shared with the doctor. This may be rather essential as it will be presented below, patients often struggle to bring over this information.

Learnings of the thematic inductive analysis

These findings have not been presented in the thematic analysis whilst they are not as such pain conceptualizations or pain perceptions. They are relevant however because they are part of, how or what the informants have revealed of information through the interview. The informants bring over information about their pain, by explaining things that they cannot do due to their pain. They do not bring over this information about their pain in the form of reflected and clear messages. It seems that this reflection and learning about their situation comes by, through answering PainData and especially by meeting a doctor at the pain-center. I have not sorted these phrases into categories of before and after, so at this point my data are imprecise. However, it is clear that the informants have been explaining themselves by their symptoms and especially by their troubles. This means that they have explained things they could not do e.g., sleep, fold socks, concentrate, remember, participate in reunions. In connection to this information, it has been found that whilst explaining these symptoms and troubles, the patients' speech is affected in several ways adding an important layer to understanding how patients conceptualize their pain. This insight connects to the IASP keynote number six '*Verbal description is only one of several behaviors to express pain*'

5.6 Narrative analysis interview data

Violet is 36 years old and lives with her husband and four-year-old son Peter. Until recently she worked in a local grocery store, loving every day of it. But many of those days became so painful that she often left early or called in sick, which in the end had the consequence of losing her job. Violet has visited her GP many times already, because of her pain. And the doctor has sent her to various examinations finding nothing. Thoughts of something dangerously wrong with her often touches her mind, and she thinks of confronting her doctor about it.

Every morning she fights her way out of bed, to take care of Peter. He needs to get dressed and get ready for kindergarten. Whilst creating a delicious lunch box for him, she decides to call the doctor for an appointment. She has read about pain-centers and believes that such a place might be able to help her. While Peter jumps up and down, on their couch Violet looks at him with loving eyes, blurred by tiredness. This is one of the things she does not understand. She goes to bed early every night, sleeps ok, does not do much throughout the day, due to her pain, and she even has a nap every day. Still, she is endlessly tired. Sometimes she is so tired that she cannot even think straight.

Amy: 1.01 *jamen altså for mig er det jo jeg har tre børn øhm og øh så for mig er mit hovedfokus og have energi til dem når de kommer hjem fra fra skole og vuggestue [] øh så så for mig er det meget meget varierende hvordan min hverdag fungerer for er jeg træt så bliver jeg nødt til at slappe af når de er afsted [] øh har jeg energien til det så kan jeg godt give det et skud men det giver bagslag i sidste ende [] øh så så det er meget at føle efter hvad hvad hvad min krop signalerer hvis man kan sige det sådan 1.41*

That's the truth of it, she believes. If I do something physical, I am going to pay in the current of intense pain. So, she tries hard to be in control of her pain.

Just the other day Violet spoke to a prior colleague, who asked about her situation and if she was going to come back to work. She explained and told about her pain, but it were as if her colleague did not understand.

Rose: 23.43 *“øhm jamen så har det været meget sådan noget altså jeg synes det er*

enormt svært og fortælle om fordi at at du ved når det ikk er nogle smerter som alle kender [] så er smert smerter meget diffuse og forklare for andre fordi det er jo sådan ligesom hvis vi to taler sammen nu eller hvis jeg siger til dig 'åh jeg har også ondt i hovedet' så vil du jo relatere det til en hovedpine du kender [] fordi det sådan vi gør som mennesker det er den måde vi forstår hinanden på og prøver og sætte os ind i noget ()” 25.15

Once a colleague asked her about her pain, what it was like. Violet tried really hard to describe it, she became all emotional and could not find the right words. Before long, her colleague tried to end of their talk.

Amy: 10.04 “jamen det jo det jo øhm åh me jamen hvordan skal man forklare dem jamen altså det det det varierer igen af hvor smerterne ligger henne øh det kan være brændende det kan være stikkende det kan være trykkende [] øh det det det er altså øh det er ts øh øh murrende øhm som ligger i overfladen øh øh ja jeg ved ikke lige hvordan jeg kan beskrive dem anderledes” 10.27

Something that made her sad and angry at the same time. She had experienced it often, while talking to friends or even her doctor. They simply don't get it they don't understand my pain and they talk to me as if I am making it up. Recognition of her pain seems hard to obtain. Sometimes it seems as if the doctor believes that I am mentally ill.

Evelyn: 7.57 ”() ja få en anerkendelse [] meget har været meget svært og få en anerkendelse [] at jeg faktisk har smerter [] og jeg har tit fået kastet i hovedet at øh af læger generelt har man bare fået kastet i hovedet at man har angst og psykiske problemer eller et eller andet selvom det er virkelig virkelig tydeligt at der er noget galt () jeg har haft jeg har simpelthen brugt så meget tid og krudt på at få banket ind i hovederne på dem at der faktisk har været noget galt 9.55

Violet picks up the phone and starts dialing the number, the secretary answers and asks so many questions. Finally, Violet is given an appointment. Some days before her appointment she gives a great deal of thought to her level of activity. Not that she worries but she wants to make sure that she has the energy and ability of explaining, what she wants and why she wants it.

Evelyn: 1.21 () så det jo det det begrænset hvad jeg sådan ligesom altså jeg skal hele tiden planlægge min dag hvis nu jeg fx at jeg ved at i morgen skal jeg gøre rent jamen så skal jeg sætte en dag af til det og jeg skal også sætte næste dag af til at vide jamen så kan jeg heller ikk mere altså så vågner jeg op næste dag og så har jeg i sindssyge smerter [] øh så jeg skal ligesom hele tiden planlægge indad jamen skal jeg noget dagen efter så skal jeg nok ikke lige gøre sådan og sådan 2.03

Finally arriving at the GP, she is exhausted beyond imagination and while she sits waiting for her turn, she looks around thinking it cannot be all that difficult for the doctor to understand that I am in pain. My knees make sounds, and everybody can see that I have trouble walking.

Alice: 30.17 “() og så knæene jamen det kan være hvor jeg oplever at det giver nogen knæk eller det knager eller det skurrer øh ft og hofterne det kan være sådan at at man er påvirket nå man går og ()” 31.19

While talking to the doctor she struggles intensely to explain, but she succeeds in being referred to a local pain-center. She is informed about waiting lists and what to expect before she heads off home steering directly towards the couch and sleeps for two hours.

Eliza: 13.09 *når nu jeg arbejder tre dage om ugen og når jeg så kommer hjem så der jeg bare færdig [] øhm 13.18*

Luckily Violet receives a phone call from the pain-center shortly after, inviting her to take a cancelation. They send all the information to her, so she can prepare herself and she is encouraged to log on to PainData.

William: 17.02 *"jeg var jeg har heller ikke været til det introduktionsmøde som der var der fordi at jeg fik jo en akut in øh indkaldelse [] der var en der lige var hoppet fra så så jeg blev jo smidt ind i det så ()"* 17.19

The next day Violet logs on to PainData and starts working her way through the many questions.

Rose: 59.56 *"øhm jeg vil mere sige at skemaet gør indtryk [] ja altså i det hele taget at lave det"* 1.00.07

Violet is surprised to learn that her pain influences her in so many ways, but then she thinks about the time it will save, when meeting up with the doctor at the pain-center, and that almost everything will be remembered.

Alice: 45.08 *"Jamen jeg synes jo egentlig det er fint at øh at man får det på forhånd så så både behandler og patient er er forberedt kan man sige og også det der med at så skal man ikke buge en halv time på og sidde og snakke om de der ting øh og kan sådan set gå lidt videre med hvad det egentlig handler om [] øhm så jeg synes jo egentlig det var det var fint altså ()"* 45.53

She spoke to her husband about it in the evening, happy that she would not have to struggle explaining and remembering everything. However, she noticed that now that she had put all her thoughts about her pain on paper their character had changed.

Amy: 22.31 *"jamen det gjorde det jo på et eller andet punkt fordi man sku jo til og og tage stilling hvordan i stedet for gemme det væk sku man til og tage stilling hvordan har jeg det egentlig [] øhm så det vil jeg sige ja det gjorde det"* 22.45

There was a body charts, you know, where I had to draw all the parts of my body that hurt. That really made it clear.

Eliza: 10.50 *"() netop det der med at man kommer rundt om det hele og får altså man kan jo også markere hvor på kroppen er det at man øh har problemerne og sån noget og det synes jeg det er godt i stedet for bare sån nogen ja nej spørgsmål ()"* 11.28

And I had never considered that my every day and social life could carry any importance about my pain situation.

Phillip: 17.10 *"ja det gjorde jeg faktisk [] øh og jeg blev da øh mere opmærksom på at øh at det handlede ikke kun om mine oplevelser ved smerten men det handlede jo*

også om øh min hverdag og min sociale side [] og øh det satte da en masse tanker i gang ()” 18.31

But I don't understand, why ask about my sexual life, she said, I do not understand why I must answer such personal things.

Cathy: 12.18 ”altså jeg var måske lidt forarget over en del af spørgsmålene () jeg kan bla huske at der var sådan noget med omkring ens sexliv og sådan nogle ting hvor jeg så tænkte det forstår jeg ikke rigtigt lige hvad det har med noget og gøre ()” 12.47

Cathy: 12.52 ”føler mig måske blottet altså sån altså fordi jeg føler jeg skulle svare på mange personlige spørgsmål [] ift. hvad jeg sån lige havde regnet med” 13.08

There were many questions about the psychological side of my life, she said, one could get the idea, that they expect me to be depressed.

Sophia: 9.03 ”øhm der er mange spørgsmål ha [] og jeg synes at mange af spørgsmålene nej men de gik på at de egentlig ikk ligeså godt ku sige at jeg havde en depression øh [] det var lidt min første tanke der når jeg fik alle de der spørgsmål at øh man ku lige så godt skrive med stort har du en depression ()”10.55

It's nice to know what I am going to talk to the doctor about, though.

Phillip: 20.10 ”jamen det har da forberedt mig på den måde at øh jeg ku se at der var eller blev ops blev opmærksom på at der var flere ting eller mange andre ting man øh sku ind og snak om end end bare hvad man følt af smerter [] ikk at det både var jamen øh søvnproblemer jamen øh samvær med andre øh øh soci ja socialt samvær øh jamen det sexuelle osse øh [] som jeg da osse godt kan se at øh det har sku da også ændret sig gennem tiden () det her påvirker øh alle andre sanser i kroppen osse ikk” 22.28

When Violet arrived at the pain-center she is met by a doctor who goes straight into speaking about the problems she has, asking her relevant questions. She is overwhelmed.

Sophia: 18.43 ”Jamen det synes jeg var rigtig godt jeg blev mødt af en rigtig god læge og en rigtig sød læge som osse skal følge mig de næste jeg tror det er halvandet år jeg skal være derude [] øhm han var meget meget sød og vi snakkede om tingene og øh sån halvt om tingene og så tror jeg det er noget man bliver snakker dybere om når man begynder på og kommer lidt mere derude tænker jeg [] øh men ellers så var han meget forstående og jeg havde min kærest med derude sån jeg osse sån fordi min hukommelse var heller ikke helt så god længere [] sån så vi var lidt flere der hørte og [] altså jeg synes han henvendte sig også sån til ham omkring hvad det var hvad hvad smerter de gør ved en person øhm [] og sån osse altså jeg synes han var mega god og så var det jo så han kom ind på den her nye slags medicin jeg ved ikk hvor ny den er men jeg sku prøve øh så så jeg synes han var mega god [] rigtig god oplevelse” 19.46

For the first time ever, she meets a doctor capable of accommodating her dark thoughts and responding to them by giving her reason to think differently.

William: 22.07 ”jeg synes han var meget sådan øh øh han var god til og og høre og lytte og også svare altså hvis eksempelvis at jeg nedgjorde mig selv så var han god til ligesom at fortælle det sådan skal man ikke tænke fordi bare fordi du er i stykker det er jo ikke ensbetydende med at du ikke er ja eksempelvis ja værd og leve og alt det der som jeg eksempelvis også har [] fortalt ham at jeg har haft tanker til og det var jo sådan noget hvor han kommer og siger det er jo ingen altså der er jo ingen grund til at tænke sådan fordi du har en barrikade og det er jo så derfor du er her det er jo for og få fjernet øh ja hvad kan man sige altså få hjælp til og få fjernet den der dårlige stemning over sig selv [] og måske til og få som han også siger de har jo både psykologer og sådan noget der kan hjælpe hvor man kan ja hvis man eksempelvis ikke kan acceptere det [] jeg har jo som sagt en gang imellem haft svært ve så har jeg jo haft svært ved og acceptere at jeg var syg [] og og kunne ikke forstå hvorfor at jeg skal være syg og [] ja så” 23.22

Now that a plan has been laid out and carefully explained, and medication has been handed out, for the slow escalation in the new medication, Violet is positive that her pain situation will become better.

Evelyn: 29.16 ”øh det var også fint fordi det var egentlig jeg havde egentlig lidt en plan om at det var det samme jeg skulle det han sagde så jeg havde lidt håbet at det var det han ville () fordi jeg vidste at der var det her medicin de kunne gøre [] som jeg tænkte kunne være en udvej for mig” 29.52

And the questions about my sexual life. It was actually nice to have a talk about it, because I was not conscious about the importance of this part of life.

Eliza: 21.45 ”hm ja deet gjorde jeg faktisk det gjorde han faktisk det var vores sexliv han kom ind på [] og det var ikk noget jeg havde tænkt over at at det ku blive påvirket øh at man havde smerter [] men det er påvirket af det [] så ja det kom han bestemt ind på” 22.15

And do you know what? It may seem silly, but the sensation of being understood not as a disease but as someone having a problem, that needs sorting out, it feels good.

William: 21.01 ”det synes jeg ikke jeg jeg synes de har været gode til og vise mig at jeg den menneske jeg er [] jeg har jeg har bare en kronisk sygdom der gør at jeg har nogle barrikader som skal skånes så jeg synes ikke at jeg er blevet set som en syg person [] der har jeg fået jeg er blevet set som en der der har nogle forhindringer som skal have hjælp [] ja” 21.29

6 Results

Introduction

This chapter presents the result of the different analyzes individually to empathize their advantages and limitations. Eventually the result will converge into an understanding of the case of conceptualizing pain and the influences of pain perception.

6.1 Partial results representing the individual analyzes

Thematic inductive primary analysis

There is a tendency that routines and structures are changed or nonexistent. Cathy and Amy, who both suffer PTSD elaborate that their day is structured primarily by the needs of their children and second by their need to be in control of their pain. The other informants seem to have found a structure ensuring that they mitigate their pain and then do what is possible.

The analysis of speech affection has revealed a long list of different examples, presented narratively in the analysis. These can be sorted into six subgroups.

1. Creating distance to the pain.
2. The informant is noticeable emotional.
3. Changes in speech expression.
4. Ways of explanation
5. Simple phrases.
6. Reflective.

Thematic inductive secondary analysis

There is an intriguing finding in connection to being met as a disease. No matter if the informants answer yes or no, all participant, except Rose (who speaks of a specialist in connection to her auto immune disease), who have given an argument in connection to their answer have argued that they had felt met as a person who had a disease or a problem (this experience is obtained when meeting up with a doctor in the pain-center). This is different from my nursing perspective (only taking care of the disease not the person in front of me). It is different because by naming their pain 'a problem' it immediately changes from something that has been tugged away due to not being recognized, to something that can be handled and solved. By presenting patients to this pain perception the doctor opens the dialogue. Whereas comments such as 'we cannot find a cause to your pain' or 'you will just have to accept living with chronic pain' closes the dialogue. I also find that this finding insinuates that chronic pain becomes part of a person's identity. A part that it is very difficult to contain, talk about, or receive recognition and understanding for. When having to suppress pain in this way it may influence other parts of life such as speech, the tiredness told of, or troubles such as memory and concentration.

Situation analysis, PainData

PainData as such, is based on clinical research, attaching it to the pain perception of ICD. However, PainData also addresses many of the issues in relation to the Biopsychosocial Model. And it

connects to the pain perception of IASP, when showing respect toward the patient. This I base on the respect, shown in the setup of PainData, where caution has been taken to remove some of the elements, that may give patients negative associations. By creating a soothing visual experience and maintaining an accommodating simple language and information option throughout the questionnaire, discomfort and reluctance is removed from the experience. Thought has also been given as to how the questionnaires are presented. First, they are not presented by their names. As a patient you may recognize that questions are about psychological issues, but the emotions that may be evoked, in connection to the names of the questionnaires, are reduced.

Whilst the informants have told of doctor's insinuation of psychological causes to their pain, with emotion and contempt. The emotions towards similar questions in PainData have not been as strong. This may also be connected to the differences of situation, computer versus a person in front of you.

The option of saving the data already inserted, taking a break, and returning later, may give the impression that care is taken towards affordability.

Based on the narrative of informants' experiences of answering PainData, I find that they may have learnt something about connections between their pain and their troubles. Some have spoken of reflecting upon their pain situation, in connection to answering PainData. And some have spoken of becoming prepared, for their first meeting with a doctor, or finding themselves reassured by having given vital information, ahead of the meeting. Information that they might, at times, struggle to remember in the situation. From this perspective answering PainData before meeting up with a doctor in the pain-center, may remove stress.

Relational analysis

For all healthcare ICD is essential, as is the continuous development which is highly dependent upon the organizational work performed internationally by WHO and IASP. These two organizations complement each other well in their purpose, as they are aiming at humanity and equality in health. ICD also aims at humanity and equality, but doctors and patients are dependent upon communicating about pain. And this may be a weak spot because the cultural perspectives that IASP refers to may equip persons very differently, as to communicating about pain. Then IASP emphasizes the fact, that putting into words (conceptualizing) the pain is only one out of many ways of communicating pain. This may refer to behaviors, non-verbal language, symptoms etcetera. However, this may not be something that doctors are trained in understanding. The ICD does not offer any help in communicating about pain. It offers structures for excluding possible diagnoses in the process of identifying a diagnosis that fits the symptoms. This may be a long and testing process for the patient.

Until now patients have experienced the importance of having an actual diagnose, whereas not having one will often craft the suspicion that psychological issues may be partially worsening or causing the pain. This relates to the ICD, pain perception, which the patient has been met by until now. It also relates to the Biopsychosocial Model that patients have been met by in the pain-center, where their comorbidity and troubles were understood and maybe explained. And then it relates to PainData, because PainData addresses physical, psychological, and social perspectives of the patients' pain situation, letting them reflect and become prepared in their own time.

The thematic inductive analysis, addressing speech affection reveals that the informants have had a lot of hassle, when verbalizing their pain situation. This I believe, will not be helpful when meeting up with a doctor, who does not know that this problem can be part of suffering chronic pain.

Another finding is the lack of routine and structure to their every day. Other than that, the informants have used symptoms as explanation. However, when the doctor or specialist works by ICD this sort of information may not be useful, and it may not be possible to validate the patients' pain by examination. In the end, GP's and specialists normally work by a tight schedule giving them comparably less time than doctors at the pain-center (journal entry 1½ hour).

The pain perception best qualified for catching on the ways in which patients bring over their personal knowledge about their pain is the Biopsychosocial model. However, the doctors of the pain-center work by the ICD as well.

An intriguing finding is that when asked if they had felt met as a disease some answered yes, some no, giving an argument. For both sides the argument was about being understood as a person suffering chronic pain and having a problem. This is interesting because it is connected to doctors in the pain-center, and it relates to the Biopsychosocial model.

As the narrative shows there are signs that PainData initiates patient reflection and understanding of such connections. Rose puts it into words by telling, that she is not doing the things she would like to do, when asked about physical activity.

By asking the patient to assess comorbidities and troubles the patients are introduced to the pain perspectives of the doctor, they are about to meet. This I expect related to ICD as such situations are documented and the questionnaires used to identify comorbidities and troubles are heavily validated.

The Biopsychosocial Model, which is adhered to by the pain-center relates to many of the issues addressed by PainData. However, the Biopsychosocial Model also considers predispositions for biological, psychological, or cultural conditions. This relates to the key notes of IASP.

Narrative analysis

the narrative analysis illustrates, that the patients have gone through hard times before coming to the pain-center. There is a strong element of not having their pain recognized, by doctors and suspicion that their pain may be caused by psychological issues. However, it appears to be ok to answer questions related to psychological issues in PainData. There seems to be an element of enlightenment. As if they achieve insight that the troubles and pain that they experience may be connected in some way. And then, when arriving at the pain-center, having their first meeting with a doctor, they seem overwhelmed, maybe even relieved to learn that a highly specialized doctor knows of their troubles, can untangle their journals, and present it in perfectly understandable phrases.

In terms of conceptualizing pain, the patients seem rather dependent upon the doctor's pain perception. When they meet up with GPs or other specialists, they meet up with doctors who have different levels of knowledge of chronic pain, comorbidity and connected troubles. Therefore, I find that their frustration is connected to their own limitations towards conceptualizing their pain. This I find is illustrated by the trouble the informants have in answering my questions. And it is worth noticing that their trouble does not only concern explaining coherently it also concerns the ways in which they chose to answer. This is especially clear in the questions related to how they

experienced answering PainData. Some tried to remember what they had answered, some answered me with their free association towards my questions and some answered that they thought it were ok to answer or elaborated upon the nature of questionnaires. It was an interviewer's challenge to bring forth the answer sought for.

The pain perception also seems to be connected to doctors' pain conceptualizations. By this I mean that the informants express indirectly, that they expect the doctor to be able to find out what their pain is caused by and find a suitable treatment. This is related to culture whilst this is the role that doctors have in societies.

6.2 How do persons suffering chronic pain conceptualize their pain and what is their pain perception?

Based on the narratives that have been presented the answer to this question is that the participants do not conceptualize their pain or do so to a minute degree. I build this upon the observation that they do not bring over well reflected and well formulated messages about their pain. Instead, they struggle addressing their pain. The concepts most often used are 'I feel pain' or 'it hurts'. The Danish reader will easily notice the difference whilst in Danish these phrases are represented by two different words 'jeg har ondt' and 'jeg har smerter'. These phrases are different when you consider the closeness. 'I feel pain' refers to something inside of me whilst 'I have pain' is transferred into a thing that you can place outside of yourself. Another perspective addresses the insufficiency of these phrases, when talking to a doctor. What might happen if a doctor is addressed only by these phrases? if the patient has no more words than these? Then the doctor would have to ask questions. Questions that will be based on the pain perception that the doctor works by. This would most likely be ICD. Then the doctor would expand the examination by referring the patient to specialists and imaging technologies. Over time every possibility will be tried out. I expect that medication will be tried out alongside this course.

As it has been illustrated through the interviews the patient's speech may be affected especially if emotion is involved. Therefore, I find it likely that the situation will become equally unpleasant for both parties.

In the narrative illustration of ways in which patients' may be affected it is also illustrated how this could be connected to pain being suppressed. Therefore, I find that a large part of the patients' conceptualization is represented by absence. Distance is created by either not using the word pain directly or by distance taken to identity. The later because pain cannot help but become a part of a person's identity. Another perspective is the attempt of explaining the intensity of the pain. This is often done by telling about things that cannot be done or by strongly emphasizing the word pain. To emphasize further there may be pausing, or slow expression in connection to the word pain, and strong synonyms may be used, like 'jeg er i sådan en pine' (an equivalent word in English would be torment).

The answer to this question is that patients/ informants conceptualize their pain by absence, by talking of symptoms, by telling what functions are not possible and by affected speech. As to the question of pain perception it too seems vague. Some cultural elements may indicate that patients rely on doctors' capability of knowing 'what is the matter?' and 'knowing what to do in terms of treatment'. Other than that, they seem to rely on the doctors, pain perception. However, I have not

found evidence that the patients know what the doctors pain perception might be or what it is founded upon.

6.3 Which influences do different pain perceptions have in the meeting between patient and doctor?

The pain perception created by ICD, is restricted to what can be measured, palpated, or illustrated by imaging technologies etcetera. This is founded upon thorough research, validated to a degree where knowledge can be extracted. Such a pain perception excludes anything that cannot be validated with significance. However, patients are persons carrying a life story, a pattern of reactions, behaviors, and responses towards pain. There may be differences between ethnicities, social stratification, and social heritage which cannot be documented using clinical research. Therefore, when a patient is met by a doctor whose main pain perception is built upon ICD, the patient will experience that, when no proof can be found that there is a cause to the pain suffered, then the conversation may be closed. Leaving the patient in a tormenting wilderness, alone.

The pain perception of IASP seeks to connect ethical respect to the biology of pain. It seems natural that there are traces of creating a ground for clinical research in pain and pain relief. The definition

“An unpleasant sensory and emotional experience associated with, or resembling that associated with, potential or actual tissue damage”

is interesting when listening to explanation given by Alice who explains her knee pain by the sounds that they make and her hip pain by the way she walks. This can be related directly to a sensory of tissue damage. While sounds and visual effects may create an emotion of unpleasantness it is not necessarily considered equivalent to pain. This convincement would close the conversation. The keynote *“A person’s report of an experience as pain should be respected”*, opens to further discussion and examination.

Based on the acknowledgement of IASP having a substantial role towards pain research internationally, I believe that this pain perception is connected to the pain perception of ICD. This means that if doctors adhere to both pain perceptions, they also create space and understanding for the qualitative perspective of diseases and lives lived with diseases, such as chronic pain.

The Biopsychosocial Model has a wider perspective by considering biological, psychological, and social dispositions for chronic pain. This pain perception seems to consider all perspectives of lives lived except the spiritual. However, during internship I had an interesting conversation with a doctor. Through this I learned that the spiritual part of a person’s being, is perceived or explained differently. He used the concept spiritual to describe how mentally active, interested, or interesting a person was. In connection to pain he explained, a person would become preoccupied or filled up with pain sensations, and that there would be little energy or surplus to have an interesting conversation. Such persons would not have much to offer. Whilst I would use the concept spiritual in connection to something religious this doctor was using the concept in connection to something cultural.

The Biopsychosocial Model gives space to talking about the perspectives of pain, and I would expect that explanations of troubles in connection to pain would be understood by this pain perception. I also find that there are relations towards both ICD and IASP.

The informants have told how the doctor has explained to them, their prior course of examination, troubles, and symptoms and that the doctor has named their pain a problem or barricade. Both refer to something outside the body. Something that can be handled. By doing this the doctors present to the patient a perspective that is tolerable and manageable. Both PainData and the doctors at the pain-center ask the patients about their wishes for treatment. Thereby handing back responsibility and trust in the patient. Illustrating that we are going to solve this together.

The pain perception of PainData seems close to that of the pain-center and as the informants have told, they have gained an understanding towards what is going to happen at the pain-center. This pain perception may have a pedagogical goal of facilitating reflection and preparedness.

7 Discussion

Initially I referred to Elaine Scarry and her statement that persons who suffer chronic pain also suffer language becoming shattered and reduced to cries and moans equivalent to the earliest stages of life. Now that I have explored the experiences of persons suffering chronic pain, I have found that their speech is profoundly affected. However, I have not found their language reduced to a level equivalent to the earliest stages of life.

Whilliam is the only informant who has told about suffering such intense pain, due to acute disease, that he had curled up in foster position and cried.

9.04 ” () *der har jeg haft så mange smerter jeg har lagt i fosterstilling og lagt og grædt*” 9.19

What I have found is a more physical and psychological situation. By this I mean that the informants struggle producing coherent sentences, finding the right words, and controlling the flux of nerve signals that produce speech. When the conversation is about the patient's pain, I find that the speech affection is most profound, sometimes letting the patient bring over next to nothing in their message. Like this example given by Amy:

I have just asked Amy how she described her pain.

10.04 “*jamen det jo det jo øhm åh me jamen hvordan skal man forklare dem jamen altså det det det varierer igen af hvor smerterne ligger henne øh det kan være brændende det kan være stikkende det kan være trykkende [] øh det det det er altså øh det er ts øh øh murrende øhm som ligger i overfladen øh øh ja jeg ved ikke lige hvordan jeg kan beskrive dem anderledes*” 10.27

Even though this answer is broken into bits and pieces, some ‘ahs’ and other stammering or incomplete pronunciations, it cannot be compared to cries and moans.

Elaine Scarry, also bring on the concepts of certainty of pain represented by the pain sufferer and doubt represented by e.g., a doctor. This statement connects to the experiences of not having pain recognized by doctors, as many informants have explained.

John Quintner and Milton Cohen (2016) refer to the concept of *Aporia* in the attempt of describing what pain is and that it cannot be verified. They describe *Aporia* as an insolvable mystery that can lead to doctor and patient not knowing what to do. The doctor may lose empathy for the patient

which can lead to the patient suffering stigmatization and poor integration of healthcare. In return the patient may become doubtful towards the doctor and the options of treatment.

William presents an equivalent experience.

(appoximatly 10 minutes into the interview)“(jamen jeg havde øh jeg har snakket med dem længe og de var sådan det var sådan en lidt ældre læge der sådan havde den holdning der at ung ligesom hvad hedder det at unge folk de kan ikke være syge []() og der ja der blev jeg træt af at gå til lægen det vil så sige jeg gik faktisk ikke til lægen i mange år fordi at jamen at han havde den holdning der at jeg fordi at jeg var ung så kunne jeg ikke blive syg eller være syg”

William is the only informant presenting this experience so directly, however other informants speak about not having their pain recognized and due to not receiving sufficient help they lose trust in doctors like Amy who puts it crudely

8.10 ”Øh hvis vi skal sige det meget meget bogstaveligt og meget meget direkte og meget meget ærligt så er det til og lukke op og skide i ” 8.16

By studying the extreme case of how patients, referred to a pain-center, conceptualize their pain and how it connects to their pain perception I have found that the informants either distance the pain from themselves or distance themselves from their identity (pain being a part of their identity, that they do not relate to).

Alice gives an example by describing her pain as the example of somebody forcing pain onto her joints.

30.17 “(når jeg fortæller om min tommelfinger så er det sådan meget ligesom om at der sidder en og trykker på det hele tiden)”31.19

By using case study applying explorative method it is possible to find such examples. This case is extreme because the patients are those who suffer the most severe cases of pain, needing specialized and multidisciplinary care and treatment. When Flyvbjerg writes about extreme cases he refers to a situation where many risks are present and that if evidence can be found that such an extreme case is safe, then less risky cases can be considered safe as well. In this case study the result can be regarded enlightening and educating. The knowledge developed will be that of practice. So, by discussing and reflecting upon the very clear cases, sensitivity towards the more subtle pain conceptualizations can be developed. The findings of this small case study have revealed several ways in which speech, routines and structures may be affected, drawing a picture of pain conceptualizations, that are not reflected and well formulated. However, the list may not be complete.

Buch and Jensen, 2019, write about professional knowledge. This concept is about being skilled within for instance chronic pain, to a degree that the knowledge becomes tacit. This in a sense represents intuition, knowing what a situation is about and what to do about it. I asked the chief physician about this during an interview, and he proved me right. Having worked as a specialized doctor for a lifetime, he does not need schedules, he picks up on the problems almost instantly. While the chief physician has experienced a number of patient cases beyond imagination, others may need to learn by being presented to patient cases as those examined here. Doctors are clinically

educated and trained and make sure to read relevant clinical research. However, ethnographic research may bring forth valuable knowledge.

Kate Smith (2017) presents a Feminist and Narrative research method. She emphasizes three perspectives of importance. First the informant's position must be identified. Whilst I for this exploration have positioned my position of research, Smith describes the importance of understanding the informant's position. Her study is about women seeking asylum in England and she describes how dominating narratives influences on these women. Her study finds that a common narrative is that those who seek asylum may be trying to cheat themselves into having privileges. The government enforces this by the forceful procedures that include police and imprisonment, if not able to prove their human right to have asylum. Second, she emphasizes the informants' resilience towards these dominating narratives. Some of the narratives that she has collected illustrate the resilience shown by these women and their children, whilst choosing illegal existence in England rather than the risk of being sent back to their home country. Third, she emphasizes identifying the dominating narratives.

