



# **Multidisciplinary Pain Rehabilitation Programs in Iceland:**

**An Exploration and Description of the Short-term and  
Long-term Effects**

**Hafdís Skúladóttir**

**Thesis for the degree of Philosophiae Doctor**

**Supervisor:**

Herdís Sveinsdóttir

**Advisors:**

Herdís Sveinsdóttir and Sigríður Halldórsdóttir

**Doctoral committee:**

Herdís Sveinsdóttir, Sigríður Halldórsdóttir

Amalía Björnsdóttir, Janean E. Holden and

Þóra Jenný Gunnarsdóttir

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**SCHOOL OF HEALTH SCIENCES**

FACULTY OF NURSING



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endurhæfingardeildum á Íslandi:  
Könnun og lýsing á skammtíma-og langtímaáhrifum**

**Hafdís Skúladóttir**

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**Umsjónarkennari:**

Herdís Sveinsdóttir

**Aðalleiðbeinendur:**

Herdís Sveinsdóttir og Sigríður Halldórsdóttir

**Doktorsnefnd:**

Herdís Sveinsdóttir, Sigríður Halldórsdóttir

Amalía Björnsdóttir, Janean E. Holden and

Póra Jenný Gunnarsdóttir

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## Ágrip

*Markmið:* Meginmarkmið þessarar rannsóknar var að kanna og lýsa skammtíma- og langtímaáhrifum meðferðar vegna langvarandi verkja á þremur endurhæfingastofnunum á alvarleika verkja og truflandi áhrifum verkja og að auki á langtímaáhrifum á sjálfsmeðhöndlun verkja, gæði svefns, almenna líðan, heilsu og heilsutengd lífsgæði.

*Innihald ritgerðar:* Ritgerðin inniheldur þrjár fræðigreinar þar sem **Grein I** lýsir niðurstöðum viðtalsrannsóknar en **Greinar II og III** lýsa niðurstöðum spurningalistakannana. Fólki með langvarandi verki sem var á biðlista eftir meðferð á endurhæfingastofnunum á Reykjalundi, Kristnesi og Heilsustofnun Náttúrulækningafélags Íslands í Hveragerði, var boðin þátttaka. Meðferðin stóð yfir í 4 – 7 vikur og var gögnum safnað fyrir meðferð, við lok meðferðar, þremur mánuðum eftir að meðferð lauk og ári eftir að meðferð lauk,

*Aðferðir:* **Grein 1** var eigindleg viðtalsrannsókn. Stuðst var við Vancouver skólann í fyrirbærafræði. Tekin voru viðtöl við 11 þátttakendur. Ellefu viðtöl fyrir meðferð og 10 viðtöl þremur mánuðum eftir að meðferð lauk. **Grein 2** var langtíma framskyggð ferilrannsókn. Þar voru lagðir fyrir spurningalistar fyrir meðferð, við lok meðferðar og ári eftir að meðferð lauk. **Grein 3** var langtíma framskyggð ferilrannsókn. Þar voru lagðir fyrir spurningalistar fyrir meðferð og ári eftir að meðferð lauk.

*Niðurstöður:* Meirihluti þátttakenda var konur. Þeir voru á aldrinum 20 - 69 ára ( $M = 47.3$  ár), og voru flestir giftir eða í sambúð. **Grein 1:** Yfirþemað var: *Leiðin að því að rjúfa vítahring langvarandi verkja.* Áður en þátttakendurnir fóru í meðferðina leið þeim eins og þeir væru að reyna að lifa af hvern dag; þeir voru fastir í vítahring langvarandi verkja og á sama tíma að reyna að draga úr og fela verkina fyrir öðrum. Að leita sér aðstoðar fagfólks var jákvæður vendipunktur. Á meðan þeir voru í meðferðinni byrjuðu þeir að brjóta upp eldri aðferðir sínar við að takast á við verkina og finna nýjar leiðir sem hentuðu þeim betur. Þremur mánuðum eftir að þeir höfðu lokið formlegri meðferð voru þeir enn að móta leiðir sem þeim fannst virka best í daglegu lífi. Verkinir voru enn til staðar en trufluðu daglegar athafnir minna en áður. **Grein 2:** Þar svaraði 81 þátttakandi öllum þremur spurningalistunum. Dregið hafði úr alvarleika verkja að jafnaði að mati þátttakenda við lok meðferðar og ári eftir að meðferð lauk ( $p < 0.001$ ), og einnig truflandi áhrifum verkja á daglegar athafnir, skap, getu til gangs, svefn og lífsánægju. Ári eftir að

meðferð lauk mátu þátttakendur heilsu sína góða eða mjög góða (21%) sem var betra en áður en þeir fóru í meðferðina (7%) ( $p < 0.001$ ). Þrjár algengustu aðferðir sem þátttakendur notuðu til að meðhöndla verki fyrir meðferð voru jákvæð hugsun (68%), lyf (58%) og dreifa huganum (58%). Engin breyting fannst á notkun aðferða til sjálfsmeðhöndlunar verkja ári seinna. **Grein 3:** Þar svöruðu 79 þátttakendur báðum spurningalistunum. Þátttakendur mátu alvarleika verkja lægra ári eftir að meðferð lauk miðað við fyrir meðferð ( $p < 0.001$ ). Eina marktæka breytingin á svefngæðum var að fleiri þátttakendur (18%) gátu sofið samfelld alla nóttina, en þeir voru einungis 6% fyrir meðferð ( $p = 0.004$ ). Algengast var að verkir og sálræn vanlíðan trufluðu svefn fyrir meðferð. Það sama átti við ári eftir að meðferð lauk. Heilsutengd lífsgæði (HRQOL) höfðu aukist ári eftir að meðferð lauk, sem birtist í hærra gildi, nema í geðrænum lífsgæðum (MCS). Líkamleg lífsgæði (PCS) fyrir meðferð var það eina sem spáði fyrir um PCS ári eftir að meðferð lauk. MCS fyrir meðferð spáði helst fyrir MCS ári eftir að meðferð lauk. Hátt menntunarstig spáði fyrir hærra gildi á MCS. Miklar og alvarlegar svefntruflanir, að vera kona, með börn yngri en 18 ára spáði fyrir lægra gildi á MCS ári eftir að meðferð lauk.

*Ályktanir:* Meðferð á endurhæfingardeild getur verið fyrsta skrefið í áttina að því að rjúfa vítahring langvarandi verkja. Meðferðin hafði borið árangur ári eftir að meðferð lauk. Það hafði dregið úr verkjum, og truflandi áhrifum verkja, heilsan var betri og líkamleg lífsgæði höfðu aukist. Svefnvandamál voru þó enn til staðar og engin breyting hafði mælst á notkun helstu meðferða við verkjum sem lögð hafði verið áhersla á í meðferðinni. Leggja þyrfti því aukna áherslu á svefnvandamál og sálræna vanlíðan í tengslum við verkina í meðferð á endurhæfingardeild. Einnig þyrfti að auka stuðning, fræðslu og eftirfylgd eftir að meðferð lýkur til að viðhalda lengur árangrinum sem næst í meðferðinni.

**Lykilorð:** langvarandi verkir, svefngæði, heilsutengd lífsgæði, endurhæfing.

## Abstract

*Aim:* The overall aim of the thesis was to explore and describe the short- and long-term effects of three multidisciplinary pain rehabilitation programs on pain severity and pain interference and the long-term effects on pain self-management, sleep quality, well-being, health, and health-related quality of life (HRQOL).

*Content of the thesis:* This thesis consists of three original papers. **Paper I** comprises a phenomenological study, while **Papers II** and **III** present results from longitudinal prospective cohort studies. People in chronic pain who were on a waiting list for multidisciplinary pain rehabilitation at one of three centres in Iceland – Reykjalundur, Kristnes and Rehabilitation and Health Clinic at Hveragerði– were invited to participate. The program lasted between four and seven weeks, with data collected pre-treatment, at program completion, three months after program completion and in a one-year follow-up.

*Methods:* **Paper I** was a phenomenological study that employed the Vancouver School of Doing Phenomenology. Eleven participants were interviewed, with 11 interviews conducted pre-treatment and 10 occurring three months after the participants had completed the intervention. **Paper II** was a longitudinal prospective cohort study with questionnaires filled out pre-treatment, at completion and at one-year follow-up. **Paper III** was a longitudinal prospective cohort study with questionnaires completed pre-treatment and at one-year follow-up.

*Results:* Most participants were women aged 20–69 ( $M = 47.3$ ) who were married or living with a partner. **Paper I:** The overarching theme was *the journey of breaking the vicious circle of chronic pain*. Prior to attending rehabilitation, the participants were in survival mode, stuck in a vicious circle of chronic pain. They used a variety of strategies to relieve and conceal their pain. Reaching out for professional help was a positive turning point. Whilst attending the pain rehabilitation program, participants learned to deconstruct their habitual but inefficient ways of dealing with chronic pain. Three months after completing the program, they were still rebuilding their daily lives. Pain was still present but interfered much less with daily activities than previously.

**Paper II:** Eighty-one participants responded to all three questionnaires. Average self-reported pain severity decreased at program completion and at

one-year follow-up ( $p < 0.001$ ), and the interference of pain with general activities, mood, walking ability, sleep and enjoyment of life also declined. At one-year follow-up, more than a fifth (21%) of participants rated their health as good or very good, which was markedly better than before treatment (7%;  $p < 0.001$ ). The three most commonly used pain self-management strategies pre-treatment were positive thinking (68%), medication (58%) and distraction (58%). No change was found in use of pain self-management strategies between pre-treatment and one-year follow-up.

**Paper III:** Seventy-nine participants responded to both questionnaires. Participants scored their pain lower at one-year follow-up than pre-treatment ( $p < 0.001$ ). At one year follow-up, three times as many participants (18%) slept through the night ( $p = 0.004$ ) as had done so pre-treatment (6%). Most had disrupted sleep, mainly because of pain and psychological problems, at both the pre-treatment and one-year follow-up time points. HRQOL increased at one-year follow-up, with higher scores in all areas except the Mental Component Summary (MCS). The pre-treatment Physical Component Summary (PCS) was the only potential predictor for PCS at one-year follow-up. Higher pre-treatment MCS scores and having pursued higher education predicted higher MCS scores at one-year follow-up. Sleep problems, being a woman and having children under 18 years predicted lower MCS scores at one-year follow-up.

*Conclusion:* Pain rehabilitation programs can be the first step toward breaking the vicious circle of chronic pain. The intervention was effective for participants at one-year follow-up. Their self-reported pain severity and pain interference had decreased. Moreover, their health and HRQOL increased. However, they had failed to continue using the methods highlighted in the pain rehabilitation program, and their sleep problems persisted. The findings reveal the need for more emphasis on sleep problems and mental health in connection with chronic pain in multidisciplinary pain rehabilitation interventions. Therefore, some sort of follow-up is recommended for support, education and maintaining the long-term effect of the intervention.

**Keywords:** Chronic pain, sleep quality, health-related quality of life, rehabilitation.

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## **List of abbreviations**

|         |   |
|---------|---|
| BMI     | Body mass index                                 |
| BP      | Bodily pain                                     |
| BPI     | Brief Pain Inventory                            |
| CBT     | Cognitive behavioural therapy                   |
| GH      | General health                                  |
| HRQOL   | Health-related quality of life                  |
| IASP    | International Association for the Study of Pain |
| M       | Mean  |
| MCS     | Mental Component Summary                        |
| MH      | Mental health                                   |
| PCS     | Physical Component Summary                      |
| PF      | Physical function                               |
| PSQI    | Pittsburgh Sleep Quality Index                  |
| QOL     | Quality of life                                 |
| RE      | Role emotional                                  |
| RHA     | University of Akureyri Research Centre          |
| RP      | Role physical                                   |
| SD      | Standard deviation                              |
| SF      | Social functioning                              |
| SF-36v2 | Short Form 36 Health Survey, version 2          |
| SPSS    | Statistical Package for the Social Sciences     |
| VT      | Vitality  |
| WHO     | World Health Organization                       |

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## List of original papers

This thesis is based on the following original publications, which are referred to in the text by their roman numerals (I–III):

- I. Skúladóttir, H., Gunnarsdóttir, Th. J., Halldórsdóttir, S., Sveinsdóttir, H., Holden, J. E., & Björnsdóttir, A. (2020). Breaking the vicious circle: Experiences of people in chronic pain on the pain rehabilitation journey. *Nursing Open*, 7, 1412-1423.  
<https://doi.org/10.1002/nop2.512>
  
- II. Skúladóttir, H., Björnsdóttir, A., Holden, J. E., Gunnarsdóttir, Th. J., Halldórsdóttir, S., & Sveinsdóttir, H. (2021). Pain rehabilitation's effect on people in chronic pain: A prospective cohort study, *International Journal of Environmental Research and Public Health*, 18(19), 10306. <https://doi.org/10.3390/ijerph181910306>
  
- III. Skúladóttir, H., Sveinsdóttir, H., Holden, J. E., Gunnarsdóttir, Th. J., Halldórsdóttir, S., & Björnsdóttir, A. (2021). Pain, sleep, and health-related quality of life after multidisciplinary intervention for chronic pain, *International Journal of Environmental Research and Public Health*, 18(19), 10233. <https://doi.org/10.3390/ijerph181910233>

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## **Declaration of contribution**

The doctoral candidate, Hafdís Skúladóttir (HS), wrote this doctoral thesis under the guidance of Herdís Sveinsdóttir, supervisor and advisor, Sigríður Halldórsdóttir, advisor, and other members of the doctoral committee: Amalía Björnsdóttir, Janean E. Holden and Þóra Jenný Gunnarsdóttir. Grants were applied for by HS with guidance from Herdís Sveinsdóttir and Sigríður Halldórsdóttir.

Paper I: All authors contributed to the study design (HS, Þóra Jenný Gunnarsdóttir, Sigríður Halldórsdóttir, Herdís Sveinsdóttir, Janean E. Holden, Amalía Björnsdóttir). HS conducted the interviews. HS, Þóra Jenný Gunnarsdóttir, Sigríður Halldórsdóttir and Herdís Sveinsdóttir contributed to the data analysis and drafting the manuscript. All authors critically revised the manuscript.

Paper II: All authors contributed to the study design (HS, Þóra Jenný Gunnarsdóttir, Sigríður Halldórsdóttir, Herdís Sveinsdóttir, Janean E. Holden, Amalía Björnsdóttir). HS, Amalía Björnsdóttir and Herdís Sveinsdóttir contributed to the data analysis and drafting the manuscript. All authors critically revised the manuscript.

Paper III: All authors contributed to the study design (HS, Þóra Jenný Gunnarsdóttir, Sigríður Halldórsdóttir, Herdís Sveinsdóttir, Janean E. Holden, Amalía Björnsdóttir). HS, Amalía Björnsdóttir and Herdís Sveinsdóttir contributed to the data analysis and drafting the manuscript. All authors critically revised the manuscript.

# 1 Introduction

For patients in chronic pain, rehabilitation is a constant challenge. Multidisciplinary pain rehabilitation programs are an accepted and beneficial method for treating chronic pain (Bögdal et al., 2021; Vartiainen et al., 2019), but more research is needed on the long-term effectiveness of such programs (Schmidt et al., 2021; Vartiainen et al., 2019). Multidisciplinary pain rehabilitation programs are a combination of psychological interventions and physical training (Gunnarsdóttir & Peden-MacAlpine, 2004; Thorarinsdottir et al., 2019). Such programs have been shown to lead to higher bodily awareness, greater mental health, increased social interaction (Bögdal et al., 2021), reduced fatigue (Saral et al., 2016), improved physical function (Leung et al., 2021; Saral et al., 2016), increased life satisfaction and reduced pain severity, along with a reduction in the negative psychological, social, and behavioural effects of pain (Hooten et al., 2012; Silvemmark et al., 2014; Wilson, 2017).

Participants in pain rehabilitation programs need to alter their behaviour by changing their thoughts and feelings, which allows them to gain new insights and understandings (Haraldseid et al., 2014). While in the program, they learn how to take care of themselves and new things about themselves (Gunnarsdóttir & Peden-McAlpine, 2004). Patients and nurses form relationships in which nurses show understanding and support when they assess patients' general health, gather information about social circumstances and take patient histories (Thorarinsdottir et al., 2019). After completing the program, patients need to integrate the knowledge, skills and behaviours learned through the program into their everyday lives (Bögdal et al., 2021).

Multidisciplinary pain rehabilitation programs for chronic low back pain have been shown to lead to improved function and greater likelihood of returning to work (Leung et al, 2021). Musculoskeletal pain can increase the risk of absenteeism and work disability (Anderson et al., 2012; Norrefalk & Borg, 2012), resulting in job changes (Breivik et al.,2006) and strained finances (Andrews et al., 2018). Breivik et al.'s (2006) survey of chronic pain patients in Europe showed that 61% were unable or less able to work outside their home, 19% had lost their jobs, and 13% had changed their jobs because of their pain.

When pain has persisted beyond normal tissue healing time and lasted longer than three months, it is typically defined as chronic pain (Treede et al., 2015), which is a common, complex, and distressing problem (Mills et al., 2019) that results in decreased physical activity (Boutevillain et al., 2017), poor psychological and physical health (Macfarlane et al., 2009) and insomnia (Aghayev et al., 2010; Alföldi et al., 2017; Bean et al., 2021). Mental disorders (e.g., depression, anxiety and suicidal thoughts) are highly prevalent in those with chronic pain conditions, which often affect mood and subjective enjoyment of life (Hooten, 2016; Malfliet et al., 2019). Chronic pain has a profound impact on both individuals and society (Mills et al., 2019) and can influence psychosocial well-being (Ojala et al., 2016), where changes in the body, self and relationships with family are experienced (Ahlsen et al., 2012; Ailshire & Burgard, 2012; Armentor, 2017).

Pain can serve as a symptom or warning of a medical condition or injury (Treede et al., 2019). Most people experience mild acute pain at some time (Baldwin et al., 2018). It is a personal experience for each person, and the lived world around a person can have a strong influence on the response to pain (Dysvik & Furnes, 2018). Pain self-management strategies include specific tasks, activities, and methods that a person in chronic pain may employ to manage symptoms and achieve certain goals, such as reduced pain interference with activities, mood, and relationships (Nicholas & Blyth, 2016).

Globally, it has been estimated that one in five adults suffers from pain and another one in ten adults is diagnosed with chronic pain each year (International Association for the Study of Pain (IASP), n.d.). Chronic pain is the second-largest contributor to disability worldwide, with low back pain being the single leading cause of disability (World Health Organization [WHO], 2021a). The incidence, prevalence, severity and accompanying disabilities of chronic pain are among the main reasons for regarding pain as a public health priority. For millions of people, chronic pain becomes an inescapable reality of life (Goldberg & McGee, 2011; WHO, 2021a).

Musculoskeletal conditions are diverse, affecting bones, joints, muscles and connective tissues; they are the greatest contributor to the global need for rehabilitation. Approximately two thirds of all adults will need rehabilitation because of musculoskeletal conditions (WHO, 2021a). Findings from a survey in Iceland showed that the most common causes of chronic pain were myalgia, old trauma, rheumatism (e.g., rheumatoid arthritis and osteoarthritis), fibromyalgia and migraines (Jonsdottir et al., 2015). Pain can

also be a consequence of accidents (Daoust et al., 2018), childhood violence (Eriksen et al., 2016) or domestic violence or abuse (Sigurdardottir & Halldorsdottir, 2013; Sigurdardottir et al., 2014). Those who are overweight or obese are more likely to have low back pain, tension or migraine headaches, abdominal and widespread chronic pain (Wright et al., 2010), fibromyalgia (Varallo et al., 2021; Wright et al., 2010) and reduced physical function (Koball et al., 2016; Varallo et al., 2021).

Chronic pain reduces quality of life (QOL; Edwards et al., 2016), and measuring health-related quality of life (HRQOL) is an important tool in studies of chronic pain patients (Jonsdottir et al., 2014; Vartiainen et al., 2019) because it describes the impact of health on people's ability to function and participate in meaningful activities (Jonsdottir et al., 2014), with which chronic pain interferes. However, findings from multidisciplinary long-term pain rehabilitation studies using HRQOL assessment are mixed. Patients with chronic pain can benefit from such programs in terms of better functioning, but the impact on pain has been lower than expected (Wilson, 2017). Meanwhile, either no long-term increase in HRQOL or a moderate to large increase that has been shown to have persisted for at least 12 months has been reported (Salathé et al., 2018).

The focus in this thesis is on the short-term (post-treatment) and long-term (three months to one year) effects of multidisciplinary pain rehabilitation programs at three rehabilitation centres in Iceland. This is the first time these three programs have been studied together, and the aim is to explore and describe their short- and long-term effects on pain severity and pain interference, along with the long-term effects on pain self-management, sleep quality, well-being, health and HRQOL.

## **1.1 Chronic pain**

Chronic pain is defined as an unpleasant sensory and emotional experience that is associated with, or resembles that which is associated with, actual and potential tissue damage and typically lasts longer than three months (IASP, n.d.-a). In chronic pain syndromes, pain can be a leading complaint, requiring special treatment and care. In fibromyalgia or nonspecific low-back pain, chronic pain can be conceived as a disease and has been called chronic primary pain (Treede et al., 2019), which refers to chronic pain that has persisted for longer than three months, is in one or more anatomical regions and is characterized by significant emotional distress or functional disability. Additionally, such pain interferes with the activities of daily life and social

participation and is not better accounted for by another chronic pain condition (Nicholas et al., 2019). In other groups, the pain is secondary to an underlying disease and has been categorized as chronic secondary pain. Examples are chronic posttraumatic and postsurgical pain, chronic secondary headache and chronic musculoskeletal pain (Treede et al., 2019).

Chronic secondary musculoskeletal pain is chronic pain arising from bones, joints, muscles, vertebral column, tendons or related soft tissues. It can be characterized either by persistent local or by systematic inflammatory illness (Perrot et al., 2019). Chronic postsurgical or posttraumatic pain develop or increases in intensity after a surgical procedure or tissue injury. Typical examples of trauma are joint injuries, acute back injury, whiplash injury and burn injury (Schug et al., 2019).

Chronic pain is often considered to be nociplastic pain or pain that arises from altered nociception despite there being no clear evidence of actual or threatened tissue damage (IASP, n.d.-b). This pain can occur in isolation or as part of a mixed pain state. Symptoms in nociplastic pain include widespread pain, intense pain, both widespread and intense pain and fatigue, along with sleep and mood problems (Fitzcharles et al., 2021).

An evidence-based chronic pain classification system called the American Pain Society Pain Taxonomy involves psychosocial concepts and processes that are essential to understanding the development and effects of chronic pain. Causes of pain can be acute pain, illness or injury, which can lead to chronic pain and then disability. The model involves factors affecting chronic pain pathways like behaviour, cognition and the central nervous system. There are examples of risk and vulnerability factors like distress, trauma, fear and catastrophizing on one hand; on the other, however, there are resilience and protective factors such as social support, acceptance and self-efficacy (Edwards et al., 2016).

## **1.2 Pain self-management**

Chronic pain can be difficult to treat because of complex and uncertain diagnostic criteria, as with fibromyalgia (Dennis et al., 2013), and limited strategies for managing pain. Before the 1960s, chronic pain conditions were viewed as primarily medical issues that required physical treatments such as medication or surgery (Edwards et al., 2016). Medication remains one of the most common pain management strategies (Mühlbacher et al., 2015; Nicholas & Blyth, 2016; Saltychev et al., 2014; Schaefer et al., 2011) and is either prescribed or obtained over the counter. Aquatic exercises are also

well known and widely used in physiotherapy for individuals with chronic musculoskeletal pain (Baena-Beato et al., 2014; Cuesta-Vargas et al., 2014).

Pain self-management strategies include the specific tasks, activities or methods that individuals in chronic pain must undertake to manage symptoms and achieve goals (Nicholas & Blyth, 2016). Some of the most common pain self-management strategies are distraction, meditation, (Nicholas & Blyth, 2016), activity pacing (Antcliff et al., 2016; Nicholas & Blyth, 2016), relaxation, exercise (Mengshoel et al., 2021; Nicholas & Blyth, 2016), hot and cold packs, herbal remedies, acupuncture, complementary or alternative medicine, dietary modifications (Axon et al., 2019), activities in warm water pools and yoga (Mengshoel et al., 2021). A significant proportion of people with chronic pain can work out their own self-management strategies, but others cannot and thus need professional support. The challenge facing health professionals is to help patients with chronic pain to identify and implement self-management options that are appropriate to their particular circumstances (Nicholas & Blyth, 2016).

Satisfactory treatment begins with a comprehensive assessment of the biological aetiology of the pain in conjunction with the patient's specific psychosocial and behavioural presentation. The assessment should focus on the entire person, using both an interview and standardized assessment tools. Self-report measures have become the gold standard for assessing patients reporting pain, and several instruments have been developed and published. Numerical rating scales and verbal rating scales are the most common; the former ask patients to rate their typical pain on a scale from zero (no pain) to 10 (the worst pain imaginable), while the latter use verbal descriptors and ask the patient to describe their pain as mild, moderate or severe (Dansie & Turk, 2013).

The relief resulting from pain management strategies can be influenced by factors such as age, gender, type of pain, level of education, socioeconomic status, occupation and access to health care (Slack et al., 2018). Life stress, other related stress and experiencing unexplained and unpredictable illnesses like fibromyalgia may hinder recovery (Mengshoel et al., 2021). The duration of a treatment program can affect the results, as Saral et al. (2016) have shown: a short-term program of two days met the needs of patients with fibromyalgia in relation to pain and health status, while a long-term program of 10 weeks was beneficial in reducing fatigue and improving physical function.

### 1.3 Sleep quality

It is important to pay attention to sleep quality in patients with chronic pain (Bean et al., 2021; Keilani et al., 2018; Vaegter et al., 2021). Sleep is a biological process that is essential for health and life itself (Medic et al., 2017). Adequate sleep is essential for daily functioning (Ailshire & Burgard, 2012). Both insomnia and daytime sleepiness are common health problems experienced by people with low back pain and are important predictors affecting their QOL (Uchmanowicz et al., 2019).

Sleep deprivation has been found to be a risk factor for chronic pain in women aged 20 to 50 (Nitter et al., 2012); in a systematic review of studies using the Pittsburgh Sleep Quality Index (PSQI) scores, sleep disturbances were found among 75% of chronic pain patients (Sun et al., 2021). Patients with sleep problems due to pain have more musculoskeletal pain than other patients (Aghayev et al., 2010), but sleep problems are frequently reported in adults living with chronic pain, and the association is bidirectional (WHO, 2021a). Increases in total sleep time have been shown to be predictive of less pain the following day, but daily pain ratings were not predictive of the relevant night's total sleep time (Davin et al., 2014). In Bean et al.'s study (2021) a night of poorer-quality sleep led to greater pain the following morning. However, Abeler et al. (2021) offer evidence of a significant effect of pain on next-night sleep quality and less convincing evidence for an effect of sleep on next-day pain.

Poor sleep quality is typically measured with indicators of delayed, disrupted or non-restorative sleep (Burgard & Ailshire, 2009). Medical conditions, psychosocial issues and lifestyle factors can all contribute to sleep problems. There are approximately 100 sleep disorder classifications that are typically manifested in one of the following ways: failure to obtain the necessary amount or quality of sleep, an inability to maintain sleep continuity, and events that occur during sleep (Medic et al., 2017).

Psychiatric morbidity in patients with chronic pain is frequent and may affect quality of sleep and QOL (Annagür et al., 2014). Chronic pain and sleep problems have been shown to be associated with symptoms of depression and anxiety (Annagür et al., 2014; Lee et al., 2018; Medic et al., 2017). In Abeler et al.'s study (2021), mental distress was the most robust predictor of pain severity but did not modify the sleep–pain associations. A meta-analysis assessing the effects of different types of regular exercise (e.g., walking, cycling and yoga) on self-reported and physiological sleep quality in adults showed improvement in subjective rather than physiological sleep quality (Xie et al., 2021).

## 1.4 Well-being, health and HRQOL

The WHO (n.d.) defines QOL as an individual's perception of his or her position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. During the 1980s, the recognition of the centrality of the patient's point of view in monitoring the quality of medical care outcomes was acknowledged as important (Geigle & Jones, 1990). This led to examinations of changes in a patient's behavioural functioning or well-being and how well the treatment results met the fundamental objectives of prolonging life, relieving distress, restoring function and preventing disability (Maruish, 2011).

The terms health, QOL and HRQOL are widely used in the literature, but there remains debate about the definition of all three (Karimi & Brazier, 2016). Health is one of the important domains of overall QOL. According to the definition in the WHO Constitution (2019), health is

a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

QOL is a complex concept that is interpreted and defined in many ways within and across various disciplines. It is an important endpoint in medical and health research and involves a variety of patient groups and different research designs (Haraldstad et al., 2019). It has been described as a cognitive judgment of satisfaction with one's life (Karimi & Brazier, 2016) and 'an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values' (Felce & Perry, 1995, pp. 60–62). However, QOL is more than health status, clinical symptoms or functional ability. There is not always a clear distinction between HRQOL, health status and QOL. Some definitions of HRQOL resemble health status as the WHO describes it, while others are closer to QOL. One definition of HRQOL states that it includes only those factors that are part of an individual's health and not the non-health aspects of QOL such as economic and political circumstances (Karimi & Brazier, 2016).

The concept of HRQOL has evolved since the 1980s. It has been defined in different ways in the literature and has been used to identify important or

common ways in which health or health care impact well-being (Karimi & Brazier, 2016). HRQOL has been defined as ‘an individual’s or group’s perceived physical and mental health over time’ (Centers for Disease Control and Prevention, n.d., ‘What is health-related quality of life?’) It has been described as the impact of health on people’s ability to function and participate in meaningful activities within the family, workplace and community (Jonsdottir et al., 2014; Vetter, 2007).

But there are also other domains: work, housing, school, neighbourhood, culture, values and so on. In recent decades, several improvements in the measurement of health status, QOL and HRQOL have been made; the SF-36 Health Survey is one such instrument and has been available since 1988 (Maruish, 2011). The findings of multidisciplinary long-term pain rehabilitation studies using HRQOL assessments are mixed. There is either no long-term increase in HRQOL or a moderate to large increase that persisted for at least 12 months (Salathé et al., 2018). Major improvement in HRQOL after multidisciplinary pain rehabilitation was positively associated with shorter duration of pain and a poorer baseline HRQOL (Vartiainen et al., 2019).

## **1.5 Multidisciplinary pain rehabilitation**

Rehabilitation is defined as ‘a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment’ (WHO, 2021b, ‘What is rehabilitation?’). Rehabilitation helps an individual be as independent as possible in daily activities and enables participation in education, work and other meaningful life roles (WHO, 2021b). It is person-centred and can be provided in different contexts, such as inpatient or outpatient hospital settings, private clinics or community settings. The rehabilitation workforce is made up of different health workers, including nurses, doctors, physical therapists, occupational therapists and psychologists (WHO, 2021b).

Multidisciplinary long-term pain rehabilitation uses a team of health-care professionals from different specialties who work together while each remains within his or her discipline. Such programs contain a combination of psychological interventions and physical training for situations where pharmacological treatment or physiotherapy have proved insufficient (Wilson, 2017). The role of nurses is depicted in several pain rehabilitation studies. They are described as observing (Takahashi et al., 2018), caring and supportive (Takahashi et al., 2018; Thorarinsdottir et al., 2019). They take part in assessment (Thorarinsdottir et al., 2019), provide cognitive

behavioural therapy (CBT) (Olason et al., 2018) and act as liaisons between specialists (Takahashi et al., 2018). In other pain rehabilitation studies, the role of nurses is not described; nor is the role of other health professionals, and there is no indication of which professional is being discussed. They are often called the 'staff', as in Gunnarsdóttir and Peden-McAlpine (2004). In that study, the participants recognized that they needed help and accepted being guided by staff to achieve their personal wellness goals. They experienced caring in the form of guidance by learning about new therapies to enhance their health (Gunnarsdóttir & Peden-McAlpine, 2004).

Existing research provides insights into how different rehabilitations can affect chronic pain patients' daily life and well-being. Multidisciplinary programs have improved physical tolerance of daily activities in patients with chronic low back pain (Leung et al., 2021), and rehabilitation has been shown to have beneficial effects on sick leave and the use of disability pensions (Norrefalk & Borg, 2012). But Salathé et al. (2018) concluded, in a systematic review of treatment efficacy and cost-effectiveness and impact on sick leave for nonspecific low back pain, that there was room for improvement in cost-effectiveness and impact on sick leave.

Pain rehabilitation programs have been found to be effective in changing behaviour by modifying people's thoughts and feelings (Haraldseid et al., 2014), reducing uncertainties and bringing hope and a positive attitude (Mengshoel et al., 2021), alleviating suffering (Dysvik et al., 2014), reducing pain levels (Olason, 2004), pain intensity and post-traumatic stress (Stålnacke & Östman, 2010). They can be effective for those who are ready to make changes in their lives (Huet et al., 2009; Merrick & Sjölund, 2009) and can also positively influence psychosocial functioning (Bullington et al., 2003; Bögdal et al., 2021; Persson et al., 2012) through higher bodily awareness, greater mental health, more happiness, increased social interaction and a better QOL (Bögdal et al., 2021). The result of successful rehabilitation can be a new sense of self and personal meaning (Bullington et al., 2003; Mengshoel et al., 2021), insight and understanding (Haraldseid et al., 2014). Some individuals learn new strategies for handling their pain (Gustafsson et al., 2004; Huet et al., 2009) and develop the personal resources to take responsibility for their daily lives (Bullington et al., 2003; Hållstam et al., 2015), improve their self-image and communication in their social environment (Gustafsson et al., 2004; Mengshoel et al., 2021), return to work (Leung et al., 2021), reduce their consumption of analgesics (Darchuck et al., 2010; Norrefalk & Borg, 2012; Olason et al., 2018;

Saltychev et al., 2014; Townsend et al., 2008) and move towards a better life (Dysvik et al., 2014).

CBT, hypnosis (Castel et al., 2012) and other mindfulness-based approaches (Doran, 2014) are well-known treatments used in pain rehabilitation programs (Sveinsdottir et al., 2012). CBT assumes that ways of thinking motivate behaviour and influence emotions (Sveinsdottir et al., 2012). Together with other treatments, CBT has been found to be beneficial for chronic back pain (Sveinsdottir et al., 2012) and fibromyalgia (Imamura et al., 2009; Redondo et al., 2004), the most common pain sites among those who attend pain rehabilitation programs (Darchuck et al., 2010; Merrick & Sjölund, 2009; Van Huet et al., 2009). The use of CBT in pain rehabilitation programs has been found to have long-term effects on patients' pain management in their daily lives (Egan et al., 2017; Hållstam et al., 2015), together with a positive influence on patients' psychosocial functioning more than their perception of disability (Persson et al., 2012). CBT-based programs can alleviate the suffering caused by chronic pain and allow participants to move towards a better life (Dysvik et al., 2014) by learning skills to help reduce pain levels (Olason, 2004).

However, not everyone who attends a pain rehabilitation program completes the program, which raises the question of whether there is a need to pay more attention to some people more than others. In a systematic review, some predictors of dropout among chronic musculoskeletal pain patients in pain rehabilitation programs were younger age, having a daytime job, having young children, experiencing higher levels of pain intensity, more severe disability and depression. Perhaps these are the people who need more attention to prevent their dropping out of pain rehabilitation programs; the question needs to be studied further (Oosterhaven et al., 2019).

In rehabilitation, the importance of meeting the needs of all patients, whether men and women, has been highlighted, because gender bias can influence professional treatment decisions (Samulowitz et al., 2018). Women have shown more improvement after pain rehabilitation programs than men, but more women than men usually participate in studies concerning chronic pain (Björnsenius et al., 2020; Rovner et al., 2017; Volker et al., 2017). For example, in Björnsenius et al.'s (2020) study, women improved in all outcomes (physical and mental health, pain intensity and interference of pain with life), whereas men did not improve on the psychological measures. Rovner et al. (2017) found a difference among male and female patients entering a rehabilitation program in how they accepted their pain. Both sexes

experienced the same pain severity, but pain acceptance and kinesiophobia (pain-related fear of movement) showed clear differences, with men reporting higher kinesiophobia and women reporting significantly more pain acceptance. This raises the question of whether pain rehabilitation programs should pay more attention to the different needs of men and women.

### **1.5.1 Multidisciplinary pain rehabilitation in Iceland**

Three rehabilitation centres offer pain management intervention in Iceland. They are in three different areas: Reykjalundur (south-west), Kristnes (north-east) and the Rehabilitation and Health Clinic at Hveragerði (south). Each year, approximately 400 individuals with chronic musculoskeletal pain attend one of these three pain rehabilitation programs.

The programs emphasize multi-disciplinary strategies with individualized, person-centred nursing and treatment. The aim is to collaborate with patients and their families to increase each patient's competence, function, security and participation in daily activities and increase their QOL. The patients' and their families' wishes and human rights are respected. The treatment takes note of each patient's personal situation, including education, family status, culture, gender, residence and community.

The intervention begins and ends with assessing the patient's condition (see Figure 2 and Figure 3). At the initial assessment, every patient is evaluated to set goals and make decisions regarding the development of rehabilitation procedures (see Paper II, Table 1). A special focus is placed on self-management strategies and minimizing or reducing the use of pain medication and sedatives. The importance of a healthy lifestyle is taught, with a focus on more regular physical exercise, fitness training, avoiding addictive substances, stress management and relaxation exercises (Olason et al., 2018).

### **1.6 Summary of and rationale for the study**

Pain can have various causes including serving as a warning sign of symptoms and medical conditions. Chronic pain is a common problem that interferes with daily activities – the ability to work, walk, sleep and communicate with others – and the basic enjoyment of life; it can be difficult to treat. Several studies have been conducted on the effects of pain management from different points of view. Medication is the most common approach to pain relief, but pain rehabilitation programs emphasize a healthy lifestyle, mindfulness, CBT and reducing the use of medication. Pain

rehabilitation programs have been shown to be effective but their impact on pain has been lower than expected, and their impact on sleep quality has not been a focus in previous studies.

Suffering from chronic pain affects health and well-being and reduces QOL. The findings from multidisciplinary long-term pain rehabilitation studies using HRQOL assessments are mixed, with either no long-term increase in HRQOL or a moderate to large increase. There appear to be gender differences in this regard, with women showing more improvement than men.

No study has been identified that examines the multidisciplinary pain rehabilitation programs at Iceland's three centres together for comparison or to shine a light on their outcomes from patient perspectives. Furthermore, no qualitative, interview-based studies have been carried out with groups of people in chronic pain attending a multidisciplinary pain rehabilitation program at one of the three centres in Iceland. All pain rehabilitation programs in Iceland are individualized and focus on each patient's needs. It is reasonable to expect that outcomes could vary between individuals.

Detailed descriptions of chronic pain and its effects on a patient's well-being before treatment, during treatment and in the following months can only be gathered through interviews. That is the main reason for choosing a longitudinal study design that employs both qualitative and quantitative data to explore and describe patients' lived experience of their pain, health and well-being, to explore and describe the short- and long-term effects on pain severity and pain interference, and the long-term effects on pain self-management, sleep quality, well-being, health and HRQOL.

## **2 Aims**

This thesis comprises three studies presented in three original papers. One uses a qualitative phenomenological approach guided by the Vancouver School of Doing Phenomenology (Vancouver School below); the other two are quantitative longitudinal prospective cohort studies. Due to a lack of knowledge about how effective multidisciplinary pain rehabilitation programs are from patient perspectives, the studies were both explorative and descriptive.

The overall aim of the thesis was to explore and describe the short- and long-term effects of three Icelandic multidisciplinary pain rehabilitation programs on pain severity and pain interference and the long-term effects on pain self-management, sleep quality, well-being, health and HRQOL.

### **2.1 Aim of Study I/Paper I**

The aim of the first study was to explore how individuals with chronic pain experienced their pain, well-being and health before and after attending one of the multidisciplinary pain rehabilitation programs.

### **2.2 Aim of Study II/Paper II**

The aim of the second study was to investigate both the short- and long-term effects of multidisciplinary pain rehabilitation interventions in Iceland on pain severity, pain interference, pain self-management, sleep and health. Specifically, the study aimed a) to explore and describe how individuals in chronic pain self-report their pain severity and pain interference with life before attending a multidisciplinary pain rehabilitation intervention (pre-treatment), upon completion of the intervention (post-treatment) and at one-year follow-up, and b) to explore changes in participants' pain self-management strategies, sleep and health at one-year follow-up.

### **2.3 Aim of Study III/Paper III**

The aim of the third study was to investigate the long-term effects of multidisciplinary pain rehabilitation interventions in Iceland by a) exploring and describing how individuals in chronic pain evaluate pain severity, sleep and HRQOL before treatment and at one-year follow-up and b) determining the factors that predict participants' HRQOL one year after the intervention.

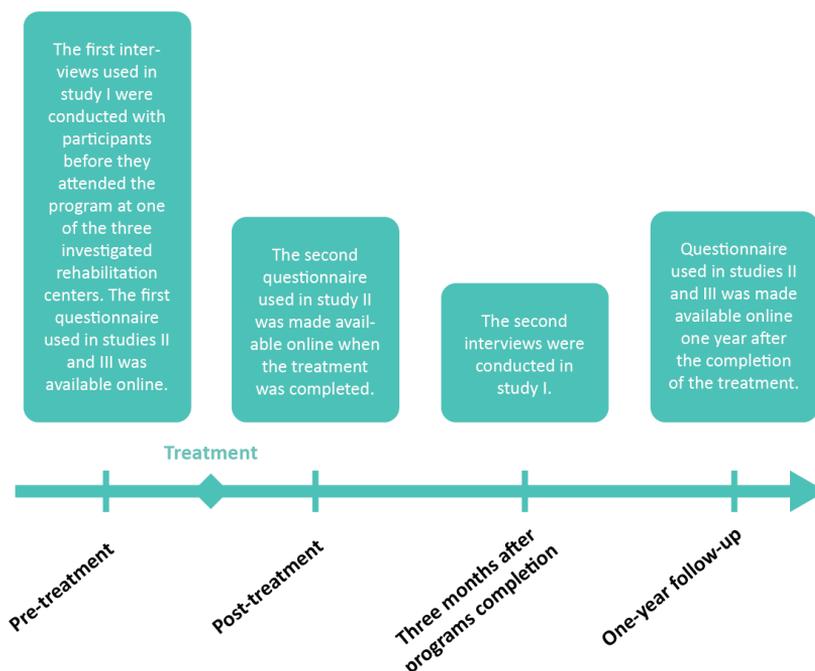


### **3 Materials and methods**

The thesis reports on three studies and consists of three papers. Data collection started in October 2015 and was completed in February 2019. Participants attended one of the three Icelandic centres offering multidisciplinary pain rehabilitation programs (Centres 1, 2 and 3): Reykjalundur (1), Kristnes (2) and Rehabilitation and Health Clinic at Hveragerði (3).

Data were collected at several time points (see Figure 1 and Figure 4):

- Pre-treatment: The first interviews used in Study I were conducted with participants before they attended a program at one of the three investigated rehabilitation centres. The first questionnaire used in Studies II and III was available online.
- Post-treatment: The second questionnaire used in Study II was made available online after a patient's treatment was completed.
- Three months after program completion: The second interviews were conducted in Study I.
- One-year follow-up: The questionnaire used in Studies II and III was made available online one year after the completion of the treatment.



**Figure 1.** Timeline for data collection

Data collection in Study I was conducted by the author of the dissertation (HS), while data collection for Studies II and III was conducted by the research assistant at the University of Akureyri Research Centre (RHA; see Procedures).

Study I was a phenomenological study in which participants were first interviewed before they attended the multidisciplinary pain rehabilitation program and again three months after the program's completion to explore how they experienced their pain, health and well-being.

Study II was a longitudinal prospective cohort study in which participants answered online questionnaires pre-treatment, post-treatment and at one-year follow-up to explore their pain severity, pain interference with life and changes in their self-management strategies, sleep and health at one-year follow-up.

Study III was a longitudinal prospective cohort study where participants answered online questionnaires pre-treatment and at one-year follow-up to explore and describe any changes in the evaluation of pain severity, sleep and HRQOL and to determine the factors that predicted their HRQOL at one-year follow-up.

See Table 1 for an overview of design, data collection, data sources and data analysis in Studies I–III.

**Table 1.** Description of the three studies

|              | Study I  | Study II   | Study III  |
|--------------|--|--|--|
| Aim          | To explore how individuals in chronic pain experienced their pain, well-being and health before and after attending one of the multidisciplinary pain rehabilitation programs.   | To explore and describe how individuals in chronic pain self-report their pain severity and pain interference with life before attending a multidisciplinary pain rehabilitation intervention (pre-treatment), upon completion of the intervention (post-treatment) and at one-year follow-up and to explore changes in the participants' pain self-management strategies, sleep and health at one-year follow-up. | To explore and describe how individuals in chronic pain evaluate pain severity, sleep and HRQOL pre-treatment and at one-year follow-up and to determine those factors that predict the participants' HRQOL at one-year follow-up. |
| Design       | A phenomenological study   | A longitudinal prospective cohort study  | A longitudinal prospective cohort study  |
| Variables    | Not applicable   | Pain causes, duration, and location<br>Pain severity<br>Pain interference<br>Pain self-management<br>Sleep<br>Health   | Pain severity<br>Sleep quality<br>HRQOL  |
| Data sources | Interview data ( $n = 11$ ): 21 interviews, 11 pre-treatment and 10 three months after program's completion. The interviews lasted 22–80 minutes ( $M = 37$ minutes). They were audio recorded and transcribed verbatim. | Three questionnaires: Pre-treatment, post-treatment and at one-year follow-up ( $n = 81$ ). Brief Pain Inventory (BPI) Three sleep questions derived from PSQI Two health questions from SF-36v2   | Two questionnaires: Pre-treatment and at one-year follow-up ( $n = 79$ ) BPI Sleep questions developed especially for the study SF-36v2  |
| Analysis     | Vancouver School NVivo 11 (QSR International qualitative data analysis software) was used to manage the dataset and for within- and between-case comparisons.  | Descriptive statistics<br>Wilcoxon signed-rank test<br>Related-samples McNemar change test<br>Paired $t$ -test with bootstrapping<br>Cohen's $d$<br>SPSS 27 statistical program was used in statistical analysis.  | Descriptive statistics<br>Paired $t$ -test with bootstrapping<br>Related-samples McNemar change test<br>Multiple linear regression<br>Cohen's $d$<br>SPSS 27 statistical program was used in statistical analysis.                 |

### 3.1 Settings of Studies I, II and III

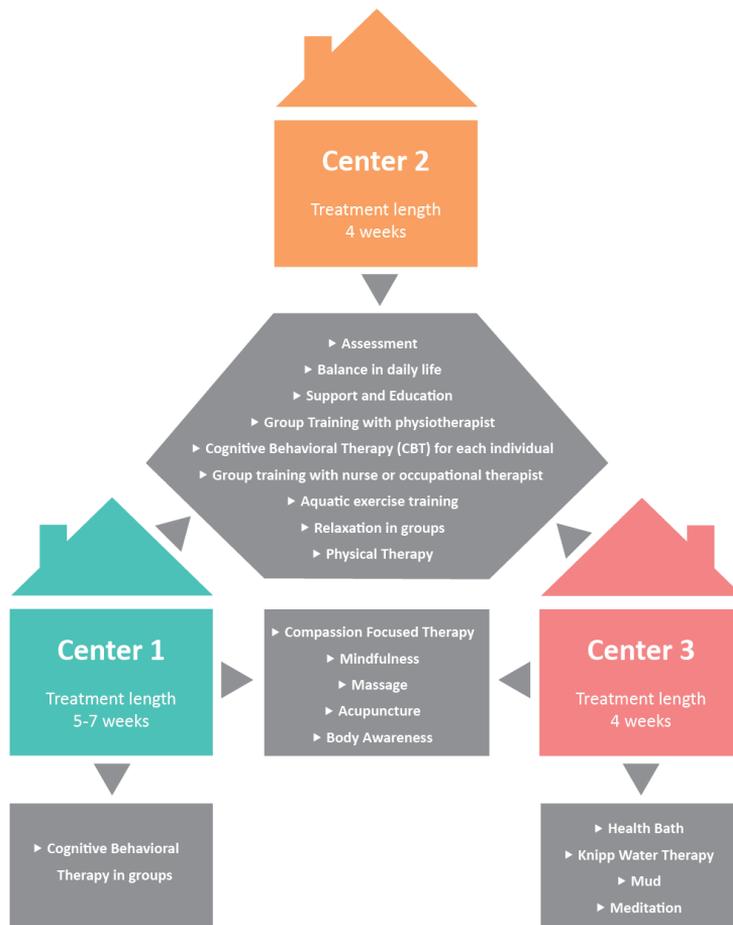
The study settings were three centres in Iceland providing multidisciplinary pain rehabilitation interventions. They were staffed by nurses, physicians, physiotherapists, psychologists, occupational therapists, social workers, nutritional consultants, massage therapists and physical activity instructors (Figure 2). No one in the research group took part in providing treatment to any of the participants.



**Figure 2.** Role of each professional

### 3.2 Intervention

The intervention was a multidisciplinary pain rehabilitation program offered at the three investigated rehabilitation centres. The standard intervention was similar in all three cases, with treatment length ranging from four (Centres 2 and 3) to seven weeks (Centre 1). The investigated treatments were not offered to people above 70 years of age (Figure 3). See Section 2.3, Table 1 in Paper II.



**Figure 3.** Standard intervention

### 3.3 Procedures

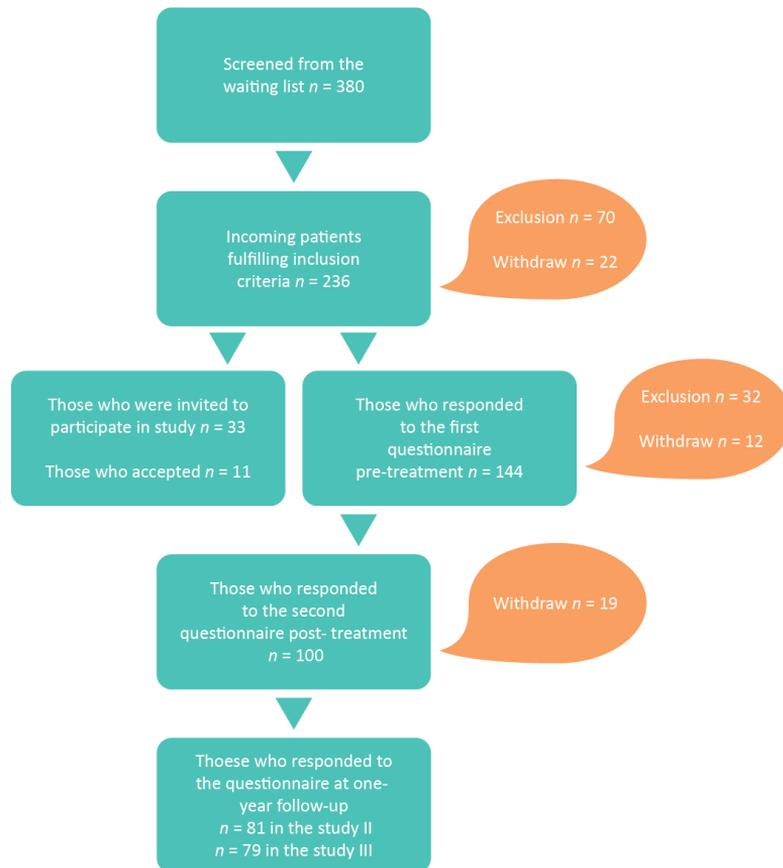
To be able to attend a pain rehabilitation program, patients needed to apply through their advisor in a vocational rehabilitation program, their general physician or a specialist physician. The inclusion criteria for participation in the three studies were as follows: chronic musculoskeletal pain lasting at least three months; the ability to speak, understand and read Icelandic; aged 18–70 years; and admission to one of the three investigated rehabilitation centres. Exclusion criteria were based on recommendations from the centres' nurse unit managers and chief physicians. Patients who did not attend the entire program, those who participated in a remote program, and those who had cancer were excluded.

The participants were recruited in collaboration with either the chief physicians or nurse unit managers at the rehabilitation centres (one contact person at each centre). These individuals went through the waiting lists of incoming patients in light of the inclusion criteria. Patients ( $N = 380$ ) were screened as soon as they were added to a program's waiting list (Figure 4). The contact person at each centre prepared a list of names and sent it to HS, who forwarded it to a research assistant at RHA who was not part of the research group.

The research assistant then telephoned the incoming patients ( $n = 236$ ), introduced the project and provided instructions on how to participate in Studies II and III. Additionally, 33 incoming patients received an introductory letter from HS about Study I that invited them to participate (Figure 4). HS chose names from the lists of incoming patients. The aim was to have a minimum of nine participants (or the number where saturation would be reached) from each centre, comprising both men and women and distributed across age groups. Only 13 responded, two of whom refused to participate because of language difficulties or insufficient energy. HS conducted all the interviews for Study I.

Those who agreed to participate in Studies II and III received an introductory letter by mail from the research assistant that contained a link and password that enabled them to access and complete an online questionnaire. Those who responded to the first questionnaire ( $n = 144$ ) received another questionnaire at the conclusion of treatment (for Study II) and another at one-year follow-up (for Studies II and III) if they met the inclusion criteria. With each iteration of survey distribution, a reminder was sent by email to those who did not respond within two weeks; a second reminder was sent a week later if there was still no response, and a final

reminder was sent four weeks later. During the data collection process, 31 patients withdrew from further participation, while 32 were excluded because they did not meet the inclusion criteria (Figure 4).



**Figure 4.** Flowchart of participant's recruitment in the studies

### 3.4 Interview guide, questions and instruments

In Study I, data were collected through interviews. HS prepared an interview guide (see Paper I, Appendix B) based on a critical literature review and discussions with the dissertation supervisors and the other members of the doctoral committee.

The socio-demographic data in Studies II and III, which were collected pre-treatment, included age (years), gender (male or female), marital status

(married, living with a partner, engaged but not living together, single, divorced or widowed), education (compulsory, upper secondary or higher), employment status (full-time, part-time or other), number of children under 18 and body mass index (BMI; kg/m<sup>2</sup>). At one-year follow-up, employment status and BMI were collected again.

The main outcome variables in Studies II and III were pain severity, pain interference, pain self-management, sleep quality, health and HRQOL. The BPI (Cleeland & Ryan, 1994) and SF-36v2 (Maruish, 2011; Ware, 2000) instruments were chosen because they had already been translated and psychometrically tested in Icelandic studies (Gunnarsdóttir et al., 2008; Jonsdóttir et al., 2014). SF-36v2 had also been used in other studies concerning chronic pain (Angst et al., 2008; Elliott et al., 2003; Jonsdóttir et al., 2014). PSQI is the most commonly used instrument to measure sleep quality (Buysse et al., 1989), and questions in Study II were derived from that instrument. Other sleep instruments, such as the Sleep Standard Evaluation Questionnaire (SEQ-Sleep; Aghayev et al., 2010) and the medical outcomes study (MOS) sleep scale (Hays et al., 2005), were also screened when the sleep quality questions in Study III were prepared. There were also questions specifically prepared for Study II, such as causes of pain, pain location, pain duration and pain self-management. See Section 2.5 in Paper II.

### **3.4.1 Interviews**

Initial interviews were conducted pre-treatment. They were audio-recorded and transcribed verbatim, without including any information that could identify the participants. There were three main questions at the beginning of the initial interviews:

‘Can you describe the pain you have today? Can you describe your health and well-being? Can you describe your social activities?’

Three months after the participants had completed the program, they were contacted again to find time to schedule a second interview. Before that second interview started, HS presented the data analysis of the participant’s first interview. They were asked to verify the information and indicate whether they agreed that it was a correct interpretation of their interview statements. The data analysis was discussed, and any necessary changes were made. The second interviews began with three main questions:

‘Can you describe the pain you had before you attended the pain management program and compare it to the pain you have today? Can you describe the pain management program’s effect on your well-being and

social activities? Can you describe your health today and compare it to your health before you attended the rehabilitation program?’

These questions were followed by questions about the effect on meaning and attitude towards pain and pain management, information and knowledge, sleep, support, communication and connection and expectations of the rehabilitation program. In the second interview, the participants were asked to compare their expectations to the treatment they received.

### **3.4.2 Measuring chronic pain**

The participants in Study II were asked to indicate what they perceived to be the primary cause of their pain, report how long they had been in pain (years/months) and identify all areas of the body in which they sensed pain. The answer options were prepared after searching the literature for the 17 most common causes of pain used in Study II (Jonsdottir et al., 2015; Stålnacke & Östman, 2010; Sigurdardottir & Halldorsdottir, 2013; Woods & Mitchell, 2012). The BPI includes two drawings that show the entire body, one from the front and the other from the back (Cleeland, 1991). In Studies II and III, the BPI was adapted to an online format; instead of using these visual aids, it was decided to use verbal questions with the option of putting a check mark next to each location where participants felt pain; there were 22 possible pain locations. In the questions about both causes and locations, there was an option to add other causes and locations not on the list.

Pain severity and pain interference with life were measured with BPI, which includes three questions regarding pain severity during the previous 24 hours, worst pain, least pain and average pain. The fourth severity item measures current pain. Pain interference is evaluated by asking questions regarding the impact of any type of pain on seven aspects of daily life (general activities, mood, walking ability, work, relations with other people, sleep and enjoyment of life). Pain severity and pain interference are rated on an 11-point scale (0 = no pain or does not interfere and 10 = the worst pain imaginable or interferes completely); see Paper II (Cleeland, 1991; Cleeland & Ryan, 1994). The BPI has been tested and used in other Icelandic studies. The internal consistency was  $\alpha = 0.91$  for the BPI as a whole,  $\alpha = 0.89$  for the severity scale and  $\alpha = 0.91$  for the interference scale (Gunnarsdottir et al., 2005; Jonsdottir et al., 2014).

### **3.4.3 Measuring pain self-management**

When preparing the questions for pain self-management, it was decided to use the most common pain self-management strategies found in the literature (Axon et al., 2019; Castel et al., 2012; Doran, 2014; Nicholas & Blyth, 2016). The BPI includes the open question, ‘What treatments or medication are you receiving for your pain?’ (Cleeland, 1991). This question was modified; participants in Study II were instead asked to indicate what measures they took to relieve their pain. Eleven possible pain management strategies were listed: a) medication (pain medication, non-steroidal anti-inflammatory drugs, sedatives); b) regular physical training; c) heat or cold; d) relaxation; e) massage; f) hypnosis; g) distraction; h) meditation; i) avoiding certain foods and beverages; j) positive thinking; and k) acupuncture. The option to write other strategies that were not listed was offered. There were five possible answers to each pain management strategy: never, 1–3 times per month, 1–3 times per week, 4–6 times per week and daily.

### **3.4.4 Measuring sleep quality**

There is no instrument specifically designed for measuring the sleep quality of people in chronic pain. Therefore, several instruments were screened when preparing the questions to measure sleep quality: SEQ-Sleep (Aghayev et al., 2010), the MOS sleep scale (Hays et al., 2005) and the PSQI (Buysse et al., 1989). SEQ-Sleep was developed for clinical studies focusing on the locomotor system, general health and pain. The sleep items in SEQ-Sleep are based on a literature review and two questionnaires: the MOS sleep scale and the PSQI. Cronbach’s alpha for SEQ-Sleep was 0.83 (Aghayev et al., 2010). The MOS sleep scale was developed for people with chronic illness, and its internal consistency was 0.73 or higher (Hays et al., 2005).

The PSQI was specifically designed to measure sleep quality in a clinical population (Buysse et al., 1989). In Study II, quality of sleep was measured with questions derived from the PSQI (Buysse et al., 1989). Participants were asked to indicate how many hours they normally slept per day and to rate their quality of sleep over the past four weeks; those who had experienced sleep problems were asked to report whether those problems were due to pain. Study III used questions developed specifically for the study. Participants were asked to rate their quality of sleep over the previous four weeks. Those who experienced sleep problems in the previous month were asked to report the reasons for those difficulties, such as pain, physical problems, need to use the bathroom, psychological problems, noise, being too hot or too cold or an uncomfortable bed. Next, they were asked if their

sleep problems affected their daytime energy. Finally, they were asked how often they experienced trouble falling asleep, felt rested, used medication (painkillers, tranquilizers, sleep medication) to be able to sleep, took naps, slept through the night and woke during the night. The five response options were never, 1–3 times per month, 1–3 times per week, 4–6 times per week and daily.

### **3.4.5 Measuring health and HRQOL**

The SF-36v2 and the earlier SF-36 are the most widely accepted and frequently used generic instruments in chronic pain studies (Annagür et al., 2014; Darchuk et al., 2010; Dysvik et al., 2010; Jonsdottir et al., 2014). The SF-36v2 comprises multiple questions; the reliability and validity of the instrument has been tested and confirmed (e.g., Beaton et al., 1997; Jonsdottir et al., 2014). It is aggregated into eight dimensions: (1) physical function (PF, 10 questions); (2) role physical (RP, 4 questions); (3) bodily pain (BP, 2 questions); (4) general health (GH, 5 questions); (5) vitality (VT, 4 questions); (6) social functioning (SF, 2 questions); (7) role emotional (RE, 3 questions); and (8) mental health (MH, 5 questions). Response options vary from yes/no answers to six-point verbal rating scales, depending on the source and wording of a given question. The combined outcomes of four of the dimensions (PF + RP + BP + GH = 10 + 4 + 2 + 5 = 21 items) constitute the physical component summary (PCS), while the sum of the other four (VT + SF + RE + MH = 4 + 2 + 3 + 5 = 14 items) form the mental component summary (MCS; Maruish, 2011; Ware, 2000). Lower scores indicate poorer health status, such as greater fatigue (Ware, 2000).

To measure health In Study II, two of the five questions from GH in SF-36v2 were used. The participants evaluated their GH and compared it to one year prior. In Study III, all the SF-36v2 questions were used to compare differences between pre-treatment and one-year follow-up and to determine what predicted HRQOL at one-year follow-up.

## **3.5 Methods of data collection and analysis in Studies I–III**

### **3.5.1 Paper I – Phenomenology**

Paper I presents the results from Study I. Data were collected through interviews, and the Vancouver School was used as a methodology. The Vancouver School is based on the philosophy of holism and existential psychology and on the premise that reality is individually constructed through lived experience (Spiegelberg, 1982). It draw on the works of Spiegelberg

(1982), Ricoeur (1980, 1981) and Schwandt (1994). In phenomenological research, the focus is on identifying and describing the common meaning that several individuals have about their lived experiences related to a concept or phenomenon (Creswell, 2013). The Vancouver School has seven main cognitive aspects that are set up as a circular process which is repeated throughout the research process: silence, reflection, identification, selection, interpretation, construction and verification (see Paper I, Figure 1). The implementation of the study was then conducted in 12 main research steps. Paper I, Table I provides details of those 12 steps and how the Vancouver School was used in Study I.

Each participant was studied as a case because the methodology involves the analysis of individual cases (Steps 1–7), which is followed by inter-case analysis (Steps 8–12). The results were then extracted (deconstruction) and assembled into a single configuration for the overall presentation of the results (reconstruction). Through text analysis methods, the researchers developed an understanding of the lived experience at hand and communicated their understanding in a published paper. To effectively achieve this outcome, the researchers needed to use abstract thought processes, especially reasoning, intuition and introspection. A temporal overlapping of the literature search, data collection and data analysis was applied, according to the Vancouver School (Halldorsdottir, 2000).

The Vancouver School requires 10–12 participants, with one or two interviews per participant to obtain a minimum of 15 interviews (Halldorsdottir, 2000). Data saturation became evident when the 19th interview was conducted. One more participant was added to the sample, at which point it was determined that enough data had been obtained to answer the research question.

NVivo 11 (QSR International) qualitative data analysis software was used to manage the dataset and for within- and between-case comparisons.

### **3.5.2 Papers II and III – Longitudinal prospective cohort studies**

Papers II and III share the common thread of evaluating and describing the long-term effects of multidisciplinary pain rehabilitation programs on pain severity and sleep quality. Both studies used a longitudinal design.

A longitudinal design is useful when there is a need to collect data at more than one point in time over an extended period to note changes over time and to ascertain the temporal sequencing of phenomena (Polit & Beck, 2021). There is no set amount of time required for a longitudinal study. They

usually last at least a year, but they can run from a few weeks to several decades (Thomas, 2021). Typically, the same people provide data at two or more points in time. The greatest challenge in longitudinal studies is the loss of participants over time. Those who drop out often differ from those who continue to participate, resulting in potential biases and concerns about the generalizability of the findings (Caruana et al., 2015; Polit & Beck, 2021).

Longitudinal research may take numerous forms. They are generally observational but can also be experimental (Caruana et al., 2015). When performing longitudinal research, there are two options: gathering new data or using data already gathered by someone else (Thomas, 2021). Repeated cross-sectional studies, prospective studies and retrospective studies are all examples of longitudinal study designs. Prospective studies where the same participants are followed over a period of time may include i) cohort panels, ii) representative panels or iii) linked panels. With cohort panels, some or all individuals in a defined population with similar exposures or outcomes are considered over time (Caruana et al., 2015). There are several advantages of longitudinal cohort studies conducted prospectively: i) the ability to identify and relate events of particular exposures; ii) establishing sequences of events; iii) following change over time in particular individuals within the cohort; iv) excluding recall bias in participants; and v) the ability to correct for the cohort effect (Caruana et al., 2015).

The IBM SPSS (v. 27.0) statistical program (SPSS Inc., Armonk, NY, USA) was used for statistical analyses and descriptive statistics in Studies II and III. Frequencies, means, standard deviation (*SDs*) and percentages were used to present the sample's demographics, pain self-management, health data and sleep status pre-treatment and at one-year follow-up. The level of significance in Studies II and III was set at  $p < 0.05$ .

In Study II, a Wilcoxon signed-rank test was used to compare the participants' pre-treatment self-evaluation of their health with their evaluations at one-year follow-up. That test is a non-parametric test that compares the median of two time points when the same participants take part at each point and is based on the difference between scores at the two points (Field, 2013). A related-samples McNemar change test was used to detect differences in sleep problems due to pain and the use of various pain self-management strategies between pre-treatment and one-year follow-up. Differences in pain severity and pain interference were interpreted in Study II using Cohen's *d* (1988) as small (0.0 to 0.2), medium (0.3 to 0.7) or large (> 0.8).

In Study III, a related-samples McNemar change test was used to detect differences in sleep quality between pre-treatment and one-year follow-up. The McNemar test is useful when there are nominal data. It is typically used when the researcher is looking for changes in people's scores and compares the number of people who changed their responses in a given direction. It is used when there are two related dichotomous variables (Field, 2013). Cohen's *d* (1988) was also used in Study III, in which differences in pain severity and HRQOL were interpreted.

Both Studies II and III used a paired *t*-test with bootstrapping to detect differences in pain severity and pain interference between pre-treatment and one-year follow-up. In Study III, the same test was used to compare differences in HRQOL. Paired *t*-tests with bootstrapping compare two means when those means have come from the same entities. Bootstrapping estimates the properties of the sampling distribution from the sample data (Field, 2013).

Two separate regression models were constructed for PCS and MCS in Study III. The fundamental idea of regression models is that an outcome for a person can be predicted from a model (Field, 2013). Five variables were introduced into each model to explore their connection to the outcome of the multidisciplinary pain rehabilitation intervention. Being female, having pursued higher education, having children under 18 and having either many or severe sleep problems were entered into both models. The pre-treatment PCS score was entered into the model for PCS at one-year follow-up, and the pre-treatment MCS score was entered into the model for MCS at one-year follow-up. When using regression, it is important to collect enough data to obtain a reliable model. With only five predictors, 50 to 75 cases are needed, based on the rule that 10–15 cases are needed for each predictor (Field, 2013).

### **3.6 Ethical considerations**

All three studies were conducted according to the guidelines of the Declaration of Helsinki (World Medical Association, 2013). The Icelandic National Bioethics Committee granted permission (VSN-15-101) to conduct the studies. The chief physicians or medical directors at the three rehabilitation centres approved the study. The research assistant at RHA gave each respondent a number, contacted them and supervised data collection, in collaboration with HS, who did not have access to the list of names with addresses and email addresses connected to the respondents'

numbers. All potential participants received oral and written information about the research before deciding whether to take part. They received an introductory letter with information on the responsible parties and contact people should they have any questions, comments or concerns. All participants in Study I were offered post-interview support from a clinical psychiatric nurse specialist; however, no one took advantage of this option. All participants were assigned pseudonyms which were used when the results were reported. Informed consent was obtained from all participants involved in the studies.



## **4 Results**

The main results of the three studies were that the multidisciplinary pain rehabilitation intervention was effective in decreasing pain severity and pain interference with general activities, mood, walking ability, sleep and enjoyment of life. HRQOL increased, and health was better than a year previously. These participants had managed to break the vicious circle of chronic pain; that is, pain no longer controlled their daily life.

The summary of the results from Studies I, II and III are presented below.

### **4.1 Participants in Studies I–III**

In Studies II and III, only the answers from those who responded to all questionnaires were analysed. In Study I, five participants came from Centre 1, four from Centre 2 and two from Centre 3. In Study II, a nearly equal number of participants attended the intervention at Centre 1 ( $n = 39$ ) and Centre 2 ( $n = 38$ ), but only four participants attended Centre 3.

Study III had the same participants as Study II, save for two participants from Centre 2 who did not complete all the questionnaires. An overview of the pre-treatment characteristics of the participants in all three studies is presented in Table 2.

**Table 2.** Participants' pre-treatment characteristics: Studies I-III

| Study I  | Study II   | Study III  |
|--|--|--|
| 11 participants: two male and nine female  | 81 participants: 13 male, 68 female  | 79 participants: 12 male, 67 female  |
| Mean pain duration of 13 years   | Mean pain duration of 10.3 years   | Mean pain duration of 10.3 years   |
| Aged 32–65 ( $M = 47.3$ )  | Aged 20–69 ( $M = 47.2$ )  | Aged 20–68 ( $M = 47.4$ )  |
| Married or living with a partner ( $n = 6$ , 54%) and with children ( $n = 10$ ); 36% were working | Married or living with a partner ( $n = 62$ , 77%); average BMI was 30.6; 38% were working | Married or living with a partner ( $n = 56$ , 71%); 57% had young children; 36% were working |
| Upper secondary ( $n = 5$ ) or higher education ( $n = 6$ )  | Upper secondary (38%) or higher education (27%)  | Upper secondary (38%) or higher education (27%)  |
| Most common causes of pain were back pain and fibromyalgia   | Most common causes of pain were fibromyalgia ( $n = 40$ ) and accidents ( $n = 36$ )       |  |

## 4.2 Study I

In Study I, the overarching theme which captured the essence of the participants' lived experience was *the journey of breaking the vicious circle of chronic pain*. Before attending the program, participants felt as if they were in survival mode, simply trying to get through each day. They were stuck in a vicious circle of chronic pain, which they were simultaneously trying to ease and conceal.

Their pain, which fluctuated in magnitude from one day to another, controlled their daily lives, and they struggled to find ways to ease the pain. They had tried medication but experienced little or no relief. They had also tried relaxation, massage, acupuncture, physical therapy, regular exercise

and hydrotherapy. Keeping an open mind, engaging in positive thinking and distraction were reported as helpful strategies.

They experienced difficulties falling and staying asleep because of pain, worries, anxiety, an uncomfortable bed or a lack of understanding from others. Sleepless nights meant more pain the following day.

Reaching out for professional help was a turning point on their chronic pain trajectory. They had reached stagnation, and nothing was changing, their strategies were ineffective, and they felt they needed help. Whilst attending the pain rehabilitation program, participants began deconstructing their old ways of dealing with chronic pain. They were ready to be in the pain rehabilitation program because it gave them time to focus entirely on themselves and on enhancing their health instead of managing their daily routines, where their focus was usually on the needs and wants of others. They all experienced personal support from family, friends and co-workers. The healthcare providers were described as caring, warm, flexible and eager to find the best schedule for everyone.

The program helped them gain new perspectives on their lives and their pain, how to think about and ease the pain and how to prevent pain attacks. The physical exercises helped improve their physical well-being and enabled them to be more active.

Three months after completing the program, they were still reconstructing their daily lives, having gained a new perception of themselves and their situations; they were more at peace with themselves. Pain was no longer their focus; instead, their well-being and health was front and centre. The participants had realized that the pain was unlikely to go away, but the pain no longer controlled everything in their daily lives and the disturbing effects on their lives had decreased. Their priorities in daily life had changed, and they were focused on making more space for regular physical exercises, physiotherapy, rest, breaks at work and relaxing. An overview of the Study I findings is presented in Paper I, Figure 2.

### **4.3 Studies II and III**

In Study II, participants were asked pre-treatment about their pain duration and the location(s) of pain on the body. The mean pain duration was 10.3 years (range: 1–55 years), and 94% reported more than one location of pain, with the low back (80%) the most common location.

At one-year follow-up, the difference in average self-reported pain severity decreased from pre-treatment by 0.7 points ( $p < 0.001$ ; a medium effect), as did pain interference with general activities, mood, walking ability, sleep, and enjoyment of life (see Paper II, Table 4). Average total hours of sleep had not changed, and sleep problems due to pain also did not decrease (see Paper II, Table 5). In Study III, the two most common reasons for having sleep problems pre-treatment and at one-year follow-up were pain (89%) and psychological problems (49%). The only significant difference in sleep was that more participants (6% vs 18%) slept through the night at one-year follow-up ( $p = 0.004$ ). The results can be seen in in Paper III, Table 3.

In Study II, the four most common pain self-management strategies used by the participants four times or more per week pre-treatment were positive thinking (68%), medication (58%), distraction (58%) and regular physical training (34%). No change was found in the use of pain self-management strategies at one-year follow-up (see Paper II, Table 5).

In Study II, 21% of participants rated their health as good or very good at one-year follow-up, compared to 7% pre-treatment ( $p < 0.001$ ), and 47% rated their health as much better or somewhat better compared to one year earlier, compared to 21% pre-treatment ( $p < 0.001$ ; see Paper II, Table 5). Study III found that participants' HRQOL had increased at one-year follow-up. The mean PCS scores were higher than pre-treatment ( $p < 0.001$ ), and the scores of all PCS subgroups had increased significantly, with medium effect size, except for general health, which had a small effect size. The mean MCS score did not increase, but two subgroups of MCS – VT ( $p = 0.011$ ) and SF ( $p = 0.038$ ) – increased significantly (see Paper III, Table 4). Higher pre-treatment MCS scores and having pursued higher education predicted higher MCS scores at one-year follow-up, and higher pre-treatment PCS scores predicted higher PCS scores at one-year follow-up. Sleep problems, being a woman, and having children under 18 predicted lower MCS scores at one-year follow-up (see Paper III, Table 5).

## 5 Discussion

Using data from three centres in Iceland, this doctoral thesis makes an important contribution to knowledge about the long-term effects of multidisciplinary pain rehabilitation programs. The main findings of the three studies showed that attending a pain rehabilitation program gave participants space and time to focus entirely on themselves and enhancing their health. After completing the program, they realized that their pain was not going away but evaluated their pain severity lower at one-year follow-up than they had pre-treatment. Pain also interfered less and did not control their lives the way it once had. Three months after they had completed the program, their priorities had changed, with more focus on preventing pain attacks and making room for physical exercise, relaxation, rest at work and physical therapy. However, there were no changes in pain self-management between one-year follow-up and pre-treatment. Their sleep quality was somewhat better, especially as to sleeping through the night, and participant health and HRQOL had improved at one-year follow-up.

### 5.1 Effect of pain rehabilitation on pain and pain self-management

What is the most important thing to know, the most valuable lesson to learn, after attending such a program? It is important to integrate the knowledge, skills and behaviours obtained from the pain rehabilitation program into everyday life (Bögdal et al., 2021). However, it seems that everyone had his or her own value of what was truly *most* important. The interventions were individualized, and so were their outcomes. The participants had gained more physical endurance and new perspectives on themselves, as has been reported in other studies (Haraldseid et al., 2014; Leung et al., 2021). They were better at accepting their pain, their existence and themselves three months after they completed the program; notably, acceptance is key to long-term changes in daily life (Edwards et al., 2016; Egan et al., 2017).

Before the rehabilitation program started, the participants in Study I described themselves as struggling to survive and unable to manage their pain. They were stagnating in a vicious circle and no longer able take care of their situation. They did not know what to expect but hoped that something would change for the better. Study II shows that their pain severity had decreased at program completion and remained that way at one-year follow-

up. Other studies have shown that multidisciplinary rehabilitation programs reduce pain intensity (Merrick & Sjölund, 2009; Salathé et al., 2018; Silvemmark et al., 2014). In this project, although participants' pain had decreased, it was still high at program completion (at around 6–8 in Study II) and remained high three months after program completion (Paper I). At the same time, participants described pain as no longer controlling their daily lives. In Study II, pain interfered less at one-year follow-up with general activity, mood, walking ability, sleep and enjoyment of life, but that was not the case with either work or relations with others.

One unexpected finding in Study II was learning how often pain management strategies were practiced. Three months after program completion, participants in Study I were eager to find space for the pain self-management strategies that had worked for them in the program. At one-year follow-up, it was the same as it had been pre-treatment (Paper II). The programs emphasized a healthy lifestyle and changing one's thoughts about and towards the pain, instead of using medication for pain (Olason et al., 2018). In Study II, participants used less medication for pain relief at one-year follow-up than they had pre-treatment, although the difference was not statistically significant. A reduction in the use of analgesics for pain as a result of pain rehabilitation programs has been seen in other studies (Olason et al., 2018; Saltychev et al., 2014). Physical training is an important method of pain self-management. However, regular physical training was used with the same frequency at both time points, even though reduced pain interference with walking ability and general activities was significant at the later point. This reflects a finding in Dysvik et al. (2013), in which training activities were the same at the starting point and 12 months later.

Although the participants were eager to find space and time, they had less time to train regularly once back in their daily routines at home. General life stress may hinder recovery (Mengshoel et al., 2021). At home, they could no longer focus entirely on themselves and their needs in the way they had in the pain rehabilitation program. There is a possibility that some chronic pain sufferers who attended a pain rehabilitation program returned to survival mode instead of continuing to rehabilitate because the sustained effort of self-managing chronic pain can be exhausting and motivation can wane as the time since an intervention increases (Devan et al., 2018). Further studies are clearly needed, and some actions need to be taken. A healthy lifestyle, including physical exercise, is emphasized in the pain rehabilitation programs and is an important method of pain self-management. Extended periods and more follow-ups are needed so patients in chronic pain can maintain their rehabilitation and receive the support and motivation they need.

Multiple causes of pain combined with a long duration of pain have been associated with poor QOL (Pagé et al., 2018). Most participants in all three studies had more than one perceived cause of pain; 94% had pain in more than one location in the body. The participants' mean length of years in pain was 10.3 years (range: 1–55 years; see Table 2), and we did not ask whether this was their first time in a pain rehabilitation program. In Vartainen et al.'s study (2019), a shorter duration of pain (less than three years) was positively associated with major improvement after a pain rehabilitation program. According to the description in Study I, the participants decided to ask for help because they had reached a stagnant phase where nothing was changing; it was then that they sought out and were offered a place in a pain rehabilitation program. Their mean length of years in pain was 13 years and they had no experience of pain rehabilitation. It is reasonable to ask about the possible effects on the results if a pain rehabilitation program had been offered to them earlier in the process. The relationship between years in pain and the long-term success of pain rehabilitation programs requires further research.

The process of transformation model in the rehabilitation of chronic illness and disability (Dubouloz et al., 2010) shares some similarities with the results of Study I, though that model does not specifically target people in chronic pain. The model is characterized by three phases: triggers, process of change and outcomes. The movement from one phase to the next in the model is called 'readiness for change'. The trigger phase includes participants' experiences of becoming ill, disabled or no longer able to function in the ways they desired, which is akin to the descriptions of the participants in Study I before they reached out for professional help; that was their positive turning point or readiness for change. Being ready to make changes in one's life has been reported as one key to positive results after pain rehabilitation programs in other studies (Huet et al., 2009; Merrick & Sjölund, 2009). In Dubouloz et al.'s (2010) model, the representation of deconstruction and reconstruction of meaning perspectives is integral to transformation and is described in similar ways as in Study I, where the outcomes involved new perspectives, new feelings and new behaviours. Changes in thoughts and feelings were also present in the findings of Study II. Positive thinking was the strategy used most often by the participants, as in other studies (Darchuk et al., 2010; Dysvik et al., 2010; Hooten et al., 2012; Ringqvist et al., 2019; Wideman et al., 2016), and probably influenced participants' self-reported health, which improved and was much better than pre-treatment.

## 5.2 Effect of pain rehabilitation on sleep quality

There were difficulties finding research that measured the effect of multidisciplinary pain rehabilitation on sleep quality. Several studies investigating the connection between chronic pain and sleep quality were found (Aghayev et al., 2010; Annagür et al., 2014; Campbell et al., 2013; Nitter et al., 2012), and the prevalence of sleep disturbance among chronic pain patients was reported to be 75% in one study (Sun et al., 2021). In Study III, 48% had many or severe sleep problems pre-treatment, so there is a clear need to place greater more emphasis on this issue in future studies of pain rehabilitation programs.

Pain severity decreased in Studies II and III, and pain interfered less with sleep (0.6 points) at one-year follow-up in Study II. However, pain (89%) and psychological troubles (49%) were the main reasons for sleep problems pre-treatment, and their influence did not change at one-year follow-up in Study III. Total hours of sleep also did not change either; it was around seven hours at both time points in Study II. In another study, increase in total sleep time was predictive of less pain the following treatment day in patients with chronic non-cancer pain undergoing interdisciplinary rehabilitation for chronic pain; a stronger association between the previous night's total sleep time and next-day pain contributed to the greatest overall treatment benefits in terms of pain reduction and total sleep time (Davin et al., 2014).

In Study III, sleeping through the night was the only significant difference found in sleep quality, though only 18% of respondents slept through the night at one-year follow-up. Interestingly, the same study found no significant change in the use of medication to sleep, so appear to have been strategies other than medication that helped participants sleep through the night. Perhaps more physical exercise helped some participants improve their sleep quality, as has been reported elsewhere (Xie et al., 2021).

Having less energy and being tired can be associated with sleep problems. In Study III, 32% of participants responded that their sleep problems affected their daytime energy. Having sleep problems was one of the five predictive variables of lower MCS scores at one-year follow-up in Study III, with the model explaining 46% of the variance. Other research has indicated that chronic pain makes people more likely to suffer from sleep problems, depression and other psychiatric disorders (Annagür et al., 2014; Campbell et al., 2013; Lee et al., 2018). This issue merits further investigation and – even though the pain rehabilitation programs focused on sleep quality – more needs to be done to deal with sleep problems in connection with pain and psychological problems.

### **5.3 Effect of pain rehabilitation on health and HRQOL**

Participating in the pain rehabilitation intervention positively influenced self-reported health. More participants rated their health as good or very good at one-year follow up (Study II) than they did pre-treatment, with many stating that their health was 'much better' than before the program. This finding is similar to those in other studies (Darchuk et al., 2010; Hooten et al., 2012; Ringqvist et al., 2019). Despite this increase in positive thinking in Study II, the results of Study III showed increased HRQOL at one-year follow-up, especially in the PCS, which has also been observed in other studies (Björnsenius et al., 2020; Pieber et al., 2014).

Although mental health issues were not the focus of this thesis, we found that participants who reported feeling anxious and depressed showed very little improvement following the intervention. At one-year follow-up, their mental health was better but had not changed to the same degree as their physical health. Pre-treatment MCS score, being a female, having children under 18 and having sleep problems at one-year follow-up all predicted a lower MCS score at one-year follow-up. The findings from multidisciplinary long-term pain rehabilitation studies using HRQOL assessments are mixed, with either no long-term increase in HRQOL or a moderate to large increase that persisted for at least 12 months (Salathé et al., 2018).

Pain interference with mood and enjoyment of life had declined one year after the intervention was completed in Study II but was still around 6 on the 11-point scale (0–10). There is a bidirectional relationship between chronic pain and mental health conditions (WHO, 2021a). Mental disorders are highly prevalent in chronic pain conditions, patients with severe pain are more likely to be depressed (Annagür et al., 2014; de Heer et al., 2018; Hooten, 2016; Malfliet et al., 2019), and depression is often unrecognized and untreated (Lee et al., 2018). Depression, anxiety and negative beliefs about pain are all related to developing pain and having worse outcomes from chronic pain (WHO, 2021a). Patients with chronic pain should be examined with respect to their mental health status (Annagür et al., 2014), and more follow-up is needed after the completion of a pain rehabilitation intervention to deal with possible mental health problems.

### **5.4 Strengths and limitations**

A major strength of all three studies is its examination of three similar pain rehabilitation programs. Albeit not identical, the standard programs shared similarities in the emphasis and were effective for the participants. All three

studies (I–III) investigated the formal combined effects of pain rehabilitation intervention in a single country. The country is small, and the sample sizes in Studies II and III were also relatively small, so the research lacks the power of large, multisite studies. Large communities are composed of smaller communities, which often mirror the larger communities of which they are a part. In Study I, the number of participants who took part was within the parameters described in phenomenological studies. None of the members of the research group was part of the group of staff members at any of the investigated centres. An experimental design with control group was not used because it was not feasible to deny any of the participants treatment. Therefore, it is impossible to make statements about direct cause and effect. A high dropout rate was expected and is also acknowledged. The already relatively small samples in Studies II and III had dropouts. A systematic review of what predicts dropouts in such programs shows that dropouts are inevitable and associated with poor treatment outcomes. The results were conflicting, but higher pain intensity and severe self-reported disability are issues worth considering in future studies (Oosterhaven et al., 2019).

The length of the standard program varied from four to seven weeks, which is a limitation. The small number of participants from Centre 3 in Studies II and III decreased the significance of some of those findings. Not everyone participated in the same intervention in the same period with the same health disciplines. The intervention was scheduled for each individual, and two of the centres did not offer certain health disciplines that were available in the third program. Therefore, drawing conclusions about the effects of the interventions was challenging. It was also difficult to conduct gender comparisons because fewer men than women participated. The group of participants were complex: the multiple causes of pain, difference in pain duration and the varied backgrounds of the subjects may have contributed to a smaller treatment effect.

The time between program completion and the second interview in Study I is a potential limitation because three months may not be long enough to fully understand the process and the progress the participants were making. Additionally, conducting the follow-up one year after program completion might not have been long enough because it is impossible to state whether participants could maintain the changes that had made for more than a year. Nevertheless, the findings of these studies have important implications for pain rehabilitation, education and research.

## **6 Conclusions**

Pain rehabilitation programs can be the first step towards breaking the vicious circle of chronic pain. The interventions were effective for the participants, but the impact of chronic pain is multifaceted. Pain rehabilitation can help sufferers confront the pain, deconstruct unhelpful ways of dealing with it, offer a different perspective on the pain and suggest new ways to reconstruct daily life. Participants' self-reported pain severity and pain interference with general activities, mood, walking ability, sleep and enjoyment of life decreased, but sleep problems due to pain and psychological problems did not change over the course of the intervention. The participants did not maintain regular physical training at one-year follow-up, but they experienced improved health post-intervention and their HRQOL increased, especially the physical component summary (PCS). The findings indicate a need for greater emphasis on the connection between pain and sleep problems and mental health in multidisciplinary pain rehabilitation interventions. Follow-up is recommended after pain rehabilitation interventions, and the participating health professionals are in a strong position to provide education and support at community health centres and rehabilitation centres or through a form of online or technical assistance. These findings support the effectiveness of multidisciplinary rehabilitation programs for pain and will be used to guide further research in pain therapeutics and the continued improvement of the intervention.

### **6.1 Future directions**

The intervention was effective, but pain self-management strategies at one-year follow-up were the same as they were before the participants attended the rehabilitation program. The effect on sleep quality was small. Pain severity decreased but only by 0.7 points in average pain. HRQOL increased for PCS, but not for MCS, which could indicate that more emphasis should be placed on mental health in the rehabilitation programs. Such programs are constantly evolving, and these findings can be a valuable input for those developmental processes. In addition, it might be beneficial to pay greater attention to sleep quality, pain and exercises and to offer people in chronic pain the opportunity to attend a pain rehabilitation program earlier in their pain experience.

Non-adherence and dropout are major problems in pain rehabilitation (Oosterhaven et al., 2019). Nurse-led motivational interviewing for patients with chronic musculoskeletal pain has had some effect when provided pre-treatment (Mertens et al., 2016). That could be an option for individuals in chronic pain who are on a waiting list for pain rehabilitation programs (Alperstein & Sharpe, 2016; Mertens et al., 2016).

Greater flexibility in the length of pain rehabilitation programs, with more intensive follow-up schedules that give patients access to healthcare professionals on a regular basis, could increase the benefits of such programs. The nurse's role in pain rehabilitation programs is not always made clear in research, which often makes no distinction made between the professionals being discussed. This murkiness could be cleared up with, for example, a detailed description of each profession on the rehabilitation centre's website and by how the various professionals introduce themselves to patients. There is an opportunity for nurses to emphasize more in measuring sleep quality, pain and mental health while people are in a pain rehabilitation program. They can play an active part in follow-ups that could focus on education and support delivered through mobile phone apps, online chatrooms or telephone interviews.

The findings in the three studies that are synthesized in this document provide valuable information which can be used for patient education at the rehabilitation centres and for further development of the rehabilitation programs. There are opportunities to add more education for patients in chronic pain after they have completed the program. At program presentations for patients and their families before a program starts – which can be provided by nurses – there could be an overview of what the patient can expect and what they need to focus on to increase both the short- and long-term effects of the program on their health and well-being. People in chronic pain need to be aware of the connection between pain and sleep, pain's effect on psychological well-being and how pain self-management strategies work to relieve their pain in both the short and long terms.

While in a rehabilitation program, people in chronic pain have the opportunity to focus entirely on their needs, but they need to be aware of the key obstacles that may arise after they complete the program. They need to know how to change their priorities in daily life and to make more space for regular physical exercise, rest, breaks at work and relaxation. Support from employers and families is vital, so they need to discuss their situations openly and any changes that are needed in their environment.

These findings can also be used in educational programs for nurses specializing in rehabilitation nursing and for undergraduate programs in nursing.

The findings of Studies I–III support the effectiveness of multidisciplinary pain rehabilitation programs but there is a need for further research.

- Future long-term studies could be developed to examine the effect of multidisciplinary rehabilitation programs on specific types of pain conditions and sleep quality in connection with pain and mental health.
- An experimental study with research and control groups could be conducted. This would include a comparison of men and women in various age groups, before and after some specific treatment, such as healthy lifestyle, decreased smoking, lowered alcohol consumption and decreased use of medication for pain and sleep. All participants would share some specific causes of pain and would be treated with equivalent hours during the intervention. A follow-up could occur one, two or three years later. The levels of support from nurses during and after the program could also be included as a matter for study. Support might be an important variable and could contribute to the long-term success of the intervention by positively affecting stress levels and strengthen physical and psychological health.
- Focus group interviews with nurses regarding their current role in pain rehabilitation programs could help enhance follow-up in terms of support and education. This would be followed by an intervention study that examined how the intervention developed in the focus groups actually worked in pain rehabilitation programs.
- A phenomenological study in which people in chronic pain who have already completed a pain rehabilitation program are interviewed one, two or three years after the program's completion could provide a deeper understanding of how they incorporated – or could not incorporate – what they learned in the program into their daily routines.



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# Paper I





## RESEARCH ARTICLE

# Breaking the vicious circle: Experiences of people in chronic pain on the pain rehabilitation journey

Hafþís Skúladóttir<sup>1</sup> | Thora J. Gunnarsdóttir<sup>2</sup> | Sigríður Halldórsdóttir<sup>3</sup> |  
Herdís Sveinsdóttir<sup>2</sup> | Janean E. Holden<sup>4</sup> | Amalía Björnsdóttir<sup>5</sup>

<sup>1</sup>Faculty of Nursing, School of Health Sciences, University of Akureyri, Akureyri, Iceland

<sup>2</sup>Faculty of Nursing, School of Health Sciences, University of Iceland, Reykjavik, Iceland

<sup>3</sup>Faculty of Graduate Studies, School of Health Sciences, University of Akureyri, Akureyri, Iceland

<sup>4</sup>University of Michigan School of Nursing, Ann Arbor, Michigan, USA

<sup>5</sup>School of Education, University of Iceland, Reykjavik, Iceland

**Correspondence**

Hafþís Skúladóttir, School of Health Sciences, University of Akureyri, Sólborg v/ Nordurslóð, 600 Akureyri, Iceland.  
Email hafdis@unak.is

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**Abstract**

**Aim:** To explore the lived experience of individuals' in chronic pain of participating in a pain rehabilitation programme in Iceland.

**Design:** Phenomenological research.

**Method:** The Vancouver School of Doing Phenomenology. Eleven participants were interviewed.

**Results:** The overarching theme was as follows: "the journey of breaking the vicious circle of chronic pain." Before the programme, the participants felt they were in survival mode, trying to survive each day; they were stuck in a vicious circle of chronic pain, simultaneously trying to ease and conceal the pain. Reaching out for professional help was a turning point. While attending the programme, participants began deconstructing their old ways of dealing with chronic pain. After completing the programme, they were still reconstructing their daily lives. In conclusion, pain rehabilitation programmes can be the first step towards breaking the vicious circle of chronic pain.

**KEYWORDS**

chronic pain, illness, interviews, pain rehabilitation, phenomenology

## 1 | INTRODUCTION

Chronic pain has been defined as pain lasting 3 months or more or as pain persisting beyond the time of expected healing (Treede et al., 2015). Chronic pain is a complex disorder interfering with all aspects of an individual's life (Sharpe, Alderson, & Collins, 2013), resulting in decreased physical activity (Boutevillain, Dupeyron, Rouch, Richard, & Coudeyre, 2017; McCracken & Gutiérrez-Martínez, 2011), poor physical health (Macfarlane et al., 2009; Zanochi et al., 2008) and insomnia (Aghayev, Sprott, Bohler, Röder, & Müller, 2010; Alfvöldi, Dragioti, Wiklund, & Gerdle, 2017; Canivet et al., 2008; Hamilton, Catley, & Karlson, 2007; Harman,

Keating, Mayes, Walsh, & MacCallum, 2014). Qualitative studies show that chronic pain can influence the sense of self (Ahlsen, Mengshoel, & Solbrække, 2012; Biguet, Nilsson Wikmar, Bullington, Flink, & Löfgren, 2016; Osborn & Smith, 2006; Sharpe et al., 2013; Smith & Osborn, 2007) and psychosocial well-being (Ojala et al., 2016), affect the ability to work (Andersen, Clausen, Burr, & Holtermann, 2012; Norrefalk & Borg, 2012; Stålnacke & Östman, 2010), result in job changes (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006), strain finances (Andrews, Steultjens, & Riskowski, 2018; Norrefalk & Borg, 2012) and negatively affect family relationships (Ailshire & Burgard, 2012; Armentor, 2017). In Europe, the estimated prevalence of chronic pain is 12%

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(Breivik et al., 2006). In Iceland, the prevalence ranges from 19% (Björnsdóttir, Jonsson, & Valdimarsdóttir, 2013) to 47.5% (Jónsdóttir, Aspelund, Jónsdóttir, & Gunnarsdóttir, 2014). Despite the prevalence and serious consequences of chronic pain, there are no easy ways to treat it.

According to Axon, Patel, Martin, and Slack (2019) systematic review of population-based studies, a substantial portion of community-dwelling adults is likely to use prescription and non-prescription medication for their pain along with non-pharmacological strategies such as hot and cold packs and exercise. Multidisciplinary pain management interventions facilitate and support the development of individual self-management strategies (Devan, Hale, Hempel, Saipae, & Perry, 2018). With professional individualized support, pain rehabilitation programmes can benefit the individuals' possibility of returning to work (Norrefalk & Borg, 2012).

Cognitive behavioural therapy (CBT), hypnosis (Castel, Cascón, Padrol, Sala, & Rull, 2012) and other mindfulness-based approaches (Doran, 2014) are well-known treatments used in pain rehabilitation programmes. CBT is based on the assumption that the way of thinking motivates behaviour and emotions (Sveinsdóttir, Eriksen, & Reme, 2012). Combined with other treatments, CBT is a beneficial treatment for chronic back pain (Sveinsdóttir et al., 2012) and fibromyalgia (Imamura, Cassius, & Fregni, 2009), which are the most common causes of pain among those who attend pain rehabilitation programmes (Gustafsson, Ekholm, & Ohman, 2004; Huet, Innes, & Whiteford, 2009; Merrick & Sjölund, 2009). CBT has been found to have long-term effect on patients' pain management in their daily lives (Egan, Lennon, Power, & Fullen, 2017; Hållstam, Stålnacke, Svensen, & Löfgren, 2015).

## 2 | BACKGROUND

When participants in pain management programmes are able to change their behaviour by changing their thoughts and feelings, they gain new insights and understandings (Haraldseid, Dysvik, & Furnes, 2014) and provide new skills to reduce pain levels and allow the participants to move towards a better life (Dysvik, Kvaløy, & Furnes, 2014). Qualitative studies focusing on the influence of pain rehabilitation programmes indicate that individuals with chronic pain acknowledge that accepting the persistency of pain is the way to move forward (Biguet et al., 2016). Moreover, using combined therapies in programmes has led to self-healing with strength and a sense of well-being (Gunnarsdóttir & Peden-McAlpine, 2004).

Even several months after using the intervention for self-managing pain, the journey continues to be exhausting and a struggle (Devan et al., 2018; Hållstam et al., 2015). However, years later, these individuals still used the key strategies to manage their pain effectively after embedding them in their daily lives to improve their quality of life (Egan et al., 2017).

Research about pain rehabilitation programmes in Iceland has focused on CBT for depression and anxiety (Ólason, Andrason, Jónsdóttir, Kristbergssdóttir, & Jensen, 2018), patients' participation in their health assessment (Thorarinsdóttir, Kristjánsson, Gunnarsdóttir, & Björnsdóttir, 2019) and the use of a combination of complementary therapies (Gunnarsdóttir & Peden-McAlpine, 2004). However, to our knowledge, no previous study has evaluated the lived experience of participating in a pain rehabilitation programme.

Therefore, this study explores the lived experience of individuals' in chronic pain who participate in a pain rehabilitation programme. Participants were interviewed before and after the programme to increase knowledge and deepen the understanding of their lived experience over time. The goal of the study was to learn how patients experience their pain, health and well-being before and after participation in the programme.

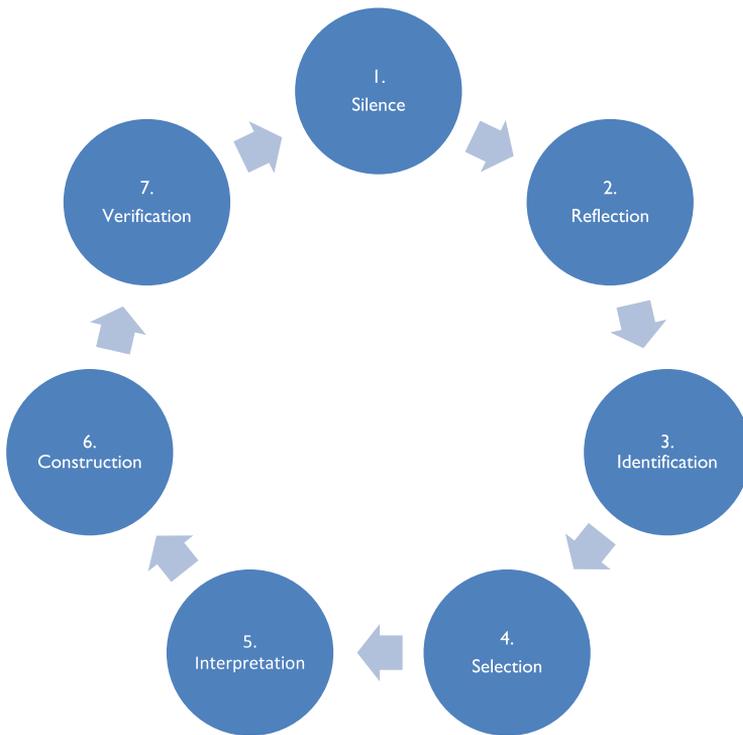
## 3 | METHODS

### 3.1 | Design

The Vancouver School of Doing Phenomenology (in short the Vancouver-School) was used in this study (Halldorsdóttir, 2000). The qualitative approach used in this study offers a useful direction to nurse researchers because of its 12-step approach (Dowling & Cooney, 2012), which has proven effective when used in the context of the lived experience of pain (Karlsdóttir, Halldorsdóttir, & Lundgren, 2014; Skuladottir & Halldorsdóttir, 2011). This methodology is based on the works of Spiegelberg (1982) (phenomenology), Ricoeur (1980, 1981) (hermeneutic phenomenology) and Schwandt (1994) (constructivism). The Vancouver-School is based on the philosophy of holism and existential psychology and on the premise that reality is individually constructed because of lived experience (Spiegelberg, 1982). In phenomenological research, the focus is on identifying and describing the common meaning several individuals have about their lived experiences related to a concept or phenomenon (Creswell, 2013). The Vancouver-School has seven main cognitive aspects that are set up as a circular process and repeated throughout the research process: silence, reflection, identification, selection, interpretation, construction and verification (Figure 1). The implementation of the study was conducted in 12 main research steps; Table 1 shows how the steps were followed.

### 3.2 | Settings

The study was conducted at the three rehabilitation centres in Iceland offering pain rehabilitation, which are referred to as Sites 1, 2 and 3. The staff members in all three rehabilitation centres include nurses, physicians, physiotherapists and psychologists and occupational therapists, social workers, nutritional consultants, massage therapists and physical activity instructors. Patients with chronic



**FIGURE 1** The process of doing phenomenology in the Vancouver-School [Modified figure from Halldorsdottir (2000) p. 56. Used with permission]. This cycle is repeated in each of the 12 steps of the Vancouver-School

pain up to 70 years of age can attend Sites 1 and 3, but Site 2 only accepts patients aged up to 60 years (programme descriptions are presented in Appendix 1).

### 3.3 | Participants

The Vancouver-School requires 10–12 participants and 1–2 interviews per participant to obtain a minimum of 15 interviews (Halldorsdottir, 2000). The inclusion criteria for participating in the study were chronic musculoskeletal pain for at least 3 months; ability to speak, understand and read Icelandic; age 18–70 years; and being admitted to one of the three rehabilitation centres. Thirty-three incoming patients received an introductory letter about the study inviting them to participate, which included information about the primary researcher, reasons for the study, the study goals and focus, the approximate lengths of the first and second interviews and the participants' ethical rights. Of the 33, 13 responded and 11 agreed to participate, which met the criteria for using the Vancouver-School. Two refused to participate because of language difficulties or insufficient energy and 20 did not reply.

Participants applied for the pain rehabilitation programme after recommendation from their advisor in the vocational rehabilitation programme, their general physician (GP) or a specialist physician (Table 1: Step 1). The participants were aged 32–65 years ( $M = 47$  years), with two male and nine female participants. Five

were from Site 1, four were from Site 2, and two were from Site 3 (Table 2).

### 3.4 | Data collection and analysis

Data were collected through interviews. Initial interviews (11) were conducted before the participants attended the pain rehabilitation programme, and the second interviews (10) were conducted 3 months after they completed the programme. The first author (hereafter, the researcher) prepared an interview guide (Appendix 2) based on a critical literature review and discussion with the co-authors and conducted all the interviews.

The interviews lasted from 22 to 80 min (mean = 37 min) and were audio-recorded and transcribed verbatim, without including any information that could identify the participants. The participants were all given pseudonyms (Table 1: Steps 2 & 3).

Every interview was conducted with an open mind because each person had a unique story to tell. In the second interviews, the researcher presented the data analysis of the participants' first interviews. This approach was used to help the participant to compare their lived experience of pain, daily life, health and expectations before the rehabilitation to the lived experience during the pain rehabilitation programme and the time after completing the programme. This approach was also done for verification. As more interviews were conducted, the researchers realized the nature of the phenomenon in more depth.

**TABLE 1** Steps in the research process of the vancouver school of doing phenomenology

| Steps  | Description of each step  | What was done in the present study   |
|--|---|--|
| Step 1<br>The sample                             | Selection of participants who have experienced the phenomenon   | The participants were recruited with collaboration from both chief physicians and head nurses at the rehabilitation sites who went through the waiting lists of incoming patients and compared it to the inclusion criteria. They then prepared a list of names and sent it to the primary researcher. This information was then used to contact potential participants by email |
| Step 2<br>Making pre-conceived ideas visible     | Preparation of the mind before the dialogues. Putting aside pre-conceived ideas                                 | The primary researcher reflected on own thoughts, pre-understandings and pre-conceptions about the phenomenon and kept a reflective journal  |
| Step 3<br>Data collection                        | One or two interviews with each participant. Number of participants is decided when saturation has been reached | The interviews took place in locations of the participants' choice, in their homes (one), telephone interviews (thirteen) or at the primary researcher's office (seven)  |
| Step 4<br>Beginning data analysis                | Sharpened awareness of ideas and concepts. Data collection and data analysis runs concurrently                  | As soon as an interview began, the data analysis began as well and continued throughout the data collection period. At first, the text was read carefully, without coding. Then, the text was read several times and items were coded  |
| Step 5<br>Individual theme analysis              | Constructing the essential structure of the phenomenon for individual participants                              | Every transcript from each participant was read several times over to begin to construct the essential structure of the phenomenon according to each participant. Trying repeatedly to answer the question: What is the essence of what each participant is saying?  |
| Step 6<br>Case construction                      | Findings developed for each participant   | The main themes of interviews were highlighted, and the most important factors were used as building blocks for the individual case construction. An overview, or analytic framework, was constructed for each participant, and care was taken that they were fully consistent with the experience of that participant and the relevant research data                            |
| Step 7<br>Verification I                         | Confirmation of the findings with each participant  | An overview of themes from the first and second interviews was prepared for each participant with first draft of structured themes: one from the first interviews and another structure from the second interviews. This was sent to each participant through email and asked for confirmation. Eight participants replied and sent their verification                           |
| Step 8<br>The overall findings                   | Ask repeatedly: What is the essential structure of the phenomenon?  | After reviewing the individual case construction, the primary researcher constructed together with two co-authors (SH and THJG) one essential structure of the phenomenon of living with chronic pain before and after rehabilitation  |
| Step 9<br>Verification II                        | The overall findings compared to the study data   | The primary researcher reread all the transcript to make sure the interpretation was based on actual data and compared them with the essential structure of the phenomena  |
| Step 10<br>Finding the essence of the phenomenon | Choosing the overall theme of the study that best describes the phenomenon                                      | The name of the study is as follows: <i>The journey of breaking the vicious circle of chronic pain</i>   |
| Step 11<br>Verification III                      | Confirmation of the overall results with some of the participants   | The overall findings were presented by the primary researcher to four participants who had attended one of the three pain rehabilitation programmes. They were satisfied with the results and verified them  |
| Step 12<br>Writing the results                   | Multi-voiced reconstruction to increase trustworthiness of the findings   | The voice of all the eleven participants was included in the writing of the results, by quoting them directly. An effort was made to put the most important evidence from the data that best described the phenomenon and thus answered the research question  |

New information was obtained that allowed the researcher to delve deeper into aspects of the phenomenon, to ask more detailed questions about relevant aspects and to determine the factors that were irrelevant to the phenomenon (Table 1: Steps 4–6).

When conducting the 19th interview from the primary sample of 10 participants, the start of data saturation became evident. After obtaining additional data from one more participant, it was determined that enough data had been obtained to answer the research question.

NVivo 11 (QSR International) qualitative data analysis software was used to manage the dataset and for within- and between-case comparisons. At each step in the data analysis, the researcher analysed the transcription for themes according to the Vancouver School protocols (Figure 1). The findings from each participant were constructed into an individual analytical framework (Table 1: Step 6) and verified by eight participants (Step 7). With two co-authors, the essential structure of the phenomenon was constructed (Step 8) and verified (Steps 9–11). The voice of all participants was included in the

TABLE 2 Participants' description

| Pseudonyms <sup>a</sup> | Age range <sup>a</sup> | Employment and family status                 | Pain sites-diagnosis   | Years in pain | Weeks in the programme |
|-------------------------|------------------------|--|--|---------------|------------------------|
| Anne                    | 55–60                  | Unemployed, married, one child               | Back pain  | Two           | Seven                  |
| Dave                    | 30–35                  | Unemployed, unmarried, no child              | Widespread pain, fibromyalgia, headaches and muscle spasm  | Nineteen      | Four                   |
| Eve                     | 40–45                  | Working full-time, divorced, four children   | Most joints, knee, back pain, headache, Raynaud's and arthritis  | Fifteen       | Five                   |
| Helen                   | 60–65                  | Unemployed, married, two children            | Back pain  | Four          | Seven                  |
| Isabella                | 40–45                  | Unemployed, unmarried, three children        | Back pain and fibromyalgia   | Twenty        | Five                   |
| John                    | 30–35                  | Unemployed, married, three children          | Gastrointestinal disease, arthritis unspecified, hip, feet, ribs and joints                                    | Three         | Six                    |
| Catherine               | 45–50                  | Working full-time, unmarried, three children | Widespread pain, neuropathic pain in the upper part of the body and face, migraine, back pain and fibromyalgia | Fifteen       | Four                   |
| Lena                    | 55–60                  | Working part-time, divorced, two children    | Psoriasis arthritis, fibromyalgia, hand, feet, shoulder and back pain  | Sixteen       | Four                   |
| Maria                   | 45–50                  | Unemployed, married, five children           | Back pain, fibromyalgia, hip and shoulder pain   | Twenty        | Five                   |
| Rose                    | 35–40                  | Unemployed, married, four children           | Back pain, hands and fibromyalgia  | Fifteen       | Five                   |
| Sarah                   | 55–60                  | Working part-time. Cohabiting, four children | Back pain and fibromyalgia   | Fifteen       | Five                   |
| MEAN                    | 47 years               | Mostly married or cohabiting with children   | Mostly back pain and fibromyalgia  | 13 years      | 5 weeks                |

<sup>a</sup>To protect participants' anonymity.

findings by quoting them directly to increase the trustworthiness of them (Step 12). We adhered closely to the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist reporting the methods, analysis and results of this study (Tong, Sainsbury, & Craig, 2007).

### 3.5 | Ethical considerations

Permission to conduct the study was granted by The National Bioethics Committee (VSN-15-10) and chief physicians at the three rehabilitation centres.

All participants were offered postinterview support from a clinical psychiatric nurse specialist; however, no one used this option. The participants signed their informed consent and were guaranteed confidentiality.

## 4 | RESULTS

The overarching theme of the study was as follows: "the journey of breaking the vicious circle of chronic pain," which captures the essence of the participants' lived experience. Before attending the programme, the participants described themselves as being in a vicious circle of

pain, trying to survive each day. After the programme, they described their journey of breaking that circle in rehabilitation and deconstructing their old ineffective ways of dealing with their chronic pain. Three months after completing the programme, the participants were still rehabilitating. However, they were no longer struggling to survive; they had started reconstructing their daily life and were more in control of their pain and starting to make goals for their future (Figure 2).

### 4.1 | Before rehabilitation: trying to survive each day

The participants reflected on their daily pain, which fluctuated in magnitude from one day to another. The pain controlled their daily life and they struggled to find ways to ease the pain. Several participants described how they were stuck in a vicious circle. Some feared their future, not knowing where their situation would lead, and they feared losing their health. Part of their experience with the vicious circle was the difficulties they experienced falling and staying asleep because of the pain, worries, anxiety, uncomfortable bed and lack of understanding from others. Eve described it in this way: "I am not able to sleep, no matter what I do. I believe I am in some vicious circle. It has been like that for a long time." Being able to get some rest and sleep through the night was important because sleepless

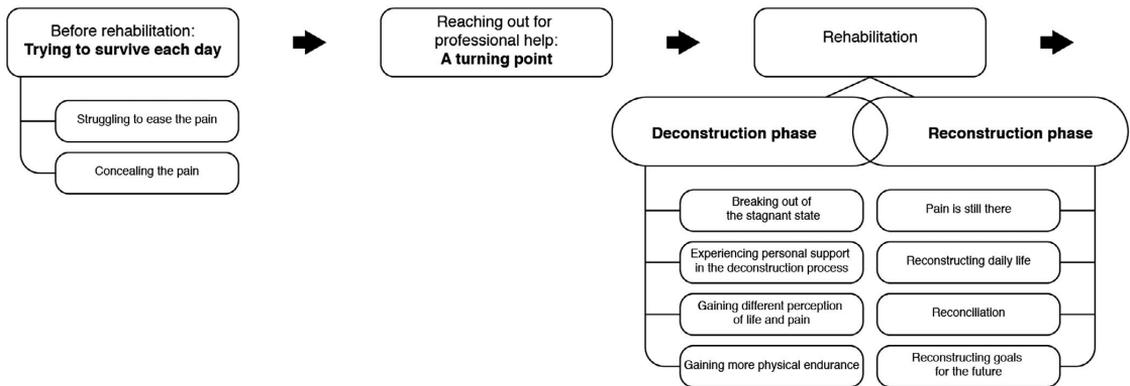


FIGURE 2 The Journey of Breaking the Vicious Circle in Chronic Pain: Overview of the study findings

nights meant more pain the following day. Several participants could not continue working because of their pain but dreamt of being able to return to work someday. They tried to survive each day without setting goals for the future. As Lena said: "I have no goals. The only goal I have these days is just surviving each day."

#### 4.1.1 | Struggling to ease the pain

The participants had tried pain medication but experienced little or no relief. Catherine described this problem: "No ordinary pain medication can relieve this pain... and it is difficult to distract your thoughts away from it." Isabella shared:

I had been going to a physical therapist once a week for more than a year and nothing worked.... Then I went to [an orthopaedic surgeon] for injections twice and that did not work and he just wished me all the best; he could not do anything else for me.

Relaxation, massage, acupuncture, reflexology, heat, physical therapy, regular exercise, walking and hydrotherapy were some of the methods participants used to try to ease their pain. Keeping an open mind and engaging in positive thinking were reported to be helpful:

If you wake up one morning and decide that this will be a miserable day, then the day will be miserable. I tell myself that I am willing to try everything with an open mind. The worst that can happen is that nothing happens, and I will be at square one.

(Isabella)

Distraction was another useful strategy. Reading and listening to music, participating in volunteer work and having a job helped to distract thoughts away from the pain: "It is the best, the best relaxation that I know of. That is either just lying down completely relaxing in the

swimming pool, just letting myself float or just lying down with some music on" (Dave).

#### 4.1.2 | Concealing the pain

In general, participants experienced that people closest to them realized what they were going through, but they did not always show concern. Other people did not understand why people who had no obvious problem could not have a job and do their "duties." The participants concealed their pain, avoided talking about it to others and said that they were feeling good even if they were not: "I do not like to talk about it [the pain]. I do not need pity from others, so I have just learned to live with it and have stopped talking about it" (Eve).

#### 4.2 | Reaching out for professional help: a turning point

At a certain point, the participants realized that they were no longer able to take care of their situation. They had reached a stagnant state where nothing was changing, the strategies they used were ineffective and they felt they needed help. They therefore searched for and found a health professional who suggested a pain rehabilitation programme.

When the application had been sent, the participants suddenly experienced some hope that something could change for the better. They did not know exactly how they would benefit from it, but they were excited about starting the pain rehabilitation programme. Some were hoping to get answers, a diagnosis and increased physical endurance. Others were hoping for some "me time" for several weeks where they could focus on their health and well-being or learn new strategies to live with the pain. No one expected to become completely pain-free. Eve stated: "I need to learn some methods to ease the pain and exercise and strengthen myself so I can continue from that. So, I can feel better."

### 4.3 | Rehabilitation: deconstruction and reconstruction phase

As demonstrated in Figure 2, rehabilitation is a dynamic process of deconstruction and reconstruction.

#### 4.3.1 | Deconstruction phase

##### *Breaking out of the stagnant state*

The participants were ready to be in the pain rehabilitation programme because the programme allowed them time to focus entirely on themselves and on enhancing their health instead of managing their daily routines where their focus was usually on the needs of others. Having children to take care of took much of the participants' effort and energy. The participants who had to go home in the afternoons or for a few days in the middle of the programme to take care of domestic chores and children experienced increased stress levels and they felt they gained less from the programme than they could have:

I am going to focus on this [the programme], focus on me, think only about me, not the needs of others, or doing something else. It will be my time to try to move on. If I cannot take care of myself then I cannot take care of others.

(Isabella)

##### *Experiencing personal support in the deconstruction process*

Experiencing personal support from family, friends and co-workers while at the rehabilitation centre was valuable to the participants. They could focus on themselves and their needs during the difficult deconstruction process. In all the three rehabilitation centres, the participants described the professional demeanour of the healthcare providers. The healthcare providers were caring, warm, flexible and eager to find the best schedule, for everyone: "The staff should be rewarded for their existence.... You always experienced so much warmth from everyone" (Rose).

Helen regained belief in people after staying in the pain rehabilitation programme. Anne said that her belief in the healthcare system improved after watching how other people regained their health in rehabilitation. The participants felt understood and respected by the staff, listened to and accepted; they were not just numbers but people who needed help with their problems:

I was in self-destructive mode. Angry... I am most grateful for how [the health professionals] helped me to keep my family. I was losing them. They helped me to keep what was most precious to me. I did not arrive as some number to go through some conveyor-belt and then be thrown out. We got deep into it... it was personal... they helped me. I did not expect that.

(John)

Some of the participants experienced personal support, acceptance and understanding from their group as well. The group members were described as kind, understanding and caring. They showed empathy, tolerance, encouragement and positivity towards each other.

##### *Gaining a different perception of life and pain*

The programme helped the participants to gain new perspectives on their lives and pain, on how to think about and ease the pain and how to prevent pain attacks. Rose compared the chronic pain to a passenger whom she was trying to move to the backseat, presumably where it had a less disturbing impact than it did on the front seat.

When John started the programme, he was angry, and he was convinced that the doctors had made a mistake. His goal was to get out of the patient role: "I was always feeling sorry for myself... nothing was my fault, always someone else's fault.... I am learning to deal with it myself and learning to do it myself" (John).

Cognitive behavioural therapy, ergonomics, body awareness, massage, relaxation, stretching, hydrotherapy, shock wave therapy, mud bath and hand waxing were valuable and helpful strategies. For one participant, the hydrotherapy was the most valuable, while for others, the shock wave therapy or physical exercises were most valuable. Some participants felt they had not heard anything new in the lectures, yet they appreciated them. The lectures about pain and pain management were described by Isabella as an acceptance of the pain's existence: "Someone else knows what it's like which is an acceptance [of chronic pain] and [proves it is] not some hysteria. Sometimes pain cannot be described, but some people have it and such pain is individual" (Isabella).

##### *Gaining more physical endurance*

Physical exercises helped to improve participants' physical well-being and enabled them to move more: "It strengthened me somehow and made me realise the state I was in when I attended [the programme] and helped me work through that. Now I respond differently to difficult periods" (Anne):

Sarah described how exhausted she was after the physical exercises and thought she was going to die and yet the programme made her realize that physical exercise was something that she needed to do every single day to feel better. She had more drive, and her health was better because of the physical exercises.

#### 4.3.2 | Reconstruction phase

For most of the participants, a reconstruction process started while they were still in the programme:

It [the programme] is like a jigsaw and I have found a lot of puzzles.... I used to focus on one specific thing which was supposed to salvage me, but then it didn't. I was always trying to find the solution. But maybe

combined, it [the treatments in the programme] created the solution.

(Lena)

#### *The pain is still there*

The pain was still there, and the participants accepted that it was unlikely to go away. However, it no longer controlled everything in their daily lives and the disturbing effects on their daily lives were less than before. Mentally, something changed for the better: "Physically, it [the programme] did not change much... for the pain, it did not change much. However, mentally, I received more than I expected" (Rose).

#### *Reconstructing daily life*

Each participant had started to reconstruct their daily life by putting together the pieces they had experienced in the pain rehabilitation programmes that were most useful and suitable for them. The priorities in the participants' daily life had changed. They were focused on making more space for regular physical exercises, physiotherapy, rest, breaks at work and relaxing. These strategies improved their well-being:

I am more aware of doing something for myself. I am not supposed to be left out. Not enforcing myself so much that I will be worse and worse and worse. I need to stop for a minute and think about myself. I need to take a break at work which I wasn't used to doing. Thinking back, I used to sit at work the whole day, just working.

(Eve)

#### *Reconciliation*

The participants accepted themselves and their pain. They accepted their existence and realized that they no longer needed to defend their existence, as if they had been a burden on their family and society previously. They stopped making excuses for their existence, and they no longer needed a job title to define who they were:

When you start to accept yourself, it's like a snowball that starts rolling. I have stopped making excuses regarding why I am the way that I am. I have stopped using the job title when I define myself. I have reached a point where I do not need to defend myself anymore.

(Rose)

Lena described how she started to define herself differently:

I started to write down what I was thinking.... I realised that I do not know who I am. I used to be so occupied with fitting into some form. I needed to stop being angry and I wasn't satisfied with that at the beginning because I had been angry for so long.

After she stopped being angry, she reconciled with her family. John described how he was at peace with himself and had learned to enjoy the moment:

I am living the dream I used to dream before I got sick. I am experiencing the balance with my family, with my life. My focus is on enjoying the moment because you never know when the next pain attack will strike.

#### *Reconstructing goals for the future*

By the second interview, the participants had not reached the end of their reconstruction process, but they were on their way. Their focus had changed to making goals for the future instead of regretting the past. "I am not going to spend the rest of my life thinking: 'What could I have done differently?'" (Lena).

Rose described how she needed to focus more on preparing herself: "I am determined to do things. I know I must prepare myself. I am finding out how I can prepare myself according to what I am going to do. I am getting there." The experience of taking the time to attend a pain rehabilitation programme and to focus on themselves and their needs made the participants realize that they needed to allow themselves time to get away from all the stress in their daily life and spend some time elsewhere.

## 5 | DISCUSSION

Interviewing the participants before and after completing the programme provided valuable insights into the programme's influence on their thoughts about their pain and daily activities. In the second interviews, the participants could compare their situation at the time of the interview to where they were before they participated in the programme. The findings showed how their priorities had changed, how their focus was more on their well-being and how the pain no longer dominated their life. Three months after completing the programme, they were still combining pieces they had experienced in the programme into a more holistic structure without knowing when and how their journey would end. They were trying to enjoy the moment of well-being while it lasted and had started to reconstruct their life.

### 5.1 | Changed priorities

Before attending pain rehabilitation, the participants were just trying to survive each day, struggling to ease the pain and they felt stuck in a vicious circle of chronic pain. However, in line with findings by other researchers (Egan et al., 2017; Hållstam et al., 2015), change was possible and the participants noticed positive changes. Three months after they completed the programme, their priorities had changed. They were going through changes, thought differently about themselves and were slowly making changes in their daily lives, as seen in another study (Egan et al., 2017). They had stopped making excuses for their existence and being angry, and they accepted themselves and their pain. As seen in previous studies (Hållstam et al., 2015), the participants received valuable

support from their family, friends and co-workers while in the rehabilitation programme. They thought more about how they could put their needs at the forefront and the attitudes of those with jobs towards their work environment changed. Similar to the findings of Gustafsson et al.'s (2004) study where rest was not possible or permitted before the programme, they became more aware of the importance of resting, both at work and at home, making it more possible and frequent after completing the programme.

As found in other studies, the participants started to make space for regular physical exercise (Hållstam et al., 2015), physiotherapy, relaxation (Gunnarsdóttir & Peden-McAlpine, 2004) and pacing (Egan et al., 2017; Hållstam et al., 2015). They managed to break the vicious circle where they were stuck before and began to reconstruct their lives. They were no longer only surviving; they were starting to live a life (Hållstam et al., 2015). As the findings of other research suggest (Doran, 2014; Dysvik et al., 2014; Egan et al., 2017; Haraldseid et al., 2014), it is possible that the CBT and mindfulness-based approaches used in the pain rehabilitation programmes had an effect on their new ways of living.

## 5.2 | Moving pain in the backseat

As found in another study (Hållstam et al., 2015), after completing the programme, the participants realized that their pain was permanent; it was a part of their life, so it was better to learn to live with it (Biguet et al., 2016). They had, however, stopped concealing their pain. They experienced more physical endurance and mental changes as well. They deconstructed their old and ineffective ways of dealing with their chronic pain and reconstructed new ways of thinking and living. Skills, such as non-pharmacological treatment, hydrotherapy, pacing and physical exercises, to reduce pain and handle life, facilitated the change process as seen in other studies (Egan et al., 2017; Hållstam et al., 2015). The recovery was not one specific thing, it was several pieces combined, similar to Gunnarsdóttir and Peden-McAlpine's (2004) findings and we found that the combination of multiple complementary alternative therapies was crucial in the participants' healing. They needed help and guidance to learn new strategies. Participants also indicated that receiving acceptance and understanding from group members and healthcare professionals who empowered them to take responsibility in their daily lives and such empowerment has been reported in other studies (Biguet et al., 2016; Egan et al., 2017; Gunnarsdóttir & Peden-McAlpine, 2004; Hållstam et al., 2015). Here, it was also clear that they were guided into a new mode of being and of no longer letting the pain dominate their life.

## 5.3 | Rehabilitation continues after the programme's completion

Three months after the programme's completion, we found that the participants were just starting to make changes and trying to realize

the best ways to put their most valuable strategies they had learned in the programme into their daily routine.

The participants in the current study described the existence of a pain rehabilitation programme as recognition of their chronic pain. Applying for such a programme was a turning point in the participants' chronic pain trajectory, which they considered the first step in the process of breaking the vicious circle of chronic pain and of their stagnant state. They were hopeful that something would change for the better after completing the programme. No one expected to become completely pain-free similar to the results of Geurts et al.'s systematic review (2017) where the patients in the papers studied expressed a want or a need for pain relief or pain cure but predicted substantial less pain relief or no pain reduction at all.

For how long does the positive influence of rehabilitation continue? Several previous studies have examined this question. For example, there is a possibility that some chronic pain sufferers who attend a pain rehabilitation programme return to survival mode instead of continuing to rehabilitate because the sustained effort of self-managing chronic pain can be exhausting and motivation can wane over time following an intervention (Devan et al., 2018).

Therefore, it is perhaps worth implementing a follow-up newsletter, refresher course, app (Egan et al., 2017), booster sessions and/or peer support groups (Devan et al., 2018) several weeks or months after the programme's completion. Additionally, a hotline and/or chatroom (online) could be set up to offer professional counselling and support.

## 5.4 | Strength and limitations

A strength of this study is that the participants attended three different programmes.

The number of participants and interviews is well within limits described in phenomenological studies. However, it is impossible to say whether more participants would have further increased our understanding of the phenomenon. Despite the effort made to obtain secondary interviews with all participants, one of the 11 participants did not reply to the messages sent to plan the second interview and only eight participants verified their individual analytical framework. Another potential limitation of the present study is the time between programme completion and the second interview. Three months may not be long enough to fully understand the process and progress the participants were making. Their reconstruction was not completed by 3 months, and future studies should examine participants outcome over a year or longer.

## 6 | CONCLUSIONS

The impact of chronic pain is multifaceted. Pain rehabilitation can assist sufferers to confront the pain, deconstruct unhelpful ways of dealing with pain, gain a different perspective about the pain and learn new ways to reconstruct daily life.

The results provide a deeper understanding of the impact of a pain rehabilitation programme and indicate what matters the most for the participants, which can be valuable for the future planning and development of these and similar programmes.

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## CONFLICT OF INTEREST

None.

## AUTHOR CONTRIBUTIONS

All authors contributed to the study design (HS, TJG, SH, HS, JH, AB). The first author (HS) conducted the interviews. HS, TJG, SH and HS contributed to the data analysis and the drafting of the manuscript. All authors critically revised the manuscript.

## ETHICAL APPROVAL

Permission to conduct the study was granted by The National Bioethics Committee (VSN-15-101) and chief physicians at the three rehabilitation centres. The participants signed informed consent and were guaranteed confidentiality.

## ORCID

Hafdis Skúladóttir  <https://orcid.org/0000-0003-3234-5356>

Thora J. Gunnarsdóttir  <https://orcid.org/0000-0002-6079-918X>

Sigríður Halldórsdóttir  <https://orcid.org/0000-0003-0629-4428>

Herdís Sveinsdóttir  <https://orcid.org/0000-0002-1766-3543>

Janean E. Holden  <https://orcid.org/0000-0002-9520-9354>

Amalía Björnsdóttir  <https://orcid.org/0000-0001-6639-2607>

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## APPENDIX 1

## Overview of the programmes in the three pain rehabilitation centres

| Site 1  | Site 2   | Site 3   |
|---|--|--|
| <p><b>Initial assessment:</b> Four days pre-programme intended for interviews, evaluation and education. Goal setting and a decision is developed for further rehabilitation. People go home with a plan, for example to decrease their medication and increase exercise. After that first meeting, some patients start to change their lifestyle. Possibility of follow-up before the standard programme begins</p> <p><b>The standard programme</b> mainly focuses on individualized schedule for lifestyle changes, assessment, education, improving physical condition, CBT, compassion-focused therapy (CFT), body awareness training, mindfulness, changing self-image, relaxation techniques, sleep disturbances, psychiatric consultation, increasing the ability to cope with pain and minimizing or reducing pain medication consumption and increasing the ability to get back to work</p> <p><b>Teaching</b> is both on an individual basis and in groups</p> <p><b>Schedule:</b> The patients stay at the rehabilitation centre only during the daytime from 8 o'clock am to 4 p.m. for 5 to 7 weeks</p> | <p><b>Initial assessment:</b> One day pre-interviewing for evaluation and education. A meeting is held with the patient, a group of healthcare professionals and preferably with a family member</p> <p><b>The standard programme</b> mainly focuses on cooperation between patients, their families and healthcare professionals, aimed at assessment, education, improving physical condition, CBT, body awareness training, changing self-image, relaxation techniques, sleep disturbances, psychiatric consultation, increasing the ability to cope with pain and minimizing or reducing pain medication consumption and increasing the ability to get back to work</p> <p><b>Teaching</b> is both on an individual basis and in groups</p> <p><b>Schedule:</b> The patients stay at the rehabilitation centre 24 hr for 5 days a week for 4 weeks.</p> <p>Follow-up week 3 months later</p> | <p><b>Initial assessment:</b> One day where each individual/group is assessed in order to develop an individualized programme</p> <p><b>The standard programme</b> mainly focuses on interviews, consultancy, assessment, observation and support, education, physiotherapy, rest and relaxation classes, where the focus is on the individual. Special emphasis is on daily mindfulness meditation, Mindfulness-based cognitive behaviour therapy (MBCBT), CFT and body awareness (tai chi), which can help individuals in chronic pain to learn to know their own limitations and coping behaviour. Also offered are water exercises, health (herb) baths, mud baths, hot and cold packs, daily use of the swimming pool, jacuzzies and sauna, massage and acupuncture, and Kneipp water therapy</p> <p><b>Teaching</b> is both on an individual basis and in groups</p> <p><b>Schedule:</b> The patients stay at the rehabilitation centre 24 hr, 7 days a week for 4 weeks</p> |

## APPENDIX 2

## Interview guide. Main questions and examples of follow-up questions

| Questions before participants attended the pain rehabilitation program:   | Questions at least 3 months after participants' programs' completion:   |
|---|---|
| Can you describe the pain you have today, your health and your daily life?  | Can you describe the pain you had before you attended the pain rehabilitation program and compare it to the pain you have today; Can you compare your health and life today to your health and life before you attended the pain rehabilitation program?  |
| <p><b>Examples of follow-up questions:</b></p> <ul style="list-style-type: none"> <li>• Background information</li> <li>• Onset of pain</li> <li>• Causes of pain</li> <li>• Diagnosis</li> <li>• Possible changes in relationships with family and friends</li> <li>• Self-image/how do you describe yourself?</li> <li>• What affects your daily physical, psychological, social, and emotional well-being and daily activities?(e.g. physical condition, food/beverages, environment, stress, sleep, insecurity, fatigue, job, disability, exercises, support/lack of support from family, friends, healthcare staff, people with pain and community, worries, isolation, domestic chores, distraction, leisure activities, education, access to healthcare, communication with healthcare staff etc)</li> <li>• Reaction and resources regarding pain</li> <li>• Roles within the family and abilities to do domestic chores</li> <li>• Something you must deny yourself because of pain? Something that brings pleasure?</li> <li>• Reasons for applying for rehabilitation program? How did that happen?</li> <li>• Did you prepare yourself in some way before attending the program?</li> <li>• Expectations regarding the program</li> <li>• Is there something I have not asked you about, that you would like to tell me because you feel it matters?</li> </ul> | <p><b>Examples of follow-up questions:</b></p> <ul style="list-style-type: none"> <li>• Compare the resources you had before to relief the pain to the ones you have now. Has there been any changes?</li> <li>• Can you describe other impacts on psychological well-being, social activities, and leisure activities? (E.g. needs, resources, work abilities, job, roles within the family, support, sleep, worries, relaxation, more/less social activities, easier to express feelings? Etc.).</li> <li>• How do you describe yourself? Has it changed after completing the program?</li> <li>• Did the program meet the expectations you had? If so, in what way?</li> <li>• Can you describe the treatment you received?</li> <li>• Can you describe the education you received?</li> <li>• Has there been any changes in what affects your daily physical, psychological, social, emotional well-being and daily activities? (e.g. physical condition, food/beverages, environment, stress, sleep, insecurity, fatigue, job, disability, exercises, support/lack of support from family, friends, healthcare staff, people with pain and community, worries, isolation, domestic chores, distraction, leisure activities, education, access to healthcare, communication with healthcare staff etc)</li> <li>• Is there something you would like to tell me, something I have not asked you about, but you feel it matters?</li> </ul> |

## Paper II





Article

# Pain Rehabilitation's Effect on People in Chronic Pain: A Prospective Cohort Study

Hafþís Skúladóttir <sup>1,\*</sup>, Amalia Björnsdóttir <sup>2</sup>, Janean E. Holden <sup>3</sup>, Thóra Jenný Gunnarsdóttir <sup>4</sup>,  
Sigrídur Halldorsdóttir <sup>1</sup> and Herdis Sveinsdóttir <sup>4</sup>

<sup>1</sup> School of Health Science, University of Akureyri, Solborg v/Nordurslod, 600 Akureyri, Iceland; sigridur@unak.is

<sup>2</sup> School of Education, Faculty of Education and Pedagogy, University of Iceland, Stakkahlid 1, 105 Reykjavík, Iceland; amaliabj@hi.is

<sup>3</sup> School of Nursing, University of Michigan, Ann Arbor, MI 48109, USA; holdenje@umich.edu

<sup>4</sup> School of Health Science, University of Iceland, Eiríksgata 34, 101 Reykjavík, Iceland; thoraj@hi.is (T.J.G.); herdis@hi.is (H.S.)

\* Correspondence: hafdis@unak.is; Tel.: +354-460-8456

**Abstract:** Multidisciplinary long-term pain rehabilitation programs with a team of healthcare professionals are an integrated approach to treat patients with chronic non-malignant pain. In this longitudinal prospective cohort study, we investigated the long-term effects of multidisciplinary pain rehabilitation on the self-reported causes of pain, pain self-management strategies, sleep, pain severity, and pain's interference with life, pre- and post-treatment. Eighty-one patients, aged 20–69 years, with chronic pain responded. The two most frequently reported perceived causes of pain were fibromyalgia and accidents. The difference in average self-reported pain severity decreased significantly at one-year follow-up ( $p < 0.001$ ), as did pain's interference with general activities, mood, walking ability, sleep, and enjoyment of life. At one-year follow-up, participants (21%) rated their health as good/very good and were more likely to state that it was better than a year before (20%). No change was found in the use of pain self-management strategies such as physical training at one-year follow-up. The intervention was effective for the participants, as reflected in the decreased pain severity and pain interference with life.



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**Keywords:** chronic pain; rehabilitation; sleep; self-management; health

## 1. Introduction

The World Health Organization (WHO) has characterized chronic pain as the second-largest contributor to disability worldwide, with lower back pain being the single leading cause of disability [1]. Chronic pain is defined as an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage and typically lasts longer than three months. Primary chronic pain refers to pain that is the presenting problem, such as with fibromyalgia or lower back pain. Secondary chronic pain is due to an identifiable cause, as in the case of chronic post-surgical or post-traumatic pain [2]. Chronic pain is often considered to be nociplastic pain or pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage [3]. This type of pain can occur in isolation (such as in fibromyalgia) or as part of a mixed-pain state (as in chronic lower back pain). The symptoms observed in nociplastic pain include widespread or intense pain (or both), fatigue, sleep, and mood problems [4]. In Iceland, the prevalence of chronic pain is as high as 48%, and among those with chronic pain, approximately 30% experience constant pain. The findings of this survey showed that the most common causes of chronic pain were myalgia, old trauma, rheumatism (e.g., rheumatoid arthritis and osteoarthritis), fibromyalgia, and migraines. Of those who reported chronic pain, 53.2% had consulted a healthcare provider for their pain,

and rheumatism (as a perceived cause of pain) predicted pain-related healthcare utilization among women [5].

In Iceland, 27% of adults are obese, meaning that they have body mass indexes (BMIs) of 30.0 or higher [6]. Research has shown that being overweight or obese increases the likelihood of lower back pain, tension or migraine headaches, fibromyalgia, abdominal pain, and chronic widespread pain [7]. In turn, these conditions can affect the outcomes of pain rehabilitation programs [8]. Pain self-management strategies (e.g., medication, distraction, relaxation, activity pacing, and exercise) include specific tasks, activities, or methods that a person in chronic pain may employ in an effort to manage their symptoms and achieve certain goals, such as reduced pain interference with activities, mood, and relationships [9].

The present study focused on the effects of the three multidisciplinary pain rehabilitation programs in Iceland among participants with various causes of chronic pain. Multidisciplinary long-term pain rehabilitation programs (also called interdisciplinary pain rehabilitation) involve a team of healthcare professionals and an integrated approach to treat patients with non-malignant pain. These programs combine psychological interventions and physical training in cases where other interventions, such as pharmacological treatment or physiotherapy, are insufficient. While multidisciplinary rehabilitation programs do not always provide complete pain relief [10–13], they have been shown to improve life satisfaction and reduce pain severity as well as the negative psychological, social, and behavioral effects of pain [14,15]. For example, sleep difficulties are common among chronic pain patients. When pain and sleep are comorbid, both must be addressed to attain the maximum response to pain rehabilitation programs [16]. A recent systematic review and meta-analysis revealed that multidisciplinary rehabilitation lessens pain intensity and disability compared to active physical interventions, and these effects appear to be sustained in the long term [17].

Most studies on the effectiveness of multidisciplinary rehabilitation have involved patients with chronic lower back pain [17]. However, programs also exist for patients with various causes of pain [18], complex chronic non-malignant pain [13], or long-term symptoms following whiplash [19]. Based on the results of systematic reviews and meta-analyses of the best evidence regarding rehabilitation for chronic lower back pain patients, Malfliet et al. [20] recommended multidisciplinary rehabilitation programs and exercises that align with patients' preferences and abilities. Furthermore, they found that exercise interventions have better, longer-lasting effects when combined with psychological components. The three multidisciplinary pain rehabilitation programs in Iceland provide both physical exercises combined with psychological components.

Four prior studies (each of which focused on a specific treatment at a single rehabilitation center) have examined the three aforementioned multidisciplinary programs, but none of these studies included all three programs within a single study, with the aim of examining their effects on pain severity and pain's interference with the participants' lives, health, and self-management strategies. One of these studies focused specifically on cognitive behavioral therapy for depression and anxiety in patients with chronic musculoskeletal pain. The results indicated that this intervention may enhance the long-term (up to three years) benefits of treatment, even though the participants reported little change in their pain intensity [21]. Another study focused on chronic pain patients' participation in health assessment practices in a nursing context. Both chronic pain patients and their nurses participated in this study, and the results showed that using the assessment tool Hermes facilitated person-centered participation in the patients' health assessments [22]. The third study used a combination of complementary therapies. The importance of the environment, the healing effects of nature, and opportunities for relaxation and distraction from normal life and daily stressors were highlighted in the findings. Furthermore, it was particularly important that the patients' healing was self-motivated and self-directed [23]. The fourth and final study compared two interventions—a traditional multidisciplinary pain management program and neuroscience education with mindfulness-based cogni-

tive therapy—for women with chronic pain. Pain intensity was measured with a visual analogue scale, and health-related quality of life was measured with the Icelandic Quality of Life scale. Both programs improved pain and health-related quality of life, but pain intensity lessened to a greater degree in the traditional program [24]. Further study is needed on the long-term effect of pain rehabilitation programs for chronic pain and the examination of variables that affect patient outcomes, such as self-managing strategies, sleep, evaluation of health, and sociodemographic variables.

The aim of the present study is to describe patients' self-reported experiences of pain and investigate the long-term effects of multidisciplinary pain rehabilitation in Iceland. Specifically, this study aimed a) to explore and describe how individuals with chronic pain self-report their pain severity and pain's interference with life before attending a multidisciplinary pain rehabilitation intervention (pre-treatment), on completion of the intervention (post-treatment), and one-year follow-up, and b) to explore changes in the participants' pain self-management strategies, sleep, and health at one-year follow-up. Data were also gathered regarding perceived causes of pain, duration, and location.

## 2. Materials and Methods

### 2.1. Study Design and Setting

This longitudinal prospective cohort study aimed to investigate pain severity and pain's interference with life in a sample of people with chronic pain attending a multidisciplinary pain rehabilitation intervention. The study settings included three rehabilitation centers in Iceland (Centers 1, 2, and 3) that provide multidisciplinary pain rehabilitation interventions. These centers are staffed with nurses, physicians, physiotherapists, psychologists, occupational therapists, social workers, nutritional consultants, massage therapists, and physical activity instructors.

### 2.2. Participants

Participants were men and women in one of three Iceland pain rehabilitation centers. The emphasis of the study was on the intervention that the participants were to receive. Based on recommendations from the centers' nurse unit managers and chief physicians, patients who did not attend the entire program, those who participated in a distance program, and those who had cancer were excluded from the study. The inclusion criteria for participation were chronic musculoskeletal pain lasting for at least three months; the ability to speak, understand, and read Icelandic; an age of 18–70 years (the investigated treatments are not offered to people older than 70 years of age); and admission to one of the three investigated rehabilitation centers.

Several reasons for exclusion were reported, such as a cancer diagnosis, program postponement, removal from the waiting list, not completing the program, and transferring to a distance program or another type of program. Those who withdrew from the study but met the inclusion criteria reported reasons such as not wanting to participate, not feeling up to it, inability to complete online questionnaires, sickness, and uncertainty as to whether they would attend the program. Final inclusion in the study comprised participants who completed the questionnaires ( $n = 81$ ). A nearly equal number of participants attended the intervention at Center 1 ( $n = 39$ ) and Center 2 ( $n = 38$ ), but only four participants attended Center 3.

Permission to conduct the study was granted by the Icelandic National Bioethics Committee (VSN-15-101) and the chief physicians at the three investigated rehabilitation centers. The introductory letter given to the participants included information on the responsible parties and contact persons should they have any questions, comments, or concerns. The methodology was explained, and the participants were informed of their right to withdraw from the study whenever they chose.

### 2.3. Intervention

The intervention in the present study was a multidisciplinary pain rehabilitation program offered at the three investigated rehabilitation centers. The concepts of interventions, treatments, and programs are used interchangeably herein. The standard intervention was similar in all three centers, and treatment lengths ranged from four (Centers 2 and 3) to seven weeks (Center 1). The intervention begins and ends with assessing each patient's condition. At the initial assessment, every patient is assessed to set goals and make decisions for the development of further rehabilitation procedures. The standard intervention includes scheduled individualized and group sessions with physical therapy (1–5 times a week), cognitive behavioral therapy (once a week), relaxation (3–7 times a week), aquatic exercise training (3–5 times a week), support, and education (5 times a week). A special focus is placed on self-management strategies and minimizing or reducing the use of pain medication. Lifestyle changes (e.g., more regular physical training, relaxation techniques, and learning how to better cope with pain) are also encouraged. The emphasis of the intervention is on education regarding different subjects related to pain and pain management, such as healthy lifestyle choices, goal setting, relaxation, stress management, sleep, medication, physical training, self-image, and coping. Two of the investigated centers (1 and 3) also offered mindfulness (3 times a week), massage (2 times a week), acupuncture (1–2 times a week), body awareness (1–2 times a week), and compassion-focused therapy (1 time a week) (Table 1). How often each week a session was applied depended on the evaluation of everyone's needs.

**Table 1.** Description of standard intervention.

| Treatment Options                                   | Center 1  | Center 2  | Center 3  |
|---|-----------|-----------|-----------|
| <b>Standard intervention in three centers</b>       |           |           |           |
| Treatment length                                    | 5–7 weeks | 4 weeks   | 4 weeks   |
| Cognitive behavioral therapy for each individual    | ×1/week   | ×1/week   | ×1/week   |
| Assessment  | ×1/week   | ×2/week   | ×1/week   |
| Support and education                               | ×5/week   | ×5/week   | ×5/week   |
| Balance in daily life                               | ×4/week   | ×5/week   | ×4/week   |
| Relaxation in groups                                | ×3/week   | ×4/week   | ×5–7/week |
| Physical therapy                                    | ×1–5/week | ×1–5/week | ×1–2/week |
| Group training with physiotherapist                 | ×1–5/week | ×5/week   | ×4/week   |
| Group training with nurse or occupational therapist | ×1–5/week | ×2/week   | ×3/week   |
| Aquatic exercise training                           | ×5/week   | ×4/week   | ×3/week   |
| <b>Other treatment options in two centers</b>       |           |           |           |
| Compassion focused therapy                          | ×1/week   |           | ×1/week   |
| Mindfulness   | ×1/week   |           | ×3/week   |
| Massage   | ×1/week   |           | ×2/week   |
| Acupuncture   | ×1/week   |           | ×1–2/week |
| Body awareness                                      | ×1/week   |           | ×2/week   |
| <b>Other treatment options in one center</b>        |           |           |           |
| Cognitive behavioral therapy in groups              | ×1/week   |           |           |
| Health bath   |           |           | ×1/week   |
| Knipp water therapy                                 |           |           | ×2–5/week |
| Mud   |           |           | ×2/week   |
| Meditation  |           |           | ×1/week   |

As described above, the three investigated centers offer similar (albeit not identical) multidisciplinary interventions. Due to the present study's emphasis on the standard intervention, the small study population, and various causes of chronic pain, it was decided that the participants would be addressed as one cohort.

### 2.4. Procedure

Patients ( $N = 380$ ) were screened by one contact person at each center (either the chief physician or a nurse unit manager) as soon as they were added to the waiting list for the program. Incoming patients ( $n = 236$ ) then received a phone call from a research assistant, who introduced the study and provided instructions on how to participate. Those who agreed to participate received an introductory letter by mail, which contained a link and a

password that enabled them to access and complete a questionnaire online. Those who responded to the first questionnaire ( $n = 144$ ) received a second and third questionnaire (also online) if they fulfilled the inclusion criteria. A reminder was sent by email to those who did not respond within two weeks, a second reminder was sent one week later if there was still no response, and a final reminder was sent four weeks later. During the data collection process, 31 patients withdrew from further participation and 32 were excluded. Data were collected between September 2015 and February 2019.

## 2.5. Measures

The study questionnaires were based on those used previously [5] as well as questions developed specifically for this study. The questionnaires measured sociodemographic information, pain, pain characteristics, self-management strategies, sleep, and health.

### 2.5.1. Sociodemographic Information

Demographic information was collected pre-treatment and included age (years), gender (male or female), education (compulsory, upper secondary, or higher), employment status (full-time, part-time, or other), marital status (married or living with a partner, single, divorced, or widowed), and BMI ( $\text{kg}/\text{m}^2$ ). Employment status and BMI were also measured at one-year follow-up.

### 2.5.2. Perceived Causes of Pain

The participants were asked to indicate what they perceived to be the primary cause of their pain and whether they had been diagnosed or had some explanation for the causes of their pain (yes/no). Those who responded “yes” were asked to mark the causes of their pain on a list of possible causes of pain (e.g., fibromyalgia, myalgia, and disc prolapse).

### 2.5.3. Pain Duration and Location

The participants were asked to report how long they had been in pain (years/months). They were also asked to indicate all areas of the body where they sensed pain by marking them on a list of 22 predefined anatomical areas of the body: (1) head, (2) face, (3) neck, (4) scapular/yoke upper back, (5) shoulder(s), (6) arm(s), (7) hand(s), (8) wrist(s), (9) finger(s), (10) upper back, (11) mid-back, (12) lower back, (13) chest, (14) hip, (15) hip joint, (16) groin, (17) abdomen, (18) pelvis, (19) foot/feet, (20) toe(s), (21) leg(s), and (22) knee(s).

### 2.5.4. Pain Severity and Pain’s Interference with Life

Pain severity and pain’s interference with life were measured with the Icelandic version of the Brief Pain Inventory (BPI; [25,26]). In studies by S. Gunnarsdottir et al. [26] and Jonsdottir et al. [5], the internal consistency of this measure was found to be  $\alpha = 0.89$  for the severity scale and  $\alpha = 0.91$  for the interference scale. The BPI includes three questions regarding pain severity during the previous 24 h, worst pain, least pain, and average pain. The fourth severity item measures current pain. Pain interference was evaluated by asking questions regarding the impact of any type of pain on seven aspects of daily life (e.g., “Mark one number that describes how, during the past 24 h, pain has interfered with your general activities, mood, walking ability, work, relations with other people, sleep, and enjoyment of life”). The participants rated their pain severity and pain interference on a 11-point scale (0 = “no pain” or “does not interfere” and 10 = “the worst pain imaginable” or “completely interferes”). According to Cleeland and Ryan [25], more daily activities are impaired as pain severity increases. For example, sleep, activity, mood, work, and life enjoyment are impaired when pain severity reaches Level 5. When pain severity reaches Level 7, the ability to walk is added to the list of impaired activities. Negative effects on relationships with others occur when pain severity reaches Level 8 [25].

### 2.5.5. Self-Management Strategies

Participants were asked to indicate the measures that they took to relieve their pain (e.g., pain medications, NSAIDs, sedatives, regular physical training, heat/cold, relaxation, distraction, avoiding certain food/beverages, or positive thinking). They also indicated how often they used these measures on a 5-point scale (never, 1–3 times per month, 1–3 times per week, 4–6 times per week, or daily). A pain self-management strategy was used regularly and as recommended [27] if the participants reported using it four times or more (4–6 times per week or daily) for both time periods.

### 2.5.6. Sleep

Quality of sleep was measured with three questions derived from the Pittsburgh Sleep Quality Index, a valid and reliable questionnaire [28]. The participants were asked to indicate for how many hours they normally slept per day. They were also asked to rate their quality of sleep over the past four weeks. The response options were (1) “I had no sleep problems at all,” (2) “I had some sleep problems,” (3) “I had many sleep problems,” and (4) “I had severe sleep problems.” Those who had experienced sleep problems in the previous month were asked to report whether they had experienced sleep problems due to pain.

### 2.5.7. Health

Two questions from the Short Form 36 Health Survey (SF-36v2) were used in this study. The participants evaluated their general health (excellent, very good, good, fair, or poor) and compared their current health to their health one year prior (much better now, somewhat better now, about the same, somewhat worse now, or much worse now; [29,30]). SF-36v2 has been widely used and the reliability and validity tested. For example, the reliability and validity of the instrument was tested and confirmed in another study in Iceland, where the internal consistency was acceptable, with Chronbach’s alpha of 0.78 for general health [31].

## 2.6. Statistical Analysis

The statistical analyses were conducted using the SPSS 27.0 statistical program (IBM SPSS Statistics for Windows, version 27.0. Armonk, NY: IBM Corp) [32]. Missing data were deleted according to a pairwise deletion procedure. Descriptive statistics (means, standard deviations, and percentages) were used to present the sample’s demographic, pain self-management, sleep, and health data. A Wilcoxon signed-rank test was used to compare the participants’ pre-treatment self-evaluation of their health with their evaluations at one-year follow-up. A related-samples McNemar change test was used to detect differences in sleep problems due to pain and the use of various pain self-management strategies (four times a week or more) between pre-treatment and one-year follow-up (Table 5). A paired *t*-test with bootstrapping was used to detect differences in pain severity and pain interference between pre-treatment and one-year follow-up. Differences in pain severity and pain interference were interpreted using Cohen’s *d* as small (0 to 0.2), medium (0.3 to 0.7), and large (>0.8) (Table 4). The level of significance established for this study was set at  $p < 0.05$ .

## 3. Results

### 3.1. Characteristics of the Sample ( $n = 81$ )

The respondents’ ages ranged from 20 to 68 years ( $M = 47.2$  years,  $SD = 11.9$  years). Most of the respondents were women (84%), 38% had completed upper secondary education, 27% had completed higher education, and 38% were working (24% full-time and 14% part-time). Most of the participants were married or living with a partner (77%). At one-year follow-up, 34% of the participants were working (20% full-time and 14% part-time). The “other” employment status included participants who were unemployed, disabled, students, homemakers, or self-employed. The average BMI was 30.6 ( $SD = 7.2$ )

pre-treatment and 30.8 ( $SD = 6.6$ ) at one-year follow-up. The participants' sociodemographic characteristics are listed in Table 2.

**Table 2.** Description of sociodemographic variables ( $n = 81$ ).

| Variables                      | <i>n</i> | %  |
|--------------------------------|----------|----|
| Gender                         | 81       |    |
| Females                        | 68       | 84 |
| Males                          | 13       | 16 |
| Age                            | 81       |    |
| 40 years or less               | 24       | 30 |
| 41–50 years                    | 23       | 28 |
| 51 years or older              | 34       | 42 |
| Education                      | 79       |    |
| Compulsory                     | 28       | 35 |
| Upper secondary                | 30       | 38 |
| Higher                         | 21       | 27 |
| Employment status              | 80       |    |
| Full-time                      | 19       | 24 |
| Part-time                      | 11       | 14 |
| Other                          | 50       | 62 |
| Marital status                 | 80       |    |
| Marriage/living with a partner | 62       | 77 |
| Single/divorced/widowed        | 12       | 15 |
| BMI                            | 77       |    |
| Underweight                    | 4        | 5  |
| Healthy weight                 | 13       | 16 |
| Overweight                     | 19       | 25 |
| Obese                          | 41       | 54 |

### 3.2. Perceived Pain Causes, Duration, and Locations

The participants presented with diverse causes of pain, duration, and location. As shown in Table 3, the most frequently reported perceived cause of pain was fibromyalgia ( $n = 40$ ), followed by accidents ( $n = 36$ ), myalgia ( $n = 33$ ), and disc prolapse ( $n = 24$ ); however, most of the participants reported more than one cause of pain. Pre-treatment, most of the participants ( $n = 72$ , 89%) reported that they had received an explanation or diagnosis for their pain.

**Table 3.** Causes of pain and pain location ( $n = 81$ ).

|                         | <i>n</i> | %  |
|-------------------------|----------|----|
| <b>Causes of pain</b>   |          |    |
| Fibromyalgia            | 40       | 49 |
| Accidents               | 36       | 44 |
| Myalgia                 | 33       | 41 |
| Disc prolapse           | 24       | 30 |
| Osteoarthritis          | 20       | 25 |
| Cartilage destruction   | 12       | 15 |
| Whiplash                | 12       | 15 |
| Migraine                | 12       | 15 |
| Chronicfatigue syndrome | 11       | 14 |
| Violence                | 7        | 9  |
| Rheumatoid arthritis    | 5        | 6  |
| Polymyalgia rheumatica  | 2        | 2  |
| Psoriasis arthritis     | 2        | 2  |
| Osteoporosis            | 1        | 1  |
| Rheumatoid spondylitis  | 1        | 1  |

**Table 3.** *Cont.*

|                            | <i>n</i> | %  |
|----------------------------|----------|----|
| <b>Location</b>            |          |    |
| Lower back                 | 63       | 80 |
| Shoulder(s)                | 56       | 71 |
| Scapular                   | 51       | 65 |
| Neck                       | 49       | 62 |
| Hip                        | 46       | 58 |
| Foot/feet                  | 44       | 56 |
| Leg(s)                     | 44       | 56 |
| Knee(s)                    | 38       | 48 |
| Hand(s)                    | 37       | 47 |
| Upper back                 | 36       | 46 |
| Mid back                   | 36       | 46 |
| Head                       | 36       | 46 |
| Arm(s)                     | 36       | 46 |
| Finger(s)                  | 36       | 46 |
| Hip joint(s)               | 33       | 42 |
| Toe(s)                     | 25       | 32 |
| Wrist(s)                   | 24       | 30 |
| Chest                      | 21       | 27 |
| Groin(s)                   | 18       | 23 |
| Abdomen                    | 15       | 19 |
| Face                       | 15       | 19 |
| Pelvis                     | 13       | 16 |
| <b>Number of locations</b> |          |    |
| 0–5                        | 24       | 30 |
| 6–10                       | 21       | 26 |
| 11–15                      | 20       | 25 |
| 16–22                      | 16       | 19 |

The mean pain duration was 10.3 years (range: 1–55 years). The most frequently reported location of pain was the lower back ( $n = 63$ , 80%), followed by the shoulder(s) ( $n = 56$ , 71%). Most of the participants ( $n = 76$ , 94%) reported pain in more than one location (Table 3).

### 3.3. Pain Severity and Pain's Interference with Life

The participants rated their pain severity significantly lower at post-treatment and at one-year follow-up compared to pre-treatment (Table 4). Average self-reported pain severity decreased significantly from pre-treatment to one-year follow-up ( $p < 0.001$ ) (medium effect), giving an estimate of the long-term effect of the treatment. In addition, there was a significant reduction in self-reported estimates of the worst pain ( $p = 0.041$ ) and current pain ( $p = 0.048$ ) from pre-treatment to one-year follow-up (small effect) (Table 4).

Average self-reported pain interference decreased from pre-treatment to post-treatment and decreased significantly for most items (all except for the ability to work and relations with other people) from pre-treatment to one-year follow-up. The average differences in pain interference between pre-treatment and one-year follow-up were statistically significant for general activities ( $p = 0.007$ ), mood ( $p = 0.012$ ), walking ability ( $p = 0.034$ ), sleep ( $p = 0.035$ ), and enjoyment of life ( $p = 0.004$ ) (small to medium effect). The observed differences in self-reported pain severity and pain's interference with life are listed in Table 4.

### 3.4. Pain Self-Management Strategies

The three most common pain self-management strategies used by participants four or more times per week pre-treatment were positive thinking (68%), medication (58%), and distraction (58%). No significant difference in the proportion (or percentage) of participants who used these strategies was found between pre-treatment and one-year follow-up (Table 5).

**Table 4.** The differences in self-reported pain severity and pain interference.

|                             |          | Pre-Treatment | Post-Treatment | One-Year Follow-Up | Pre-Treatment/One-Year Follow-Up | Pre-Treatment/One-Year Follow-Up |
|-----------------------------|----------|---------------|----------------|--------------------|----------------------------------|----------------------------------|
|                             | <i>n</i> | <i>M (SD)</i> | <i>M (SD)</i>  | <i>M (SD)</i>      | <i>p-Value *</i>                 | <i>Cohen d</i>                   |
| <b>Pain severity</b>        |          |               |                |                    |                                  |                                  |
| Worst now                   | 79       | 7.4 (1.78)    | 6.9 (2.07)     | 6.9 (2.08)         | <b>0.048</b>                     | 0.23                             |
| Worst                       | 79       | 8.4 (1.56)    | 7.6 (1.97)     | 7.9 (1.97)         | <b>0.041</b>                     | 0.23                             |
| Least                       | 79       | 4.5 (1.93)    | 4.1 (2.02)     | 4.4 (2.01)         | 0.517                            | 0.07                             |
| Average                     | 79       | 6.6 (1.65)    | 5.9 (1.90)     | 5.9 (1.83)         | <b>0.001</b>                     | 0.42                             |
| <b>Pain interference</b>    |          |               |                |                    |                                  |                                  |
| General activity            | 76       | 7.7 (2.11)    | 6.5 (2.49)     | 6.7 (2.63)         | <b>0.007</b>                     | 0.32                             |
| Mood                        | 79       | 6.7 (2.71)    | 5.3 (2.46)     | 5.8 (2.52)         | <b>0.012</b>                     | 0.29                             |
| Walking ability             | 78       | 6.6 (3.02)    | 5.6 (2.75)     | 5.9 (2.89)         | <b>0.034</b>                     | 0.24                             |
| Work                        | 75       | 8.4 (2.90)    | 7.9 (3.13)     | 7.9 (3.24)         | 0.190                            | 0.15                             |
| Relations with other people | 78       | 6.0 (3.03)    | 4.9 (2.67)     | 5.3 (2.78)         | 0.079                            | 0.21                             |
| Sleep                       | 77       | 7.6 (2.86)    | 6.2 (2.84)     | 7.0 (2.80)         | <b>0.035</b>                     | 0.24                             |
| Enjoyment of life           | 79       | 7.6 (2.28)    | 5.7 (2.71)     | 6.5 (2.67)         | <b>0.004</b>                     | 0.34                             |

\* Values in bold indicate statistically significant differences ( $p < 0.05$ ). *M* = mean; *SD* = standard deviation. Paired *t*-test bootstrap was only used for differences between pre-treatment and one-year follow-up.

**Table 5.** The differences in self-managing strategies, sleep, and health ( $n = 81$ ).

|   | Pre-Treatment | %  | One-Year Follow-Up | %  | <i>p Value *</i> |
|---|---------------|----|--------------------|----|------------------|
|   | <i>n</i>      |    | <i>n</i>           |    |                  |
| <b>Self-managing pain</b>               |               |    |                    |    |                  |
| <b>4 times or more per week</b>         |               |    |                    |    |                  |
| Positive thinking                       | 48/71         | 68 | 55/71              | 77 | 0.167            |
| Medication                              | 43/74         | 58 | 37/74              | 50 | 0.307            |
| Distraction                             | 40/69         | 58 | 41/69              | 59 | 1.00             |
| Regular physical training               | 25/74         | 34 | 26/74              | 35 | 1.00             |
| Avoid certain foods/beverages           | 23/73         | 30 | 31/71              | 44 | 0.181            |
| Relaxation                              | 20/66         | 30 | 21/66              | 32 | 1.00             |
| Heat/cold                               | 18/69         | 26 | 20/69              | 29 | 0.804            |
| <b>Sleep</b>                            |               |    |                    |    |                  |
| Sleep problems due to pain              | 73/81         | 90 | 67/81              | 83 | 0.146            |
| <b>Health</b>                           |               |    |                    |    |                  |
| Very good                               | 0/81          | 0  | 3/79               | 4  |                  |
| Good                                    | 6/81          | 7  | 13/79              | 17 |                  |
| Fair                                    | 28/81         | 35 | 47/79              | 60 |                  |
| Poor                                    | 47/81         | 58 | 16/79              | 20 | <b>&lt;0.001</b> |
| <b>Comparing health to one year ago</b> |               |    |                    |    |                  |
| Much better now                         | 3/81          | 4  | 16/79              | 20 |                  |
| Somewhat better now                     | 14/81         | 17 | 21/79              | 27 |                  |
| About the same                          | 22/81         | 27 | 24/79              | 30 |                  |
| Somewhat worse now                      | 25/81         | 31 | 14/79              | 18 |                  |
| Much worse now                          | 17/81         | 21 | 4/79               | 5  | <b>&lt;0.001</b> |

\* Values in bold indicate statistically significant differences ( $p < 0.05$ ). Related-samples McNemar change test was used to compare the difference in sleep problems due to pain and in using various pain self-management strategies 4 times per week or more between the two time points. Wilcoxon signed-rank test was used to compare evaluation of health and compare health to one year ago at pre-treatment and one-year follow-up.

### 3.5. Sleep

As shown in Table 5, 90% of the participants reported sleep problems due to pain pre-treatment vs. 83% at one-year follow-up; however, this reduction was not statistically significant ( $p = 0.146$ ). Furthermore, the average total hours of sleep did not change between pre-treatment ( $M = 6.9$  h,  $SD = 1.6$  h) and one-year follow-up ( $M = 7.0$  h,  $SD = 1.5$  h).

### 3.6. Health

Importantly, at one-year follow-up, 21% of the participants reported that their health was good/very good (vs. 7% pre-treatment). Furthermore, 20% stated that their health was much better at one-year follow-up than one year prior (vs. 4% pre-treatment: Table 5)

## 4. Discussion

The aim of the current study was to describe patients' self-reported experiences of pain and investigate the long-term effects of a multidisciplinary pain rehabilitation intervention offered by three main programs in Iceland.

One of the most significant findings in the current study was that the intervention appeared to influence the participants' self-reported pain in a positive manner. The participants' self-reported pain was significantly lower at one-year follow-up than pre-treatment. These results were similar to those of other studies, which have shown that multidisciplinary rehabilitation programs reduce pain intensity [15,33]. However, pain intensity was still high (around 6–8) and the least pain had decreased post-treatment, but at one-year follow-up, it was the same as pre-treatment (around 4.5).

Pain's interference with walking ability and general activities differed significantly between pre-treatment and one-year follow-up in the current study. Surprisingly, the participants had not used any particular pain self-management strategy more frequently than any other at one-year follow-up. Even regular physical training (an emphasis of the intervention) was used as a method of pain self-management with the same frequency at one-year follow-up as pre-treatment. This result was similar to the findings of a study by Dysvik et al. [34], in which training activities were similar at the starting point and at 12-month follow-up. This could be explained by the fact that the participants had less time to train regularly in their daily routine at home than they had while participating in the program, in which they could focus entirely on themselves and their needs and take a break from their normal lives and daily stressors [23]. Physical training is an important method of pain self-management and it is possible that an extended period in the intervention or more follow-up is needed. This needs to be studied further.

Participating in the intervention positively influenced self-reported health. More participants rated their health as good or very good at one-year follow-up than they did pre-treatment, and many stated that their health was much better than before the program; this finding was similar to the findings of other studies [13,14,35]. It is likely that positive thinking, the strategy used most by participants, influenced this positive view of their health. This result is similar to the findings of a study by Dysvik et al. [36], in which 81% of participants with chronic pain reported positive and important changes after multidisciplinary pain rehabilitation, in part due to positive thinking. The importance of positive thinking was also underscored by a study conducted by Wideman et al. [12], in which patients with chronic pain experienced high levels of negative pain-related factors (e.g., disability) while simultaneously taking steps toward personal growth; these participants looked at growth positively instead of concentrating on information that was not useful, as focusing on negative information only caused them frustration.

Mental disorders (e.g., depression, anxiety, and suicidal thoughts) are highly prevalent in chronic pain conditions, which often affect mood and subjective enjoyment of life [20,37]. In the current study, pain's interference with mood and enjoyment of life was reduced one year after the intervention was completed. However, it was still high (around 6), which raises the question of whether it is time to reorganize the intervention and start to plan more follow-up with support, education, and assessment of mental conditions.

Sleep deprivation is a risk factor for chronic pain [16]. Pain's interference with sleep was reduced in the current study. Total sleep time was the same at one-year follow-up as it was pre-treatment. While sleep problems due to pain were slightly lower at one-year follow-up than they were pre-treatment, this difference was not significant. The results of Davin et al. [16] showed that a stronger association between the previous night's total sleep time and next-day pain contributed to the greatest overall treatment benefits in terms of pain reduction and total sleep time. This raises the question of whether enough is done in the intervention to deal with sleep problems in connection with pain. Further study is needed to explore the effect of the intervention regarding sleep and to specifically target sleep problems due to pain [16,20].

One unexpected finding in the present study was that pain's interference with work decreased one year after the intervention was completed but not significantly. The proportion of participants who worked full-time or part-time did not change significantly from one-year follow-up (34%) to pre-treatment (38%). The proportion of working participants in this study was higher than in a study by Silvemarm et al. [15], in which the proportion of participants who described their source of income as paid work was 27.3% at admission and 25% at one-year follow-up. The reasons for this difference are not clear, but it may be that the majority of participants were younger than 50 years of age (58%), with either upper secondary or higher education (65%), which might have given them more opportunities to find jobs. Additionally, pain's interference with relations with others was also reduced at one-year follow-up, but not significantly in the current study. This difference may be explained by differences in marital status since most of the participants (77%) were either married or lived with a partner.

Weight (especially increased BMI) has been studied in connection with chronic pain and chronic pain treatment [20]. It is known that comprehensive pain rehabilitation programs improve physical and psychological functioning in patients in as little as three weeks, regardless of weight status [38]. However, following outpatient physical therapy, disability improved in overweight patients but not in obese patients [39], and severely obese subjects showed less improvement than the non-obese subjects following an interdisciplinary treatment program aimed specifically at patients with fibromyalgia [8]. In the current study, most of the participants were obese both pre-treatment and at one-year follow-up, and no associations were found between BMI and any other variables. Because studies have shown reduced pain in chronic lower back pain patients after a nonsurgical weight loss program involving physical exercise and changes in dietary behavior [20], it may be time to place more emphasis on weight loss and physical exercise in pain rehabilitation.

One non-significant finding of the present study was that the participants used less medication for pain relief at one-year follow-up than they did pre-treatment. A follow-up study with greater statistical power than the present study should be undertaken to further examine this finding. This result tends to support the findings of Saltychev et al. [40], in which the purchase of prescription medication decreased significantly following a one-year rehabilitation program emphasizing analgesics, and the work of Norrefalk and Borg, in which the use of any analgesics decreased significantly after one year following an eight-week rehabilitation study [11]. However, specific questions regarding medication usage, type, and duration were not addressed in the current study and this area requires further study.

The best solution for people with chronic pain may be to reinforce the use of pain self-management strategies over a longer period by implementing better follow-up strategies after they complete pain rehabilitation. Other researchers have concluded that there is a need for an individualized form of follow-up with several intervention options [18,41,42]. For example, a program could be developed in which the patient can choose between in-person, technology-assisted [43], and Internet-based self-management activities to reduce their pain and improve their quality of life [44]. Furthermore, the ability to choose between regular contact through apps [45], telephone calls, chat rooms, support groups [41], and consultations at community health centers could also provide individualization.

## 5. Strengths and Limitations

The present study took place in a small country and lacked the power of large multisite studies. Nevertheless, large communities are composed of smaller communities, which often mirror the larger communities of which they are a part. Consequently, the description and analysis of small communities are relevant in the larger context.

One strength of this study was that it investigated a formal pain rehabilitation intervention in a single country. None of the members of the research group were part of the group of staff members at the investigated centers. The intervention was effective in several areas of pain management, which is a valuable finding. No control groups were used because it was expected that there would be clear differences between the effects of the interventions. The small number of participants from Center 3 has decreased the significance of some of the findings. The high proportion of dropouts in this study is also acknowledged. Although the reasons for withdrawal were not systematically addressed, several explanations were supplied by some of the non-responders.

Finally, the sample size of the present study was relatively small, resulting in the study's relatively low statistical power. It is impossible to state whether the patients could maintain the changes that they achieved in this study for more than a year.

When participants were asked to indicate what they perceived to be the cause of their pain, the most commonly reported causes were fibromyalgia, accidents, myalgia, and disc prolapse. In the current study, 94% of the participants had pain in more than one location, which may have made it difficult to answer questions concerning pain severity. Therefore, the participants were not asked specifically about pain in each location but were asked about pain in general. Future studies could be developed that study the role of multidisciplinary rehabilitation programs on more specific types of pain conditions.

## 6. Implications for Pain Rehabilitation

The results of this study indicate that follow-up after the completion of pain rehabilitation could help patients to continue to engage in healthy lifestyle activities (e.g., regular physical training for pain relief) four or more times a week. This does not necessarily mean that all patients should return to their rehabilitation centers; rather, patients could choose between attending these centers and using some form of online or technical assistance several months after the intervention. The health professionals in the present study assessed the health status of each patient before the intervention, during the intervention, and at the intervention's completion. It could be valuable to screen for and remain aware of chronic pain patients' perceived causes of pain, BMIs, pain self-management strategies, levels of pain severity, and levels of pain interference with life. Furthermore, health professionals can provide education and support through rehabilitation centers, community health centers, apps, chat rooms, Zoom, videoconferencing, or telephone calls. The findings and implications of the present study must be studied further with more statistical power to determine the effects of the examined intervention over longer periods of time.

## 7. Conclusions

The multidisciplinary pain rehabilitation program of three major centers in Iceland was effective in decreasing pain severity and pain's interference with general activities, mood, walking ability, sleep, and enjoyment of life in subjects with a wide range of chronic pain problems. Moreover, the participants experienced improved health post-intervention. However, the participants did not maintain regular physical training at one-year follow-up, and their sleep problems due to pain did not change over the course of the intervention. Follow-up is recommended after pain rehabilitation interventions, and the participating health professionals are in a strong position to provide education and support at community health centers, at rehabilitation centers, or through some form of online or technical assistance. These findings support the effectiveness of multidisciplinary rehabilitation programs for pain and will be used to guide further research.

**Author Contributions:** All the authors contributed to the study design H.S. (Hafdis Skúladóttir), H.S. (Herdis Sveinsdóttir), A.B., J.E.H., T.J.G. and S.H. The first author, H.S. (Hafdis Skúladóttir) and the co-authors, A.B. and H.S. (Herdis Sveinsdóttir), contributed to the data analysis and the drafting of the manuscript. All the authors critically revised the manuscript. All authors have read and agreed to the published version of the manuscript.

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## Paper III





Article

# Pain, Sleep, and Health-Related Quality of Life after Multidisciplinary Intervention for Chronic Pain

Hafþís Skúladóttir <sup>1,\*</sup>, Herdís Sveinsdóttir <sup>2</sup>, Janean E. Holden <sup>3</sup>, Thóra Jenný Gunnarsdóttir <sup>2</sup>, Sigrídur Halldorsdóttir <sup>1</sup> and Amalía Björnsdóttir <sup>4</sup>

<sup>1</sup> School of Health Sciences, University of Akureyri, Solborg v/Nordurslod, 600 Akureyri, Iceland; sigridur@unak.is

<sup>2</sup> School of Health Sciences, Faculty of Nursing, University of Iceland, Eiríksgata 34, 101 Reykjavík, Iceland; herdis@hi.is (H.S.); thoraj@hi.is (T.J.G.)

<sup>3</sup> School of Nursing, University of Michigan, Ann Arbor, MI 48109, USA; holdenje@umich.edu

<sup>4</sup> School of Education, Faculty of Education and Pedagogy, University of Iceland, Stakkahlíð 1, 105 Reykjavík, Iceland; amaliabj@hi.is

\* Correspondence: hafdis@unak.is; Tel.: +354-460-8456

**Abstract:** Multidisciplinary pain-management programs have the potential to decrease pain intensity, improve health-related quality of life (HRQOL), and increase sleep quality. In this longitudinal prospective cohort study, the aim was to investigate the long-term effects of multidisciplinary pain rehabilitation interventions in Iceland. More precisely, we (a) explored and described how individuals with chronic pain evaluated their pain severity, sleep, and HRQOL at pre-treatment and at one-year follow-up and (b) examined what predicted the participants' one-year follow-up HRQOL. Seventy-nine patients aged 20–68 years, most of whom were women (85%), responded. The participants scored their pain lower at one-year follow-up ( $p < 0.001$ ). According to their response, most of them had disrupted sleep, mainly because of pain. One year after the treatment, more participants slept through the night ( $p = 0.004$ ), and their HRQOL increased. Higher pre-treatment mental component summary (MCS) scores and having pursued higher education predicted higher MCS scores at one-year follow-up, and higher pre-treatment physical component summary (PCS) scores predicted higher PCS scores at one-year follow-up. Sleep problems, being a woman, and having children younger than 18 years of age predicted lower MCS scores at one-year follow-up. These findings are suggestive that patients should be examined with respect to their mental status, and it could be beneficial if they received some professional support after completing the intervention.

**Keywords:** chronic pain; rehabilitation; health-related quality of life; sleep



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## 1. Introduction

Chronic pain has been defined as pain that persists beyond normal tissue healing time [1] and typically lasts longer than three months. Pain is the second largest contributor to disability worldwide, with low back pain being the single leading cause of disability [2]. The incidence, prevalence, severity, and accompanying impairments of chronic pain are among the main reasons for regarding pain as a public health priority, and for millions of people, pain is an inescapable reality of life [1,3]. For example, in Iceland, the prevalence of chronic pain is as high as 48%, and of those with chronic pain, approximately 30% experienced constant pain. Such pain levels affect every aspect of functioning [4].

Multidisciplinary long-term pain rehabilitation, also called interdisciplinary pain rehabilitation, uses a team of health-care professionals and an integrated approach to treat patients with non-malignant pain. Such programs are a combination of psychological interventions and physical training for situations where pharmacological treatment or physiotherapy are insufficient [5].

Health-related quality of life (HRQOL) describes the impact of health on people's ability to function and participate in meaningful activities within the family, workplace, and community [6,7]. Measuring HRQOL is an important outcome in studies of patients with chronic pain [6,8,9] and is another way to assess patients' subjective perspectives on their pain experience and its impact on their lives [6].

The finding from multidisciplinary long-term pain rehabilitation studies using HRQOL assessment are mixed. For example, patients with chronic pain benefit from multidisciplinary pain management programs in terms of better functioning, but the impact on pain was lower than expected [5]. Salathé et al.'s systematic review showed that long-term pain rehabilitation produces either no long-term increase in HRQOL or a moderate to large increase that persisted for at least 12 months [10].

In patients with chronic musculoskeletal pain, multidisciplinary or interdisciplinary pain rehabilitation either improved HRQOL, or it did not [10–14]. However, major improvement in HRQOL after pain rehabilitation programs positively associated with shorter duration of pain and worse baseline HRQOL [15]. Similarly, two years after participating in a pain program for patients with mixed chronic musculoskeletal pain, improvements in pain and function were maintained, health-care usage decreased, and the number of working hours increased [16]. Taken together, these findings are suggestive that further study is needed on the effect of pain rehabilitation programs for chronic pain and examination of variables that affect patient outcomes.

One variable known to impact pain is sleep. Sleep problems are frequently reported in adults with chronic pain, and the association is bidirectional [1]. For instance, sleep disorders among patients with low back pain decrease quality of life, and the level of sleepiness is influenced by the intensity of pain [17]. Among individuals with rheumatic diseases, feeling rested after sleep and having a good sleep structure predict better HRQOL outcomes [18]. When pain and sleep are comorbid, both must be addressed to reap the maximum response to pain rehabilitation programs [19].

With its 360,000 inhabitants, Iceland has three main multidisciplinary long-term pain rehabilitation programs. Only a single study has examined the effects of these programs on chronic pain, HRQOL, and sleep. Women with chronic pain who participated in a rehabilitation program that offered either traditional multidisciplinary pain management or neuroscience education and mindfulness-based cognitive therapy were studied. The results indicate that both programs improved quality of life and reduced pain intensity [20] and that the improvements lasted six months after the program's completion [21]. No Icelandic study focusing specifically on the long-term effects of these programs on chronic pain, sleep, and HRQOL was found.

The aim of the present study was to investigate the long-term effects of multidisciplinary pain rehabilitation interventions in Iceland by (a) exploring and describing how individuals with chronic pain evaluate pain severity, sleep, and HRQOL pre-treatment and at one-year follow-up and by (b) determining those factors that predict the participants' HRQOL one year after the intervention.

## 2. Materials and Methods

This longitudinal prospective cohort study aimed to investigate pain severity, sleep, and HRQOL in a sample of people with chronic pain undergoing a multidisciplinary pain rehabilitation intervention. Questionnaires were used at two different time points: pre-treatment and at one-year follow-up.

### 2.1. Participants

Participants were men and women in one of three Iceland pain rehabilitation centers. The emphasis of the study was on the intervention that the participants were to receive. Based on recommendations from the nurse unit managers and chief physicians in each center, patients who did not attend the entire program, who participated in a distance program, and who had cancer were excluded from the study. The inclusion criteria for

participation were chronic musculoskeletal pain lasting at least three months; the ability to speak, understand, and read Icelandic; an age of 18–70 years (the investigated treatments are not offered to people older than 70 years of age); and admission to one of the three investigated rehabilitation centers.

The reasons for exclusion and withdrawal were not systematically assessed. However, several reasons for exclusion were reported, such as not meeting the inclusion criteria due to a cancer diagnosis, program postponement, removal from the waiting list, not completing the program, and transferring to a distance program or another type of program. Those who withdrew from the study but met the inclusion criteria reported reasons such as not wanting to participate, sickness, not feeling up to it, inability to complete online questionnaires, and uncertainty as to whether they would attend the program.

Permission to conduct the study was granted by the Icelandic National Bioethics Committee (VSN-15-101 on 3 July 2015) and the chief physicians at the three investigated rehabilitation centers. The introductory letter given to the participants included information on the responsible parties and contact persons able to address their questions, comments, or concerns. The methodology was explained, and the respondents were informed about their right to withdraw from the study at any time.

## 2.2. Intervention

The intervention in the present study was a multidisciplinary pain rehabilitation program offered at three rehabilitation centers. These centers are staffed with nurses, physicians, physiotherapists, psychologists, occupational therapists, social workers, nutritional consultants, massage therapists, and physical activity instructors. The standard intervention was similar in all three centers, and treatment lengths ranged from four (centers 2 and 3) to seven weeks (center 1). The intervention began and ended with assessing each patient's condition. At the initial assessment, every patient was asked to set goals and make decisions regarding the development of further rehabilitation procedures. The standard intervention included scheduled individualized and group sessions comprising physical therapy, cognitive behavioral therapy, relaxation, aquatic exercise training, support, and education. The emphasis of the education piece regarding different subjects related to pain and pain management, such as healthy lifestyle choices, goal setting, relaxation, stress management, sleep, medication, physical training, self-image, and coping. Two of the investigated centers (1 and 3) also offered mindfulness, massage, acupuncture, body awareness, and compassion-focused therapy.

As described above, the three investigated centers offer similar (albeit not identical) multidisciplinary interventions. Due to the emphasis on standard multidisciplinary interventions, the small number of participants, and the variety of causes of chronic pain, it was decided that the participants would be addressed as one cohort.

## 2.3. Procedure

The patients ( $n = 380$ ) were screened according to the inclusion criteria by a contact person at each center (either the chief physician or the nurse unit manager) as soon as they were added to the waiting list for the program. Incoming patients who fulfilled the inclusion criteria ( $n = 236$ ) then received a phone call from a research assistant who introduced the study and provided instructions on how to participate. Those who agreed to participate received an introductory letter by mail with a link and password that enabled them to access and complete a questionnaire online. Those who responded to the first questionnaire ( $n = 144$ ) received a second questionnaire (also online). A reminder was sent by email to those who did not respond within two weeks, a second reminder was sent a week later if there was still no response, and a final reminder was sent four weeks later. During the data-collection process, 31 patients withdrew from further participation, and 32 were excluded. The data were collected between September 2015 and February 2019.

The study questionnaires were based on questionnaires that had been used in another study in Iceland [4] but also included questions developed specifically for this study. The

questionnaires measured sociodemographic information, pain severity, pain characteristics, sleep, and HRQOL.

#### 2.4. Sociodemographic Information

Demographic information was collected pre-treatment and included age (years), gender (male or female), education (compulsory, upper secondary, or higher), employment status (full-time, part-time, or other), marital status (married or living with a partner, engaged not living together, single, divorced, or widowed), and number of children younger than 18 years of age.

#### 2.5. Pain Duration, Causes, and Pain Severity

The participants were asked to report how long they had been in pain (years/months). They were also asked to indicate what they perceived to be the primary cause of their pain and whether they had been diagnosed or had an explanation for the cause of their pain (yes/no). Those who responded “yes” were asked to choose the cause of their pain from a list of possible causes (e.g., accidents, fibromyalgia, disc prolapse, and myalgia).

Pain severity was measured using the Icelandic version of the Brief Pain Inventory (BPI) [22,23]. The BPI includes four questions regarding pain severity (worst, least, average, and pain now). The participants rated their pain severity on a 11-point scale (0 = “no pain,” and 10 = “the worst pain imaginable”).

#### 2.6. Sleep

Quality of sleep and sleep problems were measured using four questions developed specifically for this study. The participants were asked to rate their quality of sleep over the past four weeks. The response options were (1) “I had no sleep problems at all,” (2) “I had some sleep problems,” (3) “I had many sleep problems,” and (4) “I had severe sleep problems.” Those who had experienced sleep problems (some, many, or severe) in the previous month were asked to report the reasons. The response options were (1) “because of pain,” (2) “because of other physical problems,” (3) “because of having to get up to use the bathroom,” (4) “because of psychological problems,” (5) “because of noises,” (6) “because I was too cold or too hot,” and (7) “because I sleep in an uncomfortable bed.”

Next, the participants were asked about the effect of their self-perceived sleep problems on their daytime energy. The response options were (1) “No,” (2) “Yes, in some way,” and (3) “Yes, I am extremely tired and have difficulties dealing with daily activities.”

Finally, they were asked how often or rarely they had experienced the following over the past four weeks: (a) “I had trouble falling asleep,” (b) “I used tranquilizers to sleep,” (c) “I used painkillers to sleep,” (d) “I napped during the day,” (e) “I woke up feeling rested,” (f) “I woke up during the night,” (g) “I slept through the night,” and (h) “I used sleep medication.” The response options were (1) “never,” (2) “1–3 times per month,” (3) “1–3 times per week,” (4) “4–6 times per week,” and (5) “daily.” Sleep problems (many and severe sleep problems) and using medication to fall asleep were considered regular if participants reported a frequency of 4–7 times per week.

#### 2.7. Health-Related Quality of Life

The Short-Form 36 Health Survey version 2 (SF-36v2) questionnaire comprises multiple-choice questions, and the reliability and validity of the instrument has been tested and confirmed [6,24]. The SF-36v2 is aggregated into eight dimensions: (1) physical function (PF, 10 questions), (2) role physical (RP, 4 questions), (3) bodily pain (BP, 2 questions), (4) general health (GH, 5 questions), (5) vitality (VT, 4 questions), (6) social functioning (SF, 2 questions), (7) role emotional (RE, 3 questions), and (8) mental health (MH, 5 questions) [25,26].

Together, the outcomes of four of the dimensions (PF + RP + BP + GH = 10 + 4 + 2 + 5 = 21 items) constitute the physical component summary (PCS), while the sum of the other four (VT + SF + RE + MH = 4 + 2 + 3 + 5 = 14 items) form the mental component summary

(MCS). The responses vary from “Yes, limited a lot”/“Yes, limited a little”/“No, not limited at all” to five-point (“None of the time” to “All the time”) or six-point (“Nothing” to “Very much”) verbal rating scales depending on the original source of the questions [24]. Standardized scores range from 0 to 100 for each dimension [6], with lower scores indicating worse health status (e.g., greater fatigue).

### 2.8. Statistical Analysis

Statistical analysis was conducted using SPSS 27 statistical program (IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY, USA: IBM Corp) [27]. Descriptive statistics (mean, standard deviation, and percentages) were used to present the sample’s demographic information and sleep status at pre-treatment and one-year follow-up. A paired *t*-test with bootstrapping was used to detect differences in pain severity between pre-treatment and one-year follow-up. A related-samples McNemar change test was used to detect the difference in sleep quality between pre-treatment and one-year follow-up. A paired *t*-test bootstrap was used to compare the differences in HRQOL. Differences in pain severity and differences in HRQOL were interpreted using Cohen’s *d* as small (0 to 0.2), medium (0.3 to 0.7), and large (>0.8). The level of significance established for this study was set at  $p < 0.05$ .

We estimated how well several factors predicted PCS and MCS at one-year follow-up by means of multiple linear regression (separate models were constructed for PCS and MCS). Five variables were introduced into each model to explore their connection to the outcome of the multidisciplinary pain rehabilitation intervention. After searching the literature for variables related to quality of life after multidisciplinary intervention, a decision was made to put these five variables in the regression models. The pre-treatment PCS score was entered into the model for PCS at one-year follow-up, and the pre-treatment MCS score was entered into the model for MCS at one-year follow-up. The sociodemographic variables of being female, having pursued higher education, and having children younger than 18 years of age were entered into both models, along with the variable having many or severe sleep problems at one-year follow-up.

## 3. Results

### 3.1. Characteristics of the Sample ( $n = 79$ )

In the end, the study comprised participants who completed both questionnaires ( $n = 79$ ). A nearly equal number of participants attended the intervention in Center 1 ( $n = 39$ ) and Center 2 ( $n = 36$ ), while  $n = 4$  participants attended Center 3. The respondents’ ages ranged from 20 to 68 years ( $M = 47.4$ ,  $SD = 11.9$  years). Most of the respondents were women (85%), 27% had completed higher education, and 36% were working (23% full time and 13% part time). Most of the participants were married or living with a partner (71%), and 57% had children younger than 18 years of age. The participants’ pre-treatment sociodemographic characteristics are listed in Table 1.

### 3.2. Pain Duration, Causes, and Pain Severity

The mean pain duration was 10.3 years (range 1–55 years). Before treatment, most of the participants ( $n = 72$ ) reported that they had received an explanation or diagnosis for their pain. The most frequently reported perceived causes were fibromyalgia ( $n = 39$ ), accidents ( $n = 35$ ), myalgia ( $n = 33$ ), and disc prolapse ( $n = 24$ ).

The participants rated their pre-treatment pain severity (0–10) higher than at one-year follow-up. The average self-reported pain severity decreased significantly from pre-treatment to one-year follow-up ( $p < 0.001$ ) (medium effect). In addition, there was a significant reduction in the self-reported estimates of the worst pain ( $p = 0.041$ ) and pain now (at the time of the survey) ( $p = 0.048$ ) from pre-treatment to one-year follow-up (small effect). The differences in self-reported pain severity are listed in Table 2.

**Table 1.** Description of sociodemographic variables ( $n = 79$ ).

| Variables                     | <i>n</i> | %  |
|-------------------------------|----------|----|
| <b>Gender</b>                 |          |    |
| Females                       | 67       | 85 |
| Males                         | 12       | 15 |
| <b>Age</b>                    |          |    |
| 43 years or less              | 27       | 34 |
| 44–54 years                   | 26       | 33 |
| 55 years or older             | 26       | 33 |
| <b>Education</b>              |          |    |
| Compulsory                    | 26       | 33 |
| Upper secondary               | 30       | 38 |
| Higher                        | 21       | 27 |
| <b>Marital status</b>         |          |    |
| Married/living with a partner | 56       | 71 |
| Engaged not living together   | 10       | 13 |
| Single/divorced/widowed       | 12       | 15 |
| <b>Employment status</b>      |          |    |
| Full time                     | 18       | 23 |
| Part time                     | 10       | 13 |
| Other                         | 54       | 64 |
| <b>Children &lt; 18 years</b> | 43       | 57 |

**Table 2.** Pain severity ( $n = 79$ ).

|               | Pre-Treatment<br><i>M (SD)</i> | One-Year Follow-Up<br><i>M (SD)</i> | <i>p</i> -Value * | Cohen <i>d</i> |
|---------------|--------------------------------|-------------------------------------|-------------------|----------------|
| Pain severity |                                |                                     |                   |                |
| Worst now     | 7.4 (1.78)                     | 6.8 (2.08)                          | <b>0.048</b>      | 0.23           |
| Worst         | 8.4 (1.56)                     | 7.9 (1.97)                          | <b>0.041</b>      | 0.23           |
| Least         | 4.5 (1.93)                     | 4.4 (2.01)                          | 0.517             | 0.07           |
| Average       | 6.6 (1.65)                     | 5.9 (1.83)                          | <b>&lt;0.001</b>  | 0.42           |

*M*, mean; *SD*, standard deviation. \* Values in bold indicate statistically significant differences.

### 3.3. Sleep Problems

Most of the participants reported disrupted sleep both before the treatment and at one-year follow-up. At pre-treatment, two of the most common reasons for having sleep problems were pain (89%) and psychological problems (49%). At one-year follow-up, the prevalence of these reasons did not change either for pain ( $p = 0.227$ ) or for psychological problems ( $p = 0.541$ ).

As shown in Table 3, the only significant difference in sleep was that more participants ( $n = 5$ , 6% vs.  $n = 14$ , 18%) slept through the night at one-year follow-up ( $p = 0.004$ ).

**Table 3.** Sleep quality ( $n = 79$ ).

| Sleep Quality   | Pre-Treatment<br><i>n (%)</i> | One-Year Follow-Up<br><i>n (%)</i> | <i>p</i> -Value * |
|---|-------------------------------|------------------------------------|-------------------|
| I had many or severe sleep problems<br>How often has the following happened<br>over the last month? | 38 (48.1)                     | 28 (35.4)                          | 0.078             |
| A. I had trouble falling asleep   | 30 (38.9)                     | 25 (32.4)                          | 0.383             |
| B. I used tranquilizers to sleep  | 19 (26.4)                     | 21 (29.2)                          | 0.791             |
| C. I used pain killers to sleep   | 23 (30.6)                     | 22 (29.3)                          | 1.00              |
| D. I napped during the day  | 11 (14.6)                     | 8 (10.6)                           | 0.581             |
| E. I woke up feeling rested   | 4 (5.3)                       | 5 (6.6)                            | 1.00              |
| F. I woke up during the night   | 49 (63.6)                     | 48 (62.3)                          | 1.00              |
| G. I slept through the night  | 5 (6.7)                       | 14 (18.7)                          | <b>0.004</b>      |
| H. I used sleep medication  | 11 (14.5)                     | 8 (10.5)                           | 0.453             |
| Effect of sleep problems on daytime energy  | 23 (32.3)                     | 16 (22.5)                          | 0.143             |

\* Values in bold indicate statistically significant differences.

### 3.4. Health-Related Quality of Life

At one-year follow-up, HRQOL had increased. The mean PCS scores were higher than before treatment ( $p < 0.001$ ), and the scores of all PCS subgroups increased significantly, with medium effect except for general health (small effect). The mean MCS score increased but not significantly ( $p = 0.123$ ). The scores of two of the MCS subgroups, VT ( $p = 0.011$ ) and SF ( $p = 0.038$ ), increased significantly, although those of the other two subgroups, RE ( $p = 0.117$ ) and MH ( $p = 0.060$ ), did not increase (Table 4).

**Table 4.** The mean difference in HRQOL pre-treatment and at one-year follow-up ( $n = 79$ ).

|                                  | <i>n</i> | Pre-Treatment<br><i>M (SD)</i> | One-Year<br>Follow-Up<br><i>M (SD)</i> | Pre/One-Year<br><i>p-Value *</i> | Cohen <i>d</i> |
|----------------------------------|----------|--------------------------------|--|----------------------------------|----------------|
| PCS (physical component summary) | 78       | 33.0 (6.2)                     | 36.2 (6.9)                             | <b>&lt;0.001</b>                 | 0.48           |
| PF (physical functioning)        | 79       | 37.5 (7.8)                     | 40.6 (7.8)                             | <b>0.002</b>                     | 0.35           |
| RP (role physical)               | 79       | 28.1 (6.4)                     | 32.3 (6.9)                             | <b>&lt;0.001</b>                 | 0.46           |
| BP (bodily pain)                 | 78       | 30.2 (5.7)                     | 34.3 (7.6)                             | <b>&lt;0.001</b>                 | 0.55           |
| GH (general health)              | 79       | 38.5 (8.4)                     | 40.5 (9.2)                             | <b>0.039</b>                     | 0.24           |
| MCS (mental component summary)   | 78       | 38.3 (10.8)                    | 40.1 (11.3)                            | 0.123                            | 0.18           |
| VT (vitality)                    | 78       | 34.4 (6.3)                     | 36.9(8.0)                              | <b>0.011</b>                     | 0.31           |
| SF (social functioning)          | 78       | 34.3 (9.05)                    | 36.6 (9.7)                             | <b>0.038</b>                     | 0.24           |
| RE (role emotional)              | 77       | 34.9 (12.8)                    | 37.5 (11.4)                            | 0.117                            | 0.17           |
| MH (mental health)               | 77       | 39.9 (9.9)                     | 42.1 (10.0)                            | 0.060                            | 0.22           |

*M*, mean; *SD*, standard deviation. \* Values in bold indicate statistically significant differences.

### 3.5. Predictors for Differences in MCS and PCS Scores

Two regression models are presented. The first model examined predictors of PCS, and the second model evaluated predictors for MCS at one-year follow-up, as shown in Table 5.

**Table 5.** Regression models 1 and 2 of potential predictors of PCS and MCS at one-year follow-up.

|                                      | <b>B</b> | 95% CI for <b>B</b> | <i>t</i> | <i>p-Value *</i> | Adjusted $R^2$ | <i>F</i> |
|--------------------------------------|----------|---------------------|----------|------------------|----------------|----------|
| Model 1 PCS at one-year follow-up    |          |                     |          |                  |                |          |
| (Constant)                           | 18.21    | 11.01               | 25.16    | 4.24             | 0.23           | 5.53     |
| Pre-treatment PCS                    | 0.49     | 0.29                | 0.72     | 4.29             | <b>0.001</b>   |          |
| Female                               | 2.33     | −0.98               | 5.35     | 1.19             | 0.131          |          |
| Children < 18 years                  | 0.27     | −2.45               | 2.97     | 0.19             | 0.838          |          |
| Higher education                     | 0.39     | −3.17               | 4.03     | 0.25             | 0.832          |          |
| Sleep problems at one-year follow-up | −2.08    | −4.77               | 0.39     | −1.40            | 0.111          |          |
| Model 2 MCS at one-year follow-up    |          |                     |          |                  |                |          |
| (Constant)                           | 28.60    | 19.23               | 38.71    | 6.18             | 0.46           | 14.23    |
| Pre-treatment MCS                    | 0.49     | 0.29                | 0.70     | 5.44             | <b>0.001</b>   |          |
| Female                               | −5.20    | −9.59               | −0.95    | −1.96            | <b>0.016</b>   |          |
| Children < 18 years                  | −4.04    | −7.57               | −0.36    | −2.08            | <b>0.040</b>   |          |
| Higher education                     | 4.71     | 0.21                | 9.29     | 2.16             | <b>0.045</b>   |          |
| Sleep problems at one-year follow-up | −6.20    | −10.49              | −2.18    | −3.02            | <b>0.006</b>   |          |

\* Values in bold indicate statistically significant differences.

Model 1 explained 23% of the variance (adjusted  $R^2 = 0.23$ ,  $p < 0.001$ ). The model included PCS at pre-treatment, being female, having pursued higher education, having children younger than 18 years of age, and having many or severe sleep problems at one-year follow-up (sleep problems at one-year follow-up). The only single variable that was a significant predictor for a higher PCS score at one-year follow-up was a higher PCS score at pre-treatment (Table 5).

Regression model 2 was also significant ( $p < 0.001$ ) and explained 46% of the variance (adjusted  $R^2 = 0.46$ ). The model included MCS at pre-treatment, being female, having

pursued higher education, having children younger than 18 years of age, and having sleep problems at one-year follow-up. The pre-treatment MCS was a significant predictor of the one-year follow-up MCS. Being a female, having children younger than 18 years of age, and having sleep problems at one-year follow-up predicted a lower MCS score at one-year follow-up, while having pursued higher education predicted a higher MCS score (Table 5).

#### 4. Discussion

The aim of the current study was to investigate the long-term effects of a multidisciplinary pain rehabilitation intervention offered by three main programs in Iceland by exploring and describing how individuals with chronic pain evaluate pain severity, sleep, and HRQOL pre-treatment and at one-year follow-up. The results indicated that the intervention for the participants decreased pain severity and increased HRQOL. Comparison of pre-and post-treatment scores revealed some small effect size with significant *p* values in pain reduction. This finding is in agreement with the systematic review of Salathé et al. on studies that examined pain intensity over 12 months (either with VAS or NRS) following multidisciplinary biopsychosocial rehabilitation. Comparison of pre-and posttreatment scores revealed either moderate to large effect size with significant *p* values in pain reduction. In assessing patients over a longer period, they showed that the reduction in pain intensity persisted for at least 24 months [10]. In the current study, although the pain severity scores decreased significantly, pain was still high (around 6), and pain did disturb sleep and HRQOL. A reduction of average pain was only 0.7 points over one-years' time, which would not be concluded as a clinically important difference for pain if compared to the results of Mease et al.'s study [28], which shows that the anchor-based minimum clinically important difference (MCID) for the BPI average pain and severity scores for fibromyalgia were 2.1 and 2.2. points, which correspond to 32.3% and 34.2% reduction from baseline in scores.

Multiple pain causes combined with a long duration of pain have been associated with poor quality of life [29]. In the current study, the participants' mean length of years in pain was 10.3 years (ranging from 1 to 55 years), and some of the participants had more than one perceived cause of pain. At one-year follow-up, HRQOL increased, especially the PCS. In Vartiainen et al.'s study, 81% experienced a major improvement, and 12% felt no change in HRQOL after a pain rehabilitation program [15]. A shorter duration of pain (<3 years) was positively associated with major improvement. In that same study, pain intensity was measured with VAS (0–100). There was no significant change in pain intensity at 12-month follow-up. HRQOL was measured with 15-D score, and the mean score of the patient in the total sample increased by 0.017 (from 0.711 to 0.728), which was a clinically important mean change.

In the current study, the mean score in all PCS subgroups significantly increased, which has been observed in other studies as well [11,12]. However, the mean scores increased significantly only in the VT and SF subgroups of MCS at one-year follow-up were during the previous month and whether their physical and emotional health interfered with communication with family and friends. Having less energy and being tired can be associated with having sleep problems; 32% of the participants in this study responded that their sleep problems affected their daytime energy, and 48% had many or severe sleep problems pre-treatment. In the second aim of the current study, we wanted to determine the factors that predicted the participants' HRQOL one year after the intervention.

Having sleep problems was one of the predictive variables of the MCS. Other findings indicate that chronic pain makes people more likely to suffer from sleep problems, depression, and other psychiatric disorders [30–32].

Sleep deprivation has been found to be a risk factor for chronic pain in a 17-year survey of women [33]. In the current study, self-reported reasons for sleep problems showed some interesting results. Concerning sleeping through the night, significant differences in sleep quality were found between pre-treatment and one-year follow-up, although only 18% of the respondents slept through the night at one-year follow-up. Although pain severity

decreased and HRQOL increased, pain and psychological troubles were still the main reasons for sleep problems. This is in accordance with other studies [30]. Even though the focus of the intervention has been on sleep, this raises the question of whether enough was done in the intervention to deal with sleep problems in connection with pain and psychological troubles.

In the current study, higher education predicted higher MCS scores, a finding that is supported by other studies [14,15,17,18]. The reasons for this finding are not clear, but it may be that higher education makes people more open to new ideas, or those with higher education are more likely or more able financially to engage in better self-care after completing pain rehabilitation programs.

One unexpected result was that being female predicted lower MCS scores in our study. Previous studies exploring multidisciplinary pain-treatment programs demonstrate that women improved more than men [11,14]. It is known that women usually participate in similar studies more than men [11,14,16], and women are more likely to report or experience pain and to seek treatment for their pain [1,4]. Having children younger than 18 years of age also predicted lower MCS score. No previous studies were found with similar results. Perhaps the responsibility of having young children at home affects women's mental health, energy, and sleep. Further studies are needed to explore these differences.

Although mental health issues were not the main focus of the current study, we found that participants who reported feeling anxious and depressed showed very little improvement following the intervention. It is well known that patients with severe pain are more likely to be depressed [30,34] and that depression is often unrecognized and untreated [31]. There is a bidirectional relationship between chronic pain and mental health conditions [1], and depression, anxiety, and negative beliefs about pain are all related to developing pain and having worse outcomes from chronic pain [1]. Patients with chronic pain should be examined with respect to their mental status [30], and more follow-up is needed after the completion of a pain rehabilitation intervention to deal with mental health problems.

## 5. Strengths and Limitations

A major strength of the current study is its examination of three similar pain rehabilitation programs in the country of Iceland. Albeit not identical, the standard programs shared similarities in the emphasis. An important finding was that the interventions were effective for the participants. It is possible that our findings apply to similar interventions in countries with larger populations and similar ethnic backgrounds, but further studies are needed.

We did not use the smallest difference scores in the domain of interest that chronic pain patients perceive beneficial (Minimal Clinical Important Difference (MCID) or Minimum Detectable Change (MDC)). The effect size of difference in pain severity and HRQOL was small to medium. Sleep quality did not change at one-year follow-up, and most participants had disrupted sleep because of pain. Their use of tranquilizers, pain killers, or sleep medication had not changed significantly. Use of medication for pain and sleep is another area that requires further study.

We did not use experimental design with control groups because it was not feasible to deny some of the participants treatment. This makes it impossible to make statements about direct cause and effect, which is a limitation of the study.

A main limitation of this study was the small number of participants and the composition of the subjects. Fewer men than women participated, which made it difficult to perform gender comparisons. The length of the standard program varied from four to seven weeks, which is a limitation. Furthermore, in two of the centers, there were some health disciplines not offered in the third program. When searching for an effect of an intervention of patients' pain, sleep, and health-related quality of life, it is easier to conclude about effect of the intervention if everyone participated in the same intervention in the same period for the same amount of time with exactly the same health disciplines. We did not

have access to waiting lists or list of incoming patients, so we could not anticipate potential subject recruitment. Additionally, this group of participants was complex: multiple causes of pain, length of pain, and varied backgrounds of the subjects may have contributed to a smaller treatment effect. Another limitation was that the intervention was scheduled for each individual, so the whole group did not necessarily attend the same number of hours in the standard program. It is possible that the intervention would have been more beneficial if subjects were treated earlier in their pain experience and with equivalent hours for the intervention. We did not evaluate the level of support each subject had, and support may be an important variable for future study. It is logical to assume that increased support would contribute to the long-term success of the intervention.

## 6. Conclusions

The results indicated that multidisciplinary pain rehabilitation program of three major centers in Iceland was effective in decreasing pain severity and increasing HRQOL one year after completing the intervention with a small to medium effect. PCS scores increased significantly, and the pre-treatment PCS score predicted the one-year follow-up PCS score. Patients should be examined with respect to their mental status and sleep problems, and it would be beneficial if they received professional support after completing the intervention. Pre-treatment MCS scores and having pursued higher education predicted higher MCS scores at one-year follow-up. However, having many or severe sleep problems, being a woman, and having children under 18 years of age predicted lower MCS scores at one-year follow-up. Sleep was still disturbed by pain and psychological problems at one-year follow-up, although more participants slept through the night than before treatment. These findings support the effectiveness of multidisciplinary rehabilitation programs for pain and will be used to guide further research in pain therapeutics.

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