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# **CHALLENGES IN SUPPORTING THE STRUGGLE FOR SENSE OF CONTROL**

**Identifying rehabilitation needs of forced resettled  
women from the Middle East diaspora living with  
chronic pain**

Viktoria Zander



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Challenges in supporting the struggle for sense of control. Identifying rehabilitation needs of forced resettled women from the Middle East diaspora living with chronic pain.

## THESIS FOR DOCTORAL DEGREE (Ph.D.)

By

**Viktoria Zander**

*Principal Supervisor:*

Associate Professor  
Maria Müllersdorf  
Mälardalen University  
School of Health, Care, and Social Welfare

*Co-supervisor(s):*

Professor  
Kyllike Christensson  
Karolinska Institutet  
Department of Women's and Children's Health  
Division of Reproductive Health

Professor  
Henrik Eriksson  
The Swedish Red Cross University College  
Department of Nursing and Care

*Opponent:*

Professor  
Mona Eklund  
Lund University  
Department of Health Sciences/ Occupational  
Therapy and Occupational Science

*Examination Board:*

Associate Professor  
Gunilla Brodda Jansen  
Karolinska Institutet  
Department of Clinical Sciences, Danderyds  
University Hospital  
Division of Rehabilitation Medicine

Associate Professor  
Carl Molander  
Karolinska Institutet  
Department of Clinical Sciences, Danderyds  
University Hospital  
Division of Rehabilitation Medicine

Associate Professor  
Lars-Eric Olsson  
University of Gothenburg  
Sahlgrenska Academy  
Institute of Health and Care Science and Centre for  
Person-Centred Care



*”Om jag ska kunna föra en människa till ett  
bestämt mål måste jag först finna henne där  
hon är, och börja just där.”*

Sören Kierkegaard



# ABSTRACT

Women who are forced to resettle from the Middle East have experienced the cumulative trauma of war, threats, flight and adjusting to a new life in the host country. Many of these women develop musculoskeletal pain. Considering the ongoing conflicts worldwide, the high number of forced resettled people in Sweden will persist. Primary healthcare faces new challenges in addressing the needs of patients who live with the physical and mental consequences of war and resettlement.

The overall aim of this thesis was to illuminate the perceived causes of musculoskeletal pain and suggestions for rehabilitation measures to be able to support identification of needs of Middle East diaspora women.

In two initial studies, women from Iraq (study I) and professionals within primary healthcare (study II) were approached with interviews and questionnaires. The goals were to explore the perceived causes and suggested measures related to chronic pain in Middle East diaspora women. The results from these two studies, together with a review of existing research, formed the basis for the development of an interview guide, which was validated by cognitive interviews and a pilot test (study III). The guide was further evaluated by healthcare professionals in an intervention study (study IV).

The perception among both the women and the healthcare representatives was that the pain is complex and is related to experienced traumas and difficulties, but the women (study I), also considered the pain a physical symptom calling for a physical treatment. A physician could provide a trustworthy diagnosis and effective treatment with the main purpose of regaining a sense of control of the life situation, by controlling the consequences of pain in the body, for everyday life, and for future plans (study I). Meeting with Swedish healthcare was perceived as complicated from the perspectives of both the women (study I) and the healthcare professionals (study II). Although being able to identify the causes of pain related to traumas and difficulties, healthcare professionals found directing measures to identified causes of pain difficult (study II). The complexity of meeting patients who have experienced cumulative traumas in the form of chronic musculoskeletal pain indicates a need for increased support for healthcare professionals. For this purpose, an interview guide was developed (study III), from a person-centered point of departure, acknowledging physical, psychological, social, and spiritual components. An evaluation of the guide (study IV), indicated that the questions were perceived as useful and relevant but also associated with challenges, such as a perceived lack of competence to handle situations and reactions caused by asking about the women's experienced traumas, as well as organizational factors such as time constraints and a lack of collaboration.

The results indicate a need for organizational changes with increased collaboration between healthcare and authorities within society. Such changes should be combined with increased knowledge and changes to routines within primary healthcare to avoid putting the patient at a disadvantage, but instead support her struggle for a sense of control over her situation. The results also indicate a need to include intersectionality and a person-centered approach in the education of healthcare professionals.

**Keywords:** biopsychosocial-spiritual, chronic pain, content analysis, Delphi, forced resettled, Grounded theory, immigrants, instrument development, intersectionality, intervention, person-centered, primary healthcare, women's health

## LIST OF SCIENTIFIC PAPERS

This thesis is based on the following studies, referred to in the thesis by their roman numerals.

- I. Zander V, Müllersdorf M, Christensson K, Eriksson H. Struggling for sense of control: Everyday life with chronic pain for women of the Iraqi diaspora in Sweden. *Scand J Public Health*. 2013;41(8):799-807. doi: 10.1177/1403494813492033
- II. Zander V, Eriksson H, Christensson K, Müllersdorf M. Rehabilitation of women from the Middle East living with chronic pain – perceptions from health care professionals. *Health Care Women Int*. 2014. doi: 10.1080/07399332.2014.989439
- III. Zander V, Eriksson H, Christensson K, Müllersdorf M. Development of an interview guide identifying the rehabilitation needs of women from the Middle East living with chronic pain. *Int J Environ Res Public Health*. 2015;12:12043-12056. doi:10.3390/ijerph121012043
- IV. Zander V. Identification of rehabilitation needs of women from the Middle East living with chronic pain – evaluation of an interview guide from the perspective of healthcare professionals. In manuscript.



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## **LIST OF ABBREVIATIONS**

GT	Grounded theory
IASP	International Association for the Study of Pain
PTSD	Post-traumatic stress disorder



# 1 INTRODUCTION

This thesis stems from a desire to understand the experience of pain in forced resettled women. The point of departure was questions raised from more than ten years of working as a physiotherapist within primary healthcare in an area with a large population from Iraq. As the sole female physiotherapist in the unit, I was the person who met with the female patients most of the time. In meeting with these women, I perceived a frustration on their part due to their inability to understand and their sense of not being understood by the Swedish healthcare system. Frustration existed because no one had been able to provide an acceptable explanation for why a cure to the pain could not be offered. Also, frustration on the part of healthcare professionals existed due to a perceived inability to reach the women. The following questions were raised: What are these women's needs, and how can those needs be met? What are the women's expectations when seeking primary healthcare? How can we meet their expectations? These questions led to a master's thesis that, in turn, brought an increased interest as new questions were raised.

The studies described in this thesis address the needs of women from the Middle East diaspora in Sweden. The first intention was to focus on women from the Iraqi diaspora. However, because healthcare professionals in general do not know the origins of their patients, the target group for studies II, III, and IV was broadened to include women from the geographical area of the Middle East. The studies were performed in regions with high proportions of people from the Iraqi diaspora, which partially ensures the inclusion of women from the originally intended target group.

Due to the specific and strained situation of asylum-seekers, the studies in this thesis focus on women who have permanent residence in Sweden.

## **2 BACKGROUND**

The forced resettled populations in Sweden are increasing. At the end of 2014, 16.5% of the population had been born abroad (1). Most of these individuals came from the Middle East, of which the largest group was from Iraq. Approximately half of these individuals were women. The resettlement to Sweden has increased exponentially during the final months of 2015 (2). Every day, there is news about people risking their lives in the hope of finding safety. With the growing number of forced resettled people in Sweden, healthcare must adjust to enable rehabilitation according to their specific needs.

### **2.1 FORCED RESETTLEMENT AND THE IMPLICATIONS FOR HEALTH**

Extensive research has been conducted on the effects of forced resettlement on health. The number of articles concerning migration and health has increased during recent years, with almost 50% of the articles in PubMed, Web of Science, and CINAHL published during the last five years.

Forced resettlement is a cumulative trauma. One trauma is added onto another and is prompted by traumas, abuse and living difficulties in the home country that have made life unbearable or life-threatening, making a move inevitable. Some individuals have experienced torture. The Red Cross in Sweden estimates that as many as 35% of the Iraqi diaspora who came to Stockholm and Sweden during 2008 had experienced some type of torture, and approximately 100,000 individuals in Sweden live with the physical and mental scars (3). Traumas such as war and abuse may result in physical scars and pain (4-8), such as that deriving from wounds from rape or other physical violence. In addition to physical injuries, there are mental consequences such as depression, anxiety, and post-traumatic stress disorder (PTSD) (6, 8-12).

PTSD is a disorder related to trauma and stress that involves re-experience, trigger avoidance, negative cognitions and mood, and hyperarousal, with longstanding and debilitating consequences (13). Torture and cumulative exposure to traumas are associated with PTSD as well as depression (6, 10, 12, 14). PTSD and depression, in turn, are associated with chronic pain (7). Most torture survivors report pain (4, 15-18), as well as depression, anxiety, and PTSD (12, 14, 16, 18, 19). There are also associations with conditions such as hypertension, dyslipidemia, HIV and tuberculosis (16).

Resettlement, especially when forced, is related to material, social, and mental loss. People who are forced to resettle are leaving their homes, families and friends behind (20). Settling in a new country often also includes the experience of losing culture, habits, status, and ultimately identity (12, 21, 22). These multiple losses result in feelings of loss and grief, anxiety, frustration, isolation and homesickness (20-23). The feelings may be so strong that many want to go back to their country of origin despite the circumstances that forced them to resettle (21, 22). Beyond the loss and grief, there is also the strain of uncertainty following

the long asylum process; people do not know whether they will be able to stay in safety (24-26).

Adjustment to a new life in a strange part of the world brings certain difficulties. Difficulties with understanding a new language result in dependency on others to communicate (27). Other difficulties involve the adjustment to a new culture and new values, family issues, difficulties finding employment, and financial problems, combined with discrimination and racism (12, 22, 25, 26). There have been reports of individuals who have left war and threats only to experience new violence and threats in the host country (12).

The cumulative effects of traumas due to forced resettlement can have quite a devastating effect on health. Mental illnesses, such as PTSD, depression, anxiety, psychosis, and dissociation have been reported among resettled populations (12, 28-31). Worldwide, tens of thousands of people who were resettled in western countries probably have PTSD. The results reported by Fazel et al. (32) suggest that approximately one in ten individuals experiencing forced resettlement has PTSD, approximately one in 20 has major depression, and approximately one in 25 has generalized anxiety disorder, with possible overlap in many people.

Research within Sweden is in line with international reports of negative health effects among dispersed populations (33-39), with reports of more longstanding illnesses, such as pain and disability, as well as of mental health symptoms, such as psychosomatic symptoms, distress and sleeping problems. There is research describing the consequences on health due to forced resettlement (36), and stress during the asylum processes (25, 36), together with stresses from life circumstances (25, 34, 39, 40). Stress is associated with resettlement and includes difficulties understanding and being understood in society, as well as employment and financial problems, together with a sense of alienation and discrimination. Many resettled people express a sense of social isolation (12, 22, 41, 42).

Regarding resettlement stressors, there are reports of experienced difficulties and discrimination that occur in conjunction with work and employment among the resettled population. People experience problems finding employment or are offered only temporary employment, and they have fewer opportunities to increase their wages and improve their skills (22). Resettlement may cause poor health, which leads to unemployment and/or sick leave as a selection effect. Resettled populations have an inferior position in the labor market, leading to poor health due to exposure effects. This influence on health is more marked for women than for men (43). For resettled women in Sweden, unemployment has been a source of frustration, as it is associated with dependence on social welfare, and a sense of exclusion. On the one hand, the perception of being dependent on social welfare has been perceived as restrictive and disempowering. On the other hand, social assistance was associated with feelings of being cared for by the host country (44).

From the research presented, it may be concluded that the cumulative trauma of forced resettlement is multidimensional. It has physical, mental and social consequences on health.

