

## Three Interrelated Experiences to Live with Chronic Pain - A Qualitative Pilot Study with a Group of Patients with Refugee Status in Swedish Primary Care

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### Abstract

The prevalence of chronic pain is greater among foreign born than among the general population. There is a knowledge gap on how patients with refugee background experience and manage chronic pain. In this current study, we explored consequences of chronic pain in everyday life in a group of patients, with refugee status, in the Swedish primary care.

A patient group with different backgrounds was requested in the purpose sampling. A total of twelve patients were recruited. Newly arrivals (up to five years after arrival) were excluded due to status and communication challenges. Data were gathered during April - May, 2017 from individual semi-structured interviews with seven patients with refugee status, diagnosed with chronic pain, registered at a healthcare center and with residence permit in Sweden. Three were women and four were men. Average age of the informants was 54 years (SD = 9.0); the youngest was age 44 and the oldest age 70. They had lived in Sweden between 13 - 42 years, two were unemployed, two on sick leave and three worked in the service sector.

A qualitative inductive constant comparative analysis was performed. Three interrelated experiences were found. The analysis generated a conceptual model named to live with chronic pain: trusting the body in everyday life, focusing on physical explanation and requiring a trustworthy physician. The discomfort drawing of chronic pain may help to create a situation where the patient feels trusted and listened too, especially when considering their chronic pain as purely physical without psychological components and may be connected with stigma. Language barriers, different social and cultural backgrounds and mistrust may affect the encounter with the physician. Our result, as it was a pilot and with qualitative design needs further studies.

**Keywords:** Refugees; Chronic Pain; Primary Care; Qualitative Interviews; Cross-Cultural Medicine; Grounded Theory

### Introduction

Chronic pain is a costly health problem in the West and one of the most common reasons for people to seek primary care [1]. Chronic pain is defined as a pain lasting more than 3 months according to the guidelines for the ICD-11 [2]. Being a patient in primary care with a war-refugee background while having comorbid psychiatric and somatic diagnoses makes an already complex case even more complicated and difficult to treat, with the risk to become a public health problem [3-5].

In a Swedish qualitative study, women with a war-refugee background from Iraq and experiences of chronic pain felt ignored and rejected by the physician they met in the primary care [6]. They had difficulty fulfilling expectations of contributing to society and were unemployed; felt isolated and had difficult financial situations. Daily life was largely about regaining a sense of control.

Swedish Association of Local Authorities and Regions presented a report in 2016 by a Swedish expert group [7] in which several deficiencies and challenges were described in both primary and specialist care in the treatment of foreign born patients with chronic pain. Rehabilitation programs require participants to understand Swedish; the patient group represents many language groups, reasons for asylum, levels of education, socioeconomic backgrounds, different kinds of pre-migration stress and belief systems [8-10].

The rationale for this study was because there is a knowledge gap of the experience of chronic pain among patients with refugee background. A qualitative design is valuable for generating such knowledge, as they may be difficult to quantify [11] and hypothesis driven in a first step which would be a pilot study.

Sweden is to a large extent a multiethnic society [12] where there are different healthcare needs in the population. In 2016, the majority of non-Western immigrants to Sweden were war-refugees or individuals being reunited with family [13]. Sweden uses a legal definition of a refugee similar to the 1948 United Nations Convention [14].

Increased knowledge of pain among refugees may be helpful in reshaping the primary care approach to chronic pain with this special population.

This pilot study aimed to explore consequences of chronic pain in everyday life in a group of patients with refugee background in the Swedish primary care.

Methods and Materials

The data is an extended version of a master thesis [15].

Informants

Inclusion criteria: A patient group with different backgrounds (gender, age, number of years in Sweden, employment) was requested in the purpose sampling. Further inclusion criteria were to have been diagnosed with long-lasting chronic pain for at least three months and be registered at a healthcare center. Newly arrivals (up to five years after arrival) were excluded due to status and communication challenges. The recruitment of informants took place between April and May, 2017 at two primary health care centers in southern Stockholm, where there were large groups of patients who corresponded to the inclusion criteria. Those who showed interest and left their contact information were contacted by telephone by the second and third authors, where times for interviews and the need for interpreter were established.

A total of twelve patients were invited. Two patients did not meet the inclusion criteria, one expressed no interest, one could not be contacted and one did not fit into the time for the framework of the study. Seven interviews were conducted; three women and four men. All the informants had varied backgrounds and work experience (Table 1). The average interview time was 37 minutes (25 - 54).

Table with 5 columns: Informant, Age, Years in Sweden, Profession in Sweden, Present employment. It lists details for 7 informants, including their ages, years in Sweden, professions, and current employment status.

Table 1: Descriptive information about the informants (N = 7).

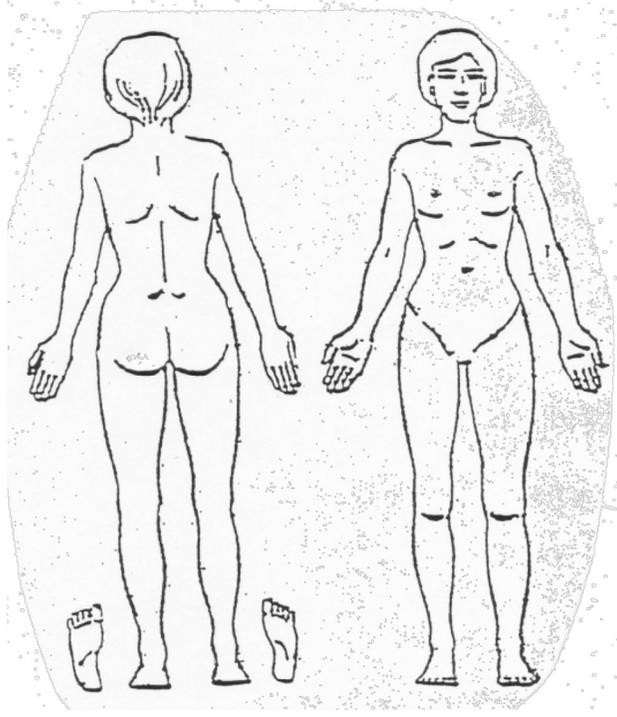
Material

Semi-structured interviews were conducted on the basis of an interview guide (Table 2) documented through two dictation recordings. To locate and pinpoint the patient's discomfort, a discomfort drawing was used (Appendix 1) which has been shown to be a reliable, easy-to-use tool for mapping different types of pain and anxiety [16], which may be specific to the refugee population because language and cultural integration issues or traumatic events on their path of migration [17]. Four pilot interviews were conducted and valuable in training by the second and third author.

Appendix 1

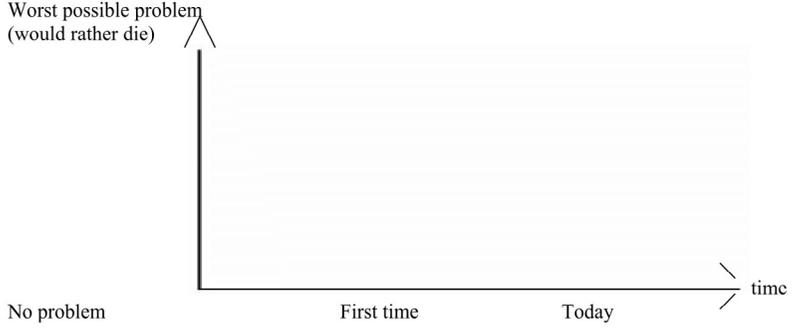
**Problem diagram, date \_\_\_\_\_**

Where and what kind of problem have you been experiencing over the last 3 months?  
**Shade in with a pencil all areas where** you have been experiencing **problems**. Vary the shading according to the degree of the problem. Next to the figure, write what kind of pain (e.g. ache, buzzing, tingling, prickling, numbness, cramp, hum).



When, and how much of a problem?  
How have your problems varied since you first noticed them? Show with a curve on the diagram below.

Worst possible problem (would rather die) ^



No problem First time Today time

1.	What do you think is the cause of your chronic pain?
2.	What do you expect in the meeting with the doctor at the health center?
3.	How did you experience your last visit to the doctor when you were looking for pain?
4.	How do you think the doctor expressed understanding of what you told?
5.	What do you have for general experience of meeting with the doctor at the health center when you applied for pain?
6.	How do you experience trust in your doctor?
7.	What are your concerns about your chronic pain?
8.	Based on your experience, what do you think the doctor needs in order to meet your requests because of the chronic pain?
At the end of the interview, the informants were asked how they experienced the interview. This was important for being able to cope with any unpleasant emotions that followed the interview, as well as having the opportunity to develop the interview technique if the need arose.	

Table 2: The interview guide.

### Procedure

Ethics approval was received for the study from the Ethics Examination Board in Stockholm (Diariennr 2016/1193-31/1). The informants provided a verbal and written consent.

Interviews took place at the Karolinska Institutet Library in Flemingsberg and at one of the two health centers where informants were recruited. One interview was conducted by telephone and one interview was conducted using a professional interpreter on site.

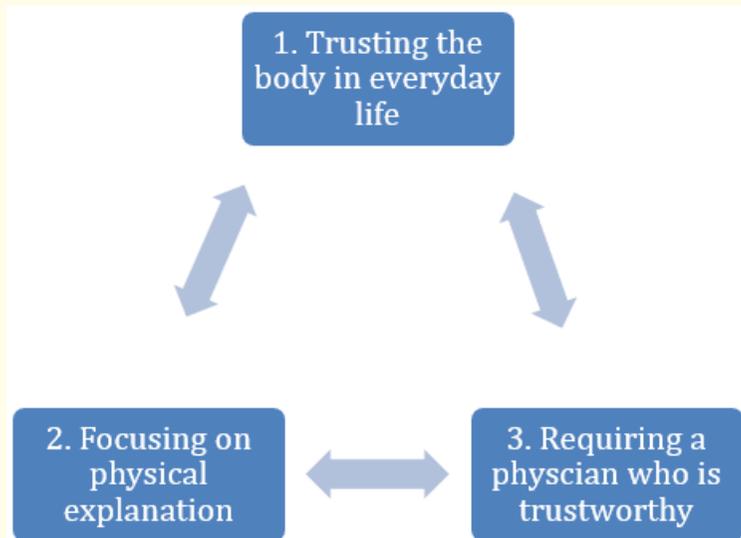
Both the second and the third authors were present during all the interviews and were asked to be interviewee and observer, respectively. After each interview, they had a shorter verbal reflection before transcribing. The recorded material was then split between them to transcribe. Collection of new material was terminated after saturation achievement. The term saturation is inconsistently applied and is proposed instead the concept "information power" to monitor adequate samples size for qualitative studies [18]. It indicates "that the more information the sample holds, relevant for the actual study, the lower amount of participants is needed.....the size of a sample with sufficient information power depends on (a) the aim of the study, (b) sample specificity, (c) use of established theory, (d) quality of dialogue and (e) analysis strategy" (page 1753).

### Data analysis

The first three authors listened to the recordings, read the transcripts, and discussed emerging categories several times to get a good idea of the content. They independently extracted coding data in Swedish and used the content analysis [19]. Categories were named in both English and Swedish. In the second step, open inductive coding was used by the first author until the core and related categories had emerged, whereupon selective coding was conducted using more conceptual codes. Incidents, codes and categories were constantly compared [20]. The concepts were named from patterns of behavior grounded in the data [21]. Memos were used to document theory development. Theoretical codes were explored to integrate categories.

### Results and Discussion

The theme was to live with chronic pain by the following three interrelated experiences emerged in the GT-analysis (Figure 1).



**Figure 1:** Three interrelated experiences to live with chronic pain in a group of patients with refugee background in Swedish primary care

### Trusting the body in everyday life

The informants had led active lives and wished they could continue as before, but the chronic pain made it impossible. Since they had been in chronic pain for a long time, everyone knew that the chronic pain could vary from day to day. They adapted their movements. Some could continue to work while others were on sick leave or lived as an early retiree and had very low income. Many experienced, shown by discomfort drawing stiffness in the body and had difficulty in performing certain movements and became sedentary and isolated instead.

The informants had more trouble than just chronic pain, it was common to have sleeping problems, headaches and concentration problems and to feel tired. Some informants described it as “walking around like a zombie” or as “a vicious circle of different inconveniences”.

The informants could often feel stressed, which made it difficult to relax. Some could even experience panic attacks. A sense of hopelessness was regularly present. Being unable to read or watch television for long periods contributed greatly to feelings of depression.

They were afraid that they eventually would be even more disabled which would make them unable to manage on their own. A common fear was to be dependent on other people, e.g. family and friends. They did not want to identify themselves with their chronic pain.

### Focusing on physical explanation

The informants were clear that their chronic pain was only physical and had no psychological explanation and found it strange that in Sweden, there was so much focus on the psychological when treating a patient for chronic pain.

Other informants had experiences with meeting psychologists, however, that contact was terminated relatively soon since they felt that it did not produce any desired effects. A contact with psychologist was only for the treatment of anxiety and depression, not chronic pain.

### Requiring a trustworthy physician

Prior to each visit, the informants responded that their physician should be cultural sensitive and read the patient journal to be familiar with each individual patient. They should appear to be knowledgeable and open to the patient. If the cause was not obvious, the physician should be persistent and work hard to find a solution.

All informants had experienced poorly prepared physicians, who displayed insufficient involvement and gave unclear messages about their condition and the future. Most informants were careful to point out that they met both "good" and "bad" physicians, but the worse medical visits had left an impression. Good consultations resulted in feeling better and feeling able to live with chronic pain to a greater extent.

They greatly appreciated getting the same physician again and again, instead of a new physician every time. Some informants felt that they had difficulty with trust because of their refugee background.

It was very important for them to feel that they had time to describe all their problems, and that there was time for the physician to listen to them during the consultation, especially those whose native language was not Swedish and needed extra time to relay their message. If an interpreter was needed, the visit took longer. Not having enough time at a physician's office contributed to informants' discomfort.

### Strength and Limitation

Our results, as it was a pilot study and with qualitative design, have to be interpreted with caution.

There are three concepts in qualitative studies that are evaluated to provide an indication of its trustworthiness [22]. The informants from the two health care centers had a relatively large spread of socioeconomic backgrounds and relatively long duration of stay. All spoke Swedish, though an interpreter was needed in one interview. All of this helped to highlight more angles and perceptions about the issue and to gather comprehensive, in-depth material, which strengthens credibility. Semi-structured interviews were used, as the area is relatively unexplored and the study examined experiences of chronic pain, which is also important for the credibility of the study. Regarding dependability, all data were collected, transcribed within a month, and coded independently by the three first authors thereby reducing the risk of changes in the analysis. The transferability is assessed by examining whether the material can be applied to people other than the informants interviewed. This study collected data for seven patients with war-refugee background but in the end, it is up to the reader to determine whether it is possible to apply the conclusions in other contexts. The strengths are that information power [18] was met and that sufficient informants were recruited. Due to the integrity and aim of the study, we did not ask details about their socio-economic background and pain history beside the inclusion criteria. A future epidemiological study may include such details as well as asking patients with different foreign status, using a brief pain inventory and a quick screening tool that provides information on both healthy functioning and distress and generalize the outcome. Another strength is that the interview time was relatively long, which may indicate that the informants felt safe enough to open up and talk about a partially sensitive subject. All participants were positive or very positive in their evaluation.

### Conclusion

The discomfort drawing may be a useful tool to start talking about chronic pain and discomfort that patient with refugee status experience. The drawing invites the patients to express all their symptoms and requires no specific language or advanced cognitive level. The drawing may also help to create a situation where the patient feels trusted and listened too, especially when considering their chronic pain as purely physical without psychological components and may be connected with stigma. Language barriers, different social and cultural backgrounds and mistrust may affect the encounter with the physician which needs further studies.

### Conflict of Interest

No conflict of interest exists.

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