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“If you look at me, you would think that I am a normal woman. However, I am almost like a pharmacy.”

A Phenomenological Study of Nine Immigrant Women’s Life Experiences and Understanding of Chronic Musculoskeletal Pain

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Abstract

This study utilized a phenomenological hermeneutical approach exploring the illness beliefs and the lived experiences of nine non-Western immigrant women with chronic pain living in Oslo, Norway. The background for this focus is the reported higher prevalence of chronic pain and psychosomatic complaints among certain non-Western immigrant groups compared with the majority population. The lived experiences of chronic pain have been extensively studied, but there is a lack of knowledge including the perspective of immigrants. Thus, the aim of the project was to develop rich data in order to develop knowledge of non-Western immigrant women perceptions and lived experience of chronic pain. Empirical data was collected through semi-structured interviews with nine non-Western immigrant women from 6 different nationalities. The study identify that the informants applied a variety of explanatory models for their pain condition including biomedical, psychosocial and traditional approaches of bodily imbalance. However, the biomedical approach was dominating in particular in relation to the search for a diagnosis with the medical physician. The data concerning the lived experience of chronic pain involved perceived strains and stress in daily life, not necessary focusing on the impact of chronic pain, but merely including challenges the informants face as immigrants. These challenges included issues relating to worries for children, little social network and support and financial strains. I interpreted these experiences as being embodied in the informants' bodies and shown in their physical pain symptoms.

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1.0 INTRODUCTION

1.1 Approach

The title of this thesis refers to a quote by “Sara,” a woman from Ethiopia who is living with chronic widespread muscle pain in Oslo, Norway. Sara uses “the pharmacy” as a metaphor for indicating that her body contains many drugs. This quote gives a glimpse into the lived experience of chronic pain and the understanding that Sara has of both her body and her condition. An analysis of the understandings and the lived experiences of chronic pain grounded in a phenomenological perspective are in this thesis approached through the pain narratives of nine non-Western immigrant women living in Norway. Qualitative semi-structural interviews facilitated the possibilities of analyzing the informants’ experiences, feelings and thoughts about their chronic pain condition.

1.2 Background

The reason for this choice of topic is my own interest, as a nurse, in immigrant health, which began a few years ago. At that time a friend of mine “Mina” worked as a general practitioner (GP) at a medical clinic in one of the most densely immigrant-populated areas of Oslo, Norway. We often met to discuss our work, and she told me that most of her patients were women from non-Western countries who spoke poor Norwegian. Patient complaints were frequently related to general pains in the head, back, neck, abdomen, or chest. Mina pursued clinical investigations, but in most cases it was not possible to determine any physical causes for the pain. During the first year that she worked at the clinic she referred several of her patients to different medical specialists or for highly expensive imaging tests, such as magnetic resonance imaging (MRI), for further investigation. However, the specialists and imaging tests could rarely give any medical answers for the pain symptoms. The patients returned to Mina for further investigation, and in some cases, asked for papers that could provide them with disability benefits. Mina found the demands challenging because she realized that she could not give the patients what they wanted. She could not provide a diagnosis and proper treatment for those patients who wanted further investigation, nor disability papers to the patients which she could not diagnose. According to Mina, the relationships she had with several of her patients were characterized by tension. Mina was frustrated with the situation because she realized that the patients’ pain was not a solely pathological problem, and that measures should be implemented at several levels, not only within the GP’s office. She also felt she lacked skills in managing the complexity of the

conditions and had little to offer apart from medication. Mina found that several of her patients were annoyed and switched GPs in their pursuit of a diagnosis, treatment, and/or welfare benefits. Subsequently, some years later, Mina stopped working as a GP, mainly due to the feeling of resentment which she experienced in the encounters with her patients.

Several years after Mina stopped working as a GP, I heard a lecture by psychiatrist Egil Martinsen. He claimed, among other things, that the most important thing one can do to help someone who suffers from chronic pain is to listen to his or her perspective of their situation: if we, as health professionals, know something about the individual's background, experiences and thoughts, we can work together towards common goals and hopefully better health for the individual (Martinsen 2012). Martinsen is accompanied by several researchers including Kleinman, Helman, and Morris, all of whom call for the inclusion of the subjective voice into the research and understanding of pain through explanatory models and pain narratives (Kleinman, Eisenberg, and Good 1978; Morris 2012; Helman 2008). They perceive that pain is, as well as being a medical problem, an everyday experience, and while the medical voice is a valid one, other voices (especially those of the subject) "are often lost or neglected in the encounter between pain and meaning" (Morris 1991, 2).

Pain is by the International Association of the study of pain (IASP) defined as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (International Association for the Study of Pain 2011). Chronic pain is defined as pain lasting more than three to six months (Wahl et al. 2009, 972). In this study, nine women's understandings and experiences of living with musculoskeletal chronic pain (MCP) are explored. MCP is often characterized by pronounced pain symptoms, despite normal findings upon clinical examination, imaging, and blood tests, and is therefore often referred to as medically unexplained symptoms (Malterud 2010, 2356). According to the Norwegian National Institute of Public Health, chronic pain explains 54% of all disability (Norwegian Institute of Public Health 2013). A study comparing 15 European countries reports that Norway has the highest prevalence of chronic pain, with a prevalence rate of 30% (Breivik et al. 2006). These data suggest that chronic pain impose on society high costs while the individual's quality of life is impaired.

Studies suggest that the incidence of muscle pain is higher in some immigrant groups, including individuals with backgrounds from Iran, Turkey, and Pakistan, than among Norwegian-born individuals (Kumar et al. 2008), which is consistent with similar studies from Sweden and Denmark (Kurita et al. 2012; Bergman et al. 2002). *Immigrants* are defined as persons born abroad of two foreign-born parents and four foreign-born grandparents, who have immigrated to Norway (Statistics Norway 2013a). Certain immigrant groups also rate their health worse and report more psychosomatic complaints than the majority of the population. They are also reported to have more frequent visits to their GPs (Blom 2008).

In various studies during the last decade, women with chronic unexplained pain have reported negative experiences during medical encounters. These negative experiences are related to the patients' feelings of being met with skepticism, lack of comprehension, or that the condition is ascribed to psychological explanations (Werner and Malterud 2003; Wuytack and Miller 2011; Müllersdorf, Zander, and Eriksson 2011). Other studies have suggested that clinicians find consultations with chronic pain patients demanding and that GPs feel ill-equipped to deal with their patients' complex conditions (Wileman, May, and Chew-Graham 2002; Steinmetz and Tabenkin 2001). Language barriers and differences in understanding and attitudes are perceived to further complicate communication between physicians and immigrant patients (Wieringen, Harmsen, and Bruijnzeels 2002). These studies suggest that different types of understanding may exist between the clinician and the patient regarding the perceptions of illness, as well as expectations related to the clinician's roles and the patient's roles. Accordingly, Arthur Kleinman (1988) argues that the outcome of the meeting between the health professional and the patient is directly dependent on the distance between the explanatory models the two parties use. *Explanatory models*, also called *illness beliefs* are ways that sick persons, their families, the community, and practitioners interpret the aspects of illness and treatment (Arthur Kleinman 1980; Helman 2007).

1.2 Aim and research questions

Phenomenological research on pain has often focused on the lived experience of chronic pain and its impact on daily life and identity. The initial aim of this study was to explore non-Western immigrant women's understandings of their pain, with regard to what they perceived to be the cause of their chronic pain, and their experiences of living with chronic pain. However, as the interviews progressed, I realized that one phenomenon was common to all of the subjects' narratives: namely, the experience of stress in their lifeworld. The lifeworld

refers to the world of experiences of the human being, how we experience our daily lives and how we give meaning to these experiences. It is a lived, concrete, practical, and interconnected world that we are often unconscious of (Råheim 2002). I interpreted this lifeworld to be a context related to how it was for the informants to live as non-Western immigrant women in Norway. It was only after the interviews that I discovered the words of Kleinman (1995), “Studying chronic pain patients means that each must be situated in a world. That world must be described, and the description must include an account of the experience in family, work-place, and community” (Kleinman 1995, 125). Therefore, this study also includes accounts of the informants’ lifeworld.

Although some research on immigrant health have been conducted in relation to chronic pain, psychosomatic complaints, and visits to the doctor, there is a scarcity of research focusing on the lived experience of chronic pain among immigrant women in Norway. In this study, a small number of women with different nationalities were interviewed. The purpose was to bring out the voices of immigrant women with non-Western backgrounds who live with chronic pain in the Norwegian society. By listening to their pain narratives, beliefs, attitudes, and understandings, I explored not only the complexity of the pain experience from the non-Western immigrant woman’s perspective, but also the lived experience of non-Western immigrant women in general. My hope is that additional knowledge in this field may inspire decision-makers to take measures to prevent and treat suffering, and health care professionals to improve the health and quality of life for the women concerned. With this in mind, my research questions are as follows:

R1: What illness beliefs do the informants use to explain their pain?

R2: What are the lived experiences of the non-western subjects with chronic pain?

I will attempt to go beyond a mere description of the informant's perceptions and experiences, and seek to interpret these experiences, locating them within a social and cultural context. As this study bases its findings on qualitative interviews, it is the informant’s expressed perception and understanding of their pain and the world they live in which underlies my analysis. My analytical approach is thematic, with themes based on my understanding of the interview material. Accordingly, the theoretical conceptual framework applied in this thesis is chosen from those themes. I take a phenomenological hermeneutical approach to this study, with phenomenology being the study of a person pursued against a background of the

understanding of the *other*, the *whole*, or the *social* (van Manen 1997, 7), which I understand to be the lifeworld or context. My work proceeds from the premise that cultural, social, political, and economic factors play crucial roles in shaping subjective experiences.

Following this introduction, chapter two presents some background information regarding immigration and health. In chapter three I will introduce the theoretical conceptual framework with aspects related to the explanatory models. The methodology is presented in chapter four, including my choice of method, my analytical approach and the ethical considerations. The findings will be presented, analyzed and discussed in chapter five. Chapter six includes a conclusion and my interpretation on the possible implications that the findings have for further management and policy strategies.

2.0 IMMIGRATION AND HEALTH

The influx of immigrants to Norway has contributed to a shift from a nearly homogenous society to an increasingly heterogeneous population. Immigrants account for 12 percent of the Norwegian population, while Norwegians born to immigrant parents account for two percent. In Oslo, the immigrants and Norwegians born to immigrant parents constitute 30 percent of the inhabitants, with certain suburbs holding around 50 percent. The largest national groups of immigrants in Norway come from Nordic and western countries such as Poland, Sweden, and Lithuania. The overall majority, however, are individuals from Asia, Africa, and Latin America. Immigrants migrating from these countries are, by the Central Bureau of Statistics (CBS), referred to as *Non-Western immigrants* (Statistics Norway 2013a). In this study I will refer mainly to Non-Western immigrants from Asia and Africa.

2.1 The Norwegian health care system

The Norwegian health care system is constructed using the ‘gatekeeping’ system, where the GPs regulate the utilization of secondary or specialist care (including radiology and hospital care). The Registered General Practitioner Scheme (RPG Scheme) states that all citizens have the right to be assigned to a registered GP. The National Insurance Scheme (NIS) provides all citizens with free universal healthcare, with limited co-payments for outpatient care. In addition, there is generally some usage of care not covered by NIS, including physiotherapy, although some physiotherapists have agreements with the local council and the clients make a limited payment (Dahl et al. 2009) .

2.2 Immigrant health

Migration is a process of moving either across an international border, or within a state (Perruchoud 2004, 41). According to Kristiansen et al. (2007), migration does not only involve movement over a border, but it also involves a process of social change during which a person moves from one cultural setting to another. The reasons why people move are varied, but involve aspects from economic and political motives to family reunification. The varied experiences generate complex interactions between migration and health, as individuals face unique health needs and barriers depending on the conditions in the country of origin, circumstances during the journey, and conditions in the recipient country (Kristiansen, Mygind, and Krasnik 2007). Accordingly, there are specific challenges in relation to health due to the nature of being a migrant.

There exist different theories of the relationships between migration and health, and one is termed the “healthy migrant effect.” Studies from the United States and Canada have reported that first-generation immigrants are found to be, on average, healthier than those who are native-born (Fennelly 2007). There are many competing explanations for this phenomenon, including health screening by recipient countries, or immigrant self-selection in which healthier and wealthier people tend to be migrants. However, gender is often not considered in these studies. Studies which include gender variable, find that middle-aged immigrant women are more likely to report poorer health than the native-born, regardless of the number of years since migration (Kobayashi and Prus 2012; Blom 2008). Studies on “the healthy migrant effect” do also suggested that the newcomers’ health advantages diminished (Fennelly 2007). European studies partially support these findings by reporting that certain immigrant populations have poorer health than the native-born populations (Bergman 2005; Blom 2008; Kumar et al. 2008; Kurita et al. 2012). The explanations for these findings are conflicting, but it seems that certain immigrant populations may experience a greater burden of morbidity than the majority of the population due to a number of psychosocial, lifestyle, and biological factors (Thapa et al. 2007; Bergman 2005).

Knowledge of immigrant health is somewhat limited in Norway, based on the fact that it is not permissible to register ethnicity in the medical records. Also, immigrants are often excluded from surveys; this is likely due to a lack of language skills or lack of professional interpreters, which makes it more expensive to conduct investigations. In addition, there may be problems motivating immigrants to participate in surveys (Kristiansen, Mygind, and

Krasnik 2007; Blom 2010). It is difficult to obtain reliable data since immigrants are comprised of a diverse group of different nationalities and socioeconomic backgrounds. In some cases, the number of individuals within a given group is so small that it is not possible to suggest any statistical significance (Blom 2010). Nevertheless, there have been three major Norwegian health surveys that include immigrant groups which have been conducted. One survey, which took place in 2002, was the Oslo immigrant health study (Immigration-HUBRO) which included 3726 persons from five major immigrant groups¹ (Kumar et al. 2008). In addition, the Central Bureau of Statistics conducted periodic surveys of immigrants from ten countries² in 1998 and 2005 (Blom 2008). These studies demonstrated that certain immigrant groups have poorer health than the majority of the population in relation to diabetes, high cholesterol, obesity, and vitamin D deficiency (Kumar et al. 2008; Jenum et al. 2005; Blom 2008).

The Immigration-HUBRO study suggested that the incidence of muscle pain was higher in some immigrant groups, including individuals with backgrounds from Iran, Turkey, and Pakistan, when compared with the Norwegian-born and other immigrant groups included in the study (Kumar et al. 2008). This is consistent with studies from other Nordic countries reporting that some ethnic groups have higher rates of chronic pain than the majority of the population (Kurita et al. 2012; Bergman et al. 2002). Blom's survey (2008) reported similar findings if one looks at factors such as self-reported health and psychosomatic complaints. He demonstrated that seven out of ten immigrants reported having non-passing psychosomatic symptoms (such as general body pain), compared with five out of ten individuals in the general population, with higher rates among individuals from Iraq, Turkey, and Pakistan. The survey also reported that immigrants had a three times higher incidence of mental health problems compared to the general population, and that non-western immigrants assessed their health as poorer than the majority (Blom 2008). Although these findings do not make conclusions about the prevalence of chronic pain, it is likely that psychosomatic ailments and chronic musculoskeletal disorders are related.

Evidence reports a correlation between social and cultural factors and chronic pain including a direct association between low income, low education, and chronic pain (Kurita et al. 2012).

¹ The study included persons born in Turkey, Iran, Pakistan, Sri Lanka, and Vietnam.

² The survey included persons born in Somalia, Turkey, Iran, Iraq, Pakistan, Vietnam, Sri Lanka, Chile, Bosnia-Herzegovina, and Serbia-Montenegro.

Other studies report similar findings of living in lower socio-economic groups, being an immigrant, living in a compromised housing area, having a lower educational level, and experiencing lower social support being associated with chronic pain (Bergman 2005; Andersen, Frydenberg, and Mæland 2009; Löfvander and Engström 2007). As a result, the following section will present some data about the socioeconomic position of immigrants in Norway.

2.3 Socioeconomic conditions

The life expectancy in Norway is among the highest in the world, with 78 years of age for men and 82 for women (Statistics Norway 2013b). Life expectancy indicates not only how many years one is expected to live, but also makes suggestions about the residents' health. The health of the Norwegian population is considered to be good. Nevertheless, it appears that these numbers conceal major systematic differences in the health of individuals. Over the last decades, there has been a resurgence of interest between the socioeconomic position and health (poorer socioeconomic position has been demonstrated to lead to the poorer health) (Galobardes, Lynch, and Smith 2007), leading to a special focus on *social inequalities in health*. *Social inequalities in health* involve health differences that vary systematically with the level of education, profession, and income level. These health differences are socially created and unfair (St.meld. nr 20 (2006-2007), 12). The Norwegian government acknowledges that certain immigrant groups fall within these less fortunate groups

One's socioeconomic position is often measured by years of education, income, and profession, with education reflecting a certain level of knowledge, cognitive skills, and communication skills, while income and profession relate to material standard. Apart from gender, age, and country of origin, health follows higher education and language skills, as well as *social network* or *social capital* such as friends and marriage (Strand and Næss 2009). *Social network* is a structure of social actors and the ties between them. An individual's social network suggests the level of social support that the individual is experiencing. *Social support* is the perception that one is cared for and valued, has assistance available from other people, and that one is part of a network founded on mutual cooperation and responsibilities (Dalgard and Sørensen 2009, 98). To have close relationships to family or friends is important for coping with difficult circumstances in life. Social support is also perceived to be among the most important preventive factors for illness (Wilkinson and Marmot 2003).

In the following section I will present data on the socioeconomic position and social capital of some immigrant groups in Norway so that the reader can gain an understanding of the circumstances in which most of my informants live. However, there is a lack of information regarding all of the groups, and the data presented is mainly drawn from Blom's survey (2009) and general statistics from CBS.

Education: According to Blom (2009), there is no system in Norway recording the education level that immigrants already possess upon entering Norway. CBS has mapped immigrants' levels of education twice, in 1990 and 1999; however, the register is incomplete, with a lack of information about previous education for four out of ten immigrants prior to 2005 (Blom 2009).

Employment: The statistics from CBS demonstrate a significant difference between immigrant groups based on their countries of origin with regard to employment. Immigrants from Western countries such as Sweden, Denmark, the UK, and the USA have employment rates of 70 percent and higher, compared with the general population with 76 percent employment. The percentages from non-Western countries vary greatly with 70 percent and above being employed from the Philippines, Sri Lanka, and Chile, while immigrants from Iraq, Afghanistan, and Somalia have a less than 50 percent employment rate. Women from Turkey, Morocco, Iraq, Afghanistan, Pakistan, and Somalia have the lowest employment rates: below 43 percent. Women from Pakistan have employment rates of 31 percent, while Somali women have a rate of 22 percent compared to the total female employment rate of 75 percent (NOU 2011:7 2013).

The reasons why certain groups have low employment rates are varied and complex. The lowest four countries of Iraq, Afghanistan, Pakistan, and Somalia have recently experienced (and are still experiencing) civil war or similar situations. It would seem plausible that people fleeing from war would have more difficulty adapting to the Norwegian labor market. Additionally, all four countries have a predominantly Muslim majority, higher than 95%. I would argue that factors such as cultural-religious norms play a significant role in the women's preconditions for employment. For instance, Blom's study suggests that 80 percent of the women from Pakistan did not work in their home country. It is also reasonable to assume that the professional skills an immigrant acquired in her or his home country will affect their opportunities in the labor market in Norway (Blom 2009). The absence of modern jobs in

some of these countries will make the transition to the highly technological jobs of Norway a considerable challenge. Furthermore, lack of language skills and lack of focus on work due to life circumstances, may also be a barrier for employment (IMDI 2012).

Income: There is a lack of data for this subject; however, according to Blom (2008), Turkish and Pakistani immigrants had (in 2005) a median income of approximately 65 percent of the population in general. Iraqi and Somali immigrants had the lowest median income at approximately 56 and 54 percent of the general income. These are also the two groups that had lived in Norway for the shortest period time at the time of the study (Blom 2009); however, there is reason to believe that their socioeconomic position has improved during the last eight years.

Housing: Housing is a status indicator of the financial resources of a family. It also forms the material framework around the lives of the people who live there (Blom 2009).

Approximately 80 percent of the Somali population rent their dwelling, while 14 percent of the Pakistani respondents do the same. With regard to the type of dwelling, between 50 and 60 percent of immigrants with backgrounds from Turkey, Somalia, and Pakistan live in a block of flats. These are the groups of immigrants that tend to live predominantly in Oslo. The survey showed that two national groups stood out as having the worst housing conditions when compared to the other groups: Somalis and Iraqis (Blom 2009).

Social network: Several of the subjects in my study reported that they lacked a social network; therefore some of the existing data is included in this paper. While people's relationships with other family members may not always be harmonious, they are ties. It has been demonstrated that barriers, including living apart and in different countries, are stressors that may cause a decrease in well-being (Blom 2009). In Blom's survey (2009), 40 percent of the immigrant population stated that they felt lonely, with the proportion who often or occasionally felt lonely being the greatest among immigrants with backgrounds from Iran and Somalia. The least lonely group was the Pakistani group, with a proportion of approximately 25 percent, which was slightly higher than the average population (21 percent) (Blom 2009). The Pakistanis are among the immigrants who have lived in Norway the longest which may explain the data. Immigrant-HUBRO also reports that social networks and support among non-Western immigrants are low. They reported a significantly lower number of friends and

less support from others when compared to the majority of the population (Kumar et al. 2008).

It is important to emphasize that these findings vary between the different immigrant groups, and that only selected groups were included in the studies. Furthermore, changes may have occurred since the last major survey in 2005.

2.4 Policies in relation to immigrants and health

One of the current government's main goals has been to reduce social inequality in health. The goal is “to elevate the health of the population with low health to the same level as those with the best health” (St.meld. nr 20 (2006-2007), 5). To achieve this goal, the government has focused on general welfare services in combination with targeted measures against vulnerable groups. Health differences are greatest in areas with low income and little education; accordingly, these are the groups that the government has chosen to prioritize. To achieve more equal health care, one of the targets of the government is to provide equitable health services. In this they add that there should be equality of access, use, and performance of the services, regardless of socioeconomic status. Furthermore, they pay attention to the specific health challenges of some groups, including vulnerable minority groups. To promote health among some immigrant groups the focus is also, to facilitate the integration of work and education, to promote positive health-related behaviors, and focus on improving the knowledge of health (St.meld. nr 20 (2006-2007)). These policy guidelines indicate that the Norwegian government perceives the need to use a comprehensive approach to address such inequalities in health.

3.0 THE THEORETICAL CONCEPTUAL FRAMEWORK

The aim of this study was to explore the understanding and the lived experiences of non-Western immigrant women with chronic pain. In order to take advantage of the understanding and the experiences the informants share, it is important to place the data in a wider theoretical perspective. In this chapter, I will present some theoretical concepts which will be applied later in my analysis of the data.

According to Malterud (2011), the theoretical framework is the spectacles we put on when we read our data, in order to identify patterns. The theoretical framework includes models, theories, definitions, and research traditions used to understand meanings and to structure the

findings (Malterud 2011). However, a theoretical framework may be inappropriate when applying a phenomenological approach, since phenomenology is useful when the intent of a study is to be as loyal as possible to the informants own perspectives and experiences, without major disruptions of the researcher's pre-understanding or any theoretical frame. Bringing in classifications from theories may bring in the danger of the terms being forced upon the data, meaning that the perspective of the subjects is dissolved by my preconceived concepts (Kelle 2006). In an attempt to reduce the influence of the theoretical framework, I have taken an inductive approach. Instead of choosing the theoretical framework based on my theoretical perspective, I have based the framework on what appears in the analysis (Thagaard 1998). I have also been influenced by Husserl's concept of "bracketing" as I have withheld an in depth literature review prior to investigation in an attempt to neutralize preconceptions (Wojnar and Swanson 2007). Several theoretical concepts which have been taken from academic fields, including medicine, medical anthropology, sociology, and psychology, will be presented in the following section

3.1 Explanatory models

Helman (2007) refers to *explanatory models* as ways of constructing reality and imposing meaning on the "chaos of the phenomenal world" (Helman 2007, 122). Explanatory models are ways that people view their illness in terms of how it happens, what causes it, how it affects them, and what will make them feel better. Kleinman (1988) refers to three sets of systems within western societies in which disease or illness are interpreted; the family (lay) sector, the popular sectors, and the professional sector. These systems use different explanatory models to understand and explain disease, which may sometimes cause conflicting understandings. Furthermore, Kleinman argues that the health outcome of the meeting between the health professional and the patient is directly dependent on the distance between their explanatory models, which is why it is important to understand the individual's explanatory model (Kleinman 1988).

There are different ways to understand pain, chronic pain in particular. The explanatory models are often divided between those who attribute pain to a physical cause and those who attribute it to psychosocial factors. The following section will present a few research studies and alternatives based explanatory models for pain.

3.2 A biomedical approach to pain

Pain as a biological phenomenon has been studied for centuries. The sensation of pain is the result of a complex and interactive network of mediators and mechanisms involving all levels of the nervous system from the sensory input via the spinal cord to higher brain structures (McEwen and Kalia 2010). The biomedical approach to pain is rooted in the Cartesian dualistic view on the mind-body relationship. According to this model, the mind and body are two separate entities which are mutually independent components of the human being (Bendelow and Williams 1995). Consequently, disease is, in its most extreme forms, divided into somatic and mental disorders which should be treated accordingly. This model views disease as being caused by intrinsically or extrinsically induced pathophysiological states which reduce organ functions (Weiner 2007). Therefore, a somatic illness is considered to be a biological and physical phenomenon, and the treatment process focuses on the part of the human body that is “sick” (Heszen 2009). In a biomedical approach, pain is a symptom for a pathophysiological abnormality that should be treated accordingly. However, if there are no objective explanations for the symptoms, such as in the CMP patients, the pain symptoms are often ascribed to merely psychological elements within the patient.

A critique of the biomedical model within chronic pain management has been raised against the obsession for obtaining test after test, x-rays, MRIs, and other investigations, thereby encouraging the patients belief that some underlying pathological disease or lesion exists. The physician may typically add medications in frustration to manage the multiplying list of subjective complaints (Weiner 2007). Furthermore, if one is suffering from something which does not fit properly into any of the categories of mind or body, such as in the case of the CMP patient, the patient may end up with a never-ending series of medical visits, facing a variety of different health care professionals, with nobody taking responsibility (Kirkengen and Thornquist 2012). The biomedical model is the underpinning model for the authorized medical health care services in Norway. While the Norwegian medical health care system recognizes the limitations of the biomedical model, and therefore includes several of the aspects in the more holistic biopsychosocial model, the dualistic view of mind and body is still persistent in medical settings (Kirkengen and Thornquist 2012; Nylehn 2009).

3.3 A biopsychosocial approach to pain

The recognition of a dynamic relationship between mental and physiological components led to a criticism of the biomedical model. Consequently, the biopsychosocial model was

introduced into Western medicine. The biopsychosocial model was launched by Engel in a series of articles in the 1970's as a counterweight to the biomedical rational about the dualistic mind-body view (Engel 1977; Engel 1996). Rather than focusing primarily on physical signs and symptoms, the biopsychosocial model takes into consideration physical, psychological, and social components of the individual's problems, acknowledging the multifactorial causes of disease with the view that the mind and the body are inherently connected. Accordingly, the biopsychosocial model has been especially influential in the area of chronic pain (Gatchel et al. 2007).

The biopsychosocial model acknowledges that there are physical aspects, including neurophysiological processes that interact with the endocrine and autonomic systems in the body, maintaining pain symptoms (the *bio* part of biopsychosocial). This includes the process of *nociception*, which refers to stimulation of nerves "that convey information about potential tissue damage to the brain" (Gatchel et al. 2007, 582).

Psychological factors involve both emotion and cognition, and according to Gatchel et al. (2007), emotion is the immediate reaction to nociception, while cognition attaches meaning to the emotional experience. Cognition can trigger further emotional responses, and thereby amplify the experience of pain as well as influence pain behavior. Factors including previous experiences with pain, and consequences of pain, mood, and stress can influence initial reactions to the pain sensation. Consequently, a vicious circle of nociception, pain, distress, and disability is maintained (Gatchel et al. 2007). In my study, several of the subjects explained that if they woke up in the morning with a high level of pain, they would stay in bed to rest. According to their reasoning, getting out of bed and moving around would increase their feelings of pain, while staying in bed would avoid the pain related to movement. This is an example of how cognition of the perception of pain attaches meaning (resting prevents pain) to the immediate emotion of nociception, thereby leading to certain pain behaviors. However, resting in bed is reported to have a detrimental effect on the chronic pain condition in general (Katz et al. 1996), suggesting that a possible negative loop is created.

The *social* dimension involves the context in which we live, including environmental stressors, interpersonal relationships, and social support, and involves the ways that these social factors interact with the *bio*- and *psycho*-dimensions. For example, in recent years

research has developed a better understanding of the influence of the environment with regard to environmental toxins, medications, diet, and psychological stressors on genes (Buchheit, Van de Ven, and Shaw 2012). Figure 1 suggests how the biological, psychological and social dimensions interact in a complex manner.

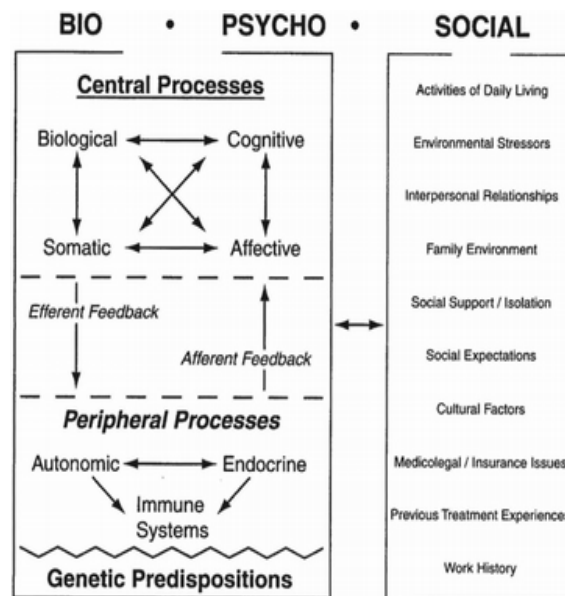


Figure 1. A conceptual model of the biopsychosocial interactive processes involved in health and illness. From “Comorbidity of Chronic Mental and Physical Health Conditions: The Biopsychosocial Perspective,” by R. J. Gatchel (2004), *American Psychologist*, 59, 792–805.

The biopsychosocial model has inspired researchers in a variety of disciplines to study the phenomenon of pain, which is reflected in the large amount of literature that exists in this field. While some researchers emphasize psychological components such as how individual’s cognitive and emotional states influence pain and pain behavior, others concentrate on how social factors, including socioeconomic position, impact on pain. However, any model that focuses on only one of the elements will be incomplete (Gatchel et al. 2007).

In the following section, the elements of stress and coping as part of the biopsychosocial model of pain are introduced because stress is a central concept in my informants’ understanding of their pain.

3.3.1 Stress

Stress has been among the main areas of focus for several decades in the understanding of chronic pain. Lazarus and Folkman (1984) defined stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or

her resources and endangering his or her well-being” (Lazarus and Folkman 1984, 19). Stress has been reported to have a damaging effect on the physical processes within the body. Normally, in an acute stress situation, hormones and the nervous system prepare the body to deal with a threat by triggering the fight or flight mechanism in emergencies: the heart rate rises, blood is diverted to the muscles, and alertness is increased. This response is not harmful if it only occurs for brief periods of time; however, if stress lasts for too long, homeostasis is disturbed and the individual becomes vulnerable to a wide range of conditions including chronic pain (Pearlin et al. 2005; McEwen and Kalia 2010).

Coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus and Folkman, 1984, 141). One talks about external influences through a stress stimulus or stressor, with a stress response as the result (Lazarus 2006). Stressors can be psychological or physical/biological nature. Physiological stressors may include climatic conditions such as severe cold or heat, or conditions such as hunger or physical illness. Psychological factors include loss of control over life circumstances, lack of predictability, and loss of social support (Chapman and Gavrin 1999; Marmot 2006). Stressors may be short-term or long-lasting, and when available resources exceed the demands, these triggers are perceived as stress, and the degree of stress increases with the degree of load over time.

Coping behaviors have been extensively studied with chronic disease and are often classified as active coping strategies, such as information-seeking and self-management, and passive coping, such as catastrophizing or excessive rest (McCracken and Eccleston 2003). Coping behaviors are influenced by the individual’s appraisal of the threat and the coping options or resources available. There is a discussion about whether to emphasize stress in a subjective sense, regardless of the objective stressors, or to perceive stress mainly as being environmentally produced. Lazarus (2006) believes that the effect stress has on a person is based more on the feelings of threat, vulnerability and the ability to cope with the situation than the stress event itself. The ways in which stress or strain are mastered depends on our cognitive and psychological state. Accordingly, a large amount of research on management strategies for chronic pain has focused on strengthening the individuals’ cognitive resources (Chen, Cole, and Kato 2004; McCracken and Eccleston 2003; Vowles and McCracken 2008). However, experts such as Marmot and Pearlin (2004; 2005) perceive stress as something socially or externally created, and look at coping as a process in which external factors in

situations and environments are crucial for successful coping. They demand that the community as a whole must take responsibility to prevent stress, especially for certain societal groups (Marmot 2004; Pearlin et al. 2005).

One of Marmot's (2006) main theories is that failing to meet the fundamental human needs of autonomy, empowerment, and human freedom is a potent cause of ill health (Marmot 2006). Inspired by Amartya Sen, Marmot defines *autonomy* as "the possibility of leading a life one values" and *empowerment* as "the need for feeling that one has control over life's circumstances" (Marmot 2006, 2082). Empowerment can act on the individual level or on the community level, and it means that one feels in control over life circumstances, reducing chronic stress and having favorable biological effects. Empowerment at the community level could mean social cohesion and social capital, which are found to have important effects on health. For example, when examining why some people cope better than others it has been shown that social support plays a crucial role in people's ability to cope, since social support may provide people with the emotional and practical resources that they need (Wilkinson and Marmot 2003).

My approach to stress and coping behaviors is to assume that both groups are right; both the individual's appraisal and cognitive capabilities, and that the societal structures or barriers influence the individual's ability to cope with subsequent impacts on well-being and health.

3.5 Humoral and ayurvedic approach to illness.

Several of the study subjects used explanatory models influenced by cultural medical systems; therefore, the humoral and ayurvedic approaches are introduced as explanatory models.

Ayurvedic and humoral medicine are considered to be forms of alternative medicine. In other countries, including Pakistan and India, these approaches are included and used in combination with conventional (Western) medicine within the national health care system. Humoral medicine is a component of ayurvedic medicine and is widespread in Asia, South America, and the Islamic world, although it takes somewhat different forms (Helman 2007). Within this tradition, illnesses are related to hot or cold imbalances in the body. In this case, "hot" and "cold" do not pertain to actual temperatures, but to symbolic powers which also take hold in other substances, such as food, medicine, and herbs. Blood and phlegm are also central to this approach, where excess blood may be seen as a feature of a hot illness (Helman 2007).

Ayurveda is an ancient naturalistic approach to health care in India, which also focuses on the balance of several factors including the three humors of wind, bile, and phlegm. Illness results from an excess or deficiency of any of these humors. Cooling or heat producing food is used in a similar way to humoral medicine, in order to reduce excesses of any of the humors (Helman 2007).

4.0 METHODOLOGICAL FRAMEWORK

I have chosen to use a qualitative approach to the phenomenon of chronic pain. Qualitative methods are research strategies for the description, exploration, and analysis of characteristics or qualities of the phenomena being studied. Qualitative data analyses are appropriate when little is known about the subjective phenomena under investigation (Malterud 2011). There is limited knowledge about the lived experiences of non-Western immigrant women with chronic pain, and I argue that the qualitative approach is an appropriate method to use. A qualitative approach brings with it some methodological implications that the researcher must be aware of. First, an important aim of qualitative studies is to gather an understanding of the phenomenon under study. Consequently, the interpretation of the findings is of particular importance; therefore I, as the researcher, am meeting special challenges with relation to my role in the production of knowledge (Thagaard 1998). Secondly, it is of importance to follow ethical considerations with relation to the informants during the process of data collection and analysis, as well as in the presentation of the findings. The result of a study is only to be considered trustworthy and valid when the groundwork of knowledge has been explicated (Thagaard 1998). In this chapter I will present the study's method.

4.1 The phenomenological hermeneutical approach

This study is grounded in hermeneutic phenomenology, which describes a method that is both descriptive and interpretive (van Manen 1997). Phenomenology describes a special interest in understanding social phenomena from the individuals' own perspective. It is a method for understanding how the world is experienced by the subjects, with the assumption that "the important reality is what people perceive it to be" (Kvale and Brinkmann 2008, 26). Svenaeus (2005) claims that to study illness within a phenomenological and hermeneutical approach, means to use the experiences and the expressed understanding of the illness as a starting point (Svenaeus 2005). He continues by stating that in order to understand illness, one has to follow the credo of phenomenology of going "back to the *things themselves*" which he has derived

from Husserl's writings (Svenaesus 2005, 17). In this context I interpret "to go back to the things themselves" as going back to the non-Western immigrant women to explore their chronic pain phenomenon. By acknowledging their understanding of their pain and their "being-in-the-world," I hope to reach a deeper understanding of their perceptions and reveal the hidden meanings behind these (van Manen 1997).

Hermeneutics focuses on the underlying meaning of what people say and do. The hermeneutical circle provides a tool for describing the continuous process of interpretation as the text progresses. Also, meaning may only be understood in the context in which the informants live (Thagaard 1998). In this thesis I try to see the informants' situation from their point of view, while I also go beyond their understanding and reconstruct meaning seen in the context of their lifeworlds. For instance, in chapter 5, parts of the informants' narratives are presented in the informants' own words, while I also present my own interpretations of their narratives understood in the context in which they live and combined with theoretical understandings.

4.2 Pain narratives

Kleinman (1988) claims that chronic pain experiences are best understood by considering the individual's explanatory model. A pain narrative is the primary component of an explanatory model, and Kleinman suggests that individuals systemize their experiences of illness through these personal narratives. Narratives of pain are stories about how and why that person fell ill. These stories are subjective and provide ways of giving meaning to the experience of pain (Helman 2007). Under the heading of pain narratives, the researcher is concerned with the aspects of the individuals' stories that relate to the beliefs and knowledge of factors that influence the onset of pain symptoms, and their effects on the body, self, and others (Bury 2001). Simultaneously, such narratives may reflect aspects of not only individual experiences, but also cultural and social processes that influence the individual in question (Groleau, Young, and Kirmayer 2006). The narratives serve to situate the individual within the complex social society where people and systems interact continuously with each other. As the focus of this study is to understand how non-western immigrant women interpret their experiences of pain, I find it relevant to use pain narratives as a method for interpretation within phenomenological hermeneutics.

Despite my role of being the interviewer and choosing the focus of the interview, the informants themselves chose which stories they wanted to include in the interview, accordingly constructing their pain narratives (Bury 2001). The material from the interviews, on which this study bases its findings, is characterized by life narratives, as well as pain narratives. This shows that it is not appropriate to define and understand the experience of pain as an isolated state, but that the experience of pain is complex and influenced by previous experiences as well as individual, cultural, and social aspects. This finding is in accordance with Morris (2012), who claims that, in a narrative context, pain emerges mainly as a verbal, lived experience “situated within a complex social world with filaments that reach beyond job, family...” (Morris 2012, 737).

4.3 My preconceptions

Within the phenomenological tradition, Husserl introduced the notion of transcendental subjectivity; an ideal condition of consciousness where the researcher is able to successfully abandon his or her own lived reality. Transcendental subjectivity may be accomplished by the process of bracketing, where prior knowledge and pre-understanding of the phenomenon of pain have been stripped away in a conscious and active way (Wojnar and Swanson 2007). While I recognize that it is not possible to bracket my own pre-understanding, I hope that through the information presented in the previous chapters I have “bracketed” aspects of it. However, I am aware that my interpretation of the findings is built partly on my pre-understanding, and is also only one among several possible interpretations of reality (Thagaard 1998).

4.4 Semi-structured interview

The main interest of this study is to explore how women perceive and understand their pain in the context of their life as a whole. According to Kvale and Brinkman (2008), the best option to obtain this information is by talking to the individual affected; “The qualitative research interview attempts to understand the world from the subject’s point of view, to unfold their meaning of their experiences, to uncover their lived world prior to scientific explanations” (Kvale and Brinkmann 2008, 1). Therefore, the qualitative interview is a research design that gives privileged access to people’s experiences of pain.

As a tool for data collection, a semi-structured interview guide was used in my study (Appendix 1). This helped to keep the focus on specific topics during the conversation. Since

it was the participants' own perspectives that were essential, questions were open-ended in order to obtain rich data (Malterud 2011). A couple of the interviewees described that they felt uncomfortable with the open ended questions, and asked for more direct or closed-ended questions. Consequently, I used the interview guide as a template, but gradually added more questions that could be adapted according to the individual's needs.

4.5 Recruiting process

Initially, the aim of this study was to interview informants from one or two nationalities, such as the Turkish and/or Pakistani women who had reported the highest incidence of psychosomatic complaints in Blom's survey (2008). I assume that the pain phenomenon is influenced by specific cultural and social contexts, which could be pointed out by interviewing individuals from these groups. Various associations and organizations working with Turkish and Pakistani women were contacted by mail and telephone, but I faced some problems in relation to recruiting. Consequently, I had to broaden my search and include interviewees of various nationalities. Finally, an adult education institution (AEI) was chosen as the location for the recruitment of informants (Appendix 2: Information Letter). This specific AEI was limited to female students with little education from their country of origin. Most of the women at the school were from non-Western countries and attended the Basic Skills courses for adults, a combination of the lower level of Primary School (1st-7th grade), and Norwegian language training. The overall aim of these courses is to teach students language- and general skills in order to facilitate for employment.

The women in my study were all in the process of preparing for the "Norwegian Test 2," a final test at level A2 which is an elementary language level. The introduction program for newly arrived immigrants states that immigrants who have been in Norway less than two years, between 16 and 55 years old, have the right and obligation to attend 600 hours of tuition in the Norwegian language and social studies (Det kongelige barne-, likestillings- og inkluderingsdepartement 2012). My informants were not included in this program because they had been living in Norway for a longer period of time. However, the 'New Chance' project is a qualification program for immigrants who, after several years in Norway, have no permanent connection to working life (NOU 2011:14). Some of the informants fell under this program, while others had special agreements with the Norwegian Labor and Welfare Administration (NAV).

The principal of the school presented information about my study to the teachers at the AEI who in turn informed their students (Appendix 3). With regard to my initial aim of only interviewing informants from Turkey or Pakistan, both the manager and the teachers at the AEI found it to be unethical to conduct the study while including only one or two ethnic groups, because chronic pain was perceived as being a universal problem among the majority of their students, regardless of ethnicity. Therefore, the only inclusion requirement was that the informants had experienced pain for a long period of time. Two teachers notified me directly about students in their classes that were interested in the study. These teachers also informed the students about important concepts, such as anonymity and confidentiality, which we considered to be unfamiliar concepts for several of these women. I came to the school twice to describe this study more thoroughly. Following the informational meeting, those women who were still interested in participating were asked to provide telephone numbers. They were also given the opportunity of using an interpreter during the interview, which they all declined. Thirteen women agreed to participate in the study, and I contacted them in order to make individual arrangements for the time and place for the interviews. However, due to long-term sick leave, three women withdraw from the study and one of the informants was excluded after the interview; she was not within the inclusion criteria. Finally, nine women from six national groups were included in the study.

4.6 Data collection

Data collection was made in the autumn of 2012. Informants could choose the place and time for the interview. All interviews were conducted in a spare room at school, usually after the last class hour. Each informant was interviewed once, and the interviews lasted between 30 and 90 minutes. The interviews were preceded by an informal sequence during which I repeated the information presented at the informational meeting, including the matters of confidentiality and possibilities for withdrawing from the study. The informants were asked if they would permit me to use a tape-recorder, and were then asked to sign the letter of consent (Appendix 4). A couple of the women were reluctant to use the tape-recorder and asked if the interview could be broadcast on the radio. When this issue was clarified, all the informants agreed to the use of the tape-recorder.

Since one cannot register non-verbal communication on audio-tapes, I used some time following the interviews to make notes in relation to clothing, facial expressions, and body language, as well as other things that I assumed were important to the analysis. I subsequently

transcribed the interviews verbatim the same day that the interview took place. Since the women were speaking in Norwegian and Norwegian is my native language, I kept the texts in Norwegian. Only after the final analysis did I translate the quotes used in the presentation from Norwegian into English. Some of the women had poor skills in the Norwegian language, particularly with regard to the pronunciation and sentence structure, which sometimes caused confusion. In the interviews I repeated the question if the answers were unclear, but I chose not to include this in my presentation of the concrete quotations. There is a disagreement within the research community if one is “allowed” to refer to quotes which have been changed by the researcher (Kvale and Brinkmann 2008; Thagaard 1998). While there is a danger that by changing words or the structure of the sentence the women's real meanings disappear, I chose to correct mispronounced words or wrong word order to enable better understanding for the reader. For instance, one of the women consistently talked about stress as “tress,” which would be confusing to the reader.

4.7 Analysis of data

According to Malterud (2011) an analysis should bridge the gap between raw data and results, when the material is organized, interpreted, and summarized. The aim is to highlight findings that could explain something that was not previously known and contribute to new reflection. While the first research question is rather direct, the overall aim of the study was to get rich data on the lived experiences of the informants. Consequently, I was inspired by Malterud's (2011) facilitation of Giorgo's phenomenological analysis. The first phase of the analytical process was to read through the transcribed texts of the nine interviews to get an overall picture. In this phase I had not selected any theoretical frame of reference, because I wanted the informants' own stories to gain the attention for further analysis. This is consistent with a phenomenological perspective. In the second phase, I identified meaningful units with different key terms and aspects that the informants had expressed. In the third phase I went deeper into the text and started to code texts with the units of meaning. The various pieces of text were put on different colored notes based on which category they belonged to and then placed together. This was a challenging phase since the pain narratives were often based on multiple and interrelated understandings, complicating the analysis. It was in this phase I realized that although the consequences of living with chronic pain was an aspect in the informants narratives, the experiences of stress in their daily life appeared to be a much more essential factor in their stories. In order to sort out the meaningful units in a systematic way, I read some of the different theories that could be used as frameworks based on the identified

units of meaning such as Kleinman's and Helman's use of explanatory models (1980; 1988; 2007), and Marmot's theories on autonomy and empowerment (2003; 2006; 2004).

To establish previous research on the topic, I did a literature search for relevant literature on selected topics several times during the research process. Literature searches were made in BIBSYS, PubMed, Medline, Science Direct, Academic Search Premier, and PsycINFO. Keywords for the search were: "chronic pain," "musculoskeletal chronic pain," "immigrant," "migrant," "coping," "management," "stress," "lived experience," and "phenomenology," alone and in combination. I presented some of this literature in chapter 2, and I will also use the literature to contextualize my findings.

4.8 Ethical considerations

Because my study involves health issues, I sent an application to the Regional Ethical Committee (REK) who concluded that the project did not require approval. The study was registered and approved by the Norwegian Social Data Service (NSD), and informed consent was obtained while the respondents' voluntary participation and anonymity were respected.

4.9 Scientific rigor and limitations

While quantitative methods are based on numerical data, qualitative material often consists of text based on interviews or observations. Where quantitative data can affirm universal truths, qualitative methods present diversity and nuances. Furthermore, qualitative methods say something about people's experiences, perceptions, values, and interactions to a larger extent than quantitative methods (Malterud 2011). By applying a qualitative approach, one develops an understanding of the phenomenon in a context; however one is not able to make any generalizations about the findings. Accordingly, the findings from my study may not be generalized.

As an alternative to generalizability, transferability may be used. Transferability refers to the inquiry if the interpretation developed within the framework of a project is applicable to other contexts (Malterud 2011). I choose to let the reader be the one to judge if there exists a potential transferability of the findings in this study.

In quantitative research, credibility is secured if knowledge is based on data from many samples. In qualitative research, knowledge is not necessarily based on empirical data

consisting of many samples. Nevertheless, by making a strategic choice, ensuring a rich and varied sample, one can develop descriptions, concepts, and theoretical models despite the fact that these are based on small sample sizes. Malterud (2011) found that a strategic choice should be selected which addresses the problem in the best way. As already indicated, I was hoping to focus on only one or two immigrant groups in the study, and the aim was to gain rich data of the understanding and the lived experience of chronic pain of a few immigrant groups. However, although six different nationalities were included in the study, I believe that the data I have obtained includes rich data. These data are not necessarily related to a specific cultural context, but to the lived experiences of being a non-Western immigrant with a limited educational background, basic language skills, and chronic pain.

Another limitation of this study is the power dynamic between the interviewer and the interviewee. The knowledge produced in the interaction between the researcher and participant is affected by time, place, and mood, and by how the researcher participates in the development of the narratives (Malterud 2011). I had only met the women once or twice before the actual interview. We had not had time to establish a close and trusting relationship, which most likely affected what they chose to tell me. In addition, the time frame of the study prevented me from interviewing the informants more than once. I tried to arrange a framework around interviews based on respect and kindness for the interviewees to feel secure. The informants could choose the time and place, and I asked open-ended questions so that the subjects would not feel forced to discuss problematic issues. Language barriers and a possible lack of trust most likely influenced the narratives, and therefore the analysis. The reader should be aware of these aspects of the study.

4.10 Presentation of informants

Nine women were included in the study. The participants represented six nationalities including Pakistan, Morocco, Tunisia, Iran, Somalia, and Ethiopia. Their ages ranged from 31-55 years, and they had between one and six children. Three of the informants were single mothers, while six of the informants were married. However, two of the informants' spouses were physically or mentally ill. The informants had been living in Norway from between three and 20 years. Their educational background varied from none to seven years of education in their home country. While some of the informants were illiterate when they arrived in Norway, and were currently learning to read and write, a number of the informants had writing skills but attended the AEI mainly to learn Norwegian. With relation to work,

none of the informants were working at the time of the study. Half of the informants had previously been employed in temporary jobs, but stopped due to illness or other barriers.

Providing anonymity to the participants in this study has been of importance during this process. Informants are not referred to by their real names, and I changed informational features such as age and years of residency.

5.0 PRESENTATION AND DISCUSSION OF FINDINGS

This chapter includes the findings with relation to the two research questions. The format of the first section reflects the first research question: “What illness beliefs do the informants use to explain their pain?” Accordingly, the explanatory models that the informants use to give meaning to their pain will be presented. Lay accounts of the onset of illness and explanatory models of disease causations have been described to continue into accounts of what is done in the face of illness (Bury 2001), which is also the case in this study. The majority include stories about how the subjects cope with their situations, both in relation to their pain condition and in their daily lives in general. I include these factors as I interpret them to be dimensions of the explanatory models used by the informants. The first section ends with a discussion of the findings regarding the first research question.

In the second section I present the findings regarding the second research question: “What are the lived experiences of the non-western subjects with chronic pain?” A prominent dimension that was brought up in the interviews by the informants was the stressors they encountered in their daily lives, which they also perceived to influence their pain condition. These are factors I understand to be particularly correlating to their post-migratory lifeworld. Therefore, three dimensions relating to their lifeworld will be presented and then discussed in the second section of the chapter.

5.1 The informants’ explanatory models

In interviews, participants were asked to discuss their understanding of their current pain experiences in terms of the upstart, cause, and progression. By opening the interview session in this manner, I hoped the informants would recall when they first remembered the pain. Thus enabling an exploration of the contexts in which they interpreted the pain to have begun, and providing indications of factors they perceived upheld the pain. Although some

informants' first response was to state that they did not know the cause of their pain, when asked to describe how and when they first experienced the pain as they knew it today, all of the informants had a story and a meaning to reveal.

All but one informant reported that the pain symptoms began a few years after their arrival in Norway. Some of the informants linked the initiation of the pain to a specific traumatic event that happened to a body part, such as a broken leg or the medical diagnosis of arthritis in the knee. Other informants related the onset of pain to a single acute life event or a combination of events that exposed them to emotional stress, such as the death of a husband or a miscarriage. Regardless of what they perceived to be the initial cause for their pain, all of the informants reported that over the years, the sensation of pain had evolved both in intensity and distribution. Their current pain condition was described as more intense than the initial diagnosis indicated, impacting several areas of their daily lives. All of the informants waver, more or less, between different explanatory understandings without conveying one single understanding. However, in order to suggest some of the main explanatory models, I am presenting the findings under the following categories: pain as a physical experience, pain as a social experience, pain as a meaning of imbalance, and pain as a description of climate. Following these categories, a section describing the informants search for a diagnosis, including aspects in relation to medical encounters, will be presented, because the search for a diagnosis is central to all of the informants' explanatory models.

5.1.1 Pain as a physical experience: “If there is pain, there must be something wrong inside the body” (Sara).

Sara is a single mother who arrived in Norway as an asylum seeker ten years previously. When asked how and when her pain started, she stated that it started a few years after her arrival in Norway. At that time she lived at a center for asylum seekers. Her knee started to ache and she approached different doctors to receive a diagnosis for her pain. According to Sara, the doctors told her that she was suffering from arthritis in her knee, and that they could execute a small exploratory surgery if she wanted. However, since they could not be sure of the success rate of such a surgery, she decided against it. As the years passed, her pain evolved both in intensity and distribution, and currently involves her thighs, legs, arms, neck, and back, causing her great suffering and a low quality of life. The pain makes it difficult for her to walk and she explains that even wearing tight clothes increases the pain. The first thing she does when she returns home from school is take off her clothes, only wearing a kanga

(African garment) or loose clothing. She does not work, and she describes her daily life activities as being solely dependent on the intensity of the pain, determining whether she will go to school and do housework. Sara explains how every morning she measures the degree of her pain on a scale in order to decide if she goes to school or not:

No matter if I have pain I try to go to school. I am often away from school. If the pain is more than ten, then I do not manage to go. But if it is five or six... In the morning I tell myself that I get worse if I stay in bed. So I take a shower, get some energy... and then I manage to come here to school and talk with the others.

During the interview, Sara goes into details about her symptoms, showing me the different places on her body which are painful, and using non-verbal communication to show the intensity of the pain. She has, what I interpret to be, an almost desperate way of describing her pain both in words and tone, as if she really wants me to understand and believe the suffering the pain causes her. She claims several times during the interview that her pain cannot be a result of stress and consistently expresses that her pain exists due to a physiological abnormality within the body, which is also reflected in her following quote:

People cannot get sick if there is nothing. Pain cannot be present without being anything.

Sofia is another of the informants who takes a rather physical approach to her pain. She is the mother of four with a husband who is ill, and has lived in Norway for the past 20 years. She explains that her pain started in her back six years after her arrival in Norway. At the time it was confirmed that she had a prolapse, but since then the pain has deteriorated and expanded to her neck, arms and legs, causing her problems with walking and moving about freely. During the interview she referred to an episode where her GP evaluated her condition to be psychological, and this evaluation is fiercely opposed during the interview:

The doctor told me: "No, you do not have a problem, you only have a psychological problem. The pain is only in your head." But I, I live with this pain! I hate my life with this pain! Why do I live with this pain if they [the doctors] do not find out what is wrong with me?

Both Sara and Sofia perceive their pain sensation to be of a physical manner, the pathological phenomenon of a “disruption of specific body structures or organ systems” (Gatchel et al. 2007, 582), although neither of them has currently received any medical diagnoses on the complex pain condition. I interpreted both Sara’s and Sofia’s quotes as essential in suggesting the logic of the meaning-making process which is present in most of the informants’ narratives: if there is nothing wrong physically, there is no reason for the pain to be present. Accordingly, without a medical diagnosis, pain symptoms are perceived as meaningless.

Furthermore, the manner in which the informants use language to describe pain symptoms suggests their understanding of their pain. When asked about how and when pain started, Sofia and Sara described their symptoms in detail, as if they were with their GP. They also used non-verbal communication, such as sighs, increasing volume of voice, facial expressions, and gestures, indicating the area and intensity of the pain. This is in accordance with Seale and Davey’s (2002) conclusions that one of the key problems that the person with pain faces is to communicate their suffering to others. Unlike the visible manifestations of the acute pain of a broken leg, for instance, CMP is privately experienced and demonstrable to others only through the individual’s narrative or nonverbal pain behavior. Fordham and Dunn (1994) reported that “pain, as an interior landscape, is a separate world not populated by others, even when the external world is shared...” (Fordham and Dunn 1994, 14–15).

The informants try to describe the physical aspects and origins of their pain in order to maintain legitimacy. It is important to be “believed” in order to get medical support or welfare benefits. I understand from their narratives that both Sara and Sofia spend a lot of time with their GPs, and they refer to several medical encounters in which they have experienced not being taken seriously by their physicians. Descriptions of pain symptoms are often found to be tailored to what people believe is meaningful to the person they speak to (Epstein et al. 2003). Consequently, in the encounter with me, I understand the informant’s (in the absence of any observable indicators of pain) struggle to convince me that their suffering is genuine. While Sara (several times) declared that stress was not the cause of her pain, later in the interview she explained that she felt that the pain increased with negative thoughts:

When I am thinking all the time on my pain, and the doctor do not find out what is the matter with me, then I get worried all the time... and I get so much pain, you know.

She believes that it is important to go to school, because she “forgets the pain a little bit” when she is with her fellow students. While Sofia did not want her GP to diagnose her with depression, Sofia explained later in the interview that she was depressed. She stated that she attended school as often as she could manage because she realized that if she stayed at home she got more depressed. She recounted that she previously saw a psychologist who told her that her depression was one of the causes for the pain. When Sofia told this story, she said:

Now, I agree with her [the psychologist] ... But, when I walk and then suddenly the pain comes ... It is in my head all the time! Night and day! I wake with my pain, and I do not know if it is in my head or not.

These thoughts suggest the complex nature of living with CMP when no diagnosis is available. I understand the findings that show the informants are caught between a desire to convey the truly physical and medical cause of their pain, while at the same time they are acutely aware of its connection with psychosocial factors. Furthermore, even in the narratives where the physical aspect of pain is expressed the most, the individual also has a psychosocial understanding of the pain.

5.1.2 Pain as a social experience: “My dream was lost” (Halgan).

The literature suggests that it is difficult for a Muslim to relate to the psychosocial factors of pain, as is often done in the Western sense, because pain is seen to be caused by a physical or medical injury or illness, or as a suffering that Allah has put on the person to test his or her faith (Hägerstam 2008). My findings do not support these suggestions. Several of the informants related their initial pain condition to what they perceived to be “stress” or “worries.” I will, in the following, give an example through Halgan’s narrative.

Halgan is a single mother from Somalia. She speaks slowly with a low but direct voice, and I get the impression that she is a woman with integrity. When I ask her if she can remember the situation which she considers to be the precursor of the pain she is in today, she begins by describing how she felt when she arrived to Norway 15 years ago. She explains that during the first few years in Norway she was optimistic about her future; she did not have any pain, and she wanted to find work. Her biggest dream was to be able to buy a house. According to Halgan, her first encounter with pain as she knows it today was through her husband, who had

been living in Norway several years before she arrived. He was complaining about general body pain, but she told him that he was just lazy and she mocked him. She laughed when she told this story during the interview. She continued to explain that during the first few years in Norway she worked in different temporary jobs, while she was hoping to get permanent work in order to be able to buy a house. However, after some years, things changed and she realized that her dream would not come true:

I had my own dream... but then that dream was broken. I worked many years in temporarily jobs, then the children arrived... and then my husband died. Everything became stressful. All my muscles got tense and I got headache all the time

Halgan perceived her lost dream, the death of her husband, and staying in temporary jobs as causing her stress, followed by pain. She expressed feeling of sadness over a life that did not turn out the way she had hoped or expected. She still keeps hoping to find a permanent job although she described the “waiting situation” as hard:

It is difficult for us, not to have a permanent work... when you do not have a plan. Since I only work temporary I am walking around, waiting for them to need me. In summer everybody plan their vacation. But I cannot plan... because when it is summer it is my time. It is hard because I should be with my children, but I am dependent on working.

While Halgan first adopts what I would label a psychosocial understanding of her pain, she recounts frequent visits to clinicians as well: “because I want to know why I am like this.” She explains that the doctor prescribed her medicines and sent her for various medical examinations; however, despite many visits, the doctor did not come up with the answer she needed. At the same time that she described the medical visits, Halgan reported (as the only one of the informants using cognitive techniques in order to lower stress):

Because I don't have any family here, I only want my brain to think positive thoughts. I want to stay positive. When the negative thoughts arrive I try to change and think positive. It makes it easier for me, in spite of pain... I thought maybe it will help... and it helps [smiles and laugh].

I interpreted Halgan's narrative to be part of what we could name, with regard to previously described approaches to pain; a psychosocial understanding of pain. She mentions not only episodes of loss of a close person, but also the loss of a dream. The fact that her husband is dead, and she lives with no extended family around to support her, leaves her with the whole responsibility of making money, maintaining housing, and raising the children. She believes that this situation has led to stress and strains, which have caused her painful muscles and headaches. One of her coping strategies is "to think positive" and she mentions later in the interview that she tries to reduce stress. At the same time, she took a biomedical approach when she turned to the doctor to give her a diagnosis. Again, Halgan's narrative showed the complexity of the CMP condition, which causes the subjects to use different understandings and approaches to deal with the situation.

In addition to Halgan, a couple of the other informants also understood that their pain was mainly a result of stress and worries. While one of the informants claimed that she is was depressed, very few of the informants discussed their psychological state, apart from describing feelings of stress, sadness, and worry. Previous research has reported that chronic pain, anxiety, and depression are frequently associated, and links between them are well documented (Leiknes et al. 2007; Larson, Clark, and Eaton 2004). The reason why a limited number of my informants relied on psychological understanding may be because a discussion about feelings and stress is culturally more acceptable than discussion about the psyche, which is also found in other studies of immigrants and chronic pain (Finnström and Söderhamn 2006; Müllersdorf, Zander, and Eriksson 2011). Nevertheless, studies report a similar finding, including Norwegian women with CMP who avoid mental associations when talking about their condition in order to avoid stigma (Werner, Isaksen, and Malterud 2004). According to Kirmayer et al. (2004), most people across cultures provide psychosomatic explanations linking problems in family and community with bodily distress.

5.1.3 Pain as a meaning of imbalance: “I have little blood” (Meryam)

Although all of the informants use aspects of what I interpret as biomedical and/or psychosocial explanatory models to understand their pain, a number of the informants also mentioned alternative explanations as part of their understanding. Nazia was from Pakistan and had lived in Norway more than 20 years. She explained that her pain started when she was still living in Pakistan and her first child died. At that time her husband was living in Norway alone, because she did not want to move from her family. According to her, the pain had evolved through the years and she had expended a lot of energy to search for an answer to her pain. When asked what she thought may have been the reason for her pain, she explained:

Some people have little blood and some people have much blood. Those with little blood have one disease, and those with little blood have other disease... like that.

Due to language problems I could not elaborate on her meaning of this, but Nazia explained that she was managing her pain in several ways, not only seeking advice from a clinician. She stated that she visits the pharmacies and asks for advice on remedies such as creams or pills that may decrease her pain, or she gets help in alternative shops where she was currently advised to eat shrimp powder.

Meryam was also from Pakistan. She had lived in Norway only a few years, and stated that after her arrival she began to suffer from a constant headache. While she sometimes wondered if there was something physically wrong in her head, she included several details about her menstruation in her pain narrative. She reported that when she was living in Pakistan she sometimes had headaches and problems with her menstruation. However, in Pakistan she received medications that she perceived as effective for her problems. She continued by stating that the drugs she received in Norway do not help her. Her explanation for this was:

I think that I am Asian and as Asians are hot they need heavy pills. But here I eat light pills. Not everybody is suited to eat light pills. I think that I need strong pills.

These narratives suggest that several of the informants use explanatory models adopted from medical and lay traditions in their home countries. The notion of hot and cold, and the focus on menstruation or volume of blood, which also incorporates other substances such as food and medicine, are aspects found to be important in ayurvedic and humoral medicine. Several

of the informants also include comparative stories about the competency of the doctors and the effectiveness of the drugs that they received in their home country, which I understand to be related to the belief that the doctor is familiar with the traditions and lay understandings. These understandings go along with the biomedical and psychosocial approaches throughout the interviews. Several of the women appeared to use the different approaches according to what they found relevant or understandable at the time.

5.1.4 Pain as an indication of climate

All of the informants arrived from countries with hot temperatures, and Norwegian weather is universally perceived by the informants to make their pain condition worse. The winter in particular is perceived to increase pain and influence well-being. The majority of the informants reported that they felt better in the summer or when they were visiting their country of origin because of the sun and the hot weather. Marwa, who suffered from headaches and stomach issues, explained:

When I travel to Tunisia during the vacation, I forget my headache there. It is warm. I need sun (...) Life in Norway is good, I am happy to be here, but the winter I do not like... I hate winter.

The weather is also perceived by a couple of the informants to be a barrier, limiting physical activity during winter because of the cold and the dark. Abyan, who is the only one of the informants currently attending a fitness center (a center that is open only to women, and used to be free to immigrant women with a prescription from a GP), stated:

I use to do physical training twice a week... different exercises for my neck and shoulder... I walk to get there. But now winter is coming and I cannot manage to go there (Why?) It is cold. I put on lots of clothes, but it does not help... It does not help at all...

A recent study including rheumatic patients who were provided with treatment rehabilitation programs in a warm and sunny climate reported that the patients improved their mobility functioning, as well as their pain symptoms, which were reduced for at least 6 months following the treatment (Staalesen Strumse et al. 2009). This study indicated that the climate had a role in pain perception. At the same time, the findings in my study may also be

interpreted by relating the informants' statements to their general longing for their home countries. The majority identify their home country not merely with warm weather, but also with family and friends and many of the positive aspects in life. Accordingly, the cold winter may be understood as partly relating to the sadness of not being home.

5.1.5 The search for a diagnosis and treatment

This heading may not appear to be appropriate because this is not an explanatory model; nevertheless, there is one distinct universal feature reported in all of the narratives, regardless of what explanatory models the informants' adopted. This is the search for a diagnosis and treatment for their pain with a medical physician. It is important because I understand that the informant's use of the biomedical understanding of pain is partly aggravated by the physician's management of the situation.

All the informants describe frequent visits to their GPs, regardless of their explanatory models. Even Halgan, who takes a rather psychosocial approach to her pain, explained this after she told me about how her pain was related to the death of her husband, and the subsequently stress. She frequently visited her GP in order to determine what the matter with her body was. She said:

I felt that my pain got worse, so I saw the doctor many times. He took many tests, but he did not find what is wrong. I did not get an answer. I saw the GP, he prescribed me with medication... but the question is why...

Halgan's quote suggests the many aspects of the pain experience. First of all, she sees the GP because she wants an answer; a diagnosis for her pain. Second, the GP provided her with medication which decreased the pain, but he was not able to give her what she really wanted. Since the medication did not treat the pain, and only provided pain relief, Halgan often returned to the GP for other tests or new drugs. Halgan's story is similar to the majority of the informants who all describe frequent visits and medication as the forms of treatment they were provided with. Sara articulates it quite strongly:

I have the pain everywhere, and sometimes I just see my GP and cry. Then they say: "OK, you cannot do anything, but try this pain killer as well. Forget the one you use, this one is stronger."

While I did not inquire about their medication, several of the informants described in detail what types of medication they used and its effect on the pain symptoms. The majority reported that they took drugs every day, and that they seldom went anywhere without carrying medication with them. At the same time, a majority of the informants expressed a fear of the side effects of the drugs, which caused the informants to moderate their intake. While all of the informants reported that they did not feel that the treatment was effective, they continued to see the GP and try new drugs or new combinations of these medications. Sara explained:

Before, I ate painkillers as food. Yes, not even food did I eat as much as I ate painkillers. But now... I see that even when I take strong pain killers, the pain return after maybe two hours... Because, you know, painkillers are not treatment... It is only to reduce the pain... because they did not find what was wrong with me.

Sara's quote suggests what Halgan was concerned about; the informants wanted to get an answer about why they had pain, but instead they were prescribed drugs which provided pain relief without treatment. The GPs were perceived to be the ones that could provide them with a diagnosis and treatment. I understand the informants' seemingly contradictory management strategies because of the lack of other strategies, and at the same time there is a fear that the pain symptoms might have a pathophysiological cause, and therefore they continue to see the physician. Sara mentions later that she changed GPs because she hoped that a new physician may provide her with some answers. She stated:

You know... I am in war with the doctor.

I interpret Sara's quote of "being in war with the doctor" as showing both Sara's and some of the other informants' dual inner conflicts. The informants are dependent on the physician to be legitimized as patients and to receive a diagnosis, but at the same time they do not trust their GPs completely. A number of the other informants shared their doubts about the Norwegian physicians. One informant mentioned that she found it strange that the GP had to read a book (Pharmaceutical Compendium) in order to prescribe her with a drug, accordingly assuming that the doctor lacked skills. Several of the women made comparisons between the Norwegian health care system with the system from their home country, claiming that in their home countries they got appointments when they wanted and the doctor immediately knew

what was wrong, providing them with effective drugs. Sara expressed her concerns in the following manner:

In the beginning I was thinking that they didn't understand me since I didn't speak Norwegian well at the time, and that's the reason why the doctor just gave some pills to take home. But even when they used a translator they didn't seem to understand my problem. So then I was thinking that they didn't take me seriously because I am not Norwegian.

Once more I used an extract from Sara's narrative to demonstrate the reflections she made in relation to the medical encounter and the distressing situation of not getting a diagnosis. Sara mentioned that she sometimes wondered if the clinicians knew that she was suffering from a serious disease, but that they did not tell her because she was not a Norwegian. She also had concerns about the Norwegian clinicians' knowledge of tropical diseases in case it was a tropical disease that she was suffering from. Additionally, Sara told a story in the interview about an immigrant acquaintance who died of cancer because the health system did not take his complaints seriously. Sofia also expressed mistrust toward the doctors, and she found that they seldom examined her properly:

If we say that we have pain here... then they say they will examine me. But they only say: lift your arms, and quick, quick and they are through. And I do not agree! If I say I am ill, then they have to listen... to see... and feel... They have to examine me properly.

While the informants showed signs of mistrust toward the medical system, or merely the physicians, the physicians are the persons they returned to for help. The reported frequent medical encounters suggest an ambivalent reality; while the informants do not perceive the "treatment" they get with the doctor to be effective, or report a general mistrust towards the GP, however they still continued to seek help there. Their narratives showed some of their inner conflicts in their struggle to find a diagnosis and a meaning for their pain. These findings are in line with other reports suggesting that sufferers of CMP are reported to see various practitioners, spending a considerable amount of time and energy searching for a diagnosis (Blom 2008; Bell 2009). In addition, McParland et al. (2011) found that the

participants in their study did “doctor shopping” in the hope of finding the right doctor that could meet the individual’s pain needs, which is also what Sara reports she had done.

A number of the informants claimed that receiving a diagnosis would make it easier to cope with the suffering and to “adapt” to the pain. However, as long as they are not completely sure that there is no problem, uncertainty causes them to continue to visit doctors. Sara says:

Okay, if it was established that my pain was not present due to a disease, then I could get used to the pain. But currently, I do not know for sure that there are no problems. If there is only pain, then ok... I can find a solution to make my situation better (...) But now I am worried and very sad because I do not know what happened inside.

I interpret Sara’s quote and the other informants’ narratives of searching for an answer to be in line with other research studying the lived experience of chronic pain. A medical diagnosis does provide the individual with an explanation, and by receiving a medical diagnosis, the individual can put away their fears and concerns about possible dangerous diseases (Malterud 2010). A diagnosis is found to create a kind of predictability for the future with relation to treatment and healing, and accordingly provides tranquility (Elstad, Grue, and Eriksen 2005). A diagnosis created a sense of relief and reassurance in individuals with fibromyalgia (Wuytack and Miller 2011; Råheim and Håland 2006; Hellström et al. 1999). In addition, a diagnosis is also a kind of identification to the surrounding world. Since CMP is not always visible to the outside world, a person suffering from CMP may experience people, including health care professionals, who do not believe them. Therefore, a diagnosis can serve as a confirmation that the individual is not simulating being sick (Elstad, Grue, and Eriksen 2005). Receiving a “label,” with the consequence of entering a sick role, is also found to be a desire of the participants for their own understanding, and as a key for social and medical acceptance (Miczo 2004). The last aspect may explain why the informant seeks help from the clinicians, because the professional health sector has the most power since a formal education and occupational status generate power (Kumar 2010).

While receiving a diagnosis may provide the informants with an answer and dignity, the informants reflect a dualism in receiving a diagnosis/not receiving a diagnosis. It is reasonable to think that one would be relieved and happy to hear that there is nothing wrong, but studies

report that individuals who experienced physical symptoms were not always reassured by normal test results (Creed, Henningsen, and Fink 2011). Several of the informants referred to a relief they felt every time they left the doctor without a diagnosis, because it meant there was no malignant disease. Simultaneously, they experienced feelings of sadness because they must continue to live with the uncertainty of what might be wrong. Sara described these mixed feelings:

Sometimes I am very sick and I'm lying in hospital for several days and they found nothing. I asked them why I am sick, but they said they did not know. Sometimes I am happy and sad when I leave the hospital. I am happy and sad... both. Because sometimes I am glad that they did not find any disease. But at the same time I think: "Why am I sick?" Then I... Ohhhh (sighs)... then everything becomes very hard for me.

The way I understand these mixed feelings is that feelings of worry and relief go hand in hand with many sufferers of CMP following visits to the GP or hospital (Creed, Henningsen, and Fink 2011).

5.1.6 Discussion of research question 1: "What illness beliefs do the informants use to explain their pain?"

The informants' adoptions of explanatory models are, as we have seen, characterized by variation. Although I have presented the different narratives within categories, in most of the narratives it is a universal trait that the informants' illness beliefs go back and forth between different explanatory models. Accordingly, they extract knowledge from a wide range of explanatory models when they try to create meaning from their pain conditions. However, the biomedical model is central in both the causative explanation and in the management of the pain. This is in line with Ingstad (2007) who found that explanatory models of the individual usually reflect a complex world where knowledge or understanding of different explanations coexist with biomedical theory (Ingstad 2007). While the medical encounter only constitutes a small percentage of the informants' lives, the narratives indicate that the clinicians are perceived as playing a major role. Most of the following discussion will, therefore, include the medical encounter.

For the majority of the subjects, this move back and forth between different explanatory models causes conflicting feelings and frustration. Unlike acute pain, which may be interpreted as a warning to change behavior in order to avoid further pain, chronic pain serves no such useful purpose. It therefore poses significant problems in meaning to people who suffer from it. This frustration is reinforced in meetings with health care professionals where GP's provide the informants with medications as treatment, and continue to refer the individuals for further clinical investigations. However, this approach to pain appears to reinforce the individual's initial belief of the pain symptoms as reflecting biomemmedical processes, which may constrain the ability to include other understandings and coping strategies for pain. In my understanding, the GPs management of the informant's pain condition may partly explain the repeated visits to the physician, and the continuous concern in relation to the pain symptoms as indications for underlying serious disease.

The narratives describing the encounter with the physician included descriptions of various expectations toward the doctor, as well as disapproval when the expectations were not met. In various studies during the last decades, women with chronic pain have reported negative experiences during medical encounters such as being questioned and judged as not being ill, suffering from an imaginary illness, or being given a psychiatric label (Johansson et al. 1996; Honkasalo 2000; Wuytack and Miller 2011; Werner and Malterud 2003). The subjects in this study reported similar encounters, but they have further barriers such as language problems and cultural beliefs that may not always be communicated in the medical encounter. I understand from the informants' narratives that several perceived the medical encounter as causing them further distress, mainly because the physician did not provide them with a diagnosis. Consequently, the informants attempted to find possible explanations why the GP did not find any medical explanations for their pain. For example, the previous sections reported how some of the informants expressed doubts about the Norwegian physicians' medical knowledge, or mistrusted the clinicians' honesty (in Sara's case). These reflections created feelings of mistrust and further stress.

In my view, a number of the informants, including Sara and Sofia, expressed what Sullivan et al. (2001) termed a catastrophizing process, where pain and the uncertainty related to the condition created negative emotions, and where negative emotions, in turn, perpetuated pain, creating a vicious circle. The condition is described within a biopsychosocial model of pain where the involvement of the individual's response and behavior towards chronic pain is

important in the process of the maintenance of that pain (Turk and Okifuji 2002).

Catastrophizing is described as the process of magnifying or exaggerating the threat or seriousness of the pain sensations, a condition of the inability to divert attention away from pain, and feelings of helplessness and pessimism, in relation to coping with pain (Sullivan et al. 2001, 53). Several studies suggested that catastrophizing was common in CMP where there was no diagnosis available. Furthermore, catastrophizing has been found to be significantly associated with pain severity and pain-related distress and disability (Severeijns et al. 2001; Sullivan et al. 2001).

A meta-analysis of studies that compared medical encounters between doctors and immigrant populations revealed that there were major differences in doctor-patient communication as a consequence of the patients' ethnic background. Doctors were found to behave less effectively when interacting with minority patients, and ethnic minority patients were perceived to be less verbally expressive, assertive, and effective during medical encounters (Schouten and Meeuwesen 2006). Five key predictors of culturally-related communication problems were also identified: (1) cultural differences in explanatory models of health and illness; (2) differences in cultural values; (3) cultural differences in patients' preferences for doctor-patient relationships; (4) racism/perceptual biases; and (5) linguistic barriers (Schouten and Meeuwesen 2006). Although most of the included studies were conducted in an American setting, I perceived these results to be of relevance in a Norwegian setting as well when discussing culturally-related communication problems in a medical encounter.

The data in my study suggested that the informants draw on cultural beliefs in their own explanatory models. This may be in the way that they include perceptions of warm and cold personalities or medicines, or the way that they include blood and menstruation into their illness beliefs. However, these alternative explanatory models were not focused upon to the same degree as the biomedical model. What I do interpret from the informants' stories, and the comparison they make between the Norwegian physician and that of their country of origin, is that the majority of the informants hold what I interpret to be culturally-related expectations toward the physician. The majority of the participant's perceptions of the physician involved a vision of the physician being an expert and an authority that should know everything in relation to medicine, provide them with a diagnosis or at least an effective treatment, and tell them what to do in order to get better. Consequently, there is a collision of their expectations when they see that the doctor reads a book in order to give them a diagnosis

or proper treatment or that the treatment fail to be effective. The informants perceived this as a weakness in the doctors' knowledge, and assumed in some cases that the doctor was unreliable. Furthermore, during the last decade, the Norwegian health care system has increased the focus on the importance of user influence through the participation in the treatment process and decision making (Dahl et al. 2009). When the patients who hold a traditional view of the physician as an expert encountered a GP who asks, "What do you think is the matter with you?" a conflict may escalate due to the different expectations related to the roles in addition to the different explanatory models used by the physician and the individual (Nissen-Meyer et al. 2008). Van Wieringen et al. (2002) demonstrated, for instant, that mutual understanding was found to be poorer in consultations with foreign-born patients compared to native-born patients which may be due to (Wieringen, Harmsen, and Bruijnzeels 2002). A clarification of both expectations and explanatory models may, therefore, lead to a more effective medical encounter.

5.2 Lifeworld as significant meaning

As a headline for the section which answers the second research question: "What are the lived experiences of the non-western subjects with chronic pain?" I use Kleinman's (1988) concept of the "lifeworld as meaning." By this he refers to a meaning that transfers vital significance from the life of the individual to the illness experience; "acting like a sponge, illness soaks up personal and social significance from the world of the sick person" (Kleinman 1988, 31). People experience an illness not as an isolated state, but in a social context, and the conditions and meanings attached to it are "socially constructed and culturally relative" (Davey 2002, 12). I believe this is true for several of the informants meaning making activities as they live in a world colored by their experiences, knowledge, values, and norms from their countries of origin, and those faced as immigrants in Norway. To understand the multiple effects of social context on lived experiences, one must consider social context as it is relevant to the experience of the social participants under consideration (Holstein and Gubrium 2006). Accordingly, the data in the following chapter is withdrawn and based on the perceptions and experiences of the informants.

The large amount of literature on the lived experience of chronic pain reports various impacts of the chronic pain conditions on the different aspects of the individual life (Wuytack and Miller 2011; Råheim and Håland 2006; Creed, Henningsen, and Fink 2011; Hellström et al.

1999). However, while the informants in my study also included aspects of the impact chronic pain imposed on daily life, the distressful life in general dominated the narratives. These factors arose when the informants talked about how they perceived stress to be influencing their pain condition. The informants' stories indicate that there are some particular challenges in light of the context in which they live: as non-Western immigrant women in Norway. I have already introduced Halgan's narrative in the previous chapter, which suggested some of the difficulties she faced as a non-Western immigrant woman in Norway. In addition, all of the informants related to stress and worries as substantial parts of their understanding of their pain as well as of their lifeworld. The context in which the informants lived, and the lived experience of pain, interrelated in the narratives and were not always possible to separate. Subsequently, I could have applied several of the narratives presented in the following section in the previous section under psychosocial understanding of pain as the informants perceived some of these stressors to directly influence their pain condition. However, I found it to be of importance that the informants' lifeworld would not "disappear" in the explanatory models, but could stand for themselves as narratives about experiences of strains and struggles. I have identified three categories within "the lifeworld" as significant: parenting, lack of social support, and financial strains.

5.2.1 Parenting - *I worry about my children.*

Former studies focusing on the lived experiences of chronic pain have demonstrated that the participants reported great concerns about family relations, and how their chronic pain influenced the relationships they had with their spouses and children (Robinson, Kennedy, and Harmon 2013; Wuytack and Miller 2011). Sara is the only informant in my study that described attempts to protect her child from showing the amount of physical suffering the pain caused her. On the other hand, the factor that the majority of the informants mentioned as one of the main stressors in their life was their concern for their children in general. A number of the informants stated that they lie awake at night thinking and worrying about their children and about what will happen in the future to them. They worried about their behavior, education, and financial situation. Studies indicate that collisions often arise between norms, values, and cultures during the process of migration and resettlement (Degni, Pöntinen, and Mölsä 2006). Some of the narratives in this study indicated that this was an essential aspect for several of the informants, especially in relation to parenting. To shed light on this aspect I present Abyan's story.

Abyan is from Somalia. When we met for the interview, I remembered her from the informational meeting where she appeared to be an outspoken woman. During this meeting there were nine women present, and she was telling a story about her doctor providing her with the advice of sun tanning to increase her level of Vitamin-D. Certain immigrant groups have been reported to suffer from vitamin D deficiency, and studies have also demonstrated a correlation between vitamin D deficiency and non-specific musculoskeletal pain (Knutsen et al. 2010). Since the sun is perceived to be the most important source for vitamin D, one way to increase vitamin D levels is through exposure to the sun. However, to Abyan and the other informants, who wear hijabs which cover the whole body except the face and hands, the advice of sun tanning was perceived as a most stupid thing to say. This is reflected in what she said in the session:

When my doctor tells me that I need vitamin D and that I should sun tan... Yes... Does he want for me to walk around naked? Or does he want me to walk around in town in a bra just as everybody else?

I understand Abyan's reference to "everybody else" as how she perceives Norwegian women to dress. The other informants were laughing when Abyan shared these thoughts on the subject. I present this story to give the reader an impression of Abyan's personality and how she appeared to me; as a frank and forthright woman with opinions. When I interviewed Abyan, she told her life story. Her first husband died while she was living in Somalia with their children, and after a while, she got married again and had two children with her new husband. She came to Norway ten years ago with her two youngest children, while her husband stayed in Africa. When she left for Norway, she also left her oldest children with her family in Somalia. Abyan explains that when she arrived to Norway she lived in a small city where she managed to get a permanent job in home nursing. She had a neighbor that looked after her children when she was working evening shifts. Abyan describes this period of her life as calm, without any stress. However, after a couple of years her older children arrived to Norway. When asked about how and when her pain started she says it was the day her children arrived because she found it difficult to take care of all the children. She explained that her problem was mainly related to her son's behavior which she described as being aggressive:

He fought with his sisters and brothers and used bad words. He started to drink... and smoke. He stole from shops. He did many bad things. And I had a lot of stress. Lot of stress! (...) Sometimes when I saw number 23... ohh... Number 23 could be from child welfare or from police... or from school: [sighing heavily] What did he do today?

All Norwegian public services' telephone numbers start with 23, explaining her feelings of worry when she saw the number. Later she explained that she wanted the child protective welfare services to take care of her son, but at some point when they turned up at the house, the son told them that he wanted to stay home, which was respected. Through the whole interview Abyan repeated the stress she experienced when dealing with her son and recounted the different situations which she found to be troublesome. A number of times Abyan compared troublesome episodes with how those episodes would have been solved in Somalia. As an example, she tells a story about how her mother solved an issue which they had with Abyan's older brother. At one point in time, he did not want to go to school, so the mother called the police. The police came to the house the following day and threatened the brother to go to school, "if not they would....!" Abyan is laughing when she tells this story before she claims:

But in Norway, you cannot do like that [laughing]... Maybe it is even the children who will call the police instead!

I understand this statement as a reference to the rights and power a child has in the Norwegian society when compared to other cultures. Later in the interview she mentioned what I interpreted to be a pressure that existed from her extended family in Africa with bringing up the children in a foreign country. The family did not agree with Abyan bringing the children to Norway:

They argued with me: "Why do you bring the children?" And then later they say: "Look, she didn't manage"... It hurts here! [pointing to her heart]

Abyan's narrative raises numerous points about the situation of raising children as a single mother and with other cultural norms for parenting. Abyan had been living in Norway for more than 10 years, and what I understand from her narrative is that she was aware of the

Norwegian norms regarding parenting. I interpreted Abyan's narrative mainly with regard to two aspects which relate to parenting. The first issue relates to the norms and values in the ways of parenting, and certain expectations of the behavior of children. The second issue is the responsibility of parenting, but the two issues interrelate.

In relation to the core values of parenting, I understand this story as an example of how the norms of raising a child are different in Norway from what they are in Abyan's home country. Savosnick (2012) interviewed 17 Pakistani and Somalia women living in Norway in her master's thesis. The informants reported that they found it difficult to parent their children in another culture. They also reported difficulties with the transition from the extended family to a core family, which caused feelings of loneliness (Savosnick 2012). Furthermore, in their study on the perceptions of parenting in Somali immigrants living in Finland Degni, Pöntinen, and Mölsä (2006) demonstrated that in the Somali culture the children had a well-defined natural duty and obligation to the family. Their natural duty was to respect, listen to, and obey their parents, and there were certain demands for their social behavior and their ability to adhere to Islamic values and traditions. In addition, in Somali family traditions, the husband, the wife, and the extended family members share the responsibilities of raising children, and the men are regarded as the heads of the families and the authorities in any decision-making. Several of the parents reported it as a challenge to raise children away from their home country. The changes in parental practices were perceived as heavy and stressful, and the women explained that childcare had become an individual matter and that they had to manage it by themselves, in contrast to Somalia where they had help from female relatives and extended family members. Some of the participants explained that their children did not listen to them anymore because they had been told in the schools that they had rights and freedoms (Degni, Pöntinen, and Mölsä 2006).

These perspectives on parenting do not apply only to immigrants groups with backgrounds from Somalia or Pakistan, but also to other non-Western immigrants who have grown up in societies where the state has no responsibility for taking care of the children. In these societies it is the extended family, neighbors, or the local community who are all responsible for the task of parenting (Mekonen 2008). I understand several of my informant's worries reflecting these issues. Furthermore, if the parents and extended families have other expectations toward the behavior of their children, as described in the Degni, Pöntinen, and Mölsä's study (2006), with regard to duties to respect and obey their parents and obedience toward Islamic values

and traditions, the Norwegian secularized norms and focus on the rights of the children may be perceived as a threat toward traditions and culture. Accordingly, one of my informants from Pakistan stated that they returned to Pakistan after living in Norway for some time to allow the children to study at a Pakistani school for a few years before they returned to Norway again. I understand my informants' narratives to suggest that the dimensions relating to parenting, with regard to the differences between norms, values, and cultures, cause additional stress in an already stressful resettlement context.

To end Abyan's story, after several years of struggling with her son's behavior, she sent him away to her brother in Africa. Her brother is parenting him with strict rules, but according to Abyan, her son is behaving well, doing well in school, but he misses his family in Norway. She has told him that he can return when he starts at the university. After the departure of her son, Abyan says her stress decreased and as a result she finds that her muscle pain is not as penetrating as before. However, she has now started to worry about her younger son's behavior.

5.2.2 Lack of social network: *I am alone.*

I have in the previous section suggested the lack of support and network in relation to parenting. Furthermore, the majority of the informants expressed concerns with not having other friends and family around when they talked about other aspects in their life. While one of the informants explained that she had so many girlfriends that she did not have time to meet them all, the majority of the participants explained that they had a small network including the closest family and a couple of close friends at most. Studies report that individuals living with chronic pain isolate themselves. The subjects found that pain created separation and distance from other people, even family (Thomas and Johnson 2000; Råheim and Håland 2006). However, these studies did not include immigrants and I interpret my informants' lack of network and social support, not to be due to the pain condition itself, but due to being an immigrant that has left friends and family behind. Zoreh, who came to Norway three years ago with her children to be with her husband, expressed it quite clearly:

Sometimes I wake during the night at 2 am, and I just lie there without being able to sleep. I am thinking about my children and family. I miss my family and my home country. And I am thinking that it is hard because I do not speak well

Norwegian, and because I do not have any relatives in Norway. I only have a husband and two children here. No family.

I understand this statement as reflecting general feelings of loneliness and longing for family that are not here. In addition, I understand several of my informants pain narratives to suggest that the longing for family impact on their pain perception. Feelings of grief over the loss of family members left in a home country were clearly associated with pain perceptions found in a similar study on Muslim immigrant women living in Sweden (Müllersdorf, Zander, and Eriksson 2011). Sara also expressed the difficulties in relation to be alone:

Life in Norway is very hard, especially when I am ill and alone and have responsibility for everything myself. For work. For pain. For life. For everything.

Immigrant-HUBRO reported that social networks and support among non-Western immigrants are low, as they reported a significantly lower number of friends and less support from others when compared to the majority (Kumar et al. 2008). Blom's survey reported similar findings (Blom 2008). I understand several of the informants' narratives to suggest that they feel isolated and alone as the process of migrating includes leaving friends and family. To be alone with the responsibility for managing life in a new country must be very difficult, especially if you are used to share responsibilities and get practical and emotional support from extended family or others. Furthermore, being alone to manage the pain condition itself is perceived to add to the stress in life. None of the informants expressed explicitly the need for more friends, but a number of them referred to family and the sorrow they are experienced in not having them around. They explained that when they visited their home country for vacation, the pain disappeared, or they "forgot" the pain. Family, the weather, not worrying about bills, and help in the house were mentioned as reasons for the disappearing pain. Sofia explains:

When I go to my home country I get less pain because of the warm weather and because of the family and so on... If you are with family you are happy. But here, we do not have family. We talk on the telephone, but we do not come together as family.

A number of the informants expressed that the move to Norway was not their choice and related it to the duty of following their spouses. Several of the husbands already lived in Norway before the informants followed. The informants explained that other family members as well as their husbands expected that they, as married women, should live together with their husbands. Nazia explained that she lived in Pakistan after she got married while her husband lived in Norway. She recounted endless arguments with her mother who told her to go and live with her husband in Norway. After several years living with her parents in Pakistan, she had to give in and moved to Norway. Meryam, also from Pakistan, tells a similar story, although she made the decision to move on her own because her children started to ask where their dad was. Meryam did not show any feelings of anger or bitterness when she told the story, nevertheless, through the entire interview she referred to how good life was in Pakistan compared to life in Norway:

In Pakistan I lived with my mother... and I did not work at home, only sometimes go to school. Apart from school... I did only relax, not working. Sometimes we visit other families or friends... and we were talking and laughing... (...)I do not like foreign country. I like my home country.

Meryam explained that she had a few distant friends and family in Norway and I understand her quote about being with friends and family in Pakistan and “talking and laughing” with them as referring to what she does not experience at a similar degree in Norway.

The feelings of loneliness were also described in relation to the responsibility the informants faced towards household chores, raising children, and income, which have partly been presented in the previous section. As the majority of the participants were single or their husbands were ill, responsibility for the household and daily survival was allocated to the women. A number of the informants reported that they experienced stress with being alone in such a situation. Sofia, with four children and a sick husband, explained with despair in her voice:

Every morning I wake up with my pain because of my worries for my children, for the economy, for everything... My children come to me for help, and I help them. And afterwards they relax and tell me that it helped. But I, I get more ill. But what can I do? I have to help. But nobody will come and help me!

Marriage is one obvious domain in which support may be offered or denied. Research has documented that morbidity and mortality are reliably lower for married individuals than unmarried individuals across a variety of acute and chronic conditions. The hypothesis is that married couples have more material resources, less stress, more social support, and less risky health habits (Kiecolt-Glaser and Newton 2001). In studies focusing on the lived experience of chronic pain, the support of spouses has been perceived to be of importance (Snelgrove, Edwards, and Lioffi 2013; Wuytack and Miller 2011), although feelings of guilt and uselessness because of a role change within the family have frequently been described (Hellström et al. 1999; Henriksson 1995; Wuytack and Miller 2011). Furthermore, limitations in fulfilling the family role have been demonstrated to intensify emotional stress (Vroman, Warner, and Chamberlain 2009; Råheim and Håland 2006). In my study, most of the informants do not report any feelings of guilt or uselessness with regard to not being able to keep their responsibilities. I interpret this finding as due to the fact that the informants fulfill their household chores, despite their pain conditions. Several of the married women explain to me how their husbands are not like Norwegian men, and that there are quite strict distinctions between “working outside” the house and “working inside” the house. The area inside belongs to the women. Yasmin from Pakistan has been living in Norway for more than 25 years. She explains:

I have a husband and... you know, foreign husband they do not organize anything... They work very well outside, but they are not good at working inside. When they grow up, it is the sisters and the mother who do everything... then it is the daughters and wife... It is what they are used to! You cannot change the old... 60 years. That is how it is.

Data suggest that the organization of daily life at home dwells with the women, with little support from their spouses. A few of the informants report that their children help out in the house, and one informant claims that her husband helps her with household chores. However, with regard to social support, the informants get little practical support in their daily lives. For emotional support, several of the informants report that they turned to a close friend (if they had one).

5.2.3 Financial strains: *In Pakistan I was rich, in Norway I am poor.*

The economy is mentioned by the majority of the informants to cause a major constraint on their daily lives. The study participants have little education from their home country, they speak Norwegian poorly, and none of them are currently working. A low amount of education from their country of origin and a relatively low level of language skills make it difficult for the study subjects to gain permanent work as is demonstrated in other studies (Blom 2008). For several of the women, the pain condition itself makes it difficult for them to work. Most of the informants received some sort of benefits from social services, but the amount they received was perceived to be too little because living expenses in Norway are high. Sofia links her financial worries directly to her pain condition and describe it as follows:

But here in Norway it is very, very difficult to live here. If you have pain, if you have low income and stuff... it is big problem. We are always thinking: "How will I manage this month... How? How? How?" ... And with these thoughts in my mind, I have pain in my body all the time... it is true. I feel it myself... When I think and think, there is a lot of pain.

In addition, a number of the informants explained that there were certain expectations from their families in their countries of origin about remittance. Meryam explains how her husband, when he was living alone in Norway, used to send money to the family in Pakistan. However, after she and the children arrived in Norway they could not send much. In the interview she described into detail about how much they earned, how much the rented apartment cost, and the other expenses that they had. When all expenses were paid, they did not have the money to give away a remittance of the same amount as her husband used to do. Explaining this to family is not easy:

It is difficult (...) I tell them that my husband work, but that it is difficult with all the expenses... to food and rent and clothes... But when I get work, then everything will be fine.

Meryam is attending the AEC in order to learn Norwegian, with the main aim of finding work so she can gain an income. I interpret Meryam's attitude not to be unwilling to help her family in Pakistan financially. However, her worries are about the high living expenses in Norway,

which combined with expectations of remittance, cause an additional pressure on the economic situation for her and for several of the informants.

Another of the participants, Nazia, a mother of four children, whispers to me in the interview that they do not have enough money as if she is ashamed or worried that somebody else is listening. She described that the night before the interview she was sitting up all night going through their accounts, hoping that there would be no more bills that month. Her husband is ill, so she is the one taking care of the family, organizing everything related to economy, performing housekeeping duties, and parenting the children.

A couple of the informants mentioned the wish for owning a house as a means to secure their old age and as economic security for the children. However, with the economic situation they are in, it is not possible for them to do so. Halgan explained it with the following quote:

If I had a house it would be a solution. Because, when you have children, and you do not have work or a permanent place to live... sometimes you think about the children: where will they live when they grow up, or where will I live when I get old? It makes me worried.

The financial situations in which the study subjects live in Norway are frequently compared with those of their home country. A number of the informants referred to the big houses, the ability to have help in the house and not working outside the house. Meryam explained it in the following extract:

In Pakistan, I was rich. When I live in Norway I am poor [laughing]... In Pakistan I didn't pay rent, but the houses... oh, so big houses with big balconies and big garden. First time I arrived here I cried a lot. I don't want this house [apartment], it's so small. Then my husband told me: this is not Pakistan, this is not your home country...

Abyan recounted how she felt after holiday in Africa:

When I visit my family in Africa, the pain disappears. But the moment the plane touches down at Gardemoen [airport in Oslo], I get stressed, I get sad and get pain

in my whole body. I have to sit down, and my son asks me: Mummy, what is wrong? I tell him that there is nothing wrong (...) But you know, the moment you return to Norway, then a lot of bills are in the mail box.

While the husbands of Meryam and several of the informants were working in Norway before they arrived, providing the family with money, Abyan's husband was the owner of a well-run company in Africa. It appears that a number of the informants lived a life with relatively high material standards in their countries of origin before they arrived. The move to Norway, where they may be living in a cramped rented apartment with few possibilities of expanding their financial situation, is perceived to be a change in social status from rich to poor for a number of the informants. For the majority, the transition from a life they perceived to be good, to a life in relative poverty causes what I interpret to be distress. In general, the majority of my informants' narratives suggested that they expended much energy and time to worry about their financial situations. Some of the participants also reported feelings of shame to be in such a situation. We know from other studies that certain immigrant groups in Norway belong to the lower social strata represented by low education, unemployment, and small and cramped apartments (Blom 2008). According to the literature, it is not unusual to perceive financial strains as major stressors in life (Bergman 2005). These data are personally reflected in my study.

5.2.4 Discussion of research question 2: "What are the lived experiences of the non-Western informants with chronic pain?"

In this section I have demonstrated certain perceived constraints that the informants live under which a number of them also perceive to influence their pain condition. The majority of these constraints relate to leaving family and friends behind, and to living in a foreign country with a small social network. In addition, the informants express worries about their financial situations, which I interpret to be because of their difficulties in finding work or inability to work. For some of the informants they describe an expectation of remittance from the family abroad, putting further pressure on their economy.

Life contains a series of critical transitions; emotional and material changes from early childhood to old age (Wilkinson and Marmot 2003). These transitions include starting primary education, moving from primary to secondary education, starting work, getting married, moving, and so on. Moving from one country to another is a transition that is often

regarded as a turning point in the continuity of life because the migration process is characterized by different losses. The migrants leave behind the social, cultural, and environmental contexts that have given meaning to their lives. They lose, at least temporally, their social networks, and it has been demonstrated that they may encounter difficulties when establishing themselves in a new context (Thapa et al. 2007). In the recipient country, they have to reorient themselves in a new culture, organize practical issues that are important to everyday life, and establish or re-establish social networks that have been cut off due to the migration process. These processes cause specific challenges, especially when there is a lack of language knowledge. The difficulties faced by immigrants are shown to be unemployment, discrimination, loss of social status, and change of roles (Kristiansen et al. 2007), suggesting that my informants are not alone facing similar challenges. Furthermore, the psychological distress of this complex process is mediated by the immigrants' social and psychological resources, which may be linked to socioeconomic position and social support.

Previous studies have indicated that the loss of social networks and isolation are factors affecting the health and mental status of many immigrants (Hägerstam 2008; Blom 2008). Social support and good social relationships make an important contribution to health, as people need emotional and practical resources, and support may help people to get what they need (Berkman et al. 2000; Umberson and Montez 2010; Wilkinson and Marmot 2003). For example, it may be that if Abyan had experienced social support, the solution of sending her 15 year old son away would not have taken place.

Economic strains are among the most powerful factors affecting health over the course of one's life (Pearlin et al. 2005). While Norway is perceived to be among the richest countries in the world, socioeconomic position matters. While material deprivation may no longer be the main issue in relation to health in Norway, there are increasingly different social inequalities in health (St.meld. nr 20 (2006-2007)). One's position in society will describe something about one's health. People in a higher position demonstrate better health when compared with people in the lower social strata. Within Oslo there is reported to be 8 years difference with regard to life expectancy between the west and wealthy side of the city, and the east and center areas (Oslo Kommune 2011). Furthermore, data demonstrates that certain non-western immigrant groups are found in the lower socioeconomic positions, suggesting a correlation between their socioeconomic position and the higher prevalence of certain diseases.

Sen (1999) claims that income is not the most important factor when discussing social inequalities in health; however, relative income is important as it translates into capabilities. What is important is not so much what you have, but what you can do with what you have, which he claims is control and social engagement (Sen 1999). Marmot (2006) states that people's capabilities to lead lives they value and the control they have over their own lives will be determined by social conditions such as socioeconomic status. Subsequently, low social position means decreased opportunity, empowerment, and security (Marmot 2006). By this I understand that although the informants' incomes may be higher compared to that of their countries of origin, their income is relatively low compared with Norwegian standards. Several of the informants recounted activities they were not able to do, such as buying a place for themselves or visiting friends and family in their country of origin. One could ask if they would have the capacity to lead lives they valued and be able to control their life circumstances if they lived in their home country. Maybe not, but they would have social support through their families and friends, which is reported to be of equal importance (Marmot 2006). With the deprivation of a social network and social support, meaningful work, and opportunities, Marmot (2004) found that it was harder to have control over one's life or be a full social participant. The low level of Norwegian knowledge and education as well as some cultural barriers may create social exclusion by preventing individuals including my informants from participating through work, and make it difficult to access services and citizenship activities.

I also want to bring up the aspect of failed expectations. Halgan's story demonstrated the consequences of holding high expectations which failed. Also, Meryam's story reflected some of these issues when she described how much she cried when she arrived in Oslo the first time, seeing the little apartment she was going to live in. Pearlin et al. (2005) claimed that for individuals who have strong but unrealized ambitions, the gaps between their dreams and the realities of their achievements can cloud their daily lives. I find this to be accurate for several of my informants.

With these reflections I argue that social and cultural dimensions influence our body and our health. The body and culture are not separated from each other, and to a large extent people "embody" the culture they live in. Maurice Merleau-Ponty, one of the most influential phenomenological philosophers, argues that the body should be understood as an embodiment body; a carrier of meaning (Merleau-Ponty 1994). To search for meaning in a painful body may therefore be of importance. I argue that the non-Western immigrant women lived

experiences of resettlement in the new and unfamiliar social world and physical surroundings, challenged their familiar norms, values, social relations, and identity in such fundamental ways that the lived experiences are expressed through the body in pain. In addition, the body contains the longing for old times or the longing for being in another place which I understand to be wounds that may never heal completely. In this perspective, my informants' CMP condition may be interpreted as bodily reactions which have evolved over time as a rational reaction to life experiences.

6.0 CONCLUSION

This study has explored the understandings and the lived experiences of chronic pain among non-Western immigrant women. The purpose was to enhance the understanding of the chronic pain phenomenon through the perspectives of the informants. The findings that emerged from this study provided valuable insights into the multiple and complex ways in which non-Western immigrant women make sense of and give meaning to CMP.

Furthermore, this study explored the dimensions of the social and cultural context, the lifeworld and its impact on the understandings and the lived experiences of the informants.

The data revealed that all of the study subjects had some form of explanation for their pain, and that they all extracted knowledge from a wide range of explanatory models when they tried to create meaning in their pain condition. I interpreted the biomedical approach to be important to most of the informants as the pain was perceived to be of a merely physical nature. Furthermore, the informants reported frequent medical encounters in their search for a diagnosis and treatment suggesting that they perceived their conditions to be medical.

However, all of the informants included social and emotional factors which they perceived to cause feelings of stress and worries influencing their pain condition. In addition, alternative understandings were included in their explanatory models.

The search for a diagnosis with the physician was central in all of the subjects' narratives, causing a mixture of feelings and frustrations. The medical encounters constituted a small percentage of the informants' lives, while at the same time the clinicians were perceived to play a major part in their lives. This opposing element is of importance for the health care professionals to take into account. The findings, supported by other studies, indicate the distress the informants face in the medical encounter when they are not understood, not

treated with dignity or when the physician is not able to provide a diagnosis. Several of the informants described situations where they felt that the doctor did not conduct proper examinations or dismissed them by relating their pain condition to psychological issues. In addition, several of the informants' narratives indicated their lack of knowledge about Norwegian doctors' competency, accordingly influencing their level of trust in the Norwegian health care system. This study suggests that there exists a foundation for potential conflicts in the medical encounters in the future between the informants and the physicians.

The second research question was related to the lived experiences of the non-Western informants. The findings suggest that the informants live in a stressful context influencing several levels of their lives as well as their pain condition. The informants described how it felt raising children in a country with different norms for children's upbringing, without the support of close relatives. There were stories about longing for family, friends, and warm weather, and for a life that once was. The informants revealed the difficulties they faced living in relative poverty, and the expectations of remittance. As immigrants, they lived in absence of their essential values such as the extended family, language, and knowledge of norms and culture. I have argued that all these experiences are embodied in the body and are reflected in the physical pain symptoms.

In the following section, possible implications for management and policy strategies will be presented

6.1 Implication for management

Based on the findings in this study I found that the informants have expectations and hope of a medical diagnosis which puts the physicians in a challenging position if no pathophysiological explanation is available. Data suggests that the CMP condition involve psychosocial aspects, and management of chronic pain condition is perceived most effective when cognitive therapies are included in the strategies (Morley, Eccleston, and Williams 1999). Many clinicians find it challenging to face chronic pain patients as they feel they have little to offer this patient group apart from analgesic drugs (Werner and Malterud 2003). My argument is that a phenomenological approach is a first step towards a holistic management of the CMP patient. In the beginning of this paper I noted that it was important to see and understand the perceptives of the person in pain, and that this could be done through phenomenology. Several researchers stress the importance of the health care professionals to

transcend their preconceptions of the traditional bio-medical approach to patients and the role as ‘experts’, to an increased focus on the lived experiences of the patients and their role as a fellow human being with the goal of empowering the individuals (Malterud and Solvang 2005; Thesen 2005). An explicit benefit of using a phenomenological approach to examine the experience and perception of non-Western immigrant women living with CMP is that the experiences are captured from the individual’s perspective. Eliciting the individuals explanatory models provides knowledge of the beliefs that the individual holds about the pain condition and the personal and social meaning which she or he attaches to it including the context in which the individual live in. It may also give knowledge about the individual’s expectations of health care and his or her coping strategies. Through open ended questions, the informants in this study included dimensions from their lifeworld enabling the researcher an understanding of the embodied body. Hence, comparison of the individual’s understanding with the clinicians understanding may enable the clinician to identify major discrepancies that may cause problem for management. Such comparisons also help the clinician to know which aspects of his explanatory model need clearer explanation to patients (and families), and what sort of patient education is most appropriate.

The findings from my study suggest that health care professionals should not in the first initial meeting argue that the pain symptoms are merely due to psychosocial dimension; the physical complaints have to be met with respect. A study of immigrant CMP patients in Sweden did demonstrate that widespread pain was nearly always explained by clinical findings, and especially by numerous tender-structure locations in women (Löfvander and Engström 2007). Based on the findings in my study I will suggest that when the bodily nature of the individuals’ suffering is validated, most individuals will acknowledge that stress, social conditions, and emotions have an effect on their physical condition. This provides an entree to applying strategies of cognitive behavioral medicine to address the psychosocial factors that contribute to chronicity and disability (Kirmayer et al. 2004). Furthermore, to feel that one is respected, believed and understood by health personnel is important (Ostlund et al. 2001) and may be crucial for effective management (Steihaug, Ahlsen, and Malterud 2002).

The literature suggests using an interdisciplinary management approach to address chronic pain conditions. An interdisciplinary approach in management of CMP attempts to incorporate elements targeting the biological, psychological, and social factors that serve to maintain and exacerbate pain. The key disciplines are medicine, psychology and rehabilitation and the ideology is that effective treatment strategies should address all aspects of the pain experience. In order to be successful, interdisciplinary care should involve the active participation of specialists from different fields including physicians, psychologists, counselors, physical therapists, case managers, occupational therapists, and other health professionals including psychiatrist and nurses (Oslund et al. 2009). The goals of interdisciplinary management include providing skills in decreasing muscle tension and sympathetic nervous system activation by addressing beliefs about pain and coping. Most interdisciplinary programs involve physical therapy, cognitive behavioral therapy, and instruction in self-regulatory techniques, enhanced with group educational meetings. A combination of different approaches including cognitive behavioral therapy (CBT), physical therapy, aquatic physical therapy, occupational therapy, group education and group relaxation have been demonstrated to improve pain severity, decreased emotional stress and increased perceived control of pain (Oslund et al. 2009; Robbins et al. 2003; Guzmán et al. 2001). Through guidance, the individuals are learning to overcome fear and avoidance behavior associated with pain. In addition, the goal is to improve physical strengthening and conditioning (Oslund et al. 2009). An interdisciplinary approach includes additional professionals than merely the GP involved in the management of the CMP patient accordingly requiring more resources than what is used in the management today.

6.2 Implications for policy strategies

There is a growing trend in policy making of holding people responsible for their life-style diseases including chronic pain causing debate in Western societies. This view may be attributed to the scarcity of resources and the belief that people who contribute to their own disease should suffer the consequences of their actions (Persson 2012). I understand the debate between Lazarus understanding of successful coping depending on the cognitive abilities of a person and Marmots theories of coping as dimensions of autonomy and empowerment depending on societal structures as an example of such a debate. I argue with Persson (2012) who states that policymakers should not hold people responsible for their health because the focus tends to overlook the life course origins of some of the

circumstances leading to decreased health (Pearlin 2005). In their pain narratives, my informants included strains which they perceived to increase their level of stress and accordingly deteriorating their pain conditions. I have interpreted several of these strains including financial strains to be strains that they cannot control. While I have in the previous section presented an interdisciplinary management approach to CMP conditions which includes cognitive therapies where people may learn to accept illness as part of life and learn cognitive techniques of relaxation to reduce stress, I also argue that policy makers have a responsibility to improve living conditions and the health of its citizens.

In chapter 2 in this paper, Norwegian policies aiming at reducing inequalities in health was presented. These policies suggest that the Norwegian government is realizing their responsibility for reducing inequalities in health. The government has also applied policies in regard of integration in order to facilitate social inclusion and increase living standards which they find to be among the main determinants for better health. This is in line with Marmot (2006) who claim that to change social conditions and to ensure that people have the freedom to lead lives they have reason to value would reduce health inequality. The Norwegian policy guidelines state that as a society we have a duty to do what we can to reduce health inequalities in groups where these are avoidable, inequitable and unfair. The Norwegian governing principle is that all residents of Norway including refugees and immigrants have equal rights and duties to health services and social assistance (St.meld. nr 20 (2006-2007)). Furthermore, one of the government main goals is to get more immigrant women into the labor force. When individuals hold little education and basic Norwegian language skills, getting work is difficult. Providing Norwegian language skills is of importance for non-Western immigrant women including my informants to improve possibilities for entering the labor force. Accordingly, the government is currently strengthening language training for female immigrants as well as implementing qualification programs for enabling inclusion into employment (St.meld nr. 6 (2012-2013)). This ideology is based on the ideas that if people work they will automatically be integrated by receiving a wider social network (thus social support), increase their socioeconomic position and have better health. However, learning to write and read as adults is demanding a major amount of resources and time. Furthermore, my informants reported that they stayed several days a month at home due to their pain, preventing them from attending school. According to the informants, the pain condition did also decrease their concentration and ability to learn. A number of my informants reported

that they did not have an income while they attend school, or that the amount they received was difficult to survive on with children. Furthermore, several of the informants reported a lack of social and emotional support. My argument is that to improve the socioeconomic position of this group and accordingly their health, more resources should be implemented. The resources may possible include further financial, practical and emotional support systems which could provide my informants and their counterpart with the possibilities to further improve their Norwegian language skills both orally and written, increase their educational level and at the same time provide them with an income that is equally sufficient to live a life one values. Furthermore, policies should be implemented to facilitate cooperation between school services, social services and health services to enable holistic management in all areas of the women's life.

7.0 REFERENCES

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8.0 APPENDICES

Appendix 1: Interviewguide.

Intervjuguide:

Løs prat (5 min)

- Uformell prat

Informasjon (5-10min)

- Si litt om temaet for samtalen
- Bakgrunn og formål
- Forklare hva intervjuene skal brukes til
- Forklar taushetsplikt og anonymitet
- Informer og spør om samtykke for opptak.

Demografiske spørsmål (5 min)

- Alder
- Hvor kommer du fra?
- Familie
- Hvor lenge har du bodd i Norge?
- Utdannelse
- Arbeidserfaring

Nøkkelspørsmål (45-50 min):

1. Husker du første gang smertene kom? Kan du fortelle litt om den situasjonen.
2. Tenk på en typisk dag: hvordan påvirker smertene deg/den?
3. Hva tror du smertene kommer av?
4. Kan du fortelle litt om opplevelser når du føler du ikke har så mye smerter?

Oppsummering (5-10 min)

- Oppsummerende funn - Har jeg forstått deg riktig?
- Er det noe du vil legge til?

Appendix 2: Information letter AEI

Oslo, september 2012

Informasjonsskriv til rektor og lærere

Jeg heter Siri Nyen og har bakgrunn som sykepleier, men studerer for tiden på Høgskolen i Oslo og Akershus til en master i internasjonal sosiale velferd og helse. I den forbindelse ønsker jeg å skrive en masteroppgave om innvandrere kvinner som lever med kroniske smerter.

Mange kvinner er plaget med diffuse/generelle smerter i kroppen som ikke alltid kan forklares og det viser seg at spesielt kvinner fra land som Pakistan, Tyrkia og Irak rapporterer høy forekomst av slike plager. Ikke bare profesjonsutøvere som arbeider i helse og sosialtjenesten, men også lærere har i mange tilfeller ikke har kunnskap nok til å møte dette. Denne gruppen opplever i mange sammenhenger å bli stigmatisert. Flere etterlyser nå å inkludere individets eget perspektiv i forståelsen av dette problemet. Dette er bakgrunnen for min masteroppgave. Jeg ønsker derfor å intervjuer kvinner med innvandrere bakgrunn om hvordan det er å leve med smerter. Formålet med dette er å øke kunnskap blant de som arbeider med denne gruppen. Jeg skal ikke hente inn helseopplysninger som er taushetsbelagte, kun snakke om den subjektive opplevelsen av å leve med smerter; hvordan det påvirker hverdagen og hva kvinnene selv tenker er årsak til smertene. Alle data vil bli anonymisert, og alt materiale vil bli destruert i etterkant av studien. Deltakerne kan når som helst trekke seg fra studien. Deltakeren bestemmer selv sted og tid for intervjuet som vil vare ca en time.

Jeg lurer på om det kunne være av interesse for noen av deres elever å være med i denne studien? Ta gjerne kontakt dersom dere har spørsmål. Mitt tlf nr er 91781177.

Med vennlig hilsen Siri Nyen

Appendix 3: Information letter to the women presented orally by the teachers.

Har du ofte vondt i hodet, magen, nakken, skuldre eller andre steder i kroppen?

~ Da lurer jeg på om du vil være med i en liten studie.

Mitt navn er Siri Nyen og jeg skriver for tiden en oppgave ved Høgskolen i Oslo og Akershus om kvinner som lever med smerter. I den forbindelse ønsker jeg å gjøre noen intervjuer. Jeg er sykepleier og ser i jobben min at mange kvinner som kommer til Norge er plaget med diffuse/generelle smerter i kroppen. Helsevesenet og andre offentlige tjenester vet ikke alltid nok til å møte deg som har slike plager. Jeg vil derfor gjerne intervju deg om hvordan det er å leve med smerter. Jeg skal ikke hente inn helseopplysninger som er taushetsbelagte, kun snakke om hvordan du selv opplever det å leve med smerter, hvordan det påvirker hverdagen din og hva du selv tenker er årsak til smertene. Formålet med dette er å øke kunnskap slik at vi kanskje kan bli flinkere til å hjelpe i det lange løp.

Samtalene vil vare ca 1-1,5 time. Du bestemmer selv hvor vi skal snakke sammen - om det er på kafe, på et senter, hjemme hos deg eller annet sted. Jeg kommer til å spørre deg om det er greit at jeg tar opp intervjuet på bånd. Dette for at jeg skal huske det vi har snakket om. All informasjon som blir gitt vil bli behandlet anonymt. Det betyr at ingen personlige opplysninger om deg vil bli oppgitt når jeg skal presentere studien. Ingen skal kjenne igjen dine uttalelser og alle opplysningene vil bli slettet når studien er fullført.

Si ifra til lærer om du har lyst til å være med.

Med vennlig hilsen Siri Nyen

Appendix 4: Letter of consent.

Samtykke til deltakelse i studien «Å leve med smerter»

Denne studien har som tema ‘Å leve med smerter’. Mange kvinner lever i dag med smerter, og denne studien ønsker å se nærmere på hvordan kvinner opplever det å leve med smerter.

Det vil bli brukt båndopptaker under intervjuene. Opptaket blir brukt for å kunne huske hva som har blitt sagt. Alle dine opplysninger vil bli anonymisert, og opptakene vil bli slettet når studien er ferdig.

Om du samtykker til å bli med i studien har du likevel rett til å trekke deg fra studien når som helst før oppgaven er ferdig.

Jeg vil være med i studien (ja/nei):

Jeg samtykker til at samtalen kan tas opp på bånd (ja/nei)

(Signert av deltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)