### **2.1.1 The health of forced resettled women**

The implications for health from resettlement are more prominent from women than men (45). Women from war-affected areas in Iraq have suffered the physical and mental consequences of traumas, have faced difficulties due to infrastructure that was damaged as a consequence of war, and have experienced loss, grief and fear for their lives and the lives of their families (45, 46). Women and children suffer from war not only because of injuries inflicted on the civilian population, but also because of how they are used as a means of warfare. Many reports describe how sexual violence is used as a war tactic (47). In the process of migration, women and girls are at high risk for abuse, both during flight and in refugee camps (45, 47). In addition to the physical and mental consequences, they must live with the shame. Many are reluctant to report abuse because the legal system blames the victim in many cases (47). Many forced resettled women have witnessed how physical, sexual, and/or emotional violence has become a part of their lives. Even if they have not been abused themselves, many of the women know others who have been abused. Many women also have relatives who had been in prison. Not knowing what happened to them leads to feelings of helplessness, and they fear for their own safety and the safety of their loved ones. The women witnessed how traumas changed them emotionally, which, in turn, affected their physical health. The perception was that life would never be the same again (45, 48). In addition to violence as a means of war, domestic violence increases during war time. Gender-based violence is connected with war, the longer a war drags on, the more frequent violence becomes (49). In 2013, almost 70% of Syrian women experienced physical or psychological violence in their home (49). Widowed women find themselves as the sole wage earners of the family, and many earn too little to feed their families. Mothers often go hungry to feed their children (46).

As previously described, traumas such as these may result in PTSD, which, according to some research, is more likely to develop in women than in men (50, 51). PTSD is commonly associated with physical conditions, including chronic pain (52). Traumas such as physical or sexual abuse among women are associated with musculoskeletal pain (53, 54).

According to the results of studies conducted in Nordic countries, forced resettled women are at a high risk for illness (35). Resettled women have reported longstanding illnesses such as pain, with more tender points, and increased pain anxiety. These women also have a higher risk of severe pain than men (33, 55), together with high degrees of fatigue and sleeping problems (33).



### **2.1.2 The embodied experience of pain**

In the previous section, research was presented to describe the physical, mental and social consequences of resettlement, including forced resettlement. Experiences of cumulative trauma, including violence and threats, together with the stress and strains of flight and adjustment to a new life in a strange part of the world, affect health. In people who have endured such journeys, the experience of pain is common. In this thesis, pain is defined according to the International Association for the Study of Pain (IASP) (56) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (p210). The experience of pain is subjective and should thus be accepted as if it would be caused by tissue damage. One possible way of categorizing pain is in terms of its duration. Acute pain lasts less than three months, and chronic pain lasts longer than three months (57). Chronic or long-standing pain persists for a prolonged period of time, sometimes a lifetime.

## **2.2 CHALLENGES FOR SWEDISH HEALTHCARE**

Considering the complexity of chronic pain in general and among forced resettled people in particular, healthcare professionals face major challenges in meeting the needs of these women. The complexity of pain in forced resettled populations makes meeting the individual’s needs difficult. This is especially true for care providers who are unfamiliar with the consequences of refugee trauma (8).

A power imbalance exists between healthcare professionals and patients, especially in encounters with patients from dispersed populations (58). As both healthcare professionals and patients bring their own background and experiences, beliefs, and values, misunderstandings and confusion can occur (59). The patient must make herself understood and properly communicate her health needs in a way that fits the healthcare professional’s expectations, which is more difficult for those who have not completely mastered the language and who do not understand the “healthcare culture”.

Language is often experienced as a major problem, making the patient dependent on others such as relatives or interpreters for communication. Although interpreters provide a valuable service, communication through an interpreter is difficult for the patient and the healthcare professional, making it more difficult to explain pain and symptoms and putting the quality of the consultation at risk. Such communication is also time consuming (58, 60, 61).

Issues such as differences regarding how to explain health and illness and differing ideas about treatment have been shown to affect meetings between care providers and patients from dispersed populations (8, 62, 63). Interviews have uncovered differing expectations on the part of patients and healthcare professionals (58). Differing expectations and contradictory views of healthcare from the patient’s country make building a relationship with the patient difficult (61). Cultural differences between healthcare professionals and patients from

dispersed populations may lead to misunderstandings and may affect treatment adherence (64).

In addition to linguistic and cultural barriers, possible low levels of health literacy among patients may pose additional challenges, especially regarding information and explanations (58, 65). It may be difficult for the patient to value the information that is provided (66).

Expanding dispersed populations in Sweden raise new challenges for healthcare professionals. The background of trauma among forced resettled individuals, linguistic problems, cultural differences, and possible low levels of health literacy contribute to the vulnerability of these patients and make working with foreign-born patients challenging for healthcare professionals (58, 66). Research describing encounters between immigrant patients and Swedish healthcare professionals points at difficulties and differences in the perception of symptoms (23, 58, 66).

Research within Swedish healthcare has recognized the difficulties and differences between the perceptions of healthcare professionals and patients from dispersed populations. One study reported the healthcare representatives' perception of immigrant patients as wanting passive treatments such as medications instead of advice regarding life-styles. They were also perceived to be exaggerating their complaints. However, what was perceived as exaggeration was, from the patients' perspective, an attempt to communicate their symptoms and complaints (58). This "exaggeration" of complaints has been recognized in another study (67), in which the initially wide spread of pain was interpreted to be a way of communicating with the physician. According to another study, physicians might perceive the pain as less intense than the patient does, suggesting that physicians are overlooking the psychological and emotional aspects of pain in dispersed populations (68). Patients have also reported that they have been given different diagnoses and explanations for their ailments when meeting different healthcare professionals, contributing to their confusion and frustration. The experiences of consultations without proper examinations, of not being offered an optimal treatment, and of not being believed or understood were seen as signs of dismissal (23).

As described in the previous section, the cumulative trauma of forced resettlement may have far-reaching and multi-dimensional effects on health. Primary healthcare professionals must be aware of the impact of migration-related life experiences on health (69), and those administering care should assess possible traumatic events with the patient to reach an understanding of the symptoms that might be associated with experienced traumas (70). At present, persons who have experienced traumas such as torture are often unrecognized in healthcare, possibly due to a lack of knowledge (3). Moreover, distress is commonly expressed in terms of somatic symptoms (62, 66, 70). Healthcare professionals must be aware that every individual is unique, with unique experiences and reactions to these experiences (69). Gaining insight into patients' reasoning and understanding about health and illness is

critical (66) to make sense of their different perspectives on illness. Otherwise, misunderstandings can occur.

The multidimensional consequences on health from forced resettlement, especially in dispersed women, makes assessing and addressing the needs of the resettled difficult, resulting in misunderstandings and frustration. There is a lack of knowledge and evidence-based literature supporting effective treatments for forced resettled populations (8, 71), especially within primary healthcare (8).

### **2.3 INTERSECTIONALITY**

Discussing the health and living conditions of diaspora women calls attention to an understanding of how different power structures in society intersect and reinforce each other, resulting in discrimination against certain individuals. These power structures play a role in the development of an individual's identity and conditions (72, 73), are relevant to the experience of pain, and are thus important to consider in treatment.

Intersectionality has its roots within feminist theory but also has connections to queer theory, post-colonialism, Marxism, and anti-racist theories (72). Intersectionality was developed with an emphasis not only on power relations based on gender, but also on relationships among women based on other social structures such as class and ethnicity that affect their life conditions (72). An intersectional perspective enlightens the interactions of structures such as gender, age, ethnicity, class, and functions and how these structures affect societal prerequisites based on current norms and values (72, 73). An intersectional analysis reveals the inequality created between and within groups that affect opportunities within society and often result in exclusion. One single structure, such as ethnicity, cannot be analyzed separately from the others. The interactions are assumed to change over time and to vary between contexts (72). As these power structures are related to norms and values, some groups of people will be valued more highly than others (73). In the present Western society, for example, being "white" is assumed to be advantageous. In Sweden, being categorized as Swedish, male, middle- or upper-class, adult but not old, and heterosexual is advantageous. None of these characteristics are assumed to be more important than another in predicting the development of power relations in different contexts (74).

### **2.4 A BIOPSYCHOSOCIAL-SPIRITUAL PERSPECTIVE**

The definition of pain (56) points at the subjective experience of pain, which recognizes the importance of a holistic approach to chronic pain. Because pain is a subjective and multifaceted experience, this thesis assumes a biopsychosocial-spiritual perspective by considering the interactions between physiological, psychological, social and spiritual factors. These interactions result in a unique experience of living with chronic pain for each individual.

The biopsychosocial perspective is widely used in chronic pain management (75, 76). It provides a framework to understand individuals within the context of their multifaceted biological, psychological, and social experiences. This approach for managing chronic pain recognizes the complexity of chronic pain as an integrated experience of biological, cognitive, sensory, affective, genetic, and social factors (75). The social part of the biopsychosocial perspective interacts with biological and psychological factors and includes daily living activities, the environment, social networks and relationships, social expectations, cultural factors, previous treatment experiences, and the individual's background (75, 76).

However, despite the holistic approach to pain management, this perspective lacks a spiritual or religious dimension (35, 77, 78). There are differing definitions of spirituality (78), sometimes suggested to be a search for meaning and purpose in life (78, 79). Most often, an overlap exists between spirituality and religiousness. The two concepts are often used interchangeably (78). In this thesis spirituality is the concept that will be used for both.

Spirituality has been shown to affect the experience of pain and the process of coping with pain. Thus, spirituality is an important dimension of a holistic understanding of pain. The use of religious and spiritual beliefs and activities to cope with pain has been studied in past research (80, 81). Spirituality alters a person's response to pain (77) and relates to a variety of health outcomes (81). Spirituality comprises a range of strategies, such as prayer, seeking spiritual support, and religious attribution, to reduce distress and generate solutions (77). Spirituality has been suggested to affect physiological, neurological, psychological, and emotional processes, which in turn influence the experience of pain (77). Positive religious coping techniques are related to better mental health. In turn, negative religious coping (feeling punished or abandoned by God) is related to poorer physical and mental health outcomes (77). Therefore, healthcare professionals should recognize and discuss spirituality with patients to build an understanding of their beliefs.

Spirituality has been described as a resource for forced resettled populations to address the grief and loss of their traumas (20). Spirituality affects health. It provides an explanation for suffering as well as techniques to diminish suffering (20), it is a strategy to make sense of suffering. Spirituality provides a sense of meaning by providing an identity, a home and a future to people in the Iraqi diaspora in Michigan (82), and it is thus a vital part of the web of conditions of well-being that constitute an individual's health (83).

Based on what has been presented, this thesis assumes a biopsychosocial-spiritual perspective in exploring the embodied experience of chronic pain in women from the Middle East diaspora in Sweden.

## **2.5 A PERSON-CENTERED APPROACH**

Expressing one's own needs is difficult, as is expressing the needs of someone else. Asking a person to express her own needs is not always possible because a person learns to need what

seems reasonable or what is possible to receive (84). To direct treatment to a person's needs, these needs must be explored. This thesis assumes a person-centered approach to rehabilitation based on the patient's narrative and her beliefs, fears and expectations. This approach is used to assess and address those needs, while keeping the patient in control of the rehabilitation process.

The right to healthcare on equal grounds is protected by Swedish law (85, 86). This right strengthens the patient's position and allows her to be more involved in her own care. In the beginning of 2015, this was complemented with another law (87) with the purpose of further strengthening the patient's position and promoting integrity, autonomy and involvement. A person-centered approach shifts the power toward the patient by making her involved in the rehabilitation, constructing a working alliance, tailoring the treatment to her needs and encouraging goal setting together.

Patient-centered medicine, which involves seeing the patient as a person within her context, was developed with an emphasis on the biopsychosocial perspective. Power is shared between the care provider and the patient, and the patient is involved in a partnership. The mutual influence that a care provider and a patient have on each other and on the care is emphasized (88). After an assessment of patient-centeredness in healthcare, the Swedish agency for health and care services analysis (Myndigheten för vårdanalys) concluded that no internationally recognized definition, standard or model for the description of patient-centeredness exists. They report the following five dimensions of patient-centered care: the patient being a co-actor; respect for individual needs, preferences, and values; coordination and continuity of healthcare; a holistic approach that considers medical, social, emotional, and spiritual needs; and the involvement of family and relatives according to the patient's wishes (89).

However, I share the belief that the patient concept is regarded as a passive recipient of medical care (90), and I support the use of the person-centered concept. This concept emphasizes the patient as a person who lives most of her life outside the healthcare system. She is a person with unique knowledge, experiences, life situations, beliefs and expectations (90, 91). In this thesis, I am also applying the following definition of person-centered care: "Identifying resources and possibilities by listening to the patient's narrative, which may form the basis for a mutually formulated health plan, and partnership. The relation between professional and patient supported by values such as mutual respect and understanding for the patient's self-esteem and wishes" (92, p79).

Central to person-centered care is the partnership between the healthcare professional and the patient. A meeting between these two is a meeting between two experts. They are both equal regardless of gender, ethnicity, or class. The healthcare professional has the specific knowledge from education and experience within his or her profession, and the patient is the expert on her own illness and health (91). The patient's narrative is the foundation for the

partnership. She can express her beliefs, fears, and expectations. Through the narrative, it is possible for the healthcare professional to explore the patient's experiences from an everyday context, together with resources and possibilities (90-92). This is the basis for trust in the meeting, which is essential to form a partnership. Decisions regarding the rehabilitation and treatment are made within this partnership. All that is said and mutually decided is written down in a document that is made available to the team including the patient and possibly her relatives (90, 92).

### 3 RATIONALE

Due to ongoing conflicts in the world, the high number of forced resettled individuals in Sweden will persist and even increase. There are many reports of women and girls being used and abused during flight and in refugee camps. People risk their lives trying to find safety. Women forced to resettle from the Middle East experience the cumulative trauma of war, threats, flight and the process of adjusting to a new life in the host country. Their living situation is further affected by different power structures in society that result in discrimination against some people. These power structures play a role in the development of an individual's identity and conditions, and they are relevant to the experiences of health and pain.

Changes within the Swedish population structure are reflected in primary healthcare, which faces new challenges in addressing the needs of patients who live with the physical and mental consequences of war and resettlement. There are reports of difficulties and frustration in the encounters between dispersed populations and the Swedish healthcare system. The complexity of the experienced pain among forced resettled women leads to difficulties in identifying rehabilitation and treatment needs. Additionally, women experience a lack of involvement in their rehabilitation.

The literature describes the importance of a holistic approach that considers the physical, mental, social and spiritual dimensions of each individual's experience of pain. This approach is even more important among forced resettled populations because of their background of war and the difficulties they experience, which make them even more vulnerable. Based on the research presented in the introduction, there is extensive knowledge of the health consequences of forced resettlement. The consequences are both mental and physical. The cumulative trauma has multi-dimensional consequences on the individual and their surroundings. However, there is currently insufficient knowledge in Sweden from a patient and healthcare provider perspective that takes this into account for women of the Middle East diaspora suffering from musculoskeletal pain. There is also a lack of instruments and treatments grounded in existing knowledge, especially in primary healthcare. To achieve an effective rehabilitation, increased knowledge among healthcare staff is needed. Additionally, instruments and interventions aimed at this patient group are required. To allow the development of such support, increased knowledge regarding the situation of Middle East diaspora women and their encounters with Swedish primary healthcare is required.

## **4 AIM**

The overall aim of the thesis was to illuminate the perceived causes of musculoskeletal pain and suggestions for rehabilitation measures to be able to support identification of needs of Middle East diaspora women.

Study I:

To elucidate everyday life with chronic pain from the perspective of women from the Iraqi diaspora in Sweden.

Study II:

To determine the perceptions of pain and pain rehabilitation directed to resettled women from the Middle East, from a variety of healthcare professionals.

Study III:

To develop an interview guide for healthcare professionals within primary healthcare, to support the identification of the rehabilitation needs of women from the Middle East living with chronic pain.

Study IV:

To, from healthcare professionals' perspective, evaluate the use of an interview guide in identification of rehabilitation needs of women from the Middle East diaspora living with chronic musculoskeletal pain.



## 5 METHODS

In the current thesis, interviews with Iraqi diaspora women (study I) formed the empirical basis for the subsequent studies, which include the first round of open questions in the Delphi study (study II) and the development of an interview guide (study III). The purpose of this interview guide was to support professionals within primary healthcare in identifying needs in encounters with women from the target group, which then were evaluated by an intervention (study IV). Finally, the results from these four studies were brought together and synthesized. These results are outlined in the results section.

### 5.1 DESIGN

The studies described in this thesis were performed to provide knowledge that can be used to develop an interview guide to support healthcare professionals within primary healthcare to address rehabilitation to the specific needs of each woman. The first study was an interview study guided by Glaser's Grounded theory (GT) (93, 94). The aim of a GT study is to explore how complex phenomena occur and to understand the meanings associated with experiences. The study is not based on a preconceived theory but begins with an area of interest. According to the theoretical sampling of GT, the sampling for data was conducted based on the questions that were raised during the research. The motives for using GT in this thesis were to explore the Iraqi women's experiences of chronic pain and to explore the meaning of their experiences to form an empirical basis for the questions that would be asked of healthcare professionals in the next study (study II). This was a consensus study using a classical Delphi approach (95) to achieve agreement among a group of experts on their perceptions of pain in the Middle East diaspora women. The motive was to use the agreed statements and the results from the interviews (study I) together with a literature search to form a basis for developing an interview guide to support healthcare professionals in identifying rehabilitation needs related to chronic pain in encounters with forced resettled women from the Middle East. The perception of support offered by the interview guide was evaluated in an intervention study with a sequential mixed methods design. Findings from the qualitative component were used to gain an understanding of the participants' evaluation in a questionnaire (96). An overview of the studies is outlined in Table 1.

**Table 1.** Overview of the studies.

<b>Study</b>	<b>Design</b>	<b>Data collection and analysis</b>	<b>Number of participants</b>
<b>I</b>	Glaser's Grounded theory	Semi-structured interviews.  Analysis according to the constant comparison method.	11
<b>II</b>	Consensus study	Delphi method.  First round with qualitative data analyzed with descriptive thematic content analysis. Subsequent two rounds analyzed descriptively.	35
<b>III</b>	Instrument development	1. Review previous literature. 2. Cognitive interviews. 3. Pilot study.	Interviews 7 Pilot study 4
<b>IV</b>	Intervention study with mixed methods	An intervention with post follow up with questionnaire and interviews.  Data from questionnaires analyzed descriptively. Written comments and individual interviews analyzed with qualitative inductive content analysis.	11 completed intervention  8 interviews

## **5.2 STUDY POPULATIONS**

The sampling for the four studies was conducted in Swedish municipalities with large Iraqi diasporas relative to the total population. The sampling was based on a survey of municipalities in Sweden with more than 2% of the population being born in Iraq. In total, 17 Swedish municipalities were identified.

### **5.2.1 Study I - theoretical sampling**

In the first study, sampling was purposeful and theoretical. In this case, the key-informants who were interviewed were forced resettled women from Iraq who had residence permits, were 18–65 years of age, and had chronic musculoskeletal pain. They were recruited in a

municipality with a large proportion of people born in Iraq by physiotherapists in primary healthcare and through a collaborative project that included the county council, the municipality, the regional social insurance agency, and the employment agency. Sampling and data collection were performed until theoretical saturation of the categories and their properties was achieved. Saturation was achieved after eleven interviews.

### **5.2.2 Study II - panel of experts**

Sampling for the second study was purposeful. Experts within the field, defined as representatives from different healthcare professions within primary healthcare in regions with large Iraqi populations and with experience with this patient group were invited to participate in the study. Within the 17 municipalities identified in the survey, 64 health centers and rehabilitation clinics with the highest proportion of immigrants were identified and informed about the study. The purpose was to gather knowledge and experiences from different professionals such as physicians, nurses, physiotherapists, occupational therapists, and psychologists who had worked in rehabilitation for at least three years. In all, 35 representatives from 16 health centers and rehabilitation units in 11 municipalities participated. The professionals represented five different professions: physiotherapists, occupational therapists, nurses, physicians, and psychotherapists.

### **5.2.3 Study III - cognitive interviews and pilot test**

In the process of validating the interview guide developed in the third study, representatives from primary healthcare in a region with a high proportion of people from the Iraqi diaspora participated. Seven cognitive interviews (97) with think-aloud methods for content were conducted with healthcare professionals. They were recruited from a single health center, and they included physiotherapists, occupational therapists, therapists, physicians, and nurses. Later, participants from the Delphi study (study II) were informed about the interview guide and were asked to participate in pilot testing of the interview guide to verify its usefulness. Although the wish was to include representatives from different professions, four physiotherapists consented to participate.

### **5.2.4 Study IV - intervention study**

Sampling for the fourth study was purposeful, based on the survey results. Within the 17 municipalities that were identified, 261 health centers and rehabilitation units in primary healthcare were contacted and informed about the study. A total of 21 healthcare professionals consented to participate. Six participants dropped out of the study, and another four had not used the interview guide during the study period, resulting in 11 participants who completed the intervention. They represented physiotherapists, counselors, and psychotherapists. Eight of these consented to participate in an interview.

## **5.3 DATA COLLECTION AND ANALYSIS**

### **5.3.1 Study I – interviews analyzed with the constant comparison method**

The first study was a qualitative interview study guided by Glaser's GT (93, 94). Semi-structured interviews were conducted to elucidate the women's perceptions of the causes and consequences of pain in everyday life together with their suggestions for measures that could be taken to manage or treat this pain. According to theoretical sampling, the interview questions emerged and changed during the process of the study. The native languages of the informants were Arabic and Kurdish Sorani. To ensure sufficient communication, two professional female interpreters were involved in the interviews. All of the interviews were recorded and transcribed.

This study was performed according to the constant comparison method (93, 94), with data analysis conducted in parallel with data collection. The analysis began with open coding; the text was read, and every sentence was given a label describing what was happening in the text. The codes were compared and sorted. Codes concerning the same topic were gathered into categories and sub-categories. According to the constant comparison, the initial codes and categories were compared and adjusted during the process of the study, so as not to lose sense of the context. As some of the categories were saturated, the direction of the questions in the interviews changed somewhat. Emerging theoretical codes and ideas concerning how different categories could be related to each other were noted as memos. Later, constant comparison and memos were used to confirm or modify hypotheses about the relationships between the categories. During the last stage of the analysis, a core category emerged.

Analysis according to GT is not a "straight line" analysis, but rather is more of a "forward-backward" analysis and can be better explained as "circular" (98). The initial codes and categories were adjusted during the process of the study, and the theoretical codes that appeared during the analysis were also adjusted. The results were validated by verifying the data, which were ensured by constant comparison and by memos written throughout the whole process. After extensive discussions within the research group, it was concluded that theoretical saturation of the categories and their properties was achieved after 11 interviews.

### **5.3.2 Study II – rounds with questionnaires analyzed with descriptive thematic content analysis and descriptive statistics**

The second study was a Delphi study (95) that was conducted in three rounds by mail or e-mail. The first round was a questionnaire with open questions about the experts' perceptions of the causes of pain and their suggestions for measures to manage chronic pain in women from the Middle East diaspora in Sweden. The questions were based on the results of the interviews conducted in the first study. The answers were analyzed and used to develop statements, resulting in 48 statements divided into five sections. In the second round, the healthcare professionals evaluated the degree to which they agreed with each statement using

a five-step Likert scale, from 1 (totally agree) to 4 (totally disagree) and 5 (I don't know). They were also asked to grade the three most important statements in each of the five sections. In the third round, the statements were sent out again, together with feedback regarding the median answers from all participating professionals and instructions to read all statements and consider re-evaluating the level of agreement with each statement.

The qualitative data from the first round of the Delphi study were analyzed using descriptive thematic content analysis according to Burnard (99) to create statements for the informants to evaluate in the coming rounds. The analysis began with the reading of the text and the noting of as many general themes as possible. Then, the text was re-read and coded to describe the content. The categories were then compared and grouped and any repeated categories were removed. To ensure that the list of categories covered all aspects of the text, the text was re-read alongside the list of categories. Finally, the text was divided into sections and placed under the appropriate categories and headings.

In the second and third round of the Delphi study, descriptive statistics were calculated using SPSS (Statistical Package for the Social Sciences). These rounds were used to establish the level of consensus for each of the 48 statements in the questionnaires. The level of consensus was set to 75%, meaning that at least 75% of the participants must agree (1 or 2 on the Likert scale) or disagree (3 or 4 on the Likert scale) to reach consensus (100).

### **5.3.3 Study III – development and validation of the interview guide**

The results from the first two studies (studies I and II) combined with a literature review were the basis for the third study, which involved the development of an interview guide in three steps: item generation, cognitive interviews and pilot testing.

1. A literature review was conducted using PubMed, Web of Science and CINAHL with the following search terms: needs, needs assessment, healthcare needs, chronic pain, rehabilitation, immigrants and refugees. A ten-year time span was specified. The overall purpose of the review was to gather research on the needs of immigrants and refugees experiencing chronic pain. Qualitative and quantitative articles concerning humans, adults, the English language, immigrants or refugees, musculoskeletal pain, and treatment suitable for primary care were included. The search resulted in 52 articles. Articles regarding older adults or children, studies focusing on substances used as medication or surgical treatments, studies focused on specific diagnoses or in-patient treatment, or studies concerning labor migration or asylum seekers were excluded. Articles were also excluded if the full text was not found. A reading of the articles narrowed the set down to 32 relevant articles. Templates from Swedish Agency for Health Technology Assessment and Assessment of Social Services (101) were modified and used to critically evaluate the studies. Descriptive thematic content analysis according to Burnard (99) was used to combine the most important themes from the literature and the results from studies I and II. The results were read, as general themes were

noted. Later, the text was re-read and coded sentence by sentence. The categories were sorted and grouped under the themes. A matrix showing themes and categories was created. During the next phase, the text was read alongside the list of categories, and necessary adjustments were made. Finally, the text was cut and placed under each theme and category. The identified themes concerned the patient's life situation; the consequences of pain; pain management; the patient's background; and the meeting with healthcare professionals. The results from this review formed a theme pool, from which items were created to cover each dimension of the themes.

2. After constructing the first draft of the guide, cognitive interviews with think-aloud methods (97) were conducted with seven representatives from primary care. They were asked to participate based on their experiences of meeting people from the Middle East diaspora in their everyday work. The purposes of the interviews were to identify questions that may be difficult to understand, to understand how the questions were perceived and interpreted, and to identify potential problems that may arise. This approach allowed for the understanding of the items in the instrument from the user's perspective rather than from the researcher's perspective (97). The interviews were recorded, transcribed, and discussed within the research group and provided a basis for revision of the guide.

3. Representatives from primary healthcare who participated in the Delphi study (study II) were informed about the interview guide and were asked to test it in their daily work. Four physiotherapists from three different health centers in different municipalities in Sweden consented to participate. They were informed about the guide and asked to use it during a five-week period when meeting with women from the Middle East who were suffering from chronic pain. At the end of the test period, they were asked to reflect on the usefulness, item interpretation, and content of the interview guide using a four-step Likert scale ranging from totally agree to totally disagree. The questionnaire also allowed for written comments. The answers were used to revise the interview guide.

#### **5.3.4 Study IV – evaluation of intervention using questionnaires and interviews analyzed with descriptive statistics and qualitative content analysis**

The participating healthcare professionals in the fourth study received the interview guide along with written and video information about the research basis of the guide. They were asked to use the interview guide during the period from January to May when meeting with Middle East diaspora women with chronic pain. After the intervention, they were asked to answer a questionnaire to evaluate whether the guide affected their meeting with the patient group, as well as the usefulness of the interview guide. They were asked to grade their answers using a five-step Likert scale ranging from 1 (not at all) to 4 (very much) and 5 (don't know). There was also an opportunity to write comments. Those who were interested also participated in an interview concerning their experiences identifying rehabilitation needs

using the interview guide. The purpose of the interviews was to gain a deeper understanding of each participant's answers on the questionnaire (96).

The evaluations of the interview guide were analyzed descriptively. The interviews and written comments provided qualitative data, which were analyzed with qualitative inductive content analysis according to Graneheim and Lundman (102). The analysis began with reading of the text to extract meaning units that referred to the aim of the study. The meaning units were condensed, and inductively labeled with a code. The codes were then compared and sorted into categories, sub-categories, and sub-sub-categories. Finally, one theme was outlined.

#### **5.4 ETHICAL CONSIDERATIONS**

The studies included in this thesis were approved by the regional ethics committee in Stockholm (2009/1819-31/2, 100111) and Uppsala, Sweden (2014/319, 140917). The heads of each participating health center and rehabilitation center were informed about the research and provided their consent.

All participants in the research project were informed about the purpose and the procedure of the study and about voluntary participation. Informed consent was obtained. Special emphasis was placed on voluntary participation and on the option to end participation without providing any specific reason. The information included the aims, procedure, possible consequences and how the data would be used. Participants were also informed about confidentiality and how the data would be treated to ensure that their participation would not be revealed. The participants were also able to contact the researcher. All information was provided both verbally and in writing. Considering the experiences of forced resettlement and limited Swedish language ability among the women in the interview study (study I), ethical concerns and the protection of informants' privacy were especially important. To allow the women to make an informed decision about participating in the research, the written information and informed consent forms were available in comprehensible Swedish as well as in Arabic. Each woman was also verbally informed in a language of her choice by a female professional interpreter.

Possible consequences for participation in the interviews were the recollection of unpleasant memories and emotions. Should the need have arisen, a therapist or physician could have been contacted. However, the interviews also provided the women an opportunity to express their experiences and opinions, which could have contributed to adjustment in their healthcare according to their specific needs. The women were also allowed to choose the place and language of the interview to ease their participation.

All but one of the women in the first study had limited knowledge of the Swedish language and needed an interpreter during the interviews. Performing interviews through an interpreter affects the depth of the interview and involves risks and biases. Without the possibility of

using a shared language, the shortcomings of using an interpreter must be weighed against the benefits of performing the study. The alternative would be to exclude persons unable to speak Swedish or to not perform the study. Participating in the interviews offered the women an opportunity to speak their minds.

For the healthcare professionals (studies II and IV), it was predicted that participation could raise thoughts about their own profession. During the process of the studies, the author had recurrent contact with all the participants, offering the opportunity for reflection and discussion. They also received contact information for the involved researchers. In the Delphi study (study II), the participating healthcare professionals were kept confidential from each other during the study to prevent them influencing from each other to the greatest extent possible.

The studies included in this thesis were performed based on the premise that they would contribute knowledge about women living with pain who have resettled in Sweden from the Middle East. An interview guide to support healthcare professionals in the identification of rehabilitation needs would also favor the women by allowing more effective rehabilitation and would lead to a rehabilitation program tailored to each woman's expectations and needs. A major ethical concern is the performance of a research project about the needs of Middle East diaspora women by a researcher from another context. However, the intention was not to speak for the women but rather to allow their voices to be heard. The often biomedical and Eurocentric perspectives of health and healthcare make it difficult to include the different perspectives of health and pain that exist in a multicultural society, which is why it is important to describe the voices of "others".

The thesis also explores the perceptions of healthcare professions. Discussing "groups" of people, such as patient groups, always involves the risk of generalizing or stereotyping. The purpose of sampling for representatives for the expert panel (study II) was to involve healthcare professionals with experience from their everyday work of rehabilitation with patients from the target group. This sampling would make sharing knowledge and personal experiences possible and would thereby avoid stereotypes. However, not generalizing healthcare professionals is also important. The professionals in these studies have similar educational backgrounds and work within the Swedish healthcare system. However, they come from different professions with different experiences and have their own beliefs and preferences. It is equally important to recognize that they work under different conditions although they all work within the Swedish primary healthcare system.

Finally, I find it important that those who have been involved in the studies also gain something from participating. For that reason, together with the purpose of validating the results from interviews (study I), additional appointments were made with the women to present and discuss the results. Participating healthcare professionals (study II) were also offered a presentation of the results of the study in their workplace, which some of them



accepted. Based on the wishes of some of the professionals that have used and evaluated the interview guide (study IV), continued contact has been maintained to further evaluate and reflect upon the interview guide and encounters with Middle East diaspora women.

## 6 RESULTS

Based on a synthesis of the results from the four studies included in this thesis, the struggle for sense of control surrounds the women's attempt to regain a sense of control that was lost due to forced resettlement in a strange part of the world. This struggle also surrounds the consequences of pain on the body, in everyday life and on plans for the future. The challenge for healthcare lies in supporting the struggle for sense of control, which consists of identifying and addressing the rehabilitation needs related to chronic pain and thereby supporting management of the consequences of pain on the body, on everyday life and on the future. For this purpose, an interview guide was developed (Appendix 1).

### 6.1 LOSS OF SENSE OF CONTROL AND FEELINGS OF DEPENDENCY (STUDIES I, II)

#### 6.1.1 Due to forced resettlement

*“It was war, and we had to escape our country. Many children or people died on the way. But we really tried. We kept the children warm with our own bodies to keep them save. We did all for the children.... if we hadn't escaped, we would have been dead. So we had to go on.”*

The target group of this thesis is women from the Middle East diaspora in Sweden experiencing musculoskeletal pain. The narratives of Iraqi women (study I) together with the experiences of healthcare professionals who met with the women (study II) inform us of the consequences of the cumulative trauma of forced resettlement. Although resettlement in Sweden meant living without fearing for their lives, the women still had concerns for relatives. Losing family members and friends or having relatives scattered around the world, along with leaving their home, disrupting their social network, and losing their social identity, resulted in grief over what was lost. Having succeeded in escaping war and other difficulties to a country in peace was associated with feelings of security and comfort. However, these feelings were simultaneously connected to a sense of alienation. Adapting to a life in Sweden was associated with difficulties due to language barriers, difficulties understanding the society, exclusion from the labor market and financial problems. Adapting to a life in Sweden involved difficulties and dependency on others for communication, understanding and upkeep.

#### 6.1.2 Due to unpredictable pain

*“Well, it (pain) affects my everyday life that I cannot do all things I should be doing. And I become sad when I realize that I am the woman in our house, I should do these things. Instead, he will have to.”*

The persistent pain that was only possible to temporarily ease was perceived as unpredictable and changing, and it had both physical and emotional effects (study I). The physical and

emotional reciprocity created a negative atmosphere among others. The consequences of pain for bodily functions made performing everyday activities difficult, resulting in dependence on others for household chores, and in changes in roles within the family. The pain also made it difficult to obtain an education, to learn the Swedish language, and to find employment. Difficulties obtaining an education, finding employment and earning money led to continued dependence on welfare, thereby creating a “nowhere land” with the pain stopping past life represented by the roles within the family, and blocking access to the future, as represented by education and employment. Such consequences affected confidence in the future. Adapting to a new life in a strange country and managing a life with pain led to an existential struggle.

## **6.2 STRUGGLE TO REGAIN A SENSE OF CONTROL (STUDIES I, II)**

*“Then (when working) I felt that I did something for the money I received. But here, I don’t do anything. I could learn the language and work at a daycare again. But now I feel I cannot do anything (because of pain).”*

The sense of control was lost as a consequence of both the resettlement and an everyday life with pain. The perception among the women (study I) was that pain management was essential to gain access to the future and to be able to improve one’s life situation. Manageable pain was associated with the possibility to regain control over the body and bodily functions. With a functioning body, performing everyday activities and reclaiming the role within the family would be possible. Benefitting from education, learning the Swedish language, and being part of the Swedish society would also be possible. Ultimately, being able to gain employment and to earn one’s own money was associated with control.

For the women (study I), the struggle was framed by a faith in God. God possessed overall power over peoples’ lives, as well as the power to offer a cure to those who deserved it. Prayers were associated with mental and emotional comfort and served as a strategy to keep spirits up.

Handling the physical and emotional reciprocity following a life with pain involved managing the pain by using medication or coping strategies and addressing emotional and mental distress (studies I, II). The purpose of this management was to keep the pain tolerable. In the women’s struggle to handle the pain in a complex living situation, social support (practical as well as emotional) from family and friends was important. Participating in social activities, keeping occupied, having someone close who cared as well as having someone to care for were important (study I).

### **6.2.1 Relying on healthcare**

*“It is only God who decides, he has created this body, and he is the one to look after it. But a physician may find a cause (to pain).”*

In the struggle to regain a sense of control over pain, the perception among the women was that, with God's help, a physician might find the causes of the pain and offer a cure (study I). The perception among both the women (study I) and the healthcare representatives (study II) was that pain is complex and is related to experienced traumas and difficulties. However, the women (study I) also considered pain to be a physical symptom that called for a physical treatment. A physician could provide a trustworthy diagnosis and an effective treatment, with the main purpose of regaining a sense of control over one's life situation, primarily via controlling the consequences of pain on the body, on everyday life, and on future plans.

Healthcare professionals recognized the need to treat the women with respect, responsiveness, and confirmation, considering their context and expectations (study II). Moreover, ensuring communication by using an interpreter when needed, taking enough time, maintaining understanding, and meeting any wish for a female therapist were also needs to be recognized. All of these needs were recognized to establish trust.

However, the meeting with the Swedish healthcare representative was perceived as complicated from the points of view of both the women (study I) and the healthcare professionals (study II). Although the causes of ill health and pain were identified as being related to traumas and difficulties, the healthcare professionals found it difficult to direct measures to those needs. Instead, they recommended evidence-based treatment such as education about pain and pain management. Differing perceptions of causes of the pain and expectations regarding treatment produced a sense of confusion and mistrust. The women found it difficult to understand the Swedish healthcare system and perceived a lack of information. A major concern was having to meet different physicians in every visit and having to re-tell and re-live previous experiences and traumas. The women were referred to examinations and treatments that had already been ineffective. Although the intent of the healthcare representatives was to do good, the result was the opposite. Not receiving help resulted in the fear of health deterioration and the continued search for a cure, with the perception that, if one physician was not able to help, another possibly could.

The inability to tailor rehabilitation to the patient's needs with regard to background, beliefs, or set of expectations puts the patient at a disadvantage. The results of the inability to support the women reduced the women's chances of regaining a sense of control over their pain. In contrast, those bad encounters contributed to the loss of sense of control.

### **6.3 SUPPORTING THE STRUGGLE FOR SENSE OF CONTROL (STUDY III)**

*"I think that many of them in this group may have a great need to talk. And that they haven't been listened to, in a way they would have needed, really. So, they need to tell these things."*

A review of existing research in the third study together with the results from studies one and two indicates that healthcare providers must transfer power to women to help them gain control of their lives in the face of chronic pain. For successful rehabilitation, gaining insight

into a woman's beliefs and reasoning about illness, including her concerns and expectations, is important. The consequences of pain on everyday life, how the woman handles these consequences, and the woman's future prospects determine the rehabilitation goals. Moreover, understanding a woman's experiences from prior contacts with healthcare, the assessments and treatments she has undergone, and her current expectations is equally important. By understanding the patient's perspective, it is possible to validate her experiences and fears and to meet her expectations.

Discussing these issues requires sufficient communication and cultural openness to possible differences in how to express and describe health and illness. A professional interpreter is crucial when the woman cannot express herself freely in Swedish. Meeting with Swedish healthcare professionals involved experiencing a different culture. The difference lies not only in the Swedish culture but also in the healthcare culture. This difference places demands on the healthcare professionals to maintain a mindset of cultural openness to prevent cultural differences from interfering with the encounter.

Health and pain experienced by the women were affected by factors associated with the cumulative trauma of forced resettlement. Insight into the woman's background from her home country, possible traumas and difficulties, reason for resettling and current living situation are important pieces of information that help healthcare providers to understand her situation. Such information also supports the understanding of psychosomatic symptoms and provides an intersectional perspective, and an understanding of how power structures such as ethnicity, gender, age, and functional capacity affect a woman's opportunities in Sweden, as well as insight into how such factors affect her social identity and health. However, with a patient focus, the family may be forgotten in the rehabilitation process. Support from family members is a factor for wellbeing in all stages of life. Family members were involved in the migration and resettlement process and were also affected by the consequences of pain. Family members were needed for practical as well as emotional support and could, in turn, also be in need of support.

Considering the complexity of health and life for these women, maintaining a holistic approach is critical. Thus, physical, social, functional, and psychological needs as well as cultural and spiritual needs must be considered during the assessment, diagnosis, and treatment. This demands collaboration between healthcare professions, together with the woman and an interpreter when needed. The complexity of the living situation put demands on healthcare, and healthcare professionals must network with other authorities in society and with the families of the women.

A person-centered approach that acknowledges the woman's background and current life situation and considers her beliefs and expectations is the basis for a holistic rehabilitation approach. This approach, together with a biopsychosocial-spiritual perspective that

recognizes the need for multi-professional collaboration and direct measures of a woman's specific needs, is a prerequisite for supporting a woman's struggle for sense of control.

#### **6.4 CHALLENGES IN SUPPORTING THE STRUGGLE FOR SENSE OF CONTROL (STUDY IV)**

*“This demands a rehabilitation team. Otherwise, it becomes difficult to identify things you cannot do anything about.”*

The results from the studies in this thesis have pointed toward needs related to forced resettlement and to pain in women from the Middle East diaspora. The results show how healthcare may support the women in their struggle to regain a sense of control. The perception from the healthcare professionals involved in the fourth study showed that supporting the women involves great challenges.

Meeting these women included handling situations that result from asking questions about past experiences. Narratives may raise feelings such as anger and sadness within the woman and the healthcare professional. Moreover, the healthcare professionals found that they had to motivate themselves to ask the questions to the women and their relatives. Some of them found it difficult to motivate themselves to ask questions about traumas, current living situations, and future plans. For some of the healthcare professionals, this difficulty also raised feelings of insufficiency and of a lack of competence.

The organizational prerequisites in primary healthcare in Sweden lead to difficulties in encounters with patients with complex needs such as the women of interest in this thesis. Perceived time constraints in everyday work and limited opportunities to make an appointment made it difficult to assess a person's needs to a degree that allowed the directing of treatment and offering of the “right” care from a biopsychosocial-spiritual perspective. Physiotherapists in particular perceived expectations upon them not only to talk during a consultation but also to include a physical assessment and to begin a treatment.

The same considerations applied to the need to collaborate across professional boundaries within healthcare and to collaborate with authorities within the community. The results from this thesis (studies I, II, III) emphasize the need for collaboration to allow the support of each woman, considering her past experiences as well as her current life situation, which affects both her health and her experience of pain. The results from the fourth study indicate a lack of collaboration at present. A lack of collaboration also means that the possibilities for the different professions to support each other will fail.

Being unable to identify and address women's needs often resulted in treatment that was not tailored to the patient's needs, which posed a further risk of distress for the patient. The patient would not have the chance to move forward toward acceptance, regain a sense of control over her pain, her body, and her everyday life, or to form goals for the future.

## **7 DISCUSSION**

The results from the studies described in this thesis have pointed toward the needs related to forced resettlement and to pain experienced by women from the Middle East diaspora and have shown how healthcare may support the women in their struggle to regain a sense of control. The studies resulted in an interview guide from a person-centered point of departure to meet the specific challenges that healthcare professionals encounter as a result of the expanding dispersed populations in Sweden. Considering the complexity of health and life situations of these women, the guide maintains a holistic approach, acknowledging physical, psychological, social and spiritual components.

The results have also suggested that assessment using the interview guide is associated with challenges due to a perceived lack of skills and organizational factors, making it difficult to identify and address the multiple dimensions of the embodied experience of pain. Therefore, individuals with complex and multi-dimensional problems such as the women in the current study do not receive care according to their individual needs. This, in turn, is a vital sign of structural discrimination, which prevents patients with complex problems from having their needs addressed.

### **7.1 FACING THE CHALLENGES**

A perceived lack of competence and the organizational structure of primary healthcare prevent a holistic and person-centered approach to rehabilitation of the embodied experience of pain in forced resettled populations.

With the perception of not having sufficient skills to handle stories of trauma, it is easy to shy away from asking questions that might lead to emotional reactions within the patient and the healthcare professional (103). This could be related to asking questions about domestic violence, which has been found to be difficult due to limited knowledge, to attitudes, and to time constraints (104). The signs of experienced traumas may be difficult to discover. Thus, healthcare professionals must maintain an open eye and have sufficient knowledge of what to look for. Attempting to understand the patient's suffering and the reasons for the suffering could be perceived as a sign of compassion (105). Omitting questions, on the other hand, leads to the loss of information about the woman's situation from a biopsychosocial-spiritual perspective. As a consequence, the woman will not be involved in the rehabilitation process, and measures will not be adjusted to her specific needs. Therefore, the consequences of not asking critical questions are that the woman will not be offered sufficient help and support.

The same issues apply to the perceived time constraints and expectations for visits that are experienced by the healthcare professionals. Primary healthcare professionals are working under constant time constraints and high pressure. During a single visit, a physician is expected to form a partnership with the patient, address problems, provide curative as well as preventive care, coordinate care with specialists, and make decisions together with the patient

(106). The physiotherapists in the fourth study reported additional expectations on them other than collecting a medical history; they expect that they should have time for a physical assessment and, preferably, time to initiate treatment. In meeting patients with complex problems, this was nearly impossible to manage. Time constraints have been reported to result in a lack of focus on patients (107). With shorter visits, the depth of understanding is diminished, often causing important psychosocial determinants of health to be missed. The consequences may also include decreased patient satisfaction (108). Resettled patients have possible language difficulties that demand interpretation, differing cultural beliefs regarding health and illness, and possibly a lower degree of health literacy; all these issues cause more time and effort to be required. Moreover, many patients may have more concerns, symptoms, illnesses, and greater psychosocial stress that causes the consultation to be more demanding (106). With longer consultations, healthcare professionals have been seen to take more time to build a relationship with the patient, listen more carefully to psychosocial problems, and provide the patient with more information (109). Although the healthcare professionals involved with the work in this thesis made an effort to maintain to a person-centered approach in their consultations with a narrative point of departure, time constraints and perceived expectations on the consultation led to the need to structure the dialogue, resulting in loss of an overall picture of the problems that may have revealed the direction for measures.

The amount of time spent on each patient consultation is partly determined by the compensation system within healthcare. Although compensation varies among the county councils in Sweden, it is generally based on the number of patients listed for each health center, combined with the number of patient consultations and the diagnoses that are made (110, 111). The trend is to prioritize high numbers and short consultation lengths rather than problem solving (110). Diagnosis-focused care therefore becomes more profitable in the short term than patient-focused care. In the longer term, however, a person-centered approach is more efficient and has better outcomes (110). With the purpose of increasing access to healthcare, Rehabiliteringsgarantin (The Rehabilitation Guarantee) was introduced to guarantee that a patient can contact his or her healthcare provider during the day and set up a consultation within seven days (112). Whether this rule leads to a need for an increased number of consultations has been discussed (113). In reality, the consequence of such a strategy could be shorter consultations, which would affect the ability of healthcare professionals to fully assess their patients' needs. This effect is especially true in the case of more complex problems such as longstanding pain. Whether this guarantee would lead to crowding out effects or whether new patients will be prioritized before follow-up visits has also been debated (113). The consequences of this rule could be that individuals such as the women discussed in this thesis, with the needs of longer and recurring visits, would risk being prevented from having their needs identified and met. Meeting patients with long-term conditions takes effort, possibly caused by the emotional distress of not being able to offer a



cure. Considering this effort, structuring the consultation with a focus on symptoms and diagnosis may be perceived as easier in high-pressure everyday work (110), especially when there is a fear that a person-centered approach might require more time and effort.

Moreover, to be able to address the different dimensions of the identified needs, we must be able to collaborate within healthcare, including collaboration with the women and their families, with other authorities in society, and with different religious communities. The results from this thesis, however, show that a lack of opportunities for collaboration makes addressing treatment and support from all the dimensions of the needs difficult in most cases. This issue has also been recognized within occupational rehabilitation, where occupational therapists experienced difficulties finding partners to collaborate with within other authorities (59). As no profession alone can address all the dimensions of health-related needs, multi-professional collaboration is required (8, 34, 114). Therefore, it is useless for one profession to have knowledge of all the dimensions of needs when it is not possible to collaborate with other professions to address them. Previous research reported that the consequences of insufficient support and collaboration make healthcare providers reluctant to get involved in pain care; instead, they give up, thinking it would cause even more trouble to care for pain-related problems without sufficient support and collaboration (114). The patients are the ones who will suffer. The lack of collaboration between healthcare professionals has negative consequences on the perception of the quality of care, which ultimately affects treatment outcomes (89).

Due to the pressure to conduct as many consultations as possible during a working day, the priority will be on short visits, allowing no time for in-depth discussions. Therefore, providing the patient with as much information as possible to allow her to share in the decision-making process will be difficult, and there will not be an opportunity to discuss patient matters with partners in healthcare, or with the patient's family. All of these are important ingredients that should be present in person-centered healthcare.

## **7.2 THE WOMEN AT A DISADVANTAGE**

By not being allowed to have their needs assessed and met, the women are discriminated against in their encounters with the Swedish primary healthcare system. Without a comprehensive assessment, healthcare professionals fail to perceive the needs that govern treatment.

Throughout this thesis, the results have suggested that notwithstanding the attempts to help the women, representatives from healthcare have missed the target. Failing to address the women's needs and expectations resulted in feelings of misunderstanding. In a state of fear of deterioration and a state of frustration, the women continued the search for a cure. The women sought healthcare with the expectations of a trustworthy diagnosis and an effective treatment. Although the healthcare professionals intended to help them, the result was the

opposite, and the women were hindered from moving toward acceptance and adjustment to a life with pain.

Failure, i.e., hindering the women from moving on and failing to address the perceived primary causes of pain, and instead advocating education about pain and pain management, could be explained to some extent by the challenges identified in this thesis. In healthcare, for various reasons such as shying away from asking uncomfortable questions, time constraints, and a lack of collaboration, there is a failure to identify and direct measures that address women's needs, and rehabilitation is not coordinated. These issues could explain why the women were referred to examinations and treatments that already were proven ineffective (study I). They could also explain why they had to re-tell their stories and re-live past traumas in every visit within the healthcare system. These issues could also explain the discrepancy between the perceived causes of pain among the women and the first treatment choice that the healthcare professionals would offer, i.e., education about the body, pain, and pain management (study II). Ultimately, due to unfamiliarity among healthcare professionals who meet persons with traumatic experiences as well as to organizational prerequisites within primary healthcare, the women were not offered treatment tailored to their needs and did not have the chance to move on toward their life goals or to regain a sense of control.

Ultimately, the deficiencies within the organization of primary healthcare are critical; they affect the rehabilitation of women, and they affect the women's struggle to regain a sense of control. The deficiencies also represent a vital sign of structural discrimination (74), as the organization and routines prevent the woman from being provided rehabilitation and support according to her needs. The Swedish agency for health and care services analysis (Myndigheten för vårdanalys) (89) reports that healthcare is often unable to meet the individual needs, values and preferences of each patient, thereby affecting outcomes and contributing to unnecessary costs. The organization of healthcare, together with personal resources and transcultural competence, affects the consultation between the healthcare professional and the patient (115). An existing power imbalance has been illustrated previously (116), whereby healthcare professionals conduct encounters that are based on the medical discourse and little time is spent on the patient's questions, worries, and anxieties. Healthcare professionals, especially physicians, are in a position of power over the patient, and they have control over resources such as treatments, certificates, and drug prescriptions (110).

The women's health is affected by their resettlement, especially by their own experiences or their family members' experiences of war, persecution, and torture. Later, their health is affected by a constant feeling of insecurity and fear that many of them are forced to live with due to ethnic discrimination and growing xenophobia (117). Structural power relations within society are reflected in healthcare. Many of the women discussed in this thesis are doubly disadvantaged due to chronic pain and being part of a dispersed population. Thus, a complex

life situation and background add to a complex illness (118), indicating a risk of these women being perceived as “difficult” in meetings with healthcare professionals. With reduced visit durations, less open communication, and poorer assessments, the development of a treatment plan according to the patient’s needs is difficult to manage (118). The treatment is thus based on the healthcare professional’s perception of what the woman needs. This might not reflect her true needs. If time is short, the consultation and treatment will be focused on symptoms and diagnosis. If the underlying causes are not addressed, the symptoms will return, and the woman will return to the healthcare system in frustration.

### **7.3 CONTINUING CHALLENGES**

Considering the demographic changes in Sweden, the number of persons with complex problems as a result of forced resettlement and intersectional structures affecting their life situation will increase within the primary healthcare system. The results from this thesis indicate shortcomings that make it difficult for patients to have their needs addressed.

Changes in population structure indicate changing needs within the population, which are reflected in healthcare. Changes in the demands placed on the Swedish healthcare system following migration have been recognized for several years (115, 119). Sundquist (115) stated in 1998 that healthcare professionals will be placed at the forefront of complex medical challenges demanding knowledge of transcultural care to be able to provide high-quality healthcare. Primary healthcare providers in particular will face new demands and increasing challenges in terms of vague symptoms and psychosocial problems (120). Considering the ongoing conflicts in the world and the increased resettlement, the challenges will continue to rise.

In their review, Fiscella et al. (106) conclude that in caring for socially disadvantaged patients, including people from minority groups and persons with low socioeconomic status, changes in the structure of primary care are required. There are needs for changes in the compensation and resources, leadership, and culture of medical practice that respect the wants, needs and preferences of patients. Therefore, the healthcare system must enable the establishment of long-term relationships. This continuity of relationship would also enable a holistic, overall picture of the rehabilitation to be created, including assessments, treatments and knowledge of the patient’s history. The healthcare professionals must also have the opportunity to discuss and coordinate care for patients with complex problems (110). The socially disadvantaged patients will require more resources, not less. There is a need for payment that considers not only quantity but also quality (106).

The professionals also need a chance to reflect on the patient encounter to become more patient focused. This idea has been emphasized in work with patients with longstanding conditions. “If healthcare professionals want to have impact on patients’ understanding of their illness, they need to explore and influence their patients’ understanding.” (107, p.210).

Once again, I would like to relate this to the assessment of domestic violence. The National Board of Health and Welfare recommends that personnel within healthcare be offered education (104). The same should apply to the assessment of previously experienced traumas related to forced resettlement. Healthcare professionals require education and training to focus on premigration stress, asylum stress, and postmigration stress, especially in forced resettled women who have been victims of traumas (35, 121). This education should be included at both the undergraduate- and post-graduate levels, as well as in continuing education for healthcare professionals. According to Ekblad et al. (35), some universities include transcultural care in the medical student curriculum, but the inclusion of this topic is not mandatory.

According to research, to improve the self-management of chronic conditions, the encounter must be individualized, and there must be a focus on the patient's concerns and perceptions (116). A person-centered approach to rehabilitation should involve the patient in the process. Her involvement will increase her power over the decisions that are made, thereby shifting power over to the patient. A client-centered approach in encounters between healthcare personnel and persons with collectivistic worldviews (as exist in the Middle East) has previously been perceived as problematic because healthcare professionals were perceived as non-authoritative (59). However, my perception of a person-centered approach involves allowing the person to be as involved as he or she wishes to be. Listening to the person's narrative, beliefs, and expectations will provide information about the degree to which he or she wishes to be involved in treatment decisions. The woman has to face the pain every day. Healthcare professionals need to support her by providing the tools for pain management – without her having to return again and again with the frustration of not being offered any answers.

#### **7.4 METHODOLOGICAL CONSIDERATIONS**

This thesis includes four studies with four different approaches. The studies were motivated by the complexity of health in resettled women, which demands the use of complex methods. Each study has a qualitative component, and three of the studies (studies II, III, IV) also have a quantitative component. All the studies have a basis in the subjective perceptions of key informants to give a voice to those who can rule on the needs of Middle East diaspora women with pain. In this case, this refers to women from the Iraqi diaspora and primary healthcare professionals with experiences working in pain management in dispersed populations. One major concern involves my role as a researcher in the data collection and analysis processes. My own background as a physiotherapist with experience meeting persons from diverse origins in a primary healthcare setting has been a concern when performing interviews with the Iraqi diaspora women and healthcare professionals and when analyzing the interviews. However, my previous knowledge and experience may also have contributed to the depth of the interviews. The main concern for me has been to record information as accurately as

possible to present their realities. By mixing quantitative and qualitative data, I had the opportunity to switch between closeness and distance. Within quantitative traditions, neutrality is pursued, whereas within qualitative traditions, the researcher is perceived as part of the research process (122).

#### **7.4.1 Participants**

Throughout the work with the studies in this thesis, sampling for participants from primary healthcare was difficult. This sampling challenge is significant and relevant to the difficulties of performing clinical research, and has been identified and discussed previously (123). Notwithstanding the problems associated with meeting forced resettled persons in primary healthcare, interest in participating in the studies was low. The reasons for refusing participation were reported to be time issues and other obligations. Other reasons in addition to these are unknown. Whatever the reasons are, they will influence the possibilities of developing healthcare, especially considering the ongoing changes within the population structure. To offer evidence-based healthcare, we must produce research to support the evidence.

The purpose of sampling throughout the thesis was to include informants that could contribute information, i.e., key informants. For the first study, women from the Iraqi diaspora were recruited via contacts with physiotherapists and a research project in a region with a high proportion of people from the Iraqi diaspora. This recruitment process may have contributed to the role of physiotherapists and project managers as gate-keepers. However, it ensured that the possible informants had received information in their own language. Because I did not want to exclude individuals due to linguistic problems, and because the women experience an everyday life with pain, contacting physiotherapists seemed suitable for the purposes of the study.

Sampling for the subsequent studies was based on a survey of municipalities in Sweden with a high proportion of people born in Iraq. The aim of the sampling for the Delphi study (study II) and the intervention study (study IV) was to recruit representatives of primary healthcare professionals. The healthcare professionals in the Delphi study represented different professions such as physiotherapists, occupational therapists, physicians, nurses, and psychotherapists. They were working in different municipalities, in areas where a large proportion of the inhabitants were from Iraq, and they all had experiences with these patients from their everyday work. Although most of them were female physiotherapists, different professions, ages, genders, and years within their professions were represented. This variation contributed to the different perspectives regarding perceptions on health and pain among the Middle East diaspora women.

The interview guide (study III) was developed to be used by different healthcare professions. Therefore, the aim was to include representatives from different professions to validate the

interview guide in both the cognitive interviews and the pilot study (97, 124). This was successful in the interviews that were performed with representatives from physicians, nurses, occupational therapists, therapists, and physiotherapists. However, in the pilot study, only four physiotherapists consented to participate. Based on the small number of cognitive interviews and the limited sample in the pilot study, further evaluation was necessary, for which the fourth study was planned.

The result from sampling in the intervention study (study IV) was 21 representatives who consented to participate, of which eleven completed the study. All except two were physiotherapists. Therefore, the sampling resulted in a limited number of representatives from a limited selection of professions, which affected the results. The findings must be interpreted in light of these facts.