If I refer these three essential concepts to patients suffering chronic pain, I will say that their position is that of, not having their chronic pain recognized, especially if a diagnose cannot be found. I would also say that the patients show resilience, whilst fighting, some of them intensely, for recognition and a part of this has for many of the informants meant asking to be referred to the pain-center. This fight for recognition is also a fight against some dominating narratives which are, if a disease that could cause pain, cannot be found, pain is likely to be caused by psychological causes. Interestingly this is the position that most of the informants refer to as the starting point of their story. The ending point (having met a doctor at the pain-center) is something quite different. Now the informants are happy, trusting and positive towards a future, not without pain, but more manageable.

If returning to Giummara et al (2016) and vicarious pain this perspective is intriguing, but I do find the developments in the ICD more promising due to expanding the knowledge about chronic pain through research. After all we do like our doctors to be utmost qualified in their discipline.

8 Perspectivation

I want to initiate this perspectivation by paying attention to what is actually going on in Denmark and internationally. The ICD-11 is going to change the lives of many people, by agreeing upon a diagnose for primary chronic pain. This I hope will prevent years of suffering chronic pain before having sufficient treatment. But this is not all. By being attentive to pain as something real, something we need to understand better both professionally and as laypersons we can break down the barriers, taboos, and resistance towards speaking about pain, just as well as other stigmatizing health conditions. We need to be patient and dare wait for pain sufferers to speak. I will bring forth an example. For many years my husband and I had financial advice by this extremely talented consultant. He was the kindest man and always interested in our lives. Do you know what. He stammered. But from day one, no matter whether we spoke on the phone or met real time, I just let him stammer. I did not try to find the words for him or in any way help him. And it was the right thing to do. It did not take long before he did not stammer at all, when we spoke. That is what we

need to do for those who suffer pain. We must *listen*, we must be *patient* and we must *ask explorative questions*. If we do so, we open the conversation, we invite these people into our lives and we let them blossom. It will be good for our society to take notice of the first signs of chronic pain. It might be a challenge, but if taken proper care of at an earlier stage, these people might not end up in such a poor state.

This ethnographic research has been about understanding how pain sufferers conceptualize their pain and what their pain perception looks like. Well, I will tell you. First, their pain perception seems to be that if I go to the doctor, he or she will be capable of helping me. Therefore, they do not seem to have a separate pain perception. If returning to the pain definition given by IASP the third keynote refers to what we learn about pain.

Through their life experiences, individuals learn the concept of pain.

So may I say, we need to put it on the schedule! Luckily the Danish Health and Medication Authorities are already working on this, creating guidelines and campaigns.

As to the question of how persons suffering pain conceptualize their pain, my finding is that they do not do so before having learnt it. At least they do not bring across a reflected and well formulated statement about their pain or troubles or even the connections between these. They give away signs that are worth understanding. Understanding in the sense that there might be a reason to their poor language, not carrying much information. Attention should be paid to what is not said, what is kept at a distance and that bringing forth information about lost functions, lost sleep, signs of poor concentration or memory and low quality of life should be taken as symptoms to act upon.

I find that persons suffering chronic pain, by distancing themselves to their pain, which has become a part of their identity, that is not recognized, destruct their self-worth and identity. And if to return to the last questions in PainData ‘wishes and personal values toward treatment’ one of the questions addresses ‘the wish to be able to talk to or tell friends and relatives about their pain’. Besides being a question, this is part of what is taught in the group therapy courses. While one perspective of this is that the patients need to learn how to speak about pain another perspective is that everybody other than the patient need to learn how to listen and maybe ask explorative questions, instead of bringing over degrading suggestions, about what the patient should do or how the patient should behave. As a Dane I find this way of communicating typical in situations of not quite understanding. I would like to share with you the very illustrative [video](#) created by the Danish Health and Medication Authorities. No further comments are needed.

9 Acknowledgment

Tværfagligt smertecenter, Aalborg Universitetshospital, who have opened their doors to my internship and a continued cooperation, making this master thesis possible.

I thank every member of the team for their openness, and interest in reflecting with me, upon their work. I thank the team members for letting me watch them while working, whenever it was possible, letting me in on the highly complex and very professional morning conferences, and letting me see and understand their interconnectedness and their humor.

I also want to give thanks to the persevering effort, given by the doctors who have explained and invited patients to participate in this project.

Supervisor Stine Willum Adrian

I want to thank for the open and very concrete way of giving advice. You have taken great care of my needs in learning, and I now have a true sense of growth.

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Henrik Bjarke Vægter has granted me access to a test version of PainData, he has spent time letting me interview him about PainData and he has kindly, patiently, and without delay answered my queries.

Thank you for your interest and contribution to my work.

My family and friends who have supported me unconditionally, even when I was so focused on my work that I did not really participate in maintaining duties of life.

Special thanks to my 98-year-old friend who despite never being acquainted with such technologies has asked me interested and inspirational questions and my friend and former colleague always supportive and interested even though receiving treatment for cancer.

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