



# **Chronic Pain, Health-Related Quality of Life, Chronic Pain-Related Health Care Utilization and Patient-Provider Communication in the Icelandic Population**

**Þorbjörg Jónsdóttir**

**Thesis for the degree of Philosophiae Doctor**

**Supervisor:**

Helga Jónsdóttir

**Advisors:**

Sigríður Gunnarsdóttir

Helga Jónsdóttir

**Doctoral committee:**

Eiríkur Línal

Harald Breivi

Thor Aspelund

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**Langvinnir verkir, heilsutengd lífsgæði, notkun á  
heilbrigðisþjónustu og samskipti við heilbrigðisstarfsmenn vegna  
langvinnra verkja meðal íslensks almennings**

**Þorbjörg Jónsdóttir**

**Ritgerð til doktorsgráðu**

**Umsjónarkennari:**

Helga Jónsdóttir

**Leiðbeinendur:**

Sigríður Gunnarsdóttir

Helga Jónsdóttir

**Doktorsnefnd:**

Eiríkur Líndal

Harald Breivik

Thor Aspelund

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## Ágrip

Langvinnir verkir trufla daglegt líf og hafa neikvæð áhrif á heilsutengd lífsgæði. Einstaklingar með langvinna verki eru meðal þeirra sem nota heilbrigðisþjónustu mest. Tengsl milli langvinnra verkja, heilsutengdra lífsgæða og notkunar á heilbrigðisþjónustu eru flókin og margþætt og aðeins hluti þeirra sem þjást af langvinnum verkjum nýta sér heilbrigðisþjónustu. Verkjatengd notkun á heilbrigðisþjónustu sem og reynsla einstaklinga af því að eiga samskipti við heilbrigðisstarfsmenn vegna langvinnra verkja getur tengst ýmsum félags- og lýðfræðilegum þáttum sem og eðli og alvarleika verkjanna.

Megintilgangur þessarar rannsóknar var að : 1 ) auka þekkingu á algengi og eðli langvinnra verkja meðal almennings á Íslandi ; 2 ) skoða hvernig langvinnir verkir hafa áhrif á daglegt líf og heilsutengd lífsgæði ; 3 ) kanna tengsl milli félags- og lýðfræðilegra breyta, verkjatengdra þátta, notkunar á heilbrigðisþjónustu vegna langvinnra verkja og reynslu einstaklinga með langvinna verki af samskiptum við heilbrigðisstarfsmenn.

**Aðferð:** Ritgerðin byggir á tveimur sjálfstæðum en tengdum rannsóknum. Rannsókn I var bæði eigindleg og megindleg, gerð til að þróa nýtt mælitæki til að meta aðgengi og notkun á heilbrigðisþjónustu (The Health Care Utilization questionnaire (HCU)) og til að þýða og meta próffræðilega eiginleika mælitækis sem mælir reynslu af samskiptum við heilbrigðisstarfsmenn (The Modified Patients' Perceived Involvement in Care Scale (M-PICS)). HCU mælitækið var þróað með því að setja saman lista af spurningum sem byggðu á fræðigreinum um efnið. Spurningar voru ræddar í rýnihóp átta einstaklinga með langvinna verki. Spurningalistinn var síðan sendur til tíu sérfræðinga í verkjameðferð sem gáfu ábendingar og álit. M-PICS mælitækið var þýtt úr ensku og íslensk útgáfa þess nefnd the Icelandic Perceived Involvement in Care Scale (I-PICS). Mælitækin tvö voru prófuð með því að leggja þau fyrir tvo hópa einstaklinga með langvinna verki, 1) 300 einstaklinga, á biðlista eftir því að fá sérhæfða endurhæfingu vegna langvinnra verkja og 2) 175 einstaklingar sem unnu líkamlega krefjandi störf sem algengt er að leiði til verkja.

Rannsókn II var megindleg þverskurðarrannsókn gerð á landsvísu þar sem þátttakendum voru sendir spurningalistar í pósti. Mælitækin tvö sem þróuð voru og prófuð í rannsókn I, auk tveggja annarra mælitækja *the Brief Pain Inventory (BPI)* og *the Short Form 36 health survey (SF-36)* voru notuð til að afla gagna um langvinna verki, áhrif verkja á daglegt líf og heilsutengd lífsgæði, notkun á heilbrigðisþjónustu vegna langvinnra verkja og reynslu

einstaklinga af samskiptum við heilbrigðisstarfsmenn. Úrtakið var slembiúrtak úr Þjóðskrá, 4500 einstaklingar á aldrinum 20-70 ára sem búsettir voru á Íslandi í apríl og maí 2011.

**Niðurstöður:** Svarhlutfall var 36,9% og 47,5 % þátttakenda voru með verki sem varað höfðu í 3 mánuði eða lengur. Rúmlega helmingur (53,2%) þeirra sem voru með langvinna verki höfðu leitað eftir heilbrigðisþjónustu vegna þeirra síðastliðna sex mánuði.

Niðurstöður benda til þess að mynstur og styrkur langvinnra verkja séu þeir þættir sem mestu ráða um það hversu mikil áhrif þeir hafa á daglegt líf og heilsutengd lífsgæði. Því tíðari og sárari sem verkirnir voru, því meiri áhrif höfðu þeir á daglegt líf og bæði líkamlega og sálræna þætti heilsutengdra lífsgæða, óháð kyni, aldri eða menntun. Niðurstöður sýna einnig að mynstur langvinnra verkja (stöðugir /daglegir) ásamt truflun þeirra á daglegu lífi og lífsgæðum eru þeir þættir sem hafa mest forspárgildi um það hvort einstaklingurinn nýti sér heilbrigðisþjónustu vegna þeirra eða ekki. Aðrar mikilvægar niðurstöður eru að þó að ekki væri tölfræðilega marktækur munur milli kynja á notkun heilbrigðisþjónustu vegna langvinnra verkja þá voru verkjatengdir áhrifabættir mismunandi hjá konum og körlum sem gáfu vísbendingar um að karlar fresti því lengur en konur að leita eftir heilbrigðisþjónustu vegna langvinnra verkja. Þegar litið er til reynslu af því að eiga samskipti við heilbrigðisstarfsmenn vegna langvinnra verkja sýna niðurstöður að hún tengist bæði lýðfræðilegum og verkjatengdum þáttum. Þessi tengsl eru þó mismunandi eftir því hvort litið er til reynslu einstaklingsins af hegðun heilbrigðisstarfsmannsins í samskiptunum eða mati hans á eigin hegðun. Mat einstaklingsins á eigin þátttöku í samskiptunum skýrðist aðallega lýðfræðilegum þáttum á meðan mat á viðmóti heilbrigðisstarfsmannsins tengdist líkamlegum þáttum heilsutengdra lífsgæða og ánægju hans með þjónustuna.

**Ályktanir:** Mikilvægt er að leggja áherslu á að hvetja fólk með langvinna verki til að nýta sér heilbrigðisþjónustu tímanlega, áður en verkirnir eru farnir að valda meiri háttar truflun daglegu lífi eða jafnvel líkamlegri fötlun. Þegar einstaklingur leitar til heilbrigðisþjónustunnar vegna verkja er mikilvægt að heilbrigðisstarfsmenn horfi ekki aðeins á verkina sjálfa, heldur á einstaklinginn með langvinna verki. Mikilvægt er að skoða hvernig langvinnir verkir hafa áhrif á líf einstaklingsins ásamt því að skoða hugmyndir hans um verkina og það hvernig hann tekst á við þá í daglegu lífi.

**Lykilorð:** Langvinnir verkir, einkenni verkja, lífsgæði, notkun á heilbrigðisþjónustu, samskipti.

## Abstract

Chronic pain interferes with daily life and affects health-related quality of life (HRQoL). Patients with chronic pain are among the most frequent users of health care. Relationships between chronic pain and HRQoL, as well as chronic pain and health care utilization, are complex and multifaceted and not all individuals with chronic pain consult health care providers. Chronic pain-related health care utilization as well as patients' perception of communication with health care providers about their chronic pain can be related to different socio-demographic, economic and pain-related factors.

The overall purpose of this thesis was to: 1) contribute to knowledge of the prevalence and characteristics of chronic pain in the general population of Iceland; 2) explore how chronic pain affects daily life and HRQoL; 3) study the relationship between socio-demographic, socioeconomic, pain-related variables, chronic pain-related health care utilization and perceived communication with health care providers.

**Method:** This thesis is based on two interdependent studies. Study I was a methodological study to develop an instrument to measure health care utilization and to translate and evaluate psychometric properties of an instrument to measure patient-provider pain-related communication. The Health Care Utilization questionnaire (HCU) was developed from a collection of questions based on previous research. Questions were then discussed in a focus group of eight individuals with chronic pain and a group of ten health care professionals, specialized in chronic pain were asked for comments and advice. The Modified Patients' Perceived Involvement in Care Scale (M-PICS) was translated into Icelandic, by the research team, to form the Icelandic Perceived Involvement in Care Scale (I-PICS). The two instruments were evaluated by distributing them to two samples of individuals experiencing pain, 1) 300 patients experiencing chronic pain and waiting for specialized treatment for pain in three rehabilitation clinics in Iceland and 2) 175 individuals working physically demanding jobs often associated with physical pain.

Study II was a quantitative population based cross-sectional postal survey. The two instruments developed in Study I were used along with two other instruments, the Brief Pain Inventory (BPI) and the Short Form 36 health survey (SF-36) to collect data on chronic pain, pain impact on daily life and HRQoL, chronic pain-related health care utilization and patient-provider communication. The study population consisted of adults aged 20-70 years living in

Iceland in April and May 2011. A sample of 4,500 individuals was randomly drawn from the Icelandic National Registry.

**Results:** The response rate was 36.9% and 47.5% of participants reported pain lasting for  $\geq 3$  months. Among participants reporting chronic pain, 53.2% had consulted a health care provider for the pain during the previous six months.

The results show that pain pattern and severity are the most important factors in the relationship between chronic pain and how chronic pain affects daily life and HRQoL. This accounts for both physical and mental domains of HRQoL, even when controlled for gender, age and education. These influences are stronger the more frequent and more severe the pain is. This study also shows that negative impact on daily life, pattern of pain and the physical domains of HRQoL, as well as perceived easy access to care, are important predictors for health care utilization for chronic pain. An important finding is that even though there was not a significant gender difference in chronic pain-related health care utilization; there were gender differences in pain-related predictors for health care utilization, indicating that men tend to postpone seeking health care for chronic pain longer than women. When it comes to patients' perception of patient-provider communication this study shows that this is related to both socio-demographic and pain-related factors. However, these relationships differ with regard to patients' perception of health care providers' behaviour, in the communication scenario, on the one hand, and one's own control and behaviour, on the other. Patients' perception of own behaviour in patient-provider communication is mostly explained by socio-demographic factors. Patients' perception of the providers' behaviour in the communication scenario is on the other hand explained by the physical components of HRQoL and with patients' satisfaction with health care provider.

**Conclusions:** Emphasis should be placed on encouraging people with chronic pain to seek health care early enough i.e., before the pain has managed to cause major interference with daily life and even physical disability. It is important to not only consider pain symptoms and severity when people seek care for pain but also the person with chronic pain. It is important to assess pain in a broad spectrum and consider different pain characteristics and their impact on daily life and HRQoL as well as the individual's understanding of pain and how they manage pain in daily life.

**Keywords:** Chronic pain, pain characteristics, quality of life, health care utilization, patient-provider communication.



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## **List of abbreviations**

List and explain all abbreviations used in the thesis.

BP	Bodily Pain (SF-36 scale)
BPI	Brief Pain Inventory
CRP	Chronic Regional Pain
CWP	Chronic Widespread Pain
GH	General Health (SF-36 scale)
HCU	Health Care Utilization Questionnaire
HCP	Health Care Provider
HCP-I	Health Care Provider Information (I-PICS factor)
HCP-FAC	Health Care Provider Facilitation (I-PICS factor)
I-PICS	Icelandic Patients' Perceived Involvement in Care Scale
MH	Mental Health (SF-36 scale)
M-PICS	Modified Patients' Perceived Involvement in Care Scale
PF	Physical Functioning (SF-36 scale)
PI	Patient Information (I-PICS factor)
PICS	Patients' Perceived Involvement in Care Scale
PDM	Patient Decision Making (I-PICS factor)
RE	Role Emotional (SF-36 scale)
RP	Role Physical (SF-36 scale)
SF	Social Functioning (SF-36 scale)
SF-36	Short Form 36 health survey
VT	Vitality (SF-36 scale)

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## **List of original papers**

This thesis is based on the following original publications:

- I. Jonsdottir, T., Jonsdottir, H., & Gunnarsdottir, S. (2013). Validation of the patients' perceived involvement in care scale among patients with chronic pain. *Scandinavian Journal of Caring Sciences*, 27(3), 740-749. doi:10.1111/j.1471-6712.2012.01066.x; 10.1111/j.1471-6712.2012.01066.x
- II. Jonsdottir, T., Aspelund, T., Jonsdottir, H., & Gunnarsdottir, S. (available online Oct 19<sup>th</sup> 2013). The relationship between chronic pain pattern, interference with life and health-related quality of life in a nationwide community sample. *Pain Management Nursing*, doi:http://dx.doi.org/10.1016/j.pmn.2013.07.005
- III. Jonsdottir, T., Jonsdottir, H., Lindal, E., Oskarsson, G. K., & Gunnarsdottir, S. (available online July 25<sup>th</sup> 2014). Predictors for chronic pain-related health care utilization: A cross-sectional nationwide study in Iceland. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*, doi:10.1111/hex.12245 [doi]
- IV. Chronic pain-related patient-provider communication: patients' perspective (Unsubmitted manuscript to be submitted to *Patient Education and Counseling*)

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## **Declaration of contribution**

### **Paper I**

Jonsdottir T., Gunnarsdottir and Jonsdottir H. designed the study. Jonsdottir T., Gunnarsdottir and Jonsdottir H. were responsible for obtaining approvals for the study and Jonsdottir T was responsible for collecting the data, with supervision from Gunnarsdottir and Jonsdottir H. and assistance from the University of Akureyri Research Centre. Jonsdottir T. and Gunnarsdottir were responsible for analyzing the data. Jonsdottir T. wrote the first draft of the paper, with supervision from Gunnarsdottir and Jonsdottir H. Gunnarsdottir and Jonsdottir H. critically revised the manuscript, edited it and gave approval of the final version of manuscript to be published.

### **Papers II - IV**

Jonsdottir T., Gunnarsdottir, Jonsdottir H. and Aspelund designed study II. Jonsdottir T., Gunnarsdottir and Jonsdottir H. were responsible for obtaining approvals for the study and Jonsdottir T was responsible for collecting the data, with supervision from Gunnarsdottir and Jonsdottir H. and assistance from the University of Akureyri Research Centre. Jonsdottir T. and Gunnarsdottir were responsible for analyzing the data with supervision from Aspelund and assistance from Oskarsson.

Jonsdottir T. wrote the first draft of the papers, with supervision from Gunnarsdottir and Jonsdottir H. as well as Lindal in paper III. Aspelund supervised with statistical work in paper II. Oskarsson participated in statistical work in paper III and IV. Jonsdottir T., Gunnarsdottir and Jonsdottir H. worked on final versions of all manuscripts. All authors gave final approval of the manuscripts to be published.



## **Introduction**

Chronic pain is a common cause of suffering, disability and impaired quality of life and has been described as the 'hidden epidemic' in many Western industrial countries (B. H. Smith et al., 2001; Thomsen, Sorensen, Sjogren, & Eriksen, 2002). Pain, especially when long lasting, interferes with daily life and affects health-related quality of life (HRQoL) and patients with chronic pain are among the most frequent users of health care (Gerdle, Bjork, Henriksson, & Bengtsson, 2004; Peolsson, Borsbo, & Gerdle, 2007). However, the relationship between chronic pain and HRQoL, as well as chronic pain and health care utilization, is complex and multifaceted (Bergman, Jacobsson, Herrstrom, & Petersson, 2004; Niv & Kreitler, 2001). Not all individuals who experience chronic pain seek health care. The reasons for this are not fully known, although several explanations have been proposed (Andersson, Ejlertsson, Leden, & Schersten, 1999a; Andersson, Ejlertsson, Leden, & Schersten, 1999b; Elliott, Smith, & Hannaford, 2004; Watkins, Wollan, Melton, & Yawn, 2006).

Pain is a personal and subjective experience, which makes patient-provider communication an essential part of the assessment and management of chronic pain (Cronje & Williamson, 2006; Travaline, Ruchinskas, & D'Alonzo, 2005). Therefore, patient-provider communication plays an important role in successful health care delivery and may be considered an indicator for quality of care (DeVoe, Wallace, & Fryer, 2009).

Nurses have a large responsibility during all stages of health care and play an important role in working with individuals experiencing chronic pain. By helping to explore the characteristics of pain and how it affects daily life, nurses can enable the person to develop an enhanced sense of predictability and control over the pain (Crowe et al., 2010). Nurses also have an important role in providing patient education and counselling to improve patients' understanding of their condition, and encourage them to assume greater responsibility for their own care (Courtenay & Carey, 2008; Mertens, Goossens, Verbunt, Koke, & Smeets, 2013). Nurses specialized in pain management also have important roles in counselling other nurses in order to improve pain management in general (Courtenay & Carey, 2008). Therefore, it is important that nurses should possess knowledge of the nature and development of chronic pain and investigate patients with chronic pain, and how people seek and perceive health service for chronic pain. Studying health care utilization in relation

to HRQoL and chronic pain, as well as patient-provider communication is, therefore, important in the field of nursing research.

The overall aim of this thesis was threefold, i.e. to: 1) contribute to the knowledge and understanding of the prevalence and characteristics of chronic pain in the general population of Iceland; 2) explore how chronic pain affects daily life and HRQoL; 3) study the relationship between socio-demographic, socioeconomic, pain-related variables and chronic pain-related health care utilization as well as perceived communication with health care providers.

## **Background**

### **Chronic pain**

#### **Definitions and prevalence**

Pain in general has been defined as ‘an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage’ (IASP, 1986). It is a necessary and accepted part of the human condition, a warning signal that all individuals can anticipate with certainty (Ghallagher, 1999). However, when pain persists over longer periods it usually loses its purpose as a warning signal. Pain that has lasted for more than 3-6 months is commonly considered to be chronic (McCaffery & Passero, 1999). Chronic pain has been defined as ‘pain that lasts beyond the usual course of acute or expected time of healing and may continue indefinitely’ (Allcock, Elkan, & Williams, 2007; McHugh & Thoms, 2001), or ‘a condition that has not responded to currently available treatment methods’ (Dysvik, Lindstrom, Eikeland, & Natvig, 2004; Dysvik, Natvig, Eikeland, & Brattberg, 2005; Gerstle, All, & Wallace, 2001). In this research, chronic pain is defined as: *continuous or intermittent discomfort that has persisted for three months or longer, or after the point at which healing would be expected to be complete or in a disease process in which healing will not occur* (McHugh & Thoms, 2001; B. H. Smith et al., 2001).

The epidemiology of chronic pain has been widely investigated. However, different studies have shown a wide range of prevalence, depending on differences in definitions,

sampling, and research methods (Takai, Yamamoto-Mitani, Okamoto, Koyama, & Honda, 2010; Turk & Okifuji, 2002; Verhaak, Kerssens, Dekker, Sorbi, & Bensing, 1998).

In a large scale multi-country random telephone interview survey in 15 European countries and Israel on prevalence, severity, treatment and impact of chronic pain among adults from the age of 18, the prevalence of chronic pain was reported to be 19% (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). The definition for chronic pain in the study was moderate or severe pain ( $\geq 5$  on a 0-10 scale), lasting more than 6 months, and experienced at least two times per week during the previous two months. Of those fulfilling all inclusion criteria, 46% reported constant pain, 54% intermittent pain, and 59% had suffered pain for two to fifteen years. The prevalence of chronic pain varied among the 16 participating countries from 12% in Spain to 30% in Norway (Breivik et al., 2006).

Breivik and colleagues defined chronic pain as pain lasting longer than 6 months. However, other investigators, using shorter time limits when defining chronic pain, have found its prevalence to be higher. In a cross-sectional postal survey, in the Grampian region of the UK, where chronic pain was defined as continuous or intermittent pain or discomfort for longer than 3 months, the prevalence was 46.5% (Elliott, Smith, Penny, Smith, & Chambers, 1999). In a Swedish cross-sectional population based study Gerdle et al. (2004) found the prevalence of chronic pain, lasting for more than three months, to be as high as 53.7 %. In these two studies discussed above, the time range for chronic pain was three months and severity limits were low, while Breivik and his colleagues defined chronic pain as lasting for longer than six months, and severity limits for inclusion were 5 or more on the 0-10 scale.

Watkins, Wollan, Melton, & Yawn (2008) criticize the variety of definitions used by investigators when studying the prevalence of chronic pain, not only in relation to duration, varying from  $>1$  to  $>6$  months, but also with regard to severity and frequency (pain pattern). Excluding people who do not experience pain most days or who do not have severe pain may lead to lower prevalence values. People with chronic recurrent or intermittent pain of mild or moderate severity are then excluded from prevalence values of chronic pain, even though they have pain that interferes with daily life and impairs their HRQoL. In their cross-sectional community based study, 8.5% of the participants reporting chronic pain for more than three months had pain less than 15 days per month, and had only "mild" pain but

reported, nevertheless, that their pain interfered with sleep or activities. This difference in definitions of chronic pain in terms of time, severity and pattern of pain, therefore, makes comparison between study results difficult.

Even though epidemiology of chronic pain has been widely investigated in many countries, limited research has been done on this subject in Iceland. Icelandic research based on data from the disability register of the Icelandic Social Insurance Administration (Tryggingastofnun), has shown that 33.9% of women and 16.6% of men receiving full-time disability benefits in December 2002 had chronic pain as a result of diseases of the musculoskeletal system (Thorlacius & Stefansson, 2004). Three years later this number had increased to 35.1% for women and 17.3% for men (Thorlacius, Stefansson, & Olafsson, 2007). However, the definitional time frame for chronic pain is not reported in those studies.

Gunnarsdottir, Ward, & Serlin, (2010) found prevalence of pain experienced for more than 3 months to be 30.6% among the general population of Iceland. Participants reported chronic pain of different locations and origins, with strain injuries resulting from work or sports activities, arthritis, mechanical problems (due to birth defects, slipped discs, etc), disease and accidents as the most commonly identified causes. In a population based study among Icelandic school children (aged 11-12 and 15-16 years) 20.6% of participants had recurrent back pain, weekly or more often (Kristjansdottir & Rhee, 2002).

From the description above it is clear that chronic pain is a common and important health problem, even though study results vary, depending on different definitions and research methods. In addition, when studying chronic pain other factors besides prevalence may be equally important to establish the scope of the problem. Some of these factors relate to temporal characteristics of pain, e.g. severity, location, spread, duration and pattern and their impact on peoples' lives (Tripp, VanDenKerkhof, & McAlister, 2006).

### **Impact on daily life and HRQoL**

Pain, especially of long duration, affects physical, emotional and psychosocial functioning and well-being of a person. These factors interact with sensory input and central-nervous-system processes to create the experience and subsequent report of pain (Baliki, Geha, Apkarian, & Chialvo, 2008; Turk & Okifuji, 1999). Pain is, therefore, not only a clinical sensory experience (duration, severity, and quality of pain), but is also something

that adversely affects the individual's everyday life and HRQoL (Turk & Okifuji, 1999). Living a life with chronic pain is not only about experiencing pain in a daily context, but also about managing the pain in the context of daily activities and routines, as well as managing everyday activities and routines in the context of pain (J. C. Richardson, Ong, & Sim, 2008). Pain affects HRQoL and HRQoL can affect the pain experience, expression and behaviour. A relatively small amount of nociception and physical pain can start a vicious circle of more pain, suffering, disability and poorer HRQoL (Baliki et al., 2008; Niv & Kreitler, 2001).

Health-related quality of life is a multidimensional concept described as the impact of health on an individual's ability to function and his or her perceived wellbeing in physical, social and psychological domains of life, (Leidy, Revicki, & Geneste, 1999; Naughton & Shumaker, 2003; Nordlund, Ekberg, & Kristenson, 2005; Revicki et al., 2000), as well as the ability to participate in meaningful activities within the family, workplace, and community (Vetter, 2007). The HRQoL concept goes beyond direct measures of population health measures, causes of death and life expectancy and although there is no universal definition HRQoL it is commonly divided into several domains. According to Naughton & Shumaker (2003) these domains include: 1) physical functioning, referring to individual's ability to perform daily life activities; 2) psychological functioning, indicating individual's emotional wellbeing; 3) social functioning and role activities, meaning individual's ability to maintain social roles and obligations at desired levels; and 4) the individual's overall life satisfaction, sense of personal wellbeing and perceptions of health status. Both Naughton & Shumaker (2003) and Tengland (2006) distinguish between health-related wellbeing and functioning or ability. Ability refers to being able to function physically and socially in the sociocultural environment. Wellbeing is on the other hand a subjective phenomenon, a personal feeling of being able to function physically and socially in the sociocultural environment and fulfilling personal goals and desires (Naughton & Shumaker, 2003; Tengland, 2006). Being able to stand, walk, talk, communicate and have relationship with others etc. are examples of function, while feeling vital, fit, strong, energetic, concentrated, calm and harmonious are examples of health-related wellbeing (Tengland, 2006). To summarize, HRQoL refers to an individual's evaluation of his or her functioning and well-being in different life domains. In this research HRQoL is defined as *an individual's perceptions of his or her own health status*

*as well as physical, psychosocial and emotional functioning and wellbeing, in relation to personal goals, expectations, standards, and concerns.*

Despite the close relationship between pain and HRQoL, pain is a phenomenon distinct from HRQoL (Niv & Kreitler, 2001). Studies show that pain interferes with general activities of daily life and sleep and has a significant adverse effect on most domains of HRQoL, primarily physical and emotional functioning and wellbeing (Lindal & Uden, 1989; Miaskowski, 2009; Naughton & Shumaker, 2003; Niv & Kreitler, 2001; Parish, 2009; Sprangers et al., 2000). The degree and kind of impact on HRQoL has been shown to depend on features of pain such as its duration, severity, spread (Bergman et al., 2004; Jamison, Fanciullo, McHugo, & Baird, 2007; Kolotylo & Broome, 2000; Lame, Peters, Vlaeyen, Kleef, & Patijn, 2005; Laursen, Bajaj, Olesen, Delmar, & Arendt-Nielsen, 2005; Peolsson et al., 2007) and pattern (Mullady et al., 2011).

In studies on the relationships between chronic pain and interference with daily life as well as HRQoL, different factors have been shown to be important. Some studies have reported interference with daily life and impaired HRQoL to be related to pain severity and the number of pain locations (spread) (Jamison et al., 2007; Lame et al., 2005; Laursen et al., 2005). However, the relationship between HRQoL impairment and pain severity alone has been shown to be weak (Lame et al., 2005). Some authors have found pain severity to be insignificant as a predictor for life interference, HRQoL impairment and disability (Kolotylo & Broome, 2000) and suggested that other factors often determine HRQoL impairment and an individual's need for treatment and advice in relation to chronic pain (B. H. Smith et al., 2001). An interactive relationship has been suggested between pain severity and pain spread (Peolsson et al., 2007) as well as between pain spread and HRQoL (Bergman et al., 2004). Peolsson et al. (2007) suggest that one possible explanation for the positive relationship between pain severity and number of pain locations could be that more severe pain not only increases the risk of chronic pain conditions, but also of spreading pain. Based on their findings, Peolsson and colleagues (2007) argue that a preventive perspective might be needed and that clinical rehabilitation requires a broad assessment of the spread of pain.

The urgency of a preventive perspective has been supported earlier by Bergman and colleagues (2004). They found HRQoL to be predictive for improvement of chronic pain or development of chronic regional pain (CRP) into chronic widespread pain (CWP). The



progress from CRP to CWP was, however, related to different dimensions of HRQoL. Pain spread significantly affected Vitality, Social Functioning, and Mental Health but not Physical Functioning. Based on the findings they suggested the mental dimension to be important in the understanding of widespread compared to regional pain syndromes. Bergman and colleagues (2004) also suggested that HRQoL not only is an outcome measure, but could also in itself be an explanatory variable for pain development over time.

According to previous research the relationship between chronic pain and its interference with daily life and HRQoL depends on several factors in the nature and characteristics of pain. However, study results differ when it comes to which of these characteristics are most important in this relationship. Figure 1 shows a hypothesized model of the relationships between variables considered important in the relationships between chronic pain and its impact on daily life and HRQoL, based on the reviewed research literature.

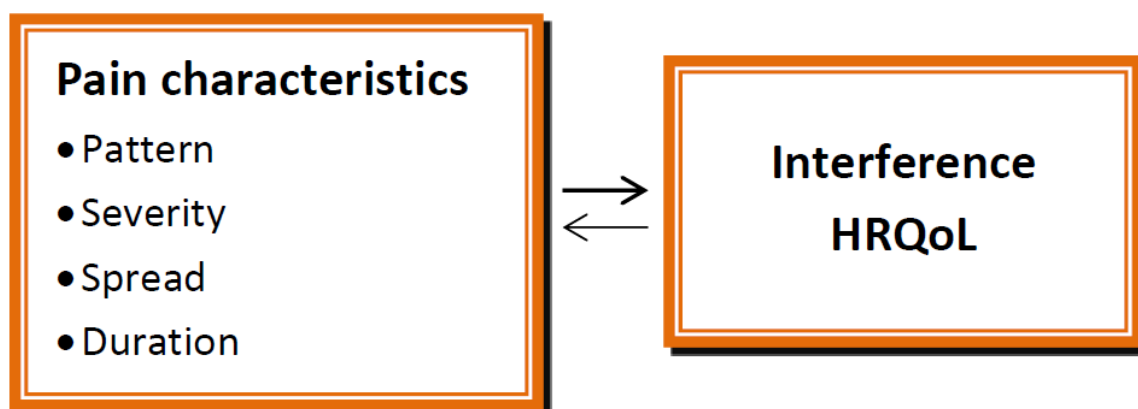


Figure 1 Variables considered to important in the relationships between chronic pain and its impact on daily life and HRQoL.

## Health care utilization

Even though pain is one of the most common causes for seeking health care and individuals with chronic pain are among the most frequent users of the health care system, earlier studies have shown that 25-60% of people with chronic pain do not consult health care for pain or discuss pain with health care providers (Andersson, Ejlertsson, Leden, & Schersten, 1999b; Elliott et al., 2004; Watkins et al., 2006), despite having considerable pain interfering with daily life (Watkins et al., 2006). There is also evidence that those who do not seek health care in spite of chronic pain report their HRQoL to be higher than those who

seek treatment for chronic pain, independent of pain severity (Elliott et al., 2004; Watkins et al., 2006).

Dixon-Woods et al. (2005) divide health care utilization into various processes including the recognition of symptoms and response to them, perception of the symptoms' seriousness, interference with daily life and perceived urgency for consulting health care. Knowledge about health issues and confidence in self-diagnosis and self-care, as well as awareness of available and appropriate health care resources, are also important factors in determining if and where to seek professional help. According to Dixon-Woods et al. (2005) all these factors may be differentially influenced by various socio-demographic characteristics.

Studying these relationships is, therefore, complex and requires a comprehensive methodological frame where the prediction of different variables is carefully and simultaneously investigated. The Behavioural Model of Health Service Use is a framework developed for viewing relationships between societal and individual variables as determinants of health care utilization (Figure 2). The model depicts the use of health care services as affected by three major components; 1) predisposing factors, including socio-demographic factors as well as health- and illness-beliefs (DeVoe et al., 2009; Ndao-Brumblay & Green, 2010) and perceived causes of symptoms (Dixon-Woods et al., 2005; Walker, Muller, & Grant, 2004); 2) enabling factors, as family income and economic as well as geographical access to care (Tripp et al., 2006; Vilhjalmsson, Jorundsdottir, Sigurdardottir, & Johannsdottir, 2001; Vilhjalmsson, 2005); and 3) need for care, referring to the individual's perceived and evaluated need (Andersen & Newman, 1973; Andersen, 1995; Bradley et al., 2002; Vilhjalmsson, 2005).

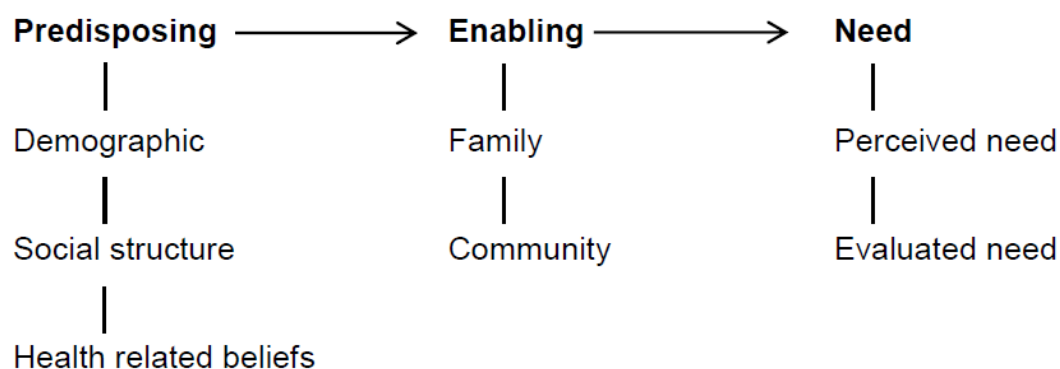


Figure 2 Outlines of The Behavioural Model of Health Service Use (Andersen, 1995).

Health care utilization and the choice of health care have been shown to be related to socio-demographic characteristics e.g. age, education and social status (Agerholm, Bruce, Ponce de Leon, & Burstrom, 2013; Cote, Cassidy, & Carroll, 2001; DeVoe et al., 2009) (Predisposing factors). Women have been demonstrated to be more frequent users of health care than men, both in general (Agerholm et al., 2013), as well as in relation to chronic pain (Rustoen, Wahl, Hanestad, Lerdal, Paul, & Miaskowski, 2004a; Walker et al., 2004). There is also evidence showing that health care utilization may be related to beliefs about health and illness as well as perceived causes and localization of symptoms (Dixon-Woods et al., 2005; Walker et al., 2004; Watkins et al., 2006).

Ronald Andersen (1995) argued that as well as considering people's experience of symptoms and whether or not they judge them to be of sufficient importance and magnitude to seek professional help, utilization of health care must also be studied in relation to access to the needed service (Enabling factors). Even though good quality health service and access to health care are considered basic human rights in Western countries, studies have shown a number of inequalities in health care access and underutilization of health care in spite of need (Cote et al., 2001; Forrest & Starfield, 1998; Lindal & Uden, 1989; Vilhjalmsson, 2005). However, societies with differences culture and at different stages of development may define access and need differently. Thus access limitations may affect people differently in different countries and societies (Gulzar, 1999).

Investigators have identified several limitations to health care access. Residence, long travel distance to health care and transportation problems are geographical factors that may act as limitations (Forrest & Starfield, 1998; Hausdorf et al., 2008; Sinay, 2002; Tripp et al., 2006; Vilhjalmsson, 2005). Financial factors relating to costs of seeking health care and insufficient health insurance can also be significant access limitations (Forrest & Starfield, 1998; Sinay, 2002; Song et al., 2010). Financial barriers, such as costs associated with health care, may act differently in various socioeconomic environments because of divergences in societal and health care systems. In societies with a highly socialized health care system and relatively low out of pocket service fees as in the Scandinavian countries, economic barriers are expected to be less important than in societies with health care systems funded by private insurance or private funds (Lindal & Uden, 1989). However, even in countries with

highly socialized health care systems, economic status can be a barrier to seeking health care (Agerholm et al., 2013).

Based on the literature discussed above, health care utilization may not only relate to the nature and severity of symptoms, but also to how symptoms influence daily life and HRQoL (Need for care), as well as being relevant to the individual's different socio-demographic and economic characteristics. Figure 3 shows a graphical representation of a hypothesized model of the relationships between these variables, based on the research literature. With regard to the Behavioural Model of Health Service Use, the socio-demographic variables and perceived causes of pain are shown as predisposing variables; access to health care and residency are shown as enabling variables; pain characteristics as perceived need variables and pain interference and HRQoL as evaluated need variables.

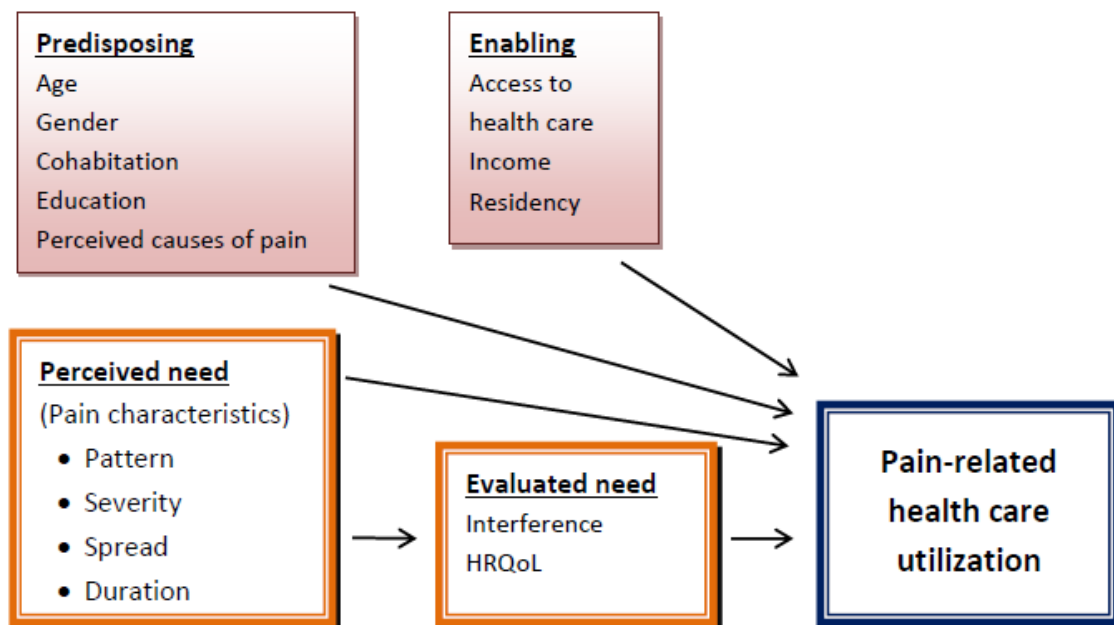


Figure 3. Hypothesized model of relationships between variables predicting chronic pain-related health care utilization.

## Patient-provider communication

Pain is a personal experience and must be communicated by the sufferer to health care providers for assessment, diagnosis, appropriate treatment and assessment of treatment outcome. In relation to chronic pain, effective communication is, therefore, an integral part of the patient-provider relationship, and indispensable to patients if they are to

make informed decisions and participate actively in treatment. Patient-provider communication involves verbal and non-verbal behaviours and includes the provider's ability to help the patient explore the implications of his/her symptoms or concerns, answer questions, give sound advice, inspire confidence, pass on relevant information to the patient and actively involve the patient in conversations about the pain and its treatment (Cronje & Williamson, 2006; C. Richardson, Adams, & Poole, 2006; Travaline et al., 2005). Therefore, good patient-provider communication plays a crucial role in successful health care delivery (DeVoe et al., 2009).

Communication has been defined as an iterative, multidimensional and dynamic process where the participant conveys and receives messages, based on his/her goals for the communication, as well as needs, beliefs, values, skills and emotions related to the topic. It occurs over time and does not only involve content, but also the relationship and attributes of the people involved (Feldman-Stewart & Brundage, 2009).

The patient's goal may be to seek treatment and cure, or explanations and advice about self-management. He or she may also have ideas or expectations about treatment options and their own participation in treatment decisions. All this is built on symptom experience, as well as the person's social and cultural context (Andersen, 1995; Dixon-Woods et al., 2005; Nielsen, Foster, Henman, & Strong, 2013), formal skills and educational background (Feldman-Stewart & Brundage, 2009). Patients' perception of patient-provider communication and satisfaction with care may be related to how well the consultation scenario meets their preferences and expectations (DeVoe et al., 2009). There is also evidence indicating that a patient's perception and interpretation of events during a meeting with a health care provider – and how far this meets his or her expectations – may have a greater impact on the patient's outcome and satisfaction than does the provider's actual conduct (M. Y. Smith, Winkel, Egert, Diaz-Wionczek, & DuHamel, 2006). Patients' desire for active involvement in making decisions regarding their care and treatment as well as their notions of own involvement in health care decisions have been shown to vary widely according to demographics and other individual patient characteristics (Frantsve & Kerns, 2007; Mira, Guilabert, Perez-Jover, & Lorenzo, 2012; S. K. Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). The higher the patients' educational level, the more likely they are to be

willing to participate in clinical decisions (Mira et al., 2012; Willems, De Maesschalck, Deveugele, Derese, & De Maeseneer, 2005).

The provider may also have his or her own personal ideas and expectations based on professional skills and experience, which may resemble or differ from the patient's goals and expectations (Feldman-Stewart & Brundage, 2009; Thornton, Powe, Roter, & Cooper, 2011). The provider's goals for the meeting with the patient should be to; 1) establish a good interpersonal patient centred relationship and open discussion; 2) promote information exchange by asking and answering questions, as well as actively listening to the patient, observing non-verbal messages and understanding the patient's perspective; 3) Encourage the patient to ask questions and participate in decision making (Makoul, 2001; M. Y. Smith et al., 2006).

Both patients' and providers' communication styles and expectations have been demonstrated to relate to patients' socio-demographic characteristics e.g. age, gender, education and economic status (DeVoe et al., 2009; S. K. Smith et al., 2009). There is evidence that participants' attitudes and expectations towards the patient-provider relationship and communication are related to disparities or similarities in their social backgrounds (Thornton et al., 2011; Villani & Mortensen, 2012). Patients with higher socioeconomic status and higher level of education tend to communicate more actively, are more forthcoming in asking questions and more involved in treatment decisions than patients from lower social and educational groups (Willems et al., 2005). Research has also shown providers to be less informative towards patients from a lower socioeconomic and educational background and to expect them to take less responsibility for their care than patients from higher social classes (Willems et al., 2005). According to Willems et al. (2005) patients from lower social classes are often disadvantaged because of providers' misperception of their ability to take part in the care process and their desire and need for information.

Patient-provider communication plays an important role in successful health care delivery and may be considered an indicator of quality of care (DeVoe et al., 2009). Studies have demonstrated that improved patient-provider communication about the nature of the pain problem and providers' attempts to gain better comprehension of patients' behaviours, as well as knowledge and understanding of pain, decreases cognitive barriers to pain

management among both providers and patients. This has also been shown to increase patient involvement in care and adherence to treatment, as well as its effectiveness (Cronje & Williamson, 2006; McIntosh & Shaw, 2003; Travaline et al., 2005). Some studies show that patients' perception of understanding and being engaged in own treatment leads to greater sense of control as well as better treatment adherence and outcome (Butow & Sharpe, 2013; Frosch & Kaplan, 1999). Other investigators have suggested that feeling supported and understood by the health care provider may be more important to some patients (Frantsve & Kerns, 2007; Lerman et al., 1990).

As seen from the literature discussed, patient-provider communication is influenced by patients' socio-demographics (DeVoe et al., 2009; S. K. Smith et al., 2009), as well as by symptoms and how they influence patients' daily life and HRQoL (DeVoe et al., 2009; Nielsen et al., 2013). Patients' perceived outcome and satisfaction with care has also been suggested to be related to how they perceive the patient-provider communication (Lerman et al., 1990; M. Y. Smith et al., 2006). Figure 4 shows a hypothesized model of relationships between patient-provider communication and variables in the predisposing, enabling and need factors according to Behavioural Model of Health Service Use. Besides these three factors, an outcome factor has been added to the model to investigate the relationship between patient-provider communication and perceived outcome as well as patients' satisfaction with health care provider.

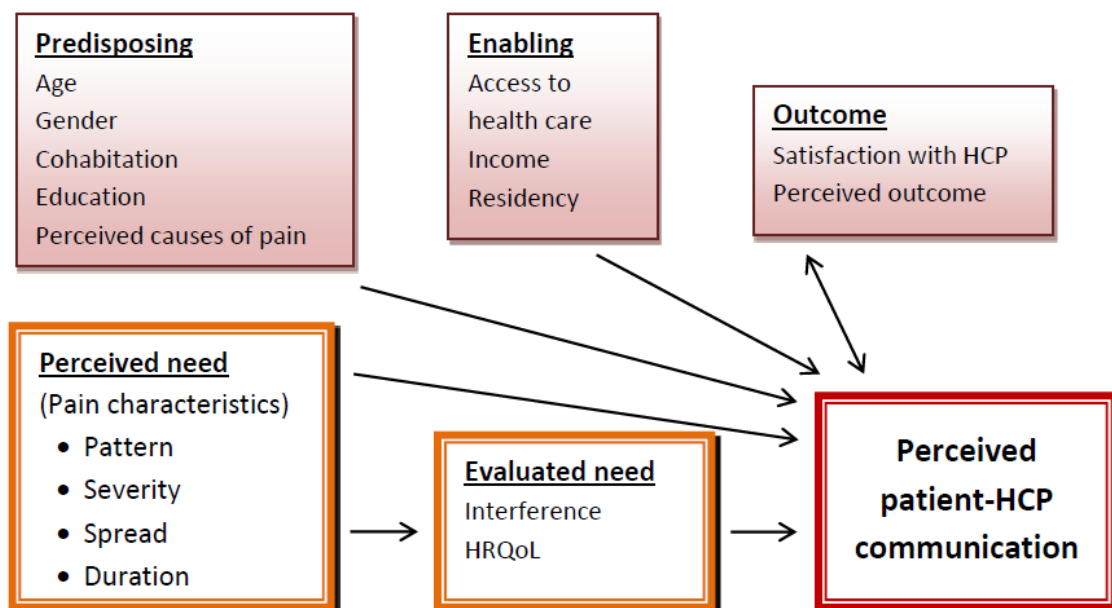


Figure 4. Hypothesized model of relationships between variables predicting patients' perception of patient-provider communication.





## **Context of the study**

This study is based on a cross-sectional sample from the total population in Iceland in April 2011. A sample of 4,500 individuals was randomly drawn by the University of Akureyri Research Centre from the Icelandic National Registry. The sample was stratified in relation to gender and residence to secure a proportional representation of men and women and people from all regions of the country.

The population of Iceland is limited to a narrow coastal belt, valleys and lowland plains, mostly in the south and south-west, with about two thirds of the people living in the capital area (Halldorsson, 2003). In January 2011 there were 318,452 inhabitants living in Iceland, of whom 203,159 were aged from 20 to 70 years; 102,798 men and 100,361 women and 8.5% of the inhabitants were non-Icelandic citizens. Seventy percent of the study population were urban residents (communities with > 15,000 inhabitants) and thirty percent rural (Statistics Iceland, e.d.)

The Icelandic health care system is publicly financed and the Ministry of Welfare is responsible for the administration of health services (Halldorsson, 2003). About 14% of health care is privately provided, mostly in dental and specialized medical care (The Boston Consulting Group, 2011). Iceland has a good quality of care compared to other European countries and a generally easy access to health care (The Boston Consulting Group, 2011). All persons who have been resident in Iceland for at least six months are entitled to health care and private health insurance hardly exists (Halldorsson, 2003; The Boston Consulting Group, 2011).

The Icelandic health care system is organized in 7 health care regions, with two main hospitals in Reykjavik and Akureyri where specialized care is provided, and smaller regional hospitals and health care centres in urban areas. Health care centres throughout the country provide primary care (Halldorsson, 2003). These are mostly run by the state, or by local communities, on the basis of a service contract with the state. In the Reykjavik area there are a few centres run by private initiatives with a service contract.

Medical specialists working in private practice in their own premises constitute an important aspect of the Icelandic health care system and most specialist outpatient care is provided by private practitioners working on their own or in rented premises (Halldorsson, 2003; The Boston Consulting Group, 2011). These private practitioners are the most rapidly

growing part of the health care sector with respect to volume. They work on a fee-for-service basis negotiated by the Icelandic medical association and the health authorities (Halldorsson, 2003; The Boston Consulting Group, 2011). There is no 'gatekeeping' system and patients are generally free to seek medical specialist care without referral (The Boston consulting group, 2011). Ambulatory care within hospital care, on the other hand, is less common than in neighbouring countries (Halldorsson, 2003).

The primary concern about the Icelandic health care system is the increasing out of pocket costs. Expenditures because of private medical specialist consultations have grown at the rate of 7% per annum, since 2008. Patients' share of this has increased by 13% and the governments share by 4%. Diagnostic specialties, anesthesiology, pediatrics and ophthalmology are the largest elements in this growth (The Boston consulting group, 2011). Approximately 35% of the total out-of-pocket payments by the patients are drug related, and around 20% constitute the patients' share of general practitioner (GP) services, medical specialist services and non-hospital physiotherapy (Vilhjalmsson, 2009). Household health expenditures increased by 29% in real terms between 1998 and 2006 (Vilhjalmsson, 2009).

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

Chronic pain interferes with daily life and affects the physical, emotional and psychosocial functioning and well-being of a person. A relatively small amount of nociception and physical pain can start a vicious circle of more pain, suffering, disability and poorer HRQoL (Baliki et al., 2008; Niv & Kreitler, 2001). Even though patients with chronic pain are among the most frequent users of health care, many individuals with chronic pain do not seek care despite extensive impairment of daily life and HRQoL (Gerdle et al., 2004; Peolsson et al., 2007). In studies on how chronic pain affects daily life and HRQoL different characteristics of pain, e.g. severity and spread, as well as an interaction of these characteristics have been shown to be important (Peolsson et al., 2007; B. H. Smith et al., 2001). The relationship between pain spread and HRQoL has also been suggested to be interactive (Bergman et al., 2004).

Multiple factors influence the relationships between chronic pain and health care utilization. Among them are socio-demographic, economic and pain-related factors (Andersen, 1995; Bedson, Mottram, Thomas, & Peat, 2007; Bradley et al., 2002; Dixon-Woods et al., 2005; Elliott et al., 2004). These factors have also been shown to be important in patients' experience of communicating chronic pain to health care providers, as well as their desire for and conceptualization of active involvement in treatment (DeVoe et al., 2009; Frantsve & Kerns, 2007; Mira et al., 2012; S. K. Smith et al., 2009).

It is important to identify salient factors in the relationship between chronic pain and its influence on daily life and HRQoL, as well as determining predictors for chronic pain-related health care utilization. This is imperative in order to be able to identify causes for delay in seeking needed treatment and to be able to direct treatment towards the most prominent factors in the relationship between chronic pain and HRQoL. Patient-provider communication combined with a reciprocal understanding between patients and providers plays an important role in the successful assessment and treatment of chronic pain as well as to patient participation in and adherence to care (DeVoe et al., 2009; Travaline et al., 2005). Therefore, it is also important to identify factors that influence and may interfere in patient-provider communication.

Few cross-sectional studies are available on the impact of chronic pain and its relationship to HRQoL in the Icelandic population. Research on chronic pain and health care

utilization in relation to chronic pain, as well as patients' perception of patient-provider communication, has not previously been carried out in the Icelandic population.

This study will provide new knowledge on the characteristics and prevalence of pain among people living in Iceland, the relationship between chronic pain and interference with daily life and HRQoL, chronic pain-related health care utilization as well as patients' perceived communication with health care providers in relation to chronic pain.

## **Overall purpose and specific aims**

The overall purpose of this thesis was to 1) develop and evaluate the psychometric properties of an instrument to assess patients' perception of patient-provider communication, and 2) to investigate the relationship between chronic pain, HRQoL and health care utilization as well as patient perceived patient-provider communication in a random stratified sample of Icelandic adults selected from the National Registry in Iceland.

The aims of the individual studies were as follows:

### **Study I**

1. To develop a questionnaire to investigate access to and use of health care for chronic pain.
2. To translate and test psychometric properties of a questionnaire to measure patients' perception of patient-provider chronic pain-related communication.

### **Study II**

3. To describe a) the prevalence and characteristics of chronic pain, including pattern, severity, spread and duration in the Icelandic population and b) to describe the relationship between pain pattern and pain impact on daily life and HRQoL.
4. To test what predicts health care utilization for chronic pain, and whether there are gender differences in those relationships.
5. To describe the relationship between perception of chronic pain-related communication with health care providers and socio-demographic factors, pain-related variables, HRQoL, perceived efficiency of care and satisfaction with health care provider.



## Methods

This thesis is based on two interdependent studies. Study I was a methodological study to a) develop an instrument to measure access to and health care utilization and b) to translate and test psychometric properties of the instrument Modified Patients' perceived Involvement in Care Scale (M-PICS) which was used to measure patient-provider pain-related communication (I-PICS). Study II was a population based cross-sectional study, where the two questionnaires developed in Study I and two other already well established and validated instruments were used to collect data on chronic pain, pain impact on daily life and HRQoL, chronic pain-related health care utilization and patient-provider communication. Table 1 presents an overview of the two studies, as well as resulting papers.

Table 1 Overview of studies, designs, methods, analysis and product

	<b>Study I</b>	<b>Study II</b>
Design	Methodological study	Cross-sectional descriptive postal survey
Method	Development of a questionnaire to investigate access to and use of health care for chronic pain Modification and translation of an instrument; psychometric validity and reliability testing (internal consistency)	Questionnaires
Analysis	Pearson's Correlations, t-test, ANOVA, Principal axis factor analysis with oblique rotation, Chronbach's $\alpha$	Descriptive statistics with frequencies, percentages, chi square tests, independent t-tests, Spearman's rho correlations, ANOVA, trend analysis, Mann-Whitney U test, hierarchical stepwise regression, backward stepwise logistic regression, linear regression
Product	<b>Paper 1</b> <i>Validation of Patients' Perceived Involvement in Care Scale among Patients with Chronic Non-Cancer Pain</i>	<b>Paper 2</b> <i>Chronic pain pattern and health-related quality of life</i> <b>Paper 3</b> <i>Predictors for chronic pain-related health care utilization</i> <b>Paper 4</b> <i>Chronic pain-related patient-provider communication: patients' perspective</i>

## **Instrument development and testing (Study I)**

**Study I** was a qualitative and quantitative study aimed at developing and testing two questionnaires to be used in the main study. This involved, on the one hand developing a questionnaire to measure access to and use of health care service. On the other hand there was a translation and validation of an instrument measuring patients' perception of patient-provider communication during a health care consultation, the Modified Patients' Perceived Involvement in Care Scale (M-PICS). The development of the Health Care Utilization Questionnaire (HCU), which was used in this study, has not yet been published. Paper I describes the psychometric testing of the Icelandic version of the M-PICS.

### **Development of the Health Care Utilization questionnaire**

In the first part of Study I, a focus group was utilized to develop a questionnaire to measure access to and use of health care service, the *Health care utilization questionnaire (HCU)*.

A pool of questions regarding access to health care, pain, chronic pain-related health care utilization and perceived outcome of health care were generated, based on the literature. Some questions were also drawn from published papers on similar subjects, with the permission of the authors (Breivik et al., 2006; Vilhjalmsson, 2005). The questionnaire was divided into two parts, where the first part dealt with access to and general use of health care and the second part focused on chronic pain and chronic pain-related health care utilization. Questions included in the first part (11 questions) related to: 1) whether people had used any kind of health care service during the past six months (yes/no) (one question); 2) what kind of health care people used when needed (one question); 3) how easy people perceived it to obtain an appointment for health care when needed (two questions); 4) how easy people perceived it to get away from work or home to visit a health care service (three questions); 5) what kind of health care, if any, was most economically difficult (two questions) and; 6) whether people had for any reason postponed or cancelled a needed health care visit, and if so, for what reason (two questions). All questions, except the first one were multiple-choice questions. The second part of the questionnaire included 18 questions on: 1) what people perceived to be the main cause of their pain (one question); 2) the pattern of pain (constant /daily /prevalent etc.) (one question); 3) whether pain had



interfered with employment (one question); 4) need for, access to and use of health care for pain especially (three questions); 5) reasons for not using health care (one question); 6) medications for pain (three questions); 7) use of complementary therapies (two questions); 8) type of health care and type of health care provider most consulted (four questions) and; 9) perceived outcome and satisfaction with the health care provider most consulted (two questions). All questions in part two were multiple-choice questions.

A convenience sample of eight individuals experiencing chronic non-cancer pain, were invited to participate in a focus group. Questions suitable for measuring study variables were explored in the focus group interview to find 'the right questions' to give a true picture of chronic pain patients' use of health care and their perception of consulting and communicating with health care providers, as well as how individuals perceive the effect of consulting health care professionals for pain (Bender, 2003; Holloway & Wheeler, 1997).

Based on results from the focus group, some revisions were made. Subsequently, ten health care professionals, specialized in chronic pain, were asked to comment on the draft of the questionnaire. Based on these comments from health care professionals, minor changes were made in the wording of a few questions and response options.

### **Translation and validation of Modified Patients' Perceived Involvement in Care Scale**

In the second part of this methodological study the validated English version of the *Modified Patients' Perceived Involvement in Care Scale (M-PICS)* (M. Y. Smith et al., 2006) was translated and evaluated for its appropriateness and application in an Icelandic sample of individuals seeking health care for chronic pain.

The Modified Perceived Involvement in Care Scale (M-PICS) was developed from an older version of the Perceived Involvement in Care Scale (PICS) (Lerman et al., 1990), designed to evaluate patients' perceptions of patient-provider communication. The original PICS scale (Lerman et al., 1990) is a 13-item scale based on statements describing the overt behaviour of patients and their provider that occurs during the health care visit as perceived by the patient. In this original version, response options for each statement are on a two-point agree/disagree scale, where disagree gives 0 points and agree gives 1 point. Higher

scores reflect a greater degree of perceived patient activity and involvement during the consultation.

In the modified version (M-PICS) (M. Y. Smith et al., 2006), six items reflecting patients' perceptions of health care providers' information-related behaviours and one pain specific item have been added to the original PICS scale (Lerman et al., 1990). The M-PICS, therefore, includes 20 statements about patients' perception of health care providers' information-related behaviours. The 20 items are divided into four subscales, reflecting specific behaviours related to patient-provider communication. The subscales are: 1) Health Care Provider Information (HCP-I) containing six items; 2) Patient Participation in Decision Making (PDM), containing four items; 3) Patient Information (PI) containing five items and; 4) Health Care Provider Facilitation (HCP-FAC) containing five items. Two of the scales (HCP-I and HCP-FAC) measure the patients' perception of the providers' openness and availability to discuss and share information and willingness to encourage the patient to be active in the information exchange process. The two other scales (PI and PDM) relate to the patients' incentive to ask questions and report symptoms, as well as patients' initiative to participate in test and treatment decisions. The response options are on a 5-point Likert scale ranging from 1 (Always) to 5 (Never), where participants rate the extent to which they agree with statements about how they perceive communication with their health care provider. One of the statements is pain specific, *"I talk about pain symptoms regardless of my health care provider's response"*.

The M-PICS is brief and easily scored, and permits simultaneous examination of patients' perceptions of their own communication behaviours, as well as those of their providers. The questionnaire has been found to be a valid and reliable instrument for assessing the dynamics of communication between health care providers and patients with cancer pain (M. Y. Smith et al., 2006). M-PICS has, however, not been validated before in a sample of patients with chronic non-cancer pain.

*Translation process.* Permission to translate and re-evaluate the M-PICS instrument was granted by the developer (personal e-mail communication with M.Y.Smith 27.05.2009 and 29.05.2009). Then the instrument was translated into Icelandic for this study, by the research team, to form the Icelandic Perceived Involvement in Care Scale (I-PICS). The Icelandic translation was back-translated into English, by a professional translator, unfamiliar

with the wording of the original English questionnaire (Jones, Lee, Phillips, Zhang, & Jaceldo, 2001). The back-translation proved to be almost completely identical to the original English version. In the Icelandic version, response options for each question are the same as in the English version of the M-PICS, a 5-point Likert scale ranging from one to five, where higher scores indicated higher endorsement of the construct in question.

### **Ethical considerations**

The study was approved by the Icelandic National Bioethics Committee (VSNb2009100005/03.7) and the Icelandic Data Protection Authority (S4363). Completing and returning the questionnaire was considered to imply informed consent for participation in the study.

### **Sample and data collection procedures for testing instruments**

For testing the psychometric properties of the instruments, subjects were recruited at two locations. First, postal questionnaires with a detailed information letter and a prepaid return envelope were sent to a non-random sample of 300 patients experiencing chronic pain and waiting for specialized treatment for pain in three rehabilitation clinics in Iceland (pain clinic sample). Two weeks after the questionnaire packages were sent out, a written reminder was sent to all participants, where those who had already responded were thanked and those who had not were encouraged to participate.

In the second phase, four companies, two in the food industry and two in community care, were visited to recruit participants (community sample). The study was verbally presented to workers by one of the researchers and those who volunteered to participate were provided with packages containing the questionnaire, a detailed information letter similar to that in phase one and a prepaid return envelope. Participants were given two choices of how to return the completed questionnaire i.e. either to leave it in a special box at their workplace, where it would be collected a week later, or to mail it to the research group.

In both phases participants were asked to evaluate the questionnaires; the perceived clarity of the instructions and the design of the questions, as well as the form for answering

the individual questions. This was done by asking participants to respond to four statements on how easy they found it to understand instructions, the wording of questions and response options, by marking on a five point Likert scale (don't agree at all – totally agree). Participants were also asked to answer how long it took them to fill in the questionnaire, whether there were questions they found difficult to understand or answer, to indicate if they felt that some questions were inappropriate for the research subject and, finally, whether they felt some questions were missing.

The mean answering time was 37 minutes (95% CI 34-40 minutes) and the majority of responders found it easy to understand instructions and questions and to answer the questions.

### **Statistical analysis**

The statistical software package SPSS (Version 20, SPSS inc. Chicago, IL, USA) was used to conduct statistical calculations and analysis. Descriptive statistics were used to describe the sample, both in terms of measured variables and socio-demographic characteristics. Pearson's Correlations, t-test and ANOVA were used to investigate relationships and differences between key variables. The Chi-square test was used to investigate similarities and differences between the two samples.

### **Validation of the Health Care Utilization Questionnaire**

Among aims for the development of the Health Care Utilization Questionnaire (HCU) was that of developing a scale to measure reasons for not using health care for chronic pain, despite pain interference with daily life and HRQoL and perceived need for care. However, the quality of data did not allow further development such as factor analysis or other psychometric testing methods. Therefore, the HCU instrument was not statistically validated and only descriptive data from part of the questionnaire were analysed in Study II. The variables used assessed, people's access to and use of health care, duration and characteristics of pain, pain-related health care utilization, satisfaction with the health care provider most consulted and perceived outcome from health care utilization for chronic pain.

## **Reliability and Construct Validity of the I-PICS**

**Reliability (Internal consistency)**, for I-PICS subscales and the whole I-PICS, was estimated by calculating Cronbach's alpha coefficients. Data from participants with no missing data on all I-PICS items were used for analysis of internal consistency.

**Construct validity of I-PICS** was examined by using a principal axis factor analysis with oblique rotation. Since it was expected that the I-PICS would consist of four subscales containing items similar to those on the M-PICS scale, a confirmatory analysis was performed, specifying four factors in congruence with the theoretical underpinnings of the questionnaire.

## **Chronic pain, HRQoL, Health Care Utilization and Patient-Provider Communication (Study II)**

**Study II** was a quantitative cross-sectional postal survey. The questionnaires developed in Study I, as well as two questionnaires already translated and validated in Icelandic samples, the Brief Pain Inventory (BPI) and the Short Form 36 health survey (SF-36) were used to measure the study variables.

### **Sample and data collection procedures**

The study population consisted of adults aged 20-70 years living in Iceland in April and May 2011. A sample of 4,500 individuals was randomly drawn from the Icelandic National Registry. The National Registry holds information about names, birth-dates, and addresses of all residents of Iceland. To secure a proportional sample of men and women and people from all regions of the country, the sample was stratified in relation to gender and residence.

Dillman's Tailored Design Method (Dillman, 2000) was used to guide the data collection with the exception that no introductory card was mailed prior to the mailing of the survey. A survey package was sent out to the sample, containing a letter with detailed information about the research, questionnaires and a prepaid envelope to send back filled questionnaires. Participants were given two options to complete the questionnaire, either

by filling out the questionnaire and sending by post or by logging into a website and answering online.

All subjects were asked to answer questions on access and use of health care service, HRQoL and whether they had felt pain during the past week. Respondents who reported pain during the past week were further asked to answer questions on duration of pain, location, severity, interference with different activities of daily life and pattern of pain, as well as what they believed to be the main cause of pain. Respondents reporting pain were also asked whether they had consulted health care for their pain in particular, during the past six months and if they had, they were requested to answer the I-PICS questionnaire on patient-provider communication.

Questionnaires were marked with an identifying number on the back-side in order to trace non-respondents while still ensuring privacy. To improve response rate, individuals who did not respond within two weeks were sent a reminder postcard and those who had not responded within four weeks received a new questionnaire along with an information letter.

### **Ethical considerations**

The study was approved by the Icelandic National Bioethics Committee (VSNb2011030002/03.7) and the Icelandic Data Protection Authority (S5197/2011). Completing and returning the questionnaire was considered to imply informed consent for participation in the study.

### **Measures and instruments**

The instruments consist of questionnaires on access to and use of health care (HCU), HRQoL, pain, patient-provider communication (I-PICS) and socio-demographic data.

#### ***Access to and use of health care***

The questionnaire developed in Study I, the Health Care Utilization questionnaire (HCU), was used to collect data on access to health service and (general as well as) pain-related health care utilization. This instrument was developed in Study I to measure access to and use of

health service, both general and for chronic pain. This instrument is divided into two sections where the first section contains questions on people's access to and use of health care in general, and the second part comprises questions on characteristics of pain, perceived causes of pain, pain interference with employment, need for and pain-related use health care, use of complementary therapies, satisfaction with health care provider most consulted and perceived outcome. In this thesis, the only analysed data collected by this instrument deal with characteristics and perceived causes of chronic pain, chronic pain-related health care utilization, satisfaction with health care provider and perceived outcome.

### ***Health-related quality of life***

A commercially available Icelandic translation of **The Short Form 36 health survey (SF-36v2)** (Ware, 2012) was used to measure HRQoL. This instrument covers issues related to HRQoL in relation to chronic pain as proposed in this study. It is the most frequently used and most widely accepted generic HRQoL measure in the world and has been suggested to be the most appropriate generic instrument for measuring perceived health status in various health conditions and diseases, (Beaton, Hogg-Johnson, & Bombardier, 1997; Vetter, 2007). The SF-36 version 2.0 (SF36v2) was introduced in 1996 to correct deficiencies identified in the original version (Ware, 2012). It has been translated and validated for use in more than 40 countries, including Iceland and more than 500 publications using translations or English-language adaptations have been published (Ware, 2012).

The SF-36 instrument is a 36-item self-rating questionnaire developed to assess some primary aspects of health-related quality of life, perceived health status in various health conditions and diseases (Beaton et al., 1997; Vetter, 2007). The instrument comprises 36 multiple choice questions, where responses vary from yes or no answers to a six-point rating scale (ordinal) (Beaton et al., 1997). Questions are designed to assess eight different health domains; 1) physical functioning (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). In addition, there is one single question asking respondents to compare their health now with how it was one year ago on a scale from 1-5 (Wallin & Raak, 2008; Ware, 2000). Each dimension is scored from 0 (worst) to 100 (best possible health

status) (Jenkinson, Stewart-Brown, Petersen, & Paice, 1999; Ware, 2000). The eight domains are hypothesized to form two distinct higher-order clusters due to the physical and mental health variance they share (Ware, 2012).

The reliability and validity of the instrument in relation to different health conditions has been widely tested and confirmed (Beaton et al., 1997; Ware, 2012). In the present study the internal consistency was acceptable for all scales, with Chronbach's alpha ranging from 0.78 (GH) to 0.94 (RP).

### ***Pain severity and interference with life***

The Icelandic version of the **Brief Pain Inventory** (BPI) was used to evaluate pain severity and interference with daily life (Cleeland & Ryan, 1994; Gunnarsdottir, Ward, & Serlin, 2008). Participants were also asked to answer questions about the duration and location of pain. The BPI contains three questions regarding pain severity during the past 24 hours, worst pain, least pain, and average pain. The fourth severity item measures pain at present. Participants rated their pain on a scale from 0 to 10, where 0 indicates no pain and 10 is the worst pain imaginable. Interference with life is evaluated by questions on the impact of pain on seven aspects of daily life; mood, walking ability, work, social activity, sleep and life enjoyment. Participants rate the impact of pain on these seven items on a scale from 0 to 10, anchored with "does not interfere" (0) and "completely interferes" (10) (Cleeland & Ryan, 1994). By taking the mean of the four severity items and the seven interference items separately, two composite scores, the Pain Severity Index and the Pain Interference Index are calculated (Zelman, Gore, Dukes, Tai, & Brandenburg, 2005).

The BPI is presented in a user-friendly format and easy to score. Although it has primarily been applied to assess cancer-related pain it has also been validated for chronic non-malignant pain (Tan et al., 2004; Gunnarsdottir et al., 2008). The BPI has been translated into Icelandic, validated in a general population sample of Icelandic adults experiencing pain of various origins and found to be both reliable and valid (Gunnarsdottir et al., 2008). In the present study the internal consistency was  $\alpha = 0.89$  for the severity scale and  $\alpha = 0.91$  for the interference scale. In the Icelandic version, the time reference used is the past week as opposed to the past 24 hours in the English version (Gunnarsdottir et al., 2008).



### ***Patient-provider communication***

The perception of patient-provider communication was measured by the Icelandic version of the Patients' Perceived Involvement in care Scale (I-PICS), translated and psychometrically tested in Study I for the purpose of this research project. I-PICS is a 19-item instrument measure consisting of four subscales measuring patients' perception of the health care provider's control over the communication, as well as own activity and involvement in information exchange and decision making. Response options for items in all subscales are on a 5-point Likert scale ranging from 1 (always) to 5 (never), where participants rate the extent to which they agree with statements about how they perceive communication with their health care provider. The subscales are: 1) 'Health Care Provider Information' (HCP-I) measuring the degree to which the provider is perceived as controlling the information-exchange process and openness to discuss symptoms and answer questions. In this scale, scores have been reversed to give this factor the same direction as the other factors. Higher scores indicate more perceived provider control over information exchange and less openness for discussions and answering questions, leading to less patient control over the information exchange; 2) 'HCP-Facilitation (HCP-FAC) measuring the patient's perception of encouragement from the provider to be active in asking questions and discussing their symptoms. In this factor higher scores indicate less perceived encouragement from provider leading to reduced patient control; 3) 'Patient Information' (PI) measuring the patient's perception of seeking or sharing information, higher scores indicating less perceived patient control over information exchange; and 4) 'Patient Decision Making (PDM) measuring the patient's perception of own participation in making decisions related to care, with higher scores indicating less perceived patient participation in care. For a more detailed description of the instrument and the developing process see Paper I.

### ***Perceived outcome and satisfaction with health care provider***

Perceived outcome and satisfaction with health care provider were measured by two questions from the HCU. Participants who reported having used health care for chronic pain in the previous six months were asked; 1) how well health care had met their needs for pain treatment (0-4 Likert scale, 0=very badly, 4=very well) and 2) to respond to the statement, 'I

*am satisfied with the health care provider, I have mostly consulted for the past 6 months'* ( 6 point scale, 0=Don't agree at all, 5=Very much agree).

### ***Perceived causes of pain***

One question from the HCU was used to measure perception of main causes of pain. Participants were asked to mark on a list of 18 possible causes what they perceived to be the main cause of their pain. Among possible causes included were, rheumatism, fibromyalgia, myalgia/wear and tear, old trauma, heart- and circulatory problems, gastro- intestinal problems, migraine, unknown causes or other causes.

### ***Socio-demographic characteristics***

The socio-demographic data collected were gender, age, marital status, education, occupation and residency (urban /rural).

### **Data analysis**

Questionnaires returned by post were scanned. Scanned data from returned paper questionnaires were analysed using SPSS for Windows (version 20.0, SPSS inc. Chicago, IL, USA), as well as data from participants who had chosen to log into a website and answer electronically. Descriptive statistics were used to present the sample's demographic characteristics, access to and use of health care and HRQoL, pain-related variables, chronic pain-related health care utilization, patient-provider communication and perceived outcome as well as satisfaction with health care provider.

In Paper II (The relationship between chronic pain pattern, interference with life and health-related quality of life in a nationwide community sample) predictors of interference with life and HRQoL (SF-36 scores) (Figure 5) were calculated by means of a hierarchical stepwise regression analysis, in which the predictors of interest; pattern, severity and spread of pain were entered in steps one to three and controlled for demographic variables (gender, age, education) by entering them in the final fourth step.

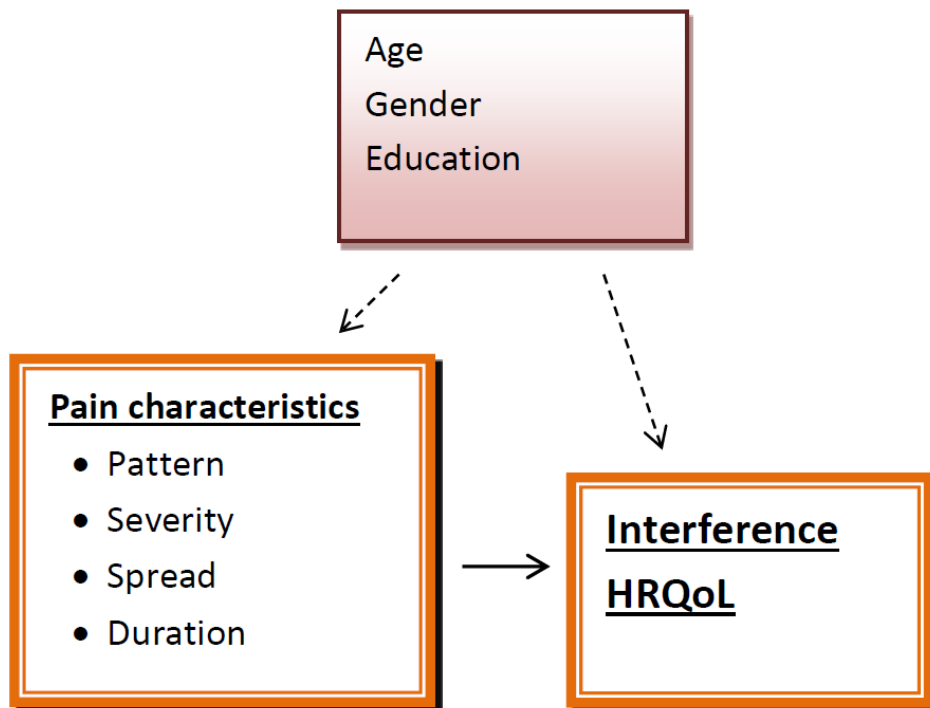


Figure 5. Variables in the hypothesized model, included in hierarchical stepwise regression analysis to investigate relationships between chronic pain pattern interference with life and HRQoL.

In Paper III (Predictors for chronic pain-related health care utilization: A cross-sectional nationwide study in Iceland) descriptive statistics were used to present the sample's characteristics as means of demographic and pain-related variables included in the Predisposing, Enabling, and Need factors, according to the Behavioural Model of Health Service Use (Andersen & Newman, 1973; Andersen, 1995) (Figure 6). The relationship between individual variables and health care utilization was examined with t-tests and chi-square. Series of backward stepwise logistic regression analysis were used to calculate conditional relationships between variables in the Predisposing, Enabling, and Need factors and the chronic pain-related health care utilization.

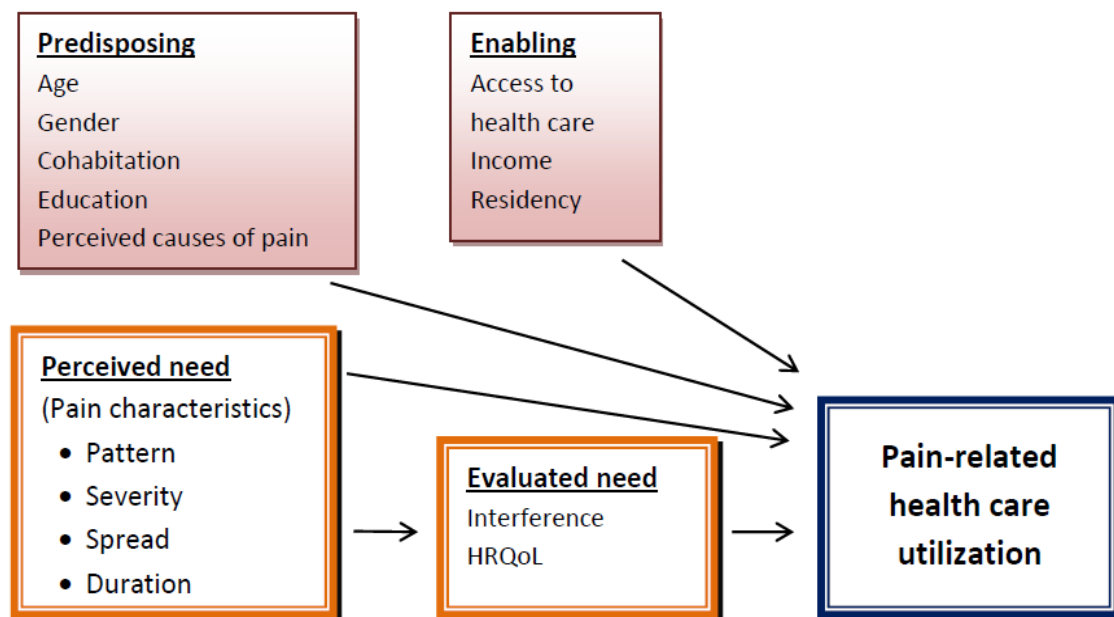


Figure 6. Variables included in bivariate analyses (t-test and Chi-square) to assess independent effect of variables in the Predisposing, Enabling, and Need factors on pain-related health care utilization.

In Paper IV (Patients' Perception of chronic pain-related patient-provider communication), the sample's characteristics were described as means of variables included in the Predisposing, Enabling and Need factors with the help of the Behavioural Model of Health Service Use (Andersen & Newman, 1973; Andersen, 1995). Besides these three factors, an outcome factor was added to the model to investigate the relationship between patient-provider communication and perceived outcome as well as patients' satisfaction with health care provider (Figure 7). Individual relationships between all variables in each of the Predisposing, Enabling, Need and Outcome factors, and each of the I-PICS factors were examined by means of a Spearman's rho correlation and Mann-Whitney U test (non categorical variables, gender and cohabitation status). Series of linear regression analysis were then used to calculate conditional relationships between each of the I-PICS scales and independent variables included in each of the Predisposing, Enabling, Need and Outcome factors, which were independently related to I-PICS factors.

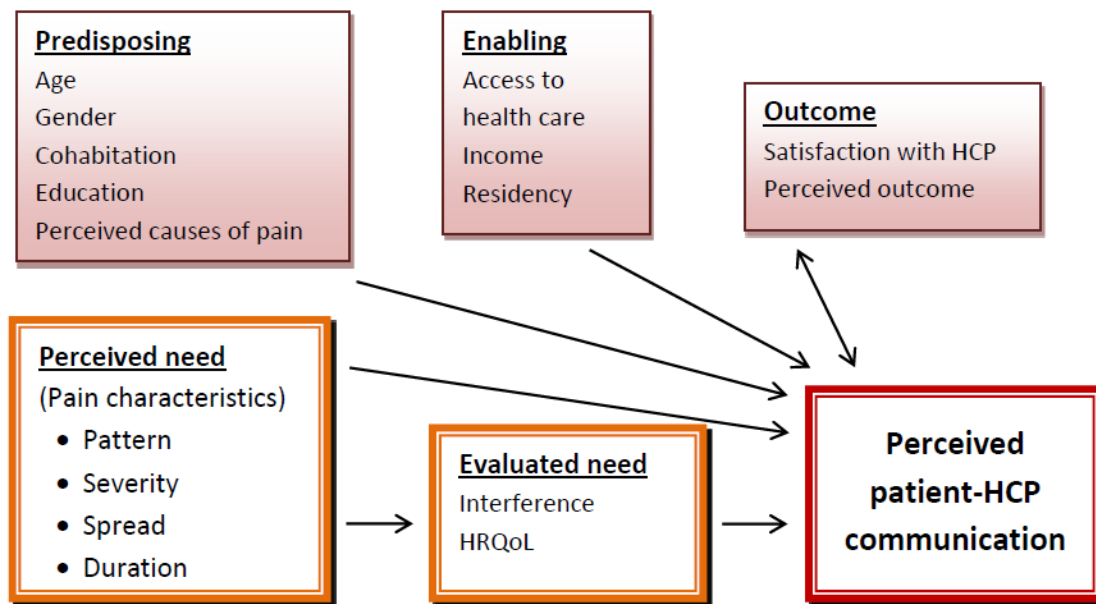


Figure 7. Variables included in Spearman's correlation and Mann\_Whitney U test (non categorical variables, gender and cohabitaion status) for testing Individual relationships between all variables in each of the Predisposing, Enabling, Need and Outcome factors, and each of the I-PICS factors.



## **Findings**

### **Instrument development and testing (Study I)**

The aim of study I was to develop a questionnaire to investigate access to and use of health care for chronic pain (HCU), and to translate and test a questionnaire to measure patients' perception of patient-provider chronic pain-related communication (I-PICS). Two samples of people with experience of chronic pain were used to test the questionnaires.

### **Response rate**

Out of 300 questionnaires sent in Phase one to patients waiting for chronic pain treatment (pain clinic sample) 90 were completed and four were returned as recipients could not be found, making the response rate 30.4%. In Phase two (community sample), 175 questionnaires were distributed and receivers who had experienced pain for  $\geq 3$  months were asked to answer. Out of these, 59 were completed, yielding a 33.7% response rate. The total response rate for both phases was therefore 31.6%.

### **Validation of the Health Care Utilization Questionnaire (HCU)**

As described earlier the quality of the data did not allow psychometric testing or further development of the HCU questionnaire. Therefore, the HCU was not statistically validated.

### **Translation and validation of the I-PICS (Paper I)**

**Construct validity of I-PICS** was examined by using a principal axis factor analysis with oblique rotation. Since it was expected that the I-PICS would consist of four subscales containing items similar to those on the M-PICS scale, a confirmatory analysis was performed, specifying four factors in congruence with the theoretical underpinnings of the questionnaire. Four factors accounted for 61.31% of the variance. Most items loaded on same factors in the new I-PICS as they had been in the M-PICS. However, four items loaded more strongly on a different factor in the I-PICS than they had done in the M-PICS. A

comparison of the factor structure and Cronbach's alpha of I-PICS and M-PICS, as well as the original PICS and a shortened version of M-PICS, is presented in Table 6 in Paper I.

The factor structure of the new I-PICS instrument is as follows:

*Factor 1.* The first factor, labelled "Health Care Provider Information" (HCP-I) measures the degree to which the health care provider is perceived as controlling the information exchange process. It contained five of the six original HCP-I items from M-PICS.

*Factor 2.* The second factor, labelled "Patient Information"(PI) measures to what extent the patient sought or shared information with his or her health care provider. It comprised four of five items included in the original PI factor.

*Factor 3.* The third factor, labelled "HCP-Facilitation" (HCP-FAC) measures patients' perceived encouragement to raise questions and discuss their symptoms with their health care provider. It contained four items. These were three of five items loading on the HCP-FAC factor in the M-PICS, and one item in addition: "My HCP asks me what I believe is causing my medical symptoms", which has moved from the PI factor in the original M-PICS.

*Factor 4.* The fourth and final factor, "Patient Decision Making" (PDM), measures the patient's perceived participation in decision making during the health care visit. It included six items. These were all four PDM items from the M-PICS, as well as two items previously belonging to the HCP-FAC factor, (Table 3). For a more detailed description see Paper 1.

One item, "My health care provider gives me a complete explanation for my medical symptoms or treatment" did not load decisively on one factor. Rather, the loadings were highly split between two factors, factor 1 and factor 2 and item-factor correlation was similar on three factors (Table 4 in Paper I). Based on this and on previous findings showing that this item has moved between factors in earlier studies of the instrument as seen in Table 6 in Paper I, it was decided to eliminate the item from further analysis.

Factor 1 (HCP-I) and factor 3 (HCP-FAC) measure the provider's control in the communication process whilst factor 2 (PI) and factor 4 (PDM) measure the patient's activity in controlling the communication process and participating in decisions around tests and treatment. The instrument may, therefore, be divided into two parts where the first measures the patient's perception of the providers appearance and the second measures the patient's perception of own activity.



### **Reliability (Internal consistency)**

Reliability for I-PICS subscales and the whole I-PICS was estimated by calculating Cronbach's alpha coefficients. Out of the 149 participants, 127 had no missing data on all I-PICS items. Data from these 127 participants were used for analysis of internal consistency. Internal consistency (Cronbach's alpha) for the total scale was 0.86. Internal consistency for the I-PICS subscales was 0.86 for the HCP-I scale (five items), 0.83 for the PI scale (four items), 0.83 for the HCP-FAC scale (four items) and 0.74 for the PDM scale (six items).

### **Scores on the I-PICS**

The mean scores (SD) for each of the I-PICS subscales (0-5 scale), were as follows: on the HCP-I scale, 1.98 (0.89) (higher scores indicating more HCP control); on the PI scale, 2.40 (0.90) (higher scores indicating less patient control); on the HCP-FAC scale, 3.03 (1.13) (higher scores indicating less provider-facilitation) and on the PDM scale 3.18 (0.77) (higher scores indicating less participation in decision making).

### **Chronic Pain, HRQoL, Health care Utilization and Patient-Provider Communication (Study II)**

The main emphasis in the results of Study II was on: 1) investigating the relationships between the pain pattern and impact on the individual's daily life and HRQoL; 2) chronic pain-related health care utilization in relation to socio-demographic, socio-economic and pain-related variables; and 3) patients' perception of patient-provider communication in relation to socio-demographic, socio-economic and pain-related variables as well as outcome variables.

### **Response Rate**

Out of the 4,500 mailed questionnaires, 191 were undelivered due to unknown address and 10 were reported unable to fill in the questionnaire. Out of the 4299 remaining questionnaires a total of 1,629 were returned (37.9%), 63 were uncompleted and 1,586

completed, thus the response rate was 36.9%. In light of the response rate, the original sample was scrutinized in the search for possible explanations as to the lack of interest in responding. Out of the 4,500 individuals in the original sample, 564 were found to have had non-Icelandic names and might therefore possibly be of non-Icelandic origin. Out of these 564 individuals, only 43 (8.6%) returned a completed questionnaire. The inclusion process of participants is outlined in Figure 1 in Paper II.

### **Sample Characteristics**

The majority of respondents were women (56.5%) and the mean age was 46.2 years (SD=13.99, range 20 – 70 years; women 45.3, men 47.3). Respondents were significantly older than non-respondents (mean age of non-participants 38.7,  $p<0.005$ ) and response rate was lower among younger individuals and men. The majority of respondents were married or cohabitating and 27.3% had less than 11 years of school education. Socio-demographic characteristics (gender, age groups, marital status, education) are listed in Paper II Table 1.

### **Prevalence and Characteristics of Chronic Pain**

Out of the respondents, 55.0% ( $n=873$ ) reported that they had had some kind of pain during the previous week (other than minor headache, sprain, toothache or menstrual pain). The vast majority of those who answered the question on duration of pain ( $n=816$ ), or 92.4% ( $n=754$ ) had experienced pain for three months or longer. Only 7.6% ( $n=62$ ) reported pain for less than three months.

The total prevalence of chronic pain ( $\geq 3$  months) was 47.5% ( $n=754$ ) with a mean duration of 9.3 years (Median= 6.0 years, SD= 10.0). The most frequently reported causes of chronic pain were myalgia /wear and tear ( $n=380$ , 50.4%), old trauma (after accidents and surgeries) ( $n=237$ , 31.4%), rheumatism (including RA and OA) ( $n=234$ , 31.0%) gastrointestinal problems ( $n=97$ , 12.9%) and fibromyalgia ( $n=90$ , 11.9%). Forty-eight (6.4%) reported that causes of pain were unknown. The most frequently reported location of chronic pain was the low back (61.5%). Other frequently reported locations were shoulders (45.6%), neck (35.7%), head (32.4%) and knee (35.7%). A minority (12%) reported one location of pain. One third (30.2%) reported pain in two to three locations and another third

(32.1%) four to six locations. A quarter of respondents reported more than six locations of chronic pain (25.6%).

Participants with chronic pain reported significantly more frequent pain than those with pain for less than three months  $\chi^2(3, n=764) = 38.93, p < 0.001$ . One third (31.9%) of those reporting pain for  $\geq 3$  months reported constant pain and only 18.9% reported periodic pain. Among those reporting pain for less than 3 months periodic (52.5%) and frequent intermittent (22%) were the most common pain patterns.

The mean value for the pain severity index for participants reporting having had pain for  $\geq 3$  months was 3.4 (SD = 1.84) and 2.32 (SD = 1.63) for those who reported pain duration to be less than 3 months ( $t=4.58; p < 0.001$ ). The pain interference index was also higher among people reporting chronic pain or 2.6 (SD = 2.20), compared to 1.6 (SD = 1.70) for people reporting shorter duration than 3 months ( $t=3.29; p=0.001$ ).

There was a significant positive relationship between duration of chronic pain and number of pain locations ( $r=0.186; p < 0.001$ ). There was also a significant positive relationship between chronic pain spread and severity ( $r=0.366; p < 0.001$ ) as well as between spread and interference ( $r=0.329; p < 0.001$ ). When comparing groups the mean score on the pain severity index was 2.7 (SD=1.52) among those reporting local pain, compared to 2.9 (SD=1.65) for two to three locations, 3.4 (SD=1.65) for four to six locations and 4.6 (SD=1.83) among those with more widespread pain ( $>6$  locations) ( $F=41.13; df=3; p < 0.001$ ). The mean for pain interference index was 1.7 (SD=1.63) among those reporting local pain, compared to 2.1 (SD=1.98) for two to three locations, 2.7 (SD=2.05) for four to six locations and 3.8 (SD=2.42) among those with more widespread pain ( $>6$  locations) ( $F=27.23; df=3; p < 0.001$ ). Post hoc Bonferroni revealed significant differences ( $p < 0.001$ ) between all groups for both pain severity and pain interference, except between local pain and 2-3 locations.

Among participants reporting chronic pain there was a positive relationship between pain duration and severity ( $r=0.136; p < 0.001$ ) but not between duration and pain interference. There was a negative relationship between chronic pain duration and the physical component of HRQoL (PF, RP, BP, GH SF-36 scores) ( $r=-0.142; p < 0.001$ ). However, the relationship between duration of chronic pain and pain interference and mental component of HRQoL (VT, SF, RE, MH SF-36 scores) was non-significant.

## Health-Related Quality of Life

Individuals with chronic pain had lower measures of all SF-36 subscales (poorer HRQoL) than both those with pain for less than 3 months and those with no pain (Table 2 in Paper II). There was a significant difference in physical component score of SF-36 between those reporting pain for <3 months and  $\geq 3$  months ( $t=-3.77$ ;  $p<0.001$ ), but not for mental components ( $t=-1.72$ ;  $p=0.087$ ). Participants with no pain had significantly higher scores in both physical ( $t=18.74$ ;  $p<0.001$ ) and mental component ( $t=3.67$ ;  $p<0.001$ ), as well as in all SF-36 scales, than those reporting pain during the past week ( $p<0.001$ ).

## General use of health care

Of all the 1586 responders 74.4% reported having visited a health care service the previous six months. There was a significant difference in the use of general health care between those reporting no pain the previous week and those reporting chronic pain ( $t=-7.74$ ;  $p<0.001$ ). Most respondents in both groups reported easy access to health care when needed and most of them reported that the usual kind of service was the family physician or nearest health care centre. However, participants with chronic pain more often consulted medical specialists than did those reporting no pain the previous week  $\chi^2(3, n=1048) = 5.8$ ,  $p=0.016$ .

When those who had visited health care the previous six months were asked what kind of, if any, cost related to visiting health care (consultation fees, travelling costs, loss of salaries related to absence from work, other expenses or 'does not influence my budget') and treatment (pharmaceutical expenses, aid, diet, other expenses or 'does not influence my budget'), was economically difficult, high consultation fees and medication cost were the most often reported by both those who had chronic pain and those without pain. However, there was a difference in this matter between the groups. A higher proportion of those with chronic pain reported high consultation fees to be the most difficult cost compared to those with no pain (64.1% vs. 60.8%;  $z=1.103$ ;  $p=0.271$ ) even though the difference was non-significant. There was also a higher proportion of those with chronic pain that reported pharmaceutical expenses as the most economically difficult treatment cost compared to those with no pain and the difference was significant (68.2% vs. 59.5%;  $z=2.959$ ;  $p=0.003$ ).

Participants with no pain were significantly more likely to report that health care costs were not economically difficult; this applied both to costs related to visiting health care (27.8% vs. 17,7%;  $z=3.449$ ;  $p<0.001$ ) and to treatment costs (30.5% vs. 17.4%;  $z=4.993$ ;  $p<0.001$ ).

## Chronic Pain Pattern, Interference with Life and Health-Related Quality of Life (Paper II)

The pain pattern was significantly related to pain severity ( $r=-0.549$ ;  $p<0.001$ ), interference ( $r=-0.424$ ;  $p<0.001$ ), spread ( $r=-0.357$ ;  $p<0.001$ ) and both physical ( $r=0.431$ ;  $p<0.001$ ) and mental ( $r=0.130$ ;  $p=0.001$ ) scores of HRQoL as well as all subdomains ( $p<0.001$ ). There was a linear trend in these relationships; the more frequent and constant the pattern of chronic pain, the more severe the pain was, the more interference with life and lower values in all HRQoL subdomains (Table 2). Pain pattern was not related to duration of chronic pain.

Table 2. Scores of Pain Interference, Severity, Spread and HRQoL (SF-36 scales) in Relation to Pain Pattern. ANOVA and Linear Trend Analyses.

	<u>Constant</u>	<u>Daily intermittent</u>	<u>Frequent intermittent</u>	<u>Periodic</u>	<u>Linear trend p-value</u>
Interference (0-10)	3.75 (2.46)	3.05 (2.00)	1.99 (1.78)	1.23 (1.30)	<.001
Severity (0-10)	4.67 (1.86)	3.82 (1.44)	2.68 (1.24)	2.12 (1.32)	<.001
Spread (number of pain locations)	6.51 (4.23)	5.45 (3.35)	3.72 (2.42)	3.41 (2.56)	<.001
Physical Functioning	67.56 (26.98)	74.83 (22.65)	86.34 (15.99)	87.44 (19.83)	<.001
Role Physical	57.28 (30.55)	61.65 (30.65)	78.45 (24.36)	84.67 (20.50)	<.001
Bodily Pain	40.56 (23.19)	46.34 (20.33)	64.16 (15.96)	72.79 (18.47)	<.001
General Health	55.88 (25.00)	58.63 (21.14)	67.83 (20.14)	72.03 (17.92)	<.001
Vitality	43.47 (21.21)	49.45 (20.12)	55.28 (19.67)	61.05 (17.05)	<.001
Social Functioning	68.28 (27.92)	76.26 (23.95)	79.45 (21.64)	84.75 (18.49)	<.001
Role Emotional	72,58 (29.49)	80,41 (24.42)	83,27 (20.49)	87,98 (17.02)	<.001
Mental Health	68.12 (21.21)	74.49 (18.55)	73.06 (18.08)	77.96 (15.65)	<.001
Physical Component Score	39.80 (11.64)	41.40 (10.07)	49.31 (7.76)	51.01 (7.77)	<.001
Mental Component Score	45.73 (13.52)	49.47 (11.49)	47.89 (11.01)	50.73 (9.27)	=.001

Predictors of interference with life and HRQoL (SF-36 scores) were calculated by means of a hierarchical stepwise regression analysis, in which the predictors of interest; pattern, severity and spread of pain were entered in steps one to three and controlled for demographic variables (gender, age, education) by entering them in the final fourth step.

In the first step, pattern variables (constant, daily intermittent and frequent intermittent vs. periodic pain) were entered. All patterns were significantly related to interference with life and all domains of HRQoL. However, the strength of this relationship differed between domains, being higher in the physical domains (PF, RP, BP and GH) compared to the mental domains (VT, SF, RE and MH). The coefficient for variance of pain pattern alone, in relation to interference with life and different HRQoL domains was lowest in MH ( $R^2=.035$ ) and RE ( $R^2=.054$ ) and highest in BP ( $R^2=.296$ ) and RP ( $R^2=.147$ ) (Table 6 in Paper II).

When pain severity and spread were added into the regression model in steps 2 and 3, severity turned out to be the most important factor for interference with life. Pattern alone explained 18.3% of variance; pain pattern and pain severity explained 44.4% and after adding spread of pain, the variance explained was 45.2%. Severity was also the strongest predictor in most HRQoL domains. Spread of pain did not add much to the variance explained except for the VT and RE domains where spread was a stronger predictor than severity.

In step 4 demographic variables (gender, age, education) were entered. None of these variables had a significant influence on the relationship between interference with life and any of the research variables (pattern, severity, spread). Gender was not significantly related to any of the HRQoL domains. Age was significantly related to PF, VT and MH, even though the relationship was weak. Education was not significantly related to any domains except PF and RE.

Pain pattern was a significant predictor for the relationship between chronic pain and interference with life ( $R^2=0.183$ ;  $p<0.001$ ) as well as in all HRQoL domains ( $R^2=0.035-0.296$ ;  $p<0.001$ ). However, this became mostly non-significant when pain severity was added to the regression model in step 2. Severity was significantly related to both interference with life score ( $R^2=0.437$ ;  $p<0.001$ ) and all HRQoL domains ( $R^2=0.063-0.494$ ;  $p<0.001$ ). Spread of pain added little to the variance of research variables, except for the VT and RE domains. Severity

was the strongest predictor for pain interference with daily life as well as for most domains of HRQoL. See tables 5 and 6 in paper II. Figure 8 shows a graphical overview over relationships between pain characteristics and interference with daily life as well as HRQoL in this study.

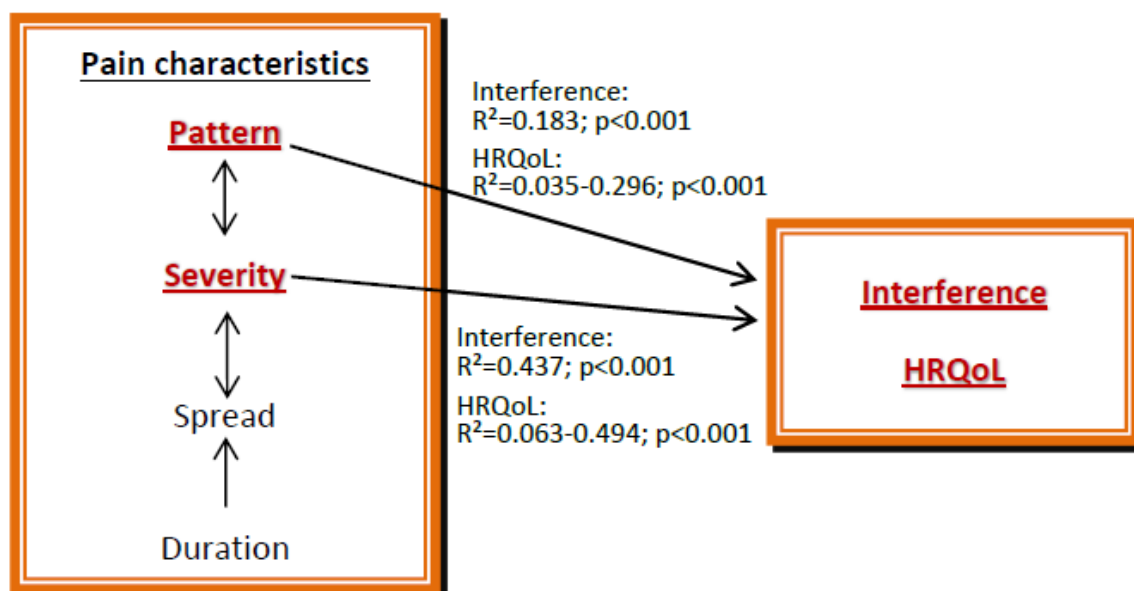


Figure 8. Interrelationships between different pain characteristics and pain interference on daily life and HRQoL

### Chronic Pain-Related Health Care Utilization (paper III)

Of those reporting chronic pain, 18% reported much or very much need for health care for their pain while 16.6% perceived no need for pain-related health care. More than half (59%) reported having easy or very easy access to health care, while 8.5% reported bad or very bad access to pain-related care. Little more than half (53.2%) had consulted a health care provider for the pain during the previous six months. Among participants reporting chronic pain 28.6% reported that they had postponed or cancelled needed health care service during the past six months and 28.4% of them reported high health care costs to be the main reason. Individuals reporting chronic pain who had consulted health care for their pain had significantly more severe and widespread pain, higher pain interference with life and poorer HRQoL than those who had not consulted health care for chronic pain (table 3).

Those who had consulted care for chronic pain also had more frequent pain  $\chi^2(3, N=672) = 49.69, p=0.016$  than those who had not consulted care for their pain.

Table 3. Comparison of Pain Interference, Severity, Spread and HRQoL (SF-36) scores between participants who had consulted Health Care for Chronic Pain previous six months and those who had not.

	Consulted health care for chronic pain past six months	Not consulted health care for chronic pain past six months	Sign (t-test)
Severity (0-10)	3.92 (1.82)	2.79 (1.66)	<.001
Spread (number of pain locations)	5.47 (3.75)	4.20 (3.25)	<.001
Interference (0-10)	3.39 (2.33)	1.65 (1.54)	<.001
Physical Functioning	72.42 (25.77)	85.67 (18.84)	<.001
Role Physical	61.15 (30.43)	80.70 (23.53)	<.001
Bodily Pain	46.19 (23.14)	65.94 (19.40)	<.001
General Health	56.84 (22.80)	70.51 (19.46)	<.001
Vitality	47.47 (21.73)	56.48 (18.54)	<.001
Social Functioning	71.14 (26.48)	82.40 (20.56)	<.001
Role Emotional	75.93 (26.48)	85.32 (19.67)	<.001
Mental Health	70.83 (20.53)	74.35 (17.70)	=.016
Physical Component Score	41.55 (10.77)	49.77 (8.73)	<.001
Mental Component Score	47.00 (12.74)	49.06 (10.61)	=.021

Chronic pain-related health care utilization was independently related to age ( $r=0.075$ ;  $p=0.049$ ) education ( $r=-.081$ ;  $p=0.036$ ), some perceived causes of pain, perceived access to health care, as well as all pain characteristics (severity ( $r=0.305$ ;  $p<0.001$ ), spread ( $r=0.186$ ;  $p<0.001$ ), pattern ( $r=0.249$ ;  $r<0.001$ ), pain interference ( $r=0.394$ ;  $p<0.001$ )) and both physical ( $r=-0.378$ ;  $p<0.001$ ) and mental ( $r=-0.086$ ;  $p=0.025$ ) components of HRQoL. People with basic education as their final education degree (<11 years) were more likely to have sought health care for chronic pain than people with longer education. Those who were retired or unemployed and people receiving disability benefits were more likely to have consulted health care for their pain during the previous six months than other occupational groups. Health care utilization was positively related to rheumatism, fibromyalgia and old trauma, as well as heart- and circulatory problems as perceived causes of pain. The same applied to perceived easy /very easy access to care when needed for pain. Chronic pain-related use of health care was significantly related to more pain severity and interference, more widespread pain and lower scores on both physical and mental



components of HRQoL (Table 3), as well as to more frequent pain ( $\chi^2(3, N=672) = 49.69, p < 0.001$ ). Chronic pain-related health care utilization was not related to gender, marital status, family income or residency, (see more detail in Paper III).

Variables in each factor, (predisposing, enabling, need), were tested against the outcome variable (pain-related health care use) in separate Backward Stepwise logistic regression models, to test their predictability in relation to other variables in the same factor.

#### *Predisposing factors*

There was a positive significant relationship with occupation and perceived causes of pain. Individuals who were retired, unemployed or on disability benefits, were more likely to have consulted health care for their pain during the previous six months (OR=2.055,  $p=0.024$ ). Pain-related consultations were significantly related to some, but not all perceived causes of pain. The most prominent predictor among perceived causes of pain (belief variables) were problems in the heart and circulatory system as a cause of pain (OR 3.587,  $p=0.013$ ). Other predictive perceived causes of pain were Rheumatism (OR 1.874,  $p=0.001$ ) and old trauma (OR 1.494,  $p=0.028$ ).

#### *Enabling factors*

Participants who reported easy access to health care when needed, were more likely to have consulted health care for their pain during the past six months than those reporting neither good nor bad or bad access (OR=1.888,  $p < 0.001$ ). Use of pain-related health care was not related to family income or place of residence (urban or rural) (Table 2 in Paper III).

#### *Need for care*

Pain-related use of health care was significantly linked to pain interference, pattern and the physical component of HRQoL (Table 2 in Paper III). Pain severity and spread (number of painful locations) did not predict consultations for pain nor did the mental component of HRQoL.

In the next step, variables included in the predisposing, enabling, and need factors in the adjusted Behavioural Model of Health Service Use were tested against the outcome variable (health care utilization), by analysing them in three block backward stepwise Logistic

Regression model with age and gender as control variables. One enabling and three need variables were found to be significant predictors. These predictors were; perceived easy access (enabling), pain interference with life, pain pattern and physical component of HRQoL (need factor). Participants who reported easy access to care were more likely to have consulted health care for their pain during the previous six months than those reporting neither good nor bad, or bad access to care (OR 3.199,  $p < 0.001$ ). The only predictor among pain characteristics was pattern. Participants who reported daily pain were significantly more likely to have consulted health care for pain in the past six months, than those reporting intermittent or periodic pain (OR 2.336,  $p = 0.014$ ). Pain severity and spread did not predict health care utilization for chronic pain. Interference with daily life (OR 1.428,  $p < 0.001$ ) and the physical component of HRQoL (OR 0.947,  $p < 0.001$ ) were significant predictors. However, the mental component of HRQoL did not predict pain-related health care utilization. Figure 9 shows a graphical overview of predictors for chronic pain-related health care utilization.

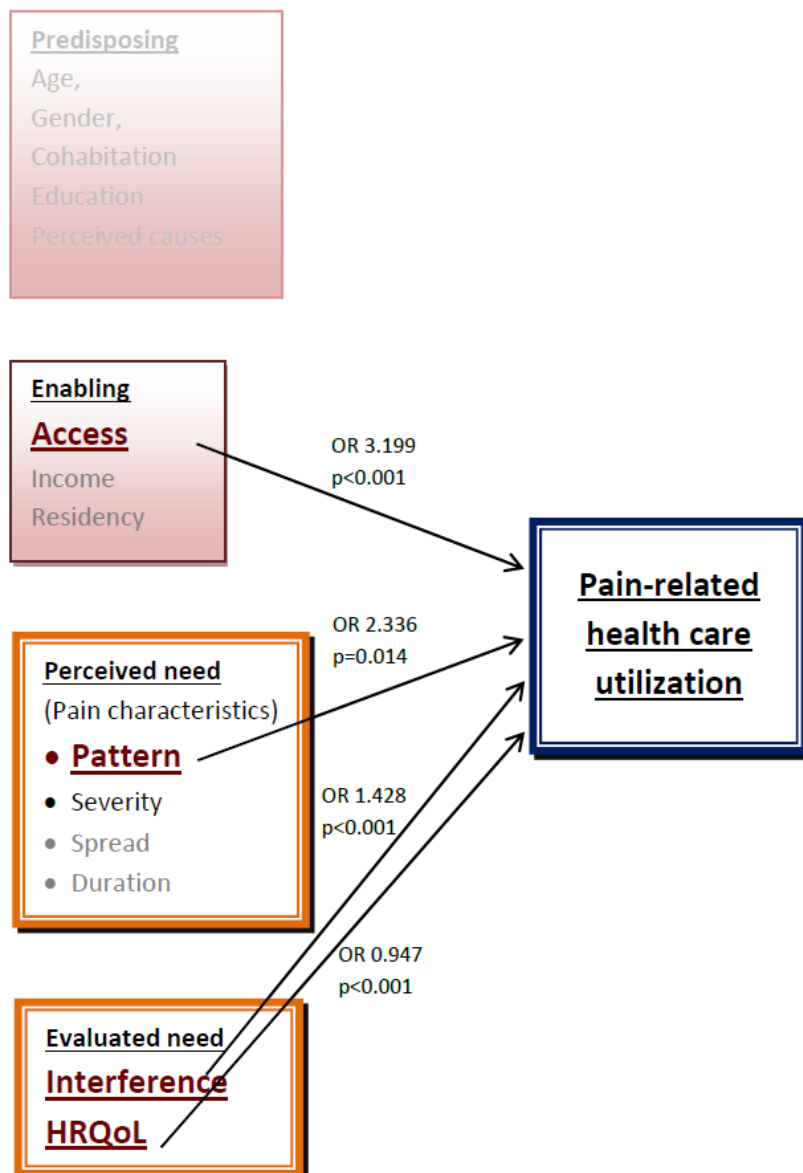


Figure 9. Predictors for chronic pain-related health care utilization.

To test gender differences in variables predicting health care utilization for chronic pain, a similar backward stepwise regression model was used separately for men and women, where predisposing, enabling, and need variables were tested against the outcome variable. Interference with life was a significant predictor for chronic pain-related health care utilization for both men (OR 1.403,  $p<0.001$ ) and women (OR 1.642,  $p<0.001$ ). However, there was a gender difference in the other two predictors. Along with interference, pattern of pain was a predictor among women, while the physical component of HRQoL, as well as interference, predicted pain-related health care utilization for men. Women with constant pain (OR 2.382,  $p=0.048$ ) and daily pain (OR 5.611,  $p<0.001$ ) were more likely to have consulted health care for chronic pain than women who did not have constant or daily pain.

Use of health care was not significantly related to HRQoL among women. Use of health care for chronic pain was significantly related to the physical component of HRQoL (OR 0.936,  $p=0.005$ ) among men but not to pattern of pain (see Table 4 in Paper III).

## Patient-Provider Communication (Paper IV)

Mean scores on the I-PICS factors on a 1-5 scale were as follows; 1.76 (SD=0.89) for HCP-Information (HCP-I) (higher scores indicating more HCP control); 3.19 (SD=1.18) for HCP-facilitation (HCP-FAC) (higher scores indicating less perceived provider-facilitation); 2.42 (SD=0.92) for Patient Information (PI) (higher scores indicating less perceived patient control over information exchange); and 3.48 (SD=0.83) for Patient Decision Making (PDM) (higher scores indicating less perceived participation in decision making). The distribution of scores in each of the four I-PICS factors are shown in figures 10-13. HCP-FAC and PI were significantly related to all other I-PICS factors. HCP-I and PDM were not related to each other but to all other I-PICS measures (Table 4).

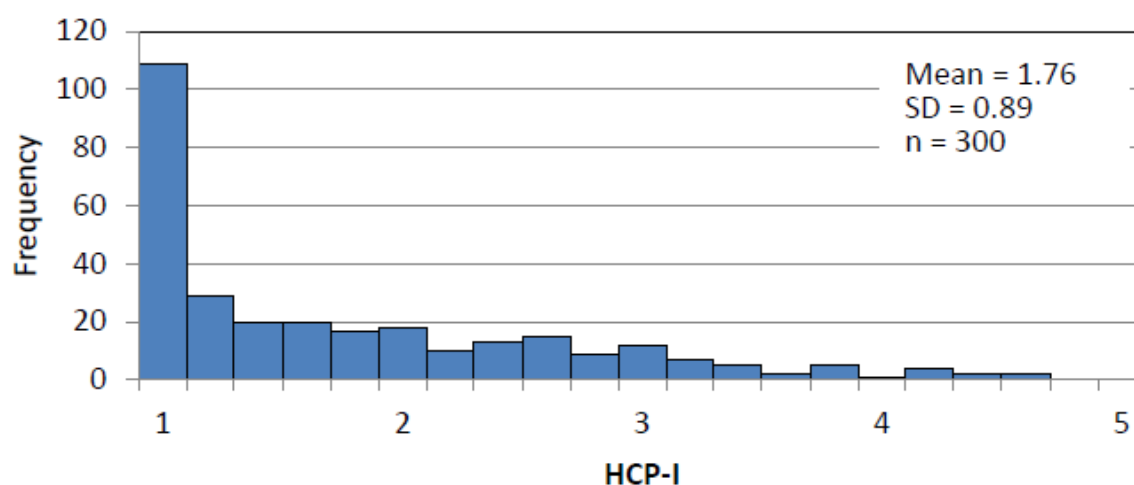


Figure 10 Distribution of scores in the HCP-I factor (HCP-Information).

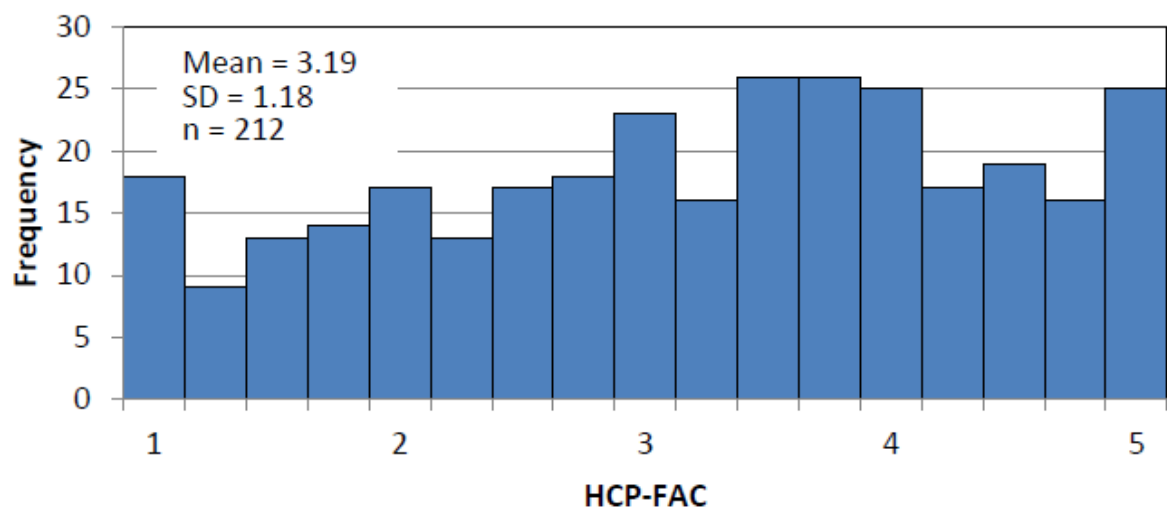


Figure 11. Distribution of scores in the HCP-FAC factor (HCP-Facilitation).

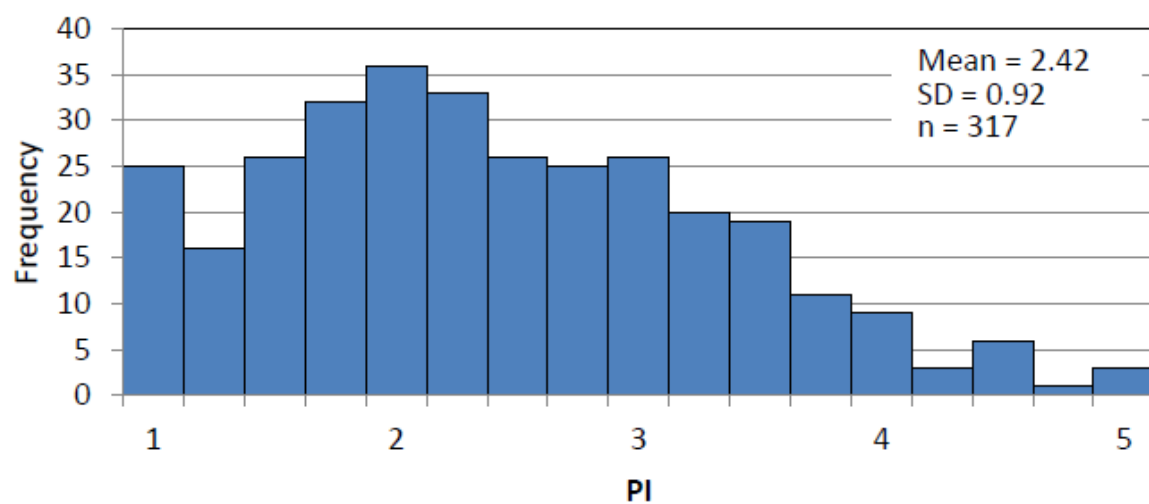


Figure 12. Distribution of scores in the PI factor (Patient Information).

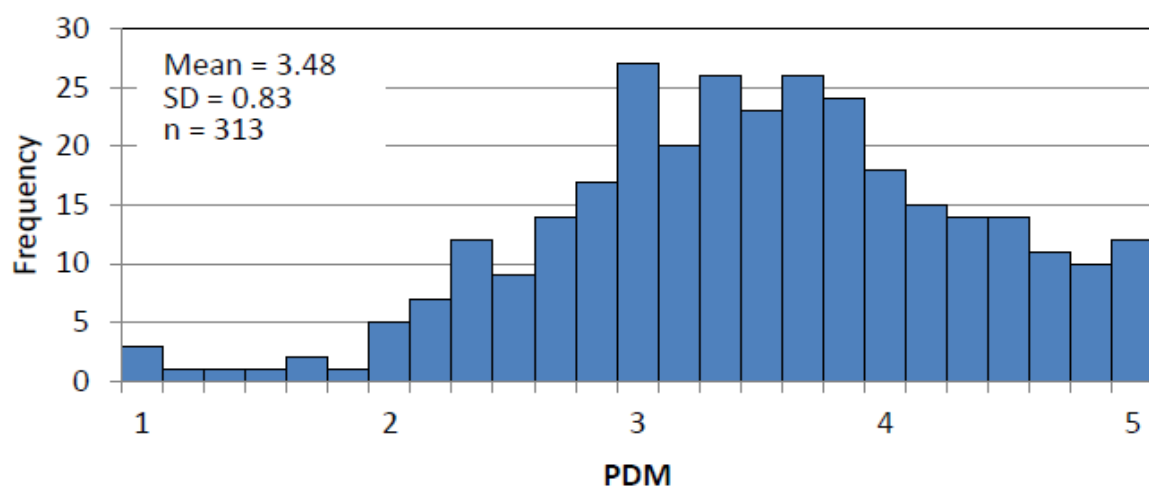


Figure 13. Distribution of scores in the PDM factor (Patient Decision Making).

The majority of participants were satisfied with the health care provider most consulted and 55% perceived that care met their needs for pain treatment well or very well. Figures 14 and 15 show an overview of how well participants perceived health care met their needs for pain treatment (outcome) and their satisfaction with the health care provider most consulted in the previous six months.

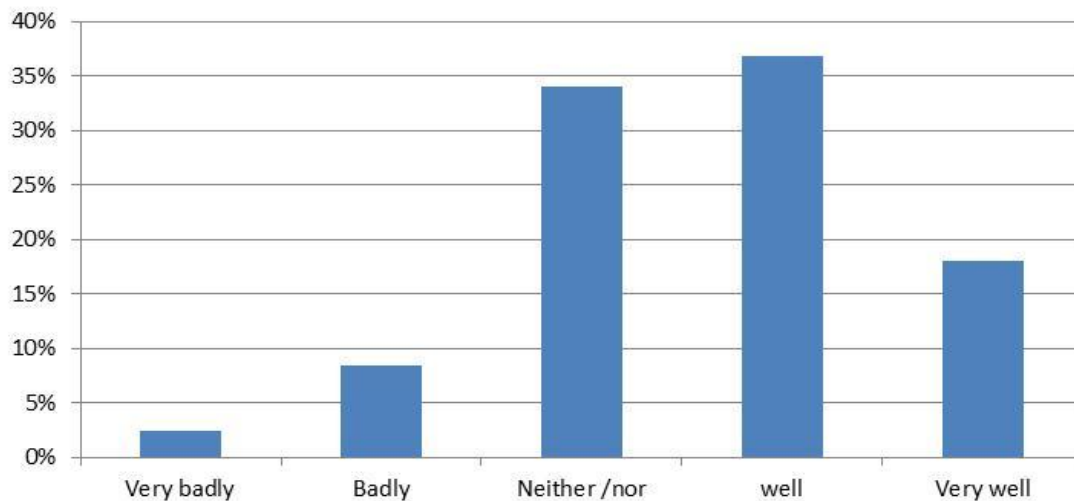


Figure 14. Perceived outcome; *“How well did care meet your needs for pain treatment”* (0-5 scale, 0=very badly, 5=very well).

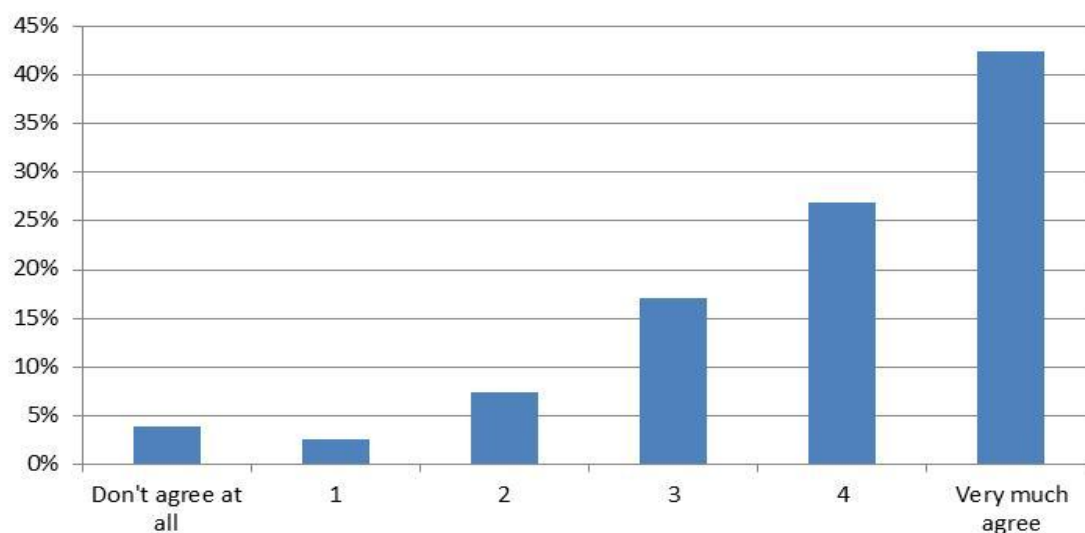


Figure 15. Satisfaction with the health care provider most consulted; *“I am satisfied with the health care provider, I have mostly consulted in the past 6 months”* (6 point scale, 0=Don't agree at all, 5=Very much agree).

Variables in each of the predisposing, Enabling, Need and Outcome factors which did not significantly correlate with any of the I-PICS factors (Spearman's rho correlation, Mann-Whitney U test), were excluded from further analysis. Variables significantly related to I-PICS

factors (Table 4) were included in series of Backward Stepwise Linear Regression analysis where conditional relationships between independent variables and each of the I-PICS scales were calculated.

Table 4. Spearman's rho – between the I-PICS scales and Predisposing, Enabling, Need and Outcome variables.

	HCP-I	HCP-FAC	PI	PDM
HCP-I		0.463**	0.178**	0.018
HCP-FAC	0.463**		0.379**	0.278**
PI	0.178**	0.379**		0.545**
PDM	0.018	0.278**	0.545**	
<b>Predisposing</b>				
Age	0.009	-0.027	0.096	0.063
Education	-0.163**	-0.086	-0.129*	-0.092
Perceived causes of pain				
Rheumatism	0.150**	0.003	0.003	-0.045
Fibromyalgia	0.115*	0.035	0.105	0.022
Myalgia /wear and tear	0.049	-0.009	0.062	0.023
Old trauma	0.010	-0.002	0.002	-0.063
No explanations	0.005	0.069	0.095	0.164**
Other causes	-0.022	-0.008	-0.021	-0.037
Heart- and circulatory problems	0.037	-0.102	-0.017	0.126*
Gastro-intestinal problems	0.063	-0.013	-0.024	-0.052
Migraine	0.126*	0.080	0.020	0.051
<b>Enabling</b>				
Family income	-0.101	-0.101	-0.131*	-0.052
Access	-0.338**	-0.202**	-0.095	-0.046
Residence (urban /rural)	0.003	0.079	0.102	0.150**
<b>Need</b>				
Pain severity index mean (0-10)	0.102	0.070	-0.004	-0.022
Pain interference index mean (0-10)	0.206**	0.089	0.037	-0.024
Pattern	-0.035	0.044	-0.028	0.023
Duration	-0.027	-0.058	0.065	-0.018
Spread - Number of locations	0.114*	-0.024	0.036	-0.075
Physical Component Score (HRQoL)	-0.135*	-0.074	-0.002	0.055
Mental Component Score (HRQoL)	-0.268**	-0.064	-0.052	0.005
<b>Outcome</b>				
Perceived effectiveness of care	-0.404**	-0.243**	-0.052	-0.028
Satisfaction with HCP	-0.576**	-0.416**	-0.166*	0.037

\*\*Correlation is significant at the 0.01 level (2-tailed). \*Correlation is significant at the 0.05 level (2-tailed).

### **HCP-Information (HCP-I)**

Education was the only socio-demographic variable related to HCP-I ( $r=-0.163$ ,  $p=0.005$ ). The higher the educational level, the less HCP control was perceived over the communication situation. There was a positive relationship between HCP-I and reporting rheumatism ( $r=0.150$ ,  $p=0.009$ ), fibromyalgia ( $r=0.115$ ,  $p=0.046$ ) and migraine ( $r=0.126$ ,  $p=0.029$ ) as the cause of pain. Access to care was the only enabling variable related to HCP-I ( $r=-0.338$ ,  $p<0.001$ ).

There was a significant relationship between HCP-I and all tested need variables except severity, pattern and duration of pain. HCP-I was positively related to pain interference ( $r=0.206$ ,  $p=0.001$ ) and pain spread ( $r=0.114$ ,  $p=0.049$ ) and negatively related to physical ( $r=-0.135$ ,  $p=0.020$ ) as well as mental ( $r=-0.268$ ,  $p<0.001$ ) components of HRQoL. There was a negative relationship between HCP-I and both outcome variables, perceived effectiveness of care ( $r=-0.404$ ,  $p<0.001$ ), and satisfaction with the HCP ( $r=-0.576$ ,  $p<0.001$ ). The less pain severity, interference and pain spread and the better HRQoL, the less participants perceived the health care provider to be controlling the communication situation and the more they perceived the health care provider to give them time to discuss their symptoms and ask questions.

When variables from the Predisposing, Enabling, Need and Outcome factors that significantly correlated with the HCP-I measure (Table 4), were tested in one backward stepwise linear Regression model, physical component score of HRQoL and satisfaction with health care provider were the only variables explaining how participants perceived the health care provider as giving time to discuss their symptoms, whereas the predisposing and enabling variables were no longer significant. Results from backward stepwise linear regression analysis are shown in table 5.

### **HCP-Facilitation (HCP-FAC)**

The only variables HCP-FAC was significantly related to were access (enabling) ( $r=-0.202$ ,  $p<0.001$ ) satisfaction with health care provider (outcome) ( $r=-0.416$ ,  $p<0.001$ ) and how well service met need (outcome) ( $r=-0.243$ ,  $p<0.001$ ). Participants who perceived easy access to care when needed for pain, perceived that health care met their needs for pain treatment and were satisfied with their health care provider, also perceived better HCP-facilitation to



express their opinions and concerns about symptoms and treatment options. HCP-FAC was not related to any of the predisposing or need variables.

When all variables were tested in one backward stepwise linear regression model, access to care and how well health care met needs were no longer significant and satisfaction with the health care provider most consulted during the past six months was the only variable predicting the HCP-FAC factor. The more the participants felt they were encouraged by the health care provider to discuss their symptoms and ask questions, the more satisfied they were.

### **Patient Information (PI)**

Perception of own activity in seeking and sharing information in the communication with the health care provider (PI) related to gender. Mean score was lower for men than women (2.26 vs. 2.52), as tested by Mann-Whitney U test, and this difference was significant ( $p=0.008$ ). PI was negatively related to education ( $r=-0.129$ ,  $p=0.024$ ) and family income ( $r=-0.131$ ,  $p=0.024$ ). Men and participants with higher education were more active in controlling the patient-provider communication than women and people with shorter education. Participants reporting monthly family income to be ISK 500,000 or higher were also more active in controlling the patient-provider communication than participants reporting family income to be less than ISK 500,000 per month. PI was not significantly related to any of the need or outcome variables.

When these variables were tested in one backward stepwise linear Regression model (Table 5), gender and family income were no longer significant and education was the only independent variable predicting the perception of being active in seeking and sharing information related to symptoms and treatment. People with higher education were more active in seeking and sharing information related to their symptoms and treatment options than people with shorter education.

### **Patient Decision Making (PDM)**

Perceived participation in making decisions related to care was positively related to reporting cause of pain being unknown ( $r=0.164$ ,  $p=0.004$ ), heart- and circulatory problems ( $r=0.126$ ,  $p=0.026$ ) and residence ( $r=0.150$ ,  $p=0.008$ ). Patients' participation was not related to any of the socio-demographic, pain-related or outcome variables. Patients living in rural areas and who reported that cause of their pain was not known or heart and circulatory

problems, were less active in discussing symptoms and participating in decision making around diagnostic tests and treatment.

When all variables that significantly correlated with PDM were tested together in one Backward Linear Regression model, only unexplained cause of pain and rural residence remained as predictors for limited patient participation (Table 5).

Table 5. Backward Stepwise Linear Regression on variables in Predisposing, Enabling, Need and Outcome factors, significantly correlated in Table 4.

	Standardized $\beta$	b	std. error	p-value	R <sup>2</sup>
HCP-I					0.338
Physical Component Score	-0.156	-0.013	0.005	0.008	
Satisfaction with HCP	-0.560	-0.398	0.041	<.001	
(Constant)		3.984	0.270	<.001	
HCP-FAC					0.187
Satisfaction with HCP	-0.433	-0.395	0.054	<.001	
(Constant)		4.728	0.225	<.001	
PI					0.027
Education	-0.163	-0.201	0.082	0.015	
(Constant)		2.808	0.169	<.001	
PDM					0.044
Unexplained pain	0.157	0.707	0.251	0.005	
Residence (urban/rural)	0.142	0.253	0.099	0.011	
(Constant)		3.123	0.139	<.001	

HCP-I, n = 199; HCP-F, n=229; PI, n= 220; PDM, n= 312

Figure 16 shows an overview of variables in Predisposing, Enabling, Need and Outcome factors, predicting patients' perception of chronic pain-related patient-provider communication in this study.

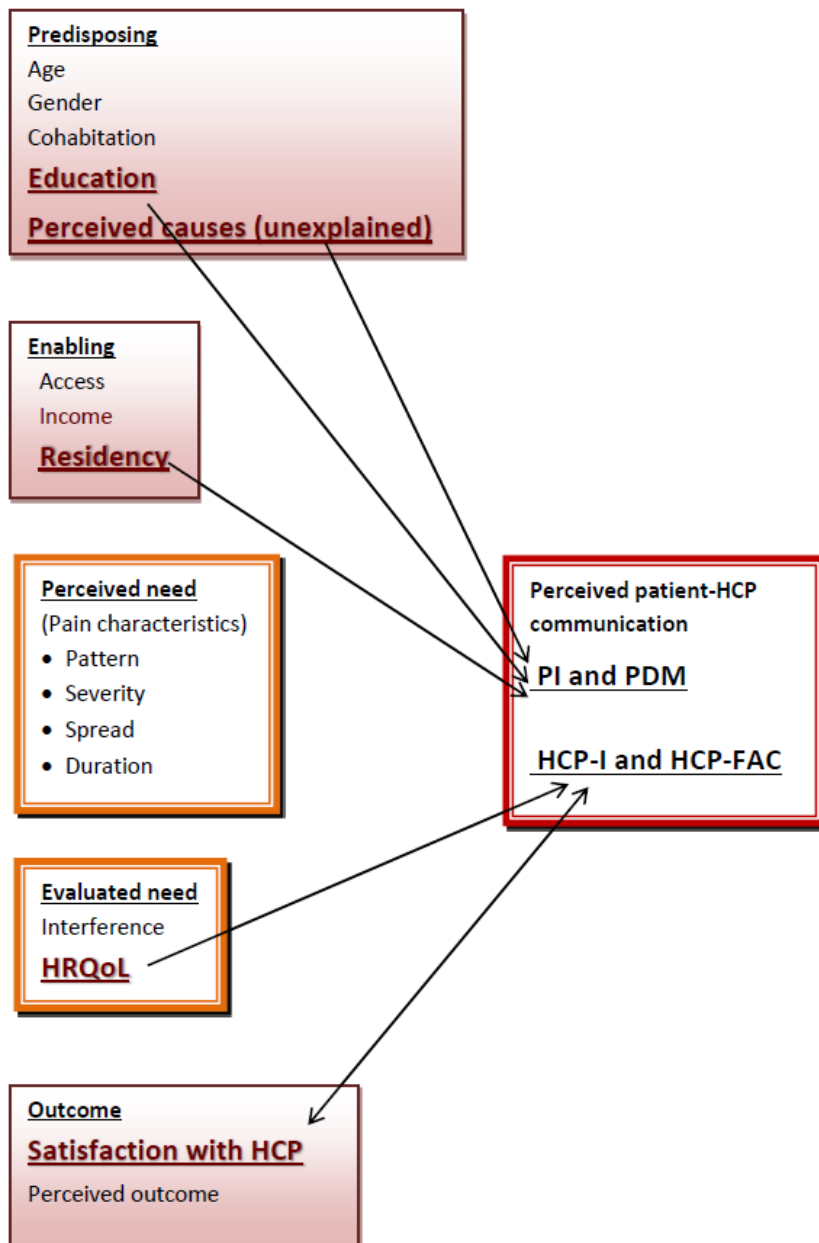


Figure 16. Overview over variables in Predisposing, Enabling and Need factors, predicting patient's perception of chronic pain-related patient-provider communication.



## **Discussion**

This thesis focuses on the characteristics and prevalence of chronic pain in the general population of Iceland, pain interference with daily life and HRQoL, chronic pain-related health care utilization and patients' perceived pain-related communication with health care providers. The thesis is divided into two parts: In Study I a new instrument was developed, Health Care Utilization Questionnaire (HCU) and another previously validated instrument, the Modified version of Patients' Perceived Involvement in Care scale (M-PICS) was translated and psychometrically validated for use in Iceland (I-PICS). Study II was a cross-sectional postal survey, based on a nationwide community sample, where the characteristics and prevalence of chronic pain and the relationships between chronic pain and interference with daily life and health-related quality of life were investigated, as well as relationships between socio-demographic and pain-related factors, and health care utilization and patient perceived patient-provider communication.

This thesis sheds some light on the characteristics and prevalence of chronic pain as well as chronic pain-related health care utilization in Iceland. The thesis offers both new knowledge as well as confirming results from earlier studies on complex relationships between chronic pain and impairment of daily life and HRQoL, as well as factors related to health care utilization and patient-provider communication in the context of chronic pain.

### **Chronic Pain and Interference with Daily Life and HRQoL**

This study highlights the importance of pain pattern and severity in the relationship between chronic pain and how it affects daily life and HRQoL. This accounts for both physical and mental domains of HRQoL, even when controlled for gender, age and education and these influences are stronger the more frequent the pain is. Spread of pain (number of pain locations) has only limited effect in this relationship.

These results are in some way different from what has been reported in earlier studies. Previous studies have indicated that pain severity and spread are the most important variables in the relationship between pain and HRQoL (Bergman et al., 2004; Jamison et al., 2007; Lame et al., 2005; Laursen et al., 2005). In some other studies, however, the importance of pain severity alone has been weak (Bergman et al., 2004; Lame et al.,

2005) and significant only if in relation to spread (Bergman et al., 2004). The fact that earlier studies have not considered the influence of pattern as one of pain characteristics in the relationship between chronic pain and its influence on daily life and HRQoL, might be the explanation for this difference.

Even though chronic pain impairment on daily life and HRQoL was not predicted by pain spread in this research as previous studies have indicated (Bergman et al., 2004; Lame et al., 2005), there were some significant relationships (correlations) between these variables. There was a significant positive relationship between spread and interference, as well as spread and both severity and duration of pain. There was also a positive relationship between pain duration and physical components of HRQoL even though mental components of HRQoL and pain impairment on daily life were not related to pain duration. This suggests that the longer the pain lasts, the more it spreads and the more frequent and severe it becomes with more impairment on daily life and HRQoL as a result.

It is also important to note that in this study pain pattern was related to duration of pain. More than half of those with chronic pain had constant or at least daily pain and the majority of individuals with shorter pain duration than 3 months reported periodic pain. However, pain pattern was not related to duration of chronic pain ( $\geq 3$  months). In this regard, it can be speculated that when pain becomes chronic the risk of constant and daily pain increases and as pain becomes more prolonged it spreads and becomes more severe with a stronger negative effect on daily life and HRQoL as a result. These interactive relationships between spread, severity and duration of chronic pain have been previously demonstrated (Bergman et al., 2004; Peolsson et al., 2007). Peolsson et al. (2007) suggested that an explanation for the positive relationship between pain severity and number of pain locations could be that more severe pain not only increases the risk of chronic pain conditions, but also of spreading pain. Furthermore, study results from Bergman et al. (2004) indicate that poor HRQoL may not only be a result of chronic pain but can predict future development of pain and higher risks of the spread of pain. In their study, individuals with poorer HRQoL (lower SF-36 scores) had a higher risk of more widespread pain three years later. The progress from regional pain to widespread pain was, however, related to different dimensions of HRQoL. It significantly affected VT, SF and but not PF (Bergman et al., 2004).

This relationship between pain spread and mental components of HRQoL was confirmed in the present study. Even though pain pattern and severity were the most important variables in the relationship between chronic pain and its impact on daily life and HRQoL and pain spread had only limited effect, pain spread was a stronger predictor than pain severity for two of the mental domains of HRQoL (VT and RE). This indicates that the spread of pain is more important than severity for at least some components of mental and emotional wellbeing among patients with chronic pain. This also confirms the suggestion by (Bergman et al., 2004) that the mental dimension is important in the understanding of widespread, compared to regional, pain syndromes.

### **Predictors for Chronic Pain-Related Health Care Utilization**

Negative impact on daily life, pattern of pain and the physical domains of HRQoL, as well as perceived easy access to care, were the most prominent predictors for health care utilization for chronic pain. Even though pain severity and number of pain locations were significantly higher among those who had sought health care for their chronic pain in the previous six months, these variables were no longer significant when controlled for other pain characteristics. Earlier studies have found similar pain characteristics to be important predictors for health care utilization, e.g. frequent pain (Gerdle et al., 2004) as well as disability and poor health related to pain (Bosworth, Butterfield, Stechuchak, & Bastian, 2000; Cornally & McCarthy, 2011a). This is also similar to results from a population based study on health care utilization among individuals with chronic pain by Elliott and colleagues (Elliott et al., 2004), where individuals with chronic pain who had used health care service in the previous 12 months had poorer HRQoL than non-users, even when controlled for pain severity. This indicates that the influence of pain on daily life is more important than the pain itself when the decision to seek health care is made.

Although some prior research has revealed that socio-demographic factors are prominent predictors of health care utilization (Andersen, 1995; Bradley et al., 2002; Dixon-Woods et al., 2005), these variables had limited significance in predicting health care use for chronic pain in this study. Even though retired and unemployed individuals and those receiving disability benefits were more likely to have consulted health care for chronic pain

during the previous six months compared to other occupation groups, this relationship was no longer significant when controlled for pain-related variables. Lack of relationships between occupation and employment status, as well as socio-demographic characteristics, among users and non-users of health care service has previously been reported (Elliott et al., 2004). The importance of need as a predictor for health care use, unrelated to socio-demographic characteristics has also been demonstrated earlier (Bedson et al., 2007).

In this study the majority of participants reported easy access to care when needed for pain. Nevertheless, easy access was one of the variables predicting pain-related health care utilization, but neither family income nor residence. Residence, long travel distance to care, and family income, have earlier been identified as limitations for access to, and use of, health care service (Hausdorf et al., 2008; Sinay, 2002). Financial barriers associated with health care have, however, been shown to act differently in different socioeconomic environments, based on variations in social and health care systems (Walker et al., 2004). In societies where health care service is run mainly by private initiatives, health care costs, insurance coverage and cost of insurance premiums are known to be predictors for health care utilization (Sinay, 2002; Song et al., 2010). In countries with a socialized health care system and relatively low out of pocket service fees as in the Nordic countries, economic barriers are expected to be less important (Lindal & Uden, 1989). In this study, a third of participants reporting chronic pain reported that they had postponed or cancelled needed health care service in the past six months and a third of them reported high health care costs to be the main reason. Consultation fees and expenses in relation to medications were most often reported as the most onerous costs. This indicates that even though, firstly, the majority of participants in this study perceived access to health care when needed as easy and, secondly, chronic pain-related health care utilization was not significantly related to economic factors, nevertheless a number of participants with chronic pain had postponed or cancelled needed health care service during the past six months because of high costs. This is worth considering in the light of results from Vilhjalmsson (2009) showing increased health expenditures among Icelandic households by 29% between 1998 and 2006.

A number of earlier studies have shown women to be more likely than men to seek health care for pain (Hagen, Bjorndal, Uhlig, & Kvien, 2000; Rustoen, Wahl, Hanestad, Lerdal, Paul, & Miaskowski, 2004a; Walker et al., 2004). This was not found to be the case in the



present study. However, there were gender differences in pain-related predictors for health care utilization. The most prominent predictors among women were interference with daily life and pattern of pain (constant or daily pain), while pain interference with life and the physical components of HRQoL were the main predictors for men. Considering that physical impairment of chronic pain is highly influenced by pattern of pain (constant and daily pain) as well as severity, it could be speculated that male participants might have waited longer than female participants before consulting care for their pain. For men, constant or daily pain may have evolved into physical impairment before they sought professional treatment. Earlier studies have shown that men are less willing to report pain and have a higher 'threshold' for seeking care than women (Cornally & McCarthy, 2011a; Robinson et al., 2001). The reason for this is not known but some kind of 'social stereotyping' has been suggested; that men are expected to have higher tolerance and endurance for pain, leading to a higher suffering threshold for reporting pain which results in more suffering and HRQoL impairment (Robinson et al., 2001). This might have played a part in the gender differences found in this study.

Studies have also suggested that negative expectations about the outcome, fear of not being believed or being labelled as a hypochondriac if symptoms are not severe 'enough' may constitute a barrier to seeking treatment (Cornally & McCarthy, 2011b; Hansson, Fridlund, Brunt, Hansson, & Rask, 2011; Sanders, Donovan, & Dieppe, 2004). This study does not indicate whether poor results from earlier treatments, or negative past experience from consulting health care professionals for chronic pain, may explain the decision not to seek professional care for chronic pain. However, earlier research has suggested that many individuals struggle with their pain as long as they can without seeking treatment for it, and do not consult health care service until the pain has started to interfere with daily life or even physical functional ability (Watkins et al., 2006). Based on the results of this study it may be concluded that this delay of seeking treatment might be more prominent among men than women.

## **Patient- Provider Communication**

This study shows that patient perception of patient-provider communication is related to both socio-demographic and pain-related factors. However, these relationships differ with regard to patients' perception of health care providers' behaviour, in the communication scenario, on the one hand, and own control and behaviour, on the other. Results from earlier studies indicating that patients' behaviour in patient-provider communication is related to socio-demographic and socio-economic factors (Mira et al., 2012; Willems et al., 2005) are confirmed here. Results from earlier studies are also confirmed here, showing perception of provider's support and facilitation, and satisfaction to be interrelated (DeVoe et al., 2009; Lerman et al., 1990; M. Y. Smith et al., 2006). However, even though a relationship has been demonstrated in earlier research between, on the one hand, perception of providers' support and openness to answer questions and explain things, and, on the other, age, gender and economic status (DeVoe et al., 2009), this is not the case here.

The relationship in this study between patients' satisfaction and perception of health care providers' openness to discuss symptoms, answer questions and provide support (HCP-I and HCP-FAC) confirm earlier research findings. Results from Lerman (1990) and Smith et.al (2006) suggest that high information exchange and the presence of a facilitative and supportive health care provider may have an immediate impact on a patient's satisfaction with care (Lerman et al., 1990; M. Y. Smith et al., 2006). Other studies have indicated that it may be more important for patients to perceive that their health care provider has listened to their problems, questions, and concerns; informed them about their health problems, and provided them with an opportunity to express their opinions than to perceive that they participate in making decisions for treatment (Feldman-Stewart & Brundage, 2009; Frantsve & Kerns, 2007). To be understood as an individual and having their pain concerns legitimized by the health care provider, is crucial for most patients even though there may be individual or situational differences in the patients' possibilities to participate in treatment decision making (Frantsve & Kerns, 2007; Lerman et al., 1990). Patient satisfaction may, therefore, be more likely to reflect patients' interpretations of health care providers' behaviours than their own conduct related to seeking or sharing information (Lerman et al., 1990).

This may also explain the relationship between pain interference and spread as well as both the physical and mental component of HRQoL and HCP-I in this study, where the physical component of HRQoL was the most prominent factor. As patients perceived more pain interference on daily life, more widespread pain and poorer HRQoL, the more likely they were to feel that the health care provider did not spend time listening to their concerns and questions and explaining treatment options (HCP-I). Cronje & Williamson (2006) have emphasized the importance of giving patients the opportunity to convey their understanding of their pain and its meaning in life in patient-provider communication. This significance may increase the more the pain interferes with daily life and HRQoL. The more widespread pain is and the more it interferes with daily life and HRQoL the more time and support the patient may be expected to need from the consulted health care provider. The higher expectations and needs are, the stronger is the likelihood that the patient perceives these needs as unmet, leading to barriers and frustrations in the patient-provider communication (DeVoe et al., 2009; Lerman et al., 1990; M. Y. Smith et al., 2006).

Earlier studies have found patient-provider communication and patient participation in care to be related to different socio-demographic and socioeconomic variables (DeVoe et al., 2009; S. K. Smith et al., 2009; Willems et al., 2005). In this study, however, this relationship was significant in only one aspect of the patient-provider communication. PI was the only scale explained by socio-demographic variables when controlled for all other variables. Perception of being active in seeking and sharing information and discussing symptoms and treatment options was mainly explained by higher educational status. PI was also significantly correlated to family income when tested by Spearman's rho, even though this was not significant when controlled for education. This is in accordance with results from earlier studies indicating that patients with higher socio-economic and educational status communicate more actively and are more active in asking questions about their symptoms and treatment options than patients from lower social and educational groups (Willems et al., 2005). However, results from earlier studies showing patients activity in care and involvement in treatment decisions to be related to social and educational status (Mira et al., 2012; S. K. Smith et al., 2009; Willems et al., 2005), were not confirmed here. Socio-demographic variables did not explain patient participation in making decisions for diagnostic tests and treatment (PDM) in this study. PDM was related to unexplained pain

and rural residence. People reporting that the cause of their pain was unexplained, were less active in discussing symptoms and participating in decision making around diagnostic tests and treatment than people not reporting cause of pain as unexplained. People living in rural areas were also less active discussing symptoms and participating in decision making than people living in urban areas.

Patient participation in decision making around tests and treatment has not been explained before in terms of residence in the research literature reviewed for this study. According to the results of this study, rural residence was related to lower level of education. Therefore, it could be speculated that even though patients' participation in making decisions for tests and treatment (PDM) was not directly related to education, educational status might play a role in the relationship between PDM and rural residence.

Another reason for suggesting that PDM might in some way be related to educational status is that education was the most important variable explaining patients' perception of own activity in seeking and sharing information (PI). These scales are interrelated and both measure patients' perception of own activity in the patient-provider communication process.

Pain interference with daily life and the physical component of HRQoL were predictors for seeking health care for chronic pain among participants in this study. When a patient seeks care he/she has needs and expectations, and satisfaction with the health care provider is highly related to how these expectations and needs are met. Therefore, it can be suggested that patients' perception of how the health care provider meets their expectations and need for understanding, explanation and facilitation, is explained by pain-related factors to a greater extent than by socio-demographic or economic factors. On the other hand, patients' perception of own control in patient-provider communication and involvement in making decision for their care and treatment is mostly related to demographic characteristics, e.g. education, as the research literature has revealed (Frantsve & Kerns, 2007; Mira et al., 2012; S. K. Smith et al., 2009).

## **Methodological considerations**

This thesis has several strengths. The major strength is that the sampling was stratified grounded in a community based nationwide sample study and provides valuable data about characteristics of chronic pain in the Icelandic population and interference with daily life and HRQoL. This study adds valuable knowledge about important predictors for chronic pain-related health care utilization, as well as patients' perception of communicating chronic pain to health care providers in relation to socio-demographic, pain-related and outcome factors.

The majority of the instruments have good psychometric properties. This applies to both I-PICS translated and psychometrically tested in Study I and used in Study II, as well as instruments used in Study II which have been validated earlier by other investigators. One instrument, the Health Care Utilization questionnaire developed in Study I, has not yet been systematically psychometrically tested. This instrument diverges from the others as it contains a number of dichotomous variables. Most of the items do not lend themselves to formation of scales. The items which were used in the study contain people's access to and use of health care, duration and characteristics of pain, pain-related health care utilization and perceived outcome from health care utilization for chronic pain.

The major limitation of this study is the relatively low response rate, despite careful attention given in the study design to maximizing the number of responses. It was possible to compare respondents and non-respondents in terms of age and gender, demonstrating a significant difference in those who responded from those who did not. The response rate was 40.7% among women and 30.0% among men. Respondents were significantly older than non-respondents, with a 21.8% response rate in the youngest age group (20-30 years) and 54.1% in the oldest group (61-70 years). Prior studies on the prevalence of pain have shown a similar pattern with lower response rate among men and in younger age groups (Rustoen, Wahl, Hanestad, Lerdal, Paul, & Miaskowski, 2004b). It is also worth noting that the majority of respondents reporting pain had felt pain for three months or longer, making the prevalence of chronic pain relatively high compared to the occurrence of pain of shorter duration. Based on this, it can be speculated whether those who were invited to participate were more likely to do so if they experienced pain and had done so for a long time, and therefore felt that they had some investment in the topic.

Another important issue in relation to the low response rate is that among the total of 4,500 individuals, 564 may have been, based purely on their names, of non-Icelandic origin. Among this sub-group the response rate was much lower than in the total sample, suggesting that a possible reason for the low response rate among them, might in part be language difficulties.

However, despite the fact that the low response rate makes it impossible to draw a conclusion about the frequency of chronic pain in the Icelandic general population, it is important to note that data on pain characteristics and pain-related health care utilization were obtained from more than 90% of those reporting chronic pain. It is also worth noting that more than 75% of those who reported having consulted health care for chronic pain in the past 6 months answered all items in the I-PICS. This provides valuable information on chronic pain-related health care utilization in the Icelandic general population. This also yields valuable knowledge on chronic pain-related health care utilization and perceived patient-provider communication in relation to socio-demographic and economic, pain-related and outcome variables among chronic pain patients in Iceland. This may be considered as an important strength of this thesis.

One more issue that might be considered as a limitation of this study is that it was not designed from the beginning using the Behavioural Model for Health Service Use (Andersen, 1995). When planning this study a hypothesized model of the relationships between study variables was designed, based on the research literature. When working on data analysis for chronic pain-related health care utilization (paper III) the Andersen's Behavioural Model for Health Service Use was adapted to this model and used to investigate relationships between variables in an already existing dataset. Therefore, some questions would have been formulated differently, if the Behavioural Model for Health Service Use had originally been incorporated in the study design.

## **Implications**

This study yields meaningful findings about relationships between chronic pain, pain interference with daily life and HRQoL and chronic pain-related health care utilization. The pattern of pain and pain severity, were the most important pain characteristics influencing

how pain interferes with daily life and HRQoL. Pain interference with daily life, pain pattern (constant and daily pain) as well as physical components of HRQoL were the main reasons for seeking care for chronic pain. This study also provides meaningful insight into different aspects of patients' perception of patient-provider communication and how it relates to various pain-related, as well as socio-demographic and economic, variables. All these relationships are important to consider in clinical practice.

Based on these findings, it is important to not only consider pain symptoms and severity, but also how pain interferes with life and affects HRQoL, as well as patients' understanding of pain and how they manage pain in daily life. When patients seek health care for pain it is, therefore, necessary to assess pain in a broad spectrum and consider different characteristics and their impact on daily life and HRQoL, as well as possible interaction between HRQoL and pain characteristics. Probing thoroughly into how pain interferes with daily life by giving the patient time and facilitate him/her to express and discuss symptoms, as well as measuring HRQoL early, might help to identify patients who are at particular risk of developing chronic pain. This is important for diminishing the risk of a vicious cycle of more frequent pain (constant or daily in pattern) as well as increased spread and severity of pain.

The results of this study indicate that pain pattern (constant or daily pain), pain interference with daily life and the physical component of HRQoL are the most important factors influencing the individual's decision to seek care for pain. This study also shows gender differences, indicating that men seem to wait longer than women to seek health care; they do not seek care until pain has started to not only interfere with daily life but also to affect physical ability. This has important clinical implications. It would be beneficial to inform the general public of the importance of seeking care early enough to prevent pain from becoming chronic. Pain may not always be curable, but the more chronic it becomes the more difficult it is to treat and keep under control. Early identification of pain and referral to suitable health care may prevent pain from becoming chronic with resulting quality of life impairment. Thus, it is important to encourage people to seek care if pain does not heal spontaneously or respond to simple self management methods, so that they may be diagnosed and treated before the pain becomes a severe handicap in their daily lives. In light of the results of this study this is especially important for men.

However, in order to prevent pain from becoming chronic, it is not enough to encourage the public to seek care early; it is no less urgent to educate health care providers about how to receive patients with pain. In this relationship it is also important to consider the environment where patient-provider communication takes place, as well as different organizational factors such as the time frame for each consultation. Lack of communication and listening on behalf of health care providers is not only their responsibility, but also relates to how health care service is organized (Blomberg, Hylander, & Tornkvist, 2008). Health care providers often do not have the opportunity to explore pain problems and discuss them thoroughly enough with patients because insufficient time is allocated for consultation. Therefore, it is easier and less time 'consuming' to handle pain in a more superficial way than to have a deep conversation with the patient. If providers were given more time for each patient and opportunity for interdisciplinary collaboration and support, this would stimulate effective patient-provider communication with better treatment outcomes as a result (Blomberg et al., 2008).

In this study the poorer HRQoL participants had, the more likely they were to perceive that the health care provider did not spend time listening to their concerns and questions and explaining treatment options. Earlier studies have indicated that the perception of being mistrusted and misbelieved, along with frustrated attempts to explain pain to providers, may lead to a breakdown in communication (Butow & Sharpe, 2013; Dow, Roche, & Ziebland, 2012). Patients may either withdraw from seeking care for their pain and suffer in silence (van Hooft, 2003) or start to seek care from a wide range of health care providers, looking for an answer and a cure for their condition rather than developing a strategy for its management in a trusted and therapeutic relationship with one or few health care providers (Parsons et al., 2012).

Both alternatives are bad both for the patient and for society, as they can cause more suffering, disability and poor HRQoL as well as high health care expenses for the individual. In addition, societal health care service costs will rise without yielding a proper return. Thus, it is important to organize health care service in a way that prevents this vicious circle. It is important to have a provider who the patient perceives as trustworthy and supportive and who has an advocacy role in helping the patient to negotiate the health care system (Dima et al., 2013). One way could be to establish a community based early consultation service in



primary care where patients could be admitted, when their pain is at an early and still manageable stage. This could be, for example, a nurse consultant specialized in pain care who would serve as patients' advocate, negotiate them through recommended tests and treatments, support, listen to patients' concerns, discuss and answer questions and inform and educate about subjects related to the pain and its treatment, as well as strategies to handle cognitions about pain. Results from a newly published study from England have indicated that a nurse-led chronic pain clinic can enable patients to access the appropriate service at an earlier stage in their condition and receive the support needed to manage the impact of their pain. This has also been shown to have a positive impact in the form of reduced primary and secondary healthcare utilization among patients with chronic pain (Ryan, Packham, T Dawes, & Jordan, 2012).



## **Conclusion**

This study sheds new light on the characteristics and prevalence of chronic pain in the Icelandic population. It explains complex relationships between characteristics of chronic pain and how it impairs daily life and HRQoL, as well as identifying factors that predict chronic pain-related health care utilization. Pain pattern and pain severity are the most important variables in the relationship between chronic pain and interference with daily life and HRQoL. As pain becomes more constant and its severity increases, the more detrimental influences there are on daily life and HRQoL.

The study shows that negative impact on daily life, pattern of pain and the physical domains of HRQoL, as well as perceived easy access to care, are the most important predictors of seeking care for chronic pain. Chronic pain-related health care utilization is not related to socio-demographic factors such as gender, age or education. However, this study shows that predictors for seeking care for chronic pain are different for men and women. While pain interference was a predictor for both men and women, the role of the other two predictors, pattern and HRQoL, differed by gender. While the pattern of pain (constant or daily pain) was a predictor for women, the physical component of HRQoL was a predictor for men. This is highly important considering that physical impairment of chronic pain was mainly related to pattern of pain (constant and daily pain) as well as pain severity, which indicates that male participants may postpone health care consultations longer than women. Constant or daily pattern of pain may have evolved into physical impairment before they seek professional treatment.

When it comes to perceived communication with the health care provider most consulted, both socio-demographic variables and pain-related variables are of importance. However, these relationships are different depending on whether they are linked to patients' perception of providers' communication behaviour towards them, or their own activity and control in the communication scenario and participation in making decisions for tests and treatment.

This study illustrates the complex relationship between chronic pain and how it affects daily life and HRQoL as well as how health care utilization and patients' perception of patient-provider communication relates to socio-demographic and pain-related factors. These results highlight the importance of assessing chronic pain in a broad spectrum and

probing thoroughly into how it affects patients' life situation, as well as suggesting how health care service for individuals with chronic pain could be improved.

## **Future studies**

Further research is needed to understand how chronic pain affects daily life and HRQoL and to understand the relationships between chronic pain and pain-related health care utilization. Patient-provider communication may be considered an indicator for quality of care. Therefore, further research is also needed to understand patient-provider communication and how it relates to patient participation with care, treatment outcome and patients' satisfaction. The present findings raise several topics for future research:

- The role of individuals' characteristics e.g. health beliefs, health literacy and self-efficacy in the relationship between chronic pain and HRQoL as well as the role of these characteristics when making decision for seeking health care for chronic pain.
- The role of earlier experience from seeking health care for pain or for other health problems when making decisions for seeking care for present pain.
- Reasons for not seeking care for chronic pain despite chronic pain interfering with daily life and HRQoL.
- More research on gender differences in seeking health care for chronic pain, e.g. a longitudinal study on the differences in how men and women deal with their pain in daily life and how they use health care service for pain.
- A longitudinal study among individuals seeking care for pain, on the relationship between pain characteristics (pattern, severity, spread) and how pain interferes with daily life and HRQoL.
- More research on the role of the causes and localisation of pain and patients' perception of patient-provider communication.
- Use of alternative treatment methods for chronic pain in relation to socio-demographic, economic and pain-related factors.
- Testing I-PICS against individuals' patient characteristics e.g. health beliefs, health literacy and self-efficacy in relation to self-care of chronic pain.



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## **Original publications**



## Paper I



## Paper II





## Paper III



## Paper IV