#### **7.4.2 Data collection and analysis**

The main limitation related to data collection and analysis involved language difficulties and performing interviews using an interpreter (study I). A third party was present during interviews to relate to the patients and to form a relationship with them during the interview. The informants had to feel comfortable and secure with the two people conducting the interview. That issue, together with the issue of having a dialogue via a third person, affected the depth of the interviews. There is also the question of trustworthiness of the interpretation performed by the interpreter. The role of the interpreter is to translate what is said, as well as to translate the informant's understanding to the interviewer (125). Thus, the interpreter bridges the horizon of two understandings. This was considered when limiting the number of interpreters to two female professional interpreters with experience in their profession. The translations were checked for congruence by sending parts of the recorded interviews for translation by independent translators (126). Comparison of the translations confirmed that the translations made by the interpreters were consistent with the women's narratives.

Because the study approaches within this thesis originate from different research traditions, they have separate criteria for ensuring good and trustworthy research. Therefore, the methodological considerations concerning data collection and analysis will be discussed for each study separately.

##### *7.4.2.1 Study I*

Use of the GT method with theoretical sampling and constant comparison indicates that the results are grounded in empirical data (93, 94, 98), which means that the results in this thesis are grounded in the women's perceptions. The results are grounded in their subjective experiences and their understanding of these experiences. The motivation for using GT in this thesis was to form an empirical basis for the questions presented to healthcare professionals in the Delphi study (study II) and to be part of the theme pool for development of the interview guide (study III).

The analysis of qualitative data is affected by the interpretations made by the researcher. Therefore, my preconceptions as a Swedish-born woman with education and several years of work in primary healthcare will influence the interviews and the analysis of data from women from another context who have their own knowledge and experiences. The influence was limited by performing parallel data collection and analysis, by which the interpretations could be compared against the data.

According to GT (93, 94, 98), the rigor of the methodology is divided into the domains of fit, relevance, workability, and modifiability. Fit relates to the degree to which the theory fits with the data. In this study, data collection and analysis were performed in parallel. The interaction of constant comparisons of the emerging concepts in relation to existing and new data as well as theoretical sampling ensured that all codes and categories achieved fit and thus were grounded empirically. The analysis and interpretations were also discussed within the research group. Categories that fit and are empirically grounded are also relevant. Relevance refers to the degree to which the study results are relevant to those concerned. In this study, the relevance was supplemented with member checking, i.e., checking my interpretation of the results against the informants' interpretation (127). The results from a GT study should also have practical relevance; thus, the results are of use to those for whom they are intended (98). The results from this study were tested in the Delphi study (study II), as the results from the GT formed the basis for the questions in the first round of open questions. As the results also formed parts of the basis for an interview guide (study III), practical relevance might refer to the degree to which this study was found to be relevant to healthcare professionals within primary healthcare in their meetings with Middle East diaspora women experiencing pain. The methods of theoretical sampling, constant comparison and recording memos of ideas and inductive hypotheses are also considered to be methods that ensure the validity of the results from a GT study. Workability indicates how well the theory explains how the problem is being solved with much variation (93) or refers to how well the results from a GT study predict and give meaning to the process being studied (98). This measure refers to the interrelation of the parts and the whole. As fit, this interrelation is achieved by the constant comparison method. A core category that achieves fit, relevance and workability should also achieve modifiability (93, 94). Therefore, the category can change whenever new data are introduced. The core category from the current study, struggling for sense of control, and its related categories have been used for further data collection. However, they have also further evolved and have been complemented with further data to develop a support for healthcare professionals treating Middle East women who struggle to regain a sense of control.

#### *7.4.2.2 Study II*

The results from the first study were used to form the open questions in the first round of the Delphi study. The method was motivated by the purpose of reaching consensus to form part

of the basis of an interview guide. The chosen method also made it possible to include participants from a large geographical area.

The validity of Delphi studies has been discussed. The flexibility of the method and the variety of ways that it has been used have been questioned (95, 100). For this study, a classical Delphi with a first round of open questions was used to design a questionnaire for the subsequent rounds. Hence, the open questions in the first round provided an empirical basis to develop statements that the experts were allowed to review and evaluate in subsequent rounds. That the results are based on group opinion and on the opinions from experts from the “real world” and that the open first round allows the experts to generate scale items help to confirm the content validity. The concurrent criterion-related validity would also be strengthened by achieving consensus among the items, for which the participants agree on the components from the first open round (95).

In the second and third rounds, Likert scales were used to evaluate agreement with the statements. Because Likert scales are most commonly used to indicate the degree of agreement (95, 128), their use was considered suitable for the Delphi study.

The motive for conducting three rounds was to reach a consensus for as many statements as possible. Sending out the statements for a third round provided the participants with the opportunity to reflect on their answers and to consider whether they would like to change their evaluation based on the median answer from the whole group of participants. Although, the method allows for further rounds, the risk of drop-outs increases as the length of the study increases (95, 100). The rounds have been shown to contribute to involvement of the participants, for example, in instrument development. They are allowed to present their points of view and to reflect over their position in certain questions, which can enhance response rates (95, 100). In this study, five experts dropped out of the study. Making more personal contacts in addition to mail or e-mail may have helped to prevent drop-out.

The results from the current Delphi study would not be generalizable to other areas because the results rely on the experiences of the included healthcare representatives. However, this was not the purpose of choosing this method. The variety of characteristics among the experts would contribute to the input of needs and measures directed to Middle East diaspora women, which was used to form a basis for the development of an interview guide.

#### *7.4.2.3 Study III*

The interview guide was developed in three steps to strengthen the validity of the content. Because instruments may be either empirically or theoretically based (129), development of the interview guide was based on previous research. The first two studies were both empirically grounded in experiences from the perspectives of the Iraqi diaspora women and the healthcare professionals. The review of existing literature was used to strengthen the content validity of the interview guide, considering that the first two studies from this thesis



included small samples. Both qualitative and quantitative research was included to provide a variety of perspectives on needs and needs assessment in relation to pain in resettled populations.

There are a number of factors that may result in misunderstandings of questions in questionnaires or other instruments. It has been argued that cognitive testing should be a part of instrument and questionnaire development. The inclusion of cognitive testing would establish whether the questions are understandable to the users and whether they understand the questions in the way that was intended (130). For this purpose, cognitive interviews were performed (97). These interviews were followed by a pilot study to reveal and to prevent upcoming problems with the questions (124). Each step of the developmental process was discussed within the research group. These measures would help explore and strengthen the face and content validity of the interview guide. Considering that the interview guide comprises open questions for the possibility of a deepened understanding of the patient's situation, further testing of the dimensions of validity and reliability was judged to be unnecessary.

#### *7.4.2.4 Study IV*

The purpose of the intervention in the fourth study was to evaluate healthcare professionals' perceptions of the usefulness of the interview guide. This evaluation was performed by using a sequential mixed method, and the qualitative component was used to deepen the understanding from the quantitative evaluation. Using qualitative data to complement the quantitative component is usually understood from a post positivist stance, focusing less on the qualitative part of the data (131). However, although complementing the quantitative data with qualitative data, this study maintained focus on the qualitative component to gain a deepened understanding of the participants' perspectives.

In an attempt to achieve trustworthiness in study IV, credibility, dependability, and transferability were considered (102, 127). As the sole author of this study, I carried the main responsibility for sampling, performing the intervention, and conducting data collection and analysis. However, these processes were conducted in an open dialogue with a team of supervisors. The mixed method approach allows for the triangulation and confirmation of results from the analysis of qualitative data with the answers from the questionnaire (131). The interviews also provided the participants with an opportunity to reflect on their responses to the questionnaire and allowed for a deeper discussion. This approach also confirmed the findings as being grounded in the participants' perceptions. The descriptive statistics were complemented with the findings from the interviews to gain a deeper understanding from healthcare representatives. A thorough description of the methods, the process, and the analysis would allow readers to assess the transferability.

## 8 CONCLUSIONS

Considering ongoing conflicts in the world, the high number of forced resettled people in Sweden will persist and probably increase. This will be reflected in primary healthcare; there will be an increased number of people with complex problems resulting from forced resettlement and intersectional structures affecting their life situation.

- The challenge for healthcare lies in identifying and addressing the rehabilitation needs related to chronic pain and thereby supporting management of the consequences of pain on the body, on everyday life and on the future.
- A person-centered approach, acknowledging the woman's background and current life situation and considering her beliefs and expectations, is the basis for a holistic approach to rehabilitation. This approach, together with a biopsychosocial-spiritual perspective that recognizes the need for multi-professional collaboration, directs measures to meet the woman's specific needs.
- A perceived lack of competence and the organizational structure of Swedish primary healthcare prevent a holistic and person-centered approach to rehabilitation of the embodied experience of pain in forced resettled populations.
- Women who are unable to have their needs assessed and met face discrimination in their encounters with people in the Swedish primary healthcare system. Without a comprehensive assessment, the consequences will be that the healthcare professionals' perception of needs will govern treatment.

## 9 CLINICAL IMPLICATIONS

Based on the results from this thesis, there is a need to increase the knowledge and understanding of structural power relations in women's everyday lives and to understand the ways these relations affect their health. These power relations are involved in their encounters with the healthcare system, placing the women at a disadvantage.

- We must understand the women's situation, including possibilities of personal traumas. They face conflicting demands based on their roles as women, wives and mothers. They have responsibilities to their homes and families, and they face demands from society as they search for employment to receive social assistance.
- We must understand the dependence on family for help when pain makes it impossible to complete everyday chores. Pain affects women's roles within their families as well as women's social identities.
- We must also understand how the women rely on healthcare for pain relief. However, they should not be put at a disadvantage, ignored or referred to examinations and treatments that have already been proven ineffective. They should also not be forced to re-tell and re-live previous traumas at every healthcare visit.
- With increased knowledge and understanding, we can begin to make changes, face the challenges, and support the women's struggles to regain a sense of control. However, this demands a healthcare organization that enables us to evolve our knowledge and understanding and to identify and address patients' needs.

## **10 FUTURE OUTLOOKS**

The intent of starting this project was to improve rehabilitation for women from the Middle East tailored to each woman's specific needs. However, from the first two studies, it was clear that from a primary healthcare perspective, the complexity of chronic pain in the women was perceived as difficult to assess and address. To be able to address each woman's specific needs, identifying those needs is necessary. This became the aim of developing the interview guide, which was tested with the perception that with a useful tool, healthcare professionals would be able to offer the women effective rehabilitation.

Nonetheless, the first intention to help rehabilitate women according to their specific needs remains. In future studies, the perception of the interview guide should be described from the Middle East diaspora women's perspective and should also possibly include their relatives' perspectives. Given the opportunity to build a network for collaboration, an intervention study from a person-centered approach should be performed, with the aim of offering women comprehensive support for pain management. The intention would be to explore whether a multi-dimensional approach that places the woman at the center would lead to more effective rehabilitation.

## 11 SVENSK SAMMANFATTNING/ SUMMARY IN SWEDISH

Kvinnor som tvingas fly till Sverige är i många fall sårbara individer med erfarenheter av krig och trauma och en påtvingad flykt till en främmande del av världen. Många utvecklar en muskuloskeletal smärta. Med tanke på pågående konflikter i världen kommer antalet ofrivilligt migrerade till Sverige fortsätta vara högt, och förmodligen öka. Förändringar i befolkningsstrukturen reflekteras inom sjukvården, och inte minst primärvården, med de nya utmaningar det innebär att möta dessa kvinnor. Det saknas kunskap om situationen för kvinnor från Mellanöstern och deras möten med den svenska primärvården, och hur man från sjukvården ska möta kvinnornas behov.

Syftet med avhandlingen var att belysa orsaker till muskuloskeletal smärta och förslag till rehabiliteringsåtgärder för att kunna stödja identifikation av behov hos kvinnor från Mellanöstern.

De två inledande studierna vände sig till irakiska kvinnor (studie I) samt till personal inom primärvården (studie II). Genom intervjuer och frågeformulär var syftet att belysa upplevda orsaker och förslag till åtgärder mot kronisk muskuloskeletal smärta hos ofrivilligt migrerade kvinnor från Mellanöstern, utifrån ett patient- och vårdgivarperspektiv. Resultaten från delstudierna har tillsammans med en litteraturöversikt använts för att utveckla en intervjuguide, som validerades genom kognitiva intervjuer och en pilot studie (studie III). Intervjuguiden utvärderades ytterligare genom en interventionsstudie (studie IV).

Uppfattningen hos både kvinnorna och sjukvårdspersonalen var att smärta är komplex, och hade samband med upplevda trauman. Men för kvinnorna (studie I), upplevdes smärtan samtidigt vara ett fysiskt symtom som kräver en fysisk behandling. Uppfattningen var att en läkare skulle ge en trovärdig diagnos och effektiv behandling för att återfå en känsla av kontroll genom att kontrollera smärtans påverkan på kroppen, vardagslivet och framtidsplanerna (studie I). Mötet med den svenska sjukvården upplevdes vara komplicerad, både från kvinnornas och från sjukvårdens perspektiv. Även om sjukvårdspersonalen kunde identifiera orsaker till smärtan vara relaterade till genomgångna trauman, upplevdes det vara svårt att rikta åtgärder mot dessa orsaker (studie II). Resultaten visade på svårigheter att identifiera och möta behoven hos personer som lider av kronisk smärta och konsekvenserna av detta. Ett ökat stöd för personal i identifiering av rehabiliteringsbehov och planering av åtgärder skulle förhoppningsvis kunna hjälpa dessa kvinnor till en mer effektiv rehabilitering. Det var syftet med att utveckla en intervjuguide (studie III), utifrån ett person-centrerat förhållningssätt, och som beaktar fysiska, psykiska, sociala, men också spirituella dimensioner. Intervjuguiden utvärderades i en interventions studie (studie IV). Syftet med intervjuguiden visade sig vara uppfyllt, dock med utmaningar såsom en upplevd avsaknad av kompetens att ta hand om uppkomna situationer och reaktioner till följd av frågor om genomgångna trauman, tillsammans med organisatoriska faktorer som bristande samarbete och tidspress.

Resultaten belyser ett behov av organisatoriska förändringar med ökat samarbete mellan sjukvården och aktörer inom samhället, liksom ökad medvetenhet och nya rutiner inom primärvården för att undvika att försätta patienten i underläge, utan istället stödja hennes kamp för att återfå en känsla av kontroll i hennes livssituation. Resultaten visar även på ett behov av inkludering av intersektionalitet och person-centrering inom utbildning av sjukvårdspersonal.

**Nyckelord:** biopsykosocialt-spirituellt perspektiv, Delphi, Grounded theory, innehållsanalys, instrumentutveckling, intersektionalitet, interventionsstudie, kronisk smärta, kvalitativa intervjuer, kvinnors hälsa, ofrivilligt migrerade, person-centrering, primärvård

## 12 ARABISK SAMMANFATTNING/ SUMMARY IN ARABIC

### الترجمة من اللغة السويدية

النساء اللاتي يجبرن على الفرار إلى السويد، يصبحن في كثير من الحالات أفراداً أكثر حساسية بما يحملن من تجارب الحرب والصدمات ونزوح قسري لمكان غير مألوف من العالم. ويصاب الكثيرون منهن باضطرابات عضلية هيكلية. ونظراً للآزمات الموجودة في العالم حالياً فمن المنتظر أن يستمر ارتفاع عدد المهاجرين قسرياً إلى السويد، وربما يتزايد.

وتعكس التغيرات في الهيكل السكاني على قطاع الرعاية الصحية، وعلى الأخص، الرعاية الصحية الأولية، مع كل هذه التحديات الجديدة التي يتضمنها لقاء هؤلاء النساء. وهناك افتقار إلى المعرفة بشأن حالة المرأة في الشرق الأوسط ولقائها مع الرعاية الصحية الأولية السويدية، والطريقة التي يلبي بها نظام الرعاية الصحية احتياجات هؤلاء النساء.

الغرض من هذا البحث هو تسليط الضوء على أسباب آلام الاضطرابات العضلية الهيكلية، وتقديم الاقتراحات المناسبة لإعادة التأهيل بغرض المساهمة في تشخيص احتياجات المرأة من الشرق الأوسط.

الدراستان الأوليتان تناولتا كلا من المرأة العراقية (الدراسة الأولى) والعاملين في الرعاية الصحية الأولية (الدراسة الثانية). من خلال المقابلات ونموذج استبيان الرأي كان الهدف هو تسليط الضوء على الأسباب الملموسة والتدابير المقترحة للآلام العضلية الهيكلية المزمنة للنساء اللاتي تعرضن للنزوح القسري من منطقة الشرق الأوسط، استناداً إلى منظور المريض- ومنظور مقدمي الرعاية. وقد استخدمت نتائج الدراسات الجزئية جنباً إلى جنب مع استعراض المراجع العلمية لإعداد دليل المقابلة، الذي تم التحقق من صحته بواسطة المقابلات المعرفية، ودراسة تجريبية (الدراسة الثالثة). تم تقييم دليل المقابلة من خلال عمل المزيد من الدراسات التداخلية التجريبية (الدراسة الرابعة).

وقد أجمع كل من النساء والعاملين في المجال الطبي على أن الألم مسألة معقدة، وتتصل بالصدمة التي عاشها الشخص. ولكن المرأة (بالدراسة الأولى)، لمست الشعور بالألم في نفس الوقت كأعراض بدنية تتطلب العلاج البدني. وكان المفهوم هو أن يقوم الطبيب بعمل تشخيص موثوق فيه والعلاج الفعال لاستعادة الشعور بالسيطرة من خلال السيطرة على أثر الألم في الجسم، والحياة اليومية والخطط المستقبلية (الدراسة الأولى). ويعتبر اللقاء مع نظام الرعاية الصحية السويدية أمراً معقداً، سواء من منظور المرأة ومنظور الصحة. وعلى الرغم من أن العاملين في المجال الطبي كانوا قادرين على تحديد أسباب الألم التي ترجع إلى الصدمات التي عاشها الشخص، إلا أنهم يشعرون بصعوبة توجيه الحلول المباشرة حيال هذه الأسباب (الدراسة الثانية). وأظهرت النتائج الصعوبات في تحديد وتلبية احتياجات الأشخاص الذين يعانون من الألم المزمن وعواقبه.

ونأمل أن تؤدي زيادة الدعم للموظفين في تحديد متطلبات إعادة التأهيل والتخطيط للتدابير، لمساعدة هؤلاء النساء في إعادة التأهيل بطريقة أكثر فعالية. وكان ذلك هو الغرض من تطوير دليل اللقاء (الدراسة الثالثة)، من خلال المنظور المحوري الشخصي، والذي يراعي الأبعاد المادية والنفسية والاجتماعية، والروحية أيضاً. وتم تقييم دليل المقابلة في دراسة تجريبية تداخلية (الدراسة الرابعة). وقد تبين استيفاء الغرض من عمل دليل المقابلة الوفاء، رغم التحديات مثل الشعور بعدم التأهيل/الاختصاص لمواجهة مثل هذه المواقف، وردود الفعل نتيجة الأسئلة المطروحة حول الصدمة، جنباً إلى جنب مع العوامل الإدارية التنظيمية مثل الافتقار إلى التعاون وضغط الوقت.

تسلط النتائج الضوء على الحاجة إلى التغيير التنظيمي مع زيادة التعاون بين الخدمات الصحية والجهات الفاعلة في المجتمع، فضلا عن زيادة الوعي واتخاذ ممارسات جديدة للرعاية الصحية الأولية، تجنب وضع المريض في وضع غير مؤات. كما أن النتائج أظهرت أيضا الحاجة إلى إدراج دراسة نظرية التقاطع والتداخل النسوية والتمحور الشخصي في تعليم وتأهيل العاملين في مجال الرعاية الصحية.



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## 15 APPENDIX 1

# Rehabiliteringsbehov hos kvinnor från Mellanöstern med kronisk smärta

Denna intervjuguide är avsedd som ett stöd för vårdpersonal inom primärvården i identifikation av specifika rehabiliteringsbehov för kronisk muskuloskeletal smärta hos kvinnor från Mellanöstern. Intervjuguiden är personcentrerad och anpassad till att användas av alla professioner inom primärvården.

Patienten bjuds in i samtalet där hennes föreställningar, farhågor och förväntningar står i fokus. Hon får identifiera svårigheter i sina vardagliga aktiviteter och får möjlighet att själv sätta mål och bli delaktig i sin egen rehabilitering. Intervjuguiden identifierar även behovet av samarbete mellan olika aktörer såväl inom vården som i samhället.

Stödord i marginalen syftar till att påminna om vad som kan vara viktigt att notera i patientens svar och vara en hjälp att klargöra syftet med frågan.

Vi tar gärna del av era erfarenheter som ni får när ni använder intervjuguiden. Vi välkomnar därför alla kommentarer från de som vill dela med sig.

Kontaktpersoner:

**Maria Müllersdorf**, docent, akademichef, Mälardalens högskola, Akademin för hälsa, vård och välfärd, Eskilstuna. [maria.mullersdorf@mdh.se](mailto:maria.mullersdorf@mdh.se), 016-153225

**Viktoria Zander**, leg sjukgymnast Landstinget Sörmland. Doktorand, Karolinska Institutet, Institutionen för kvinnors och barns hälsa, Stockholm. [viktoria.zander@ki.se](mailto:viktoria.zander@ki.se)

**Henrik Eriksson**, professor, Röda korsets högskola, Stockholm. [henrik.eriksson@rkh.se](mailto:henrik.eriksson@rkh.se)

**Kyllike Christensson**, professor, Karolinska Institutet, Institutionen för kvinnors och barns hälsa, Stockholm. [kyllike.christensson@ki.se](mailto:kyllike.christensson@ki.se)



7. Livssituation i Sverige? \_\_\_\_\_

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Boende,  
sysselsättning,  
ekonomi, socialt  
nätverk, trivsel

8. Vad eller vilka i hennes omgivning påverkar hur hon mår? \_\_\_\_\_

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9. Har patienten:

Sömnsvårigheter?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Mardrömmar?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Återkommande huvudvärk?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Lätt att bli arg?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Återkommande tankar om smärtsamma tidigare händelser?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Känslor av rädsla?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Problem med minnet?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>
Svårt att koncentrera sig?	Ja <input type="checkbox"/>	Nej <input type="checkbox"/>

Övervägande  
jakande svar anger  
risk för  
traumatisering

10. Vilka planer har patienten för sitt liv? \_\_\_\_\_

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11. Vad behöver hon göra för att förverkliga planerna? \_\_\_\_\_

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12. Vilka svårigheter upplever patienten i vardagen? \_\_\_\_\_

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\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Vardagsaktiviteter  
Arbete/hemarbete  
Fritid

13. Vilka sätt/strategier har patienten för att hantera vardagen? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Aktiva strategier  
Passiva strategier  
Spirituella  
Emotionella

14. Identifierade aktiviteter:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

15. Genomförande:

Aktivitet 1: \_\_\_\_\_ Aktivitet 2: \_\_\_\_\_ Aktivitet 3: \_\_\_\_\_

16. Tillfredsställelse:

Aktivitet 1: \_\_\_\_\_ Aktivitet 2: \_\_\_\_\_ Aktivitet 3: \_\_\_\_\_

Lista tre aktiviteter i vardagen som patienten har svårt att utföra och som hon prioriterar att förbättra

**Skatta genomförande:**

1. Kan inte utföra
2. Kan utföra delvis
3. Kan utföra

**Skatta tillfredsställelse med genomförande:**

1. Inte nöjd alls
2. Ganska nöjd
3. Nöjd

**ÅTGÄRDER:**

Kommunen Ja  Nej

*Behov av åtgärder:*

Primärvård Ja  Nej

*Behov av åtgärder:*

Specialistvård Ja  Nej

*Behov av åtgärder:*

Gemensam bedömning vilka åtgärder patienten behöver i relation till målsättning