Chronic pain in an elderly population in Sweden

Impact on costs and quality of life

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SAMMANFATTNING

Kronisk smärta bland äldre är sedan länge ett välkänt problem, både i termer av samhälleliga kostnader och i termer av nedsatt livskvalitet hos drabbade individer. I syfte att uppskatta omfattningen av problemen med kronisk smärta i den äldre befolkningen insamlades data avseende såväl kostnader som livskvalitet. Ett frågeformulär sändes med post ut till ett stratifierat urval om 10 000 invånare 65 år och äldre i Linköpings och Norrköpings kommuner. Frågeformuläret innehöll frågor om demografi, levnadsvanor, livssituation samt olika frågor och instrument relaterade till personernas mående (t.ex. livskvalitet och smärtspecifika frågor). I frågeformuläret tillfrågades respondenterna om huruvida de mottog någon hjälp, informell vård, från någon närstående. Om så var fallet tillfrågades respondenten om tillstånd att kontakta dennes informella vårdgivare, samt kontaktuppgifter. Mängden informell vård tillhandahållen av närstående undersöktes med hjälp av ett frågeformulär innehållande frågor om tid som använts till informella vårdinsatser.

Uppgifter om kostnader inhämtades från register avseende konsumtion av sjukvård, läkemedel och kommunala insatser.

Studiens resultat visade på ett mycket tydligt samband mellan å ena sidan förekomst och grad av kronisk smärta och å andra sidan samhälleliga kostnader. Studiepopulationen delades in i tre grupper med avseende på kronisk smärta eller inte, och smärtintensitet på en 10-gradig skala under den senaste veckan (0–4 = lindrig, 5–7 = måttlig, 8–10 = svår). Med hänsyn tagen till alla kostnader (sjukvård, läkemedel, kommunal service och informell vård) konsumerade personerna med svår kronisk smärta i snitt 72% mer resurser än personerna med måttlig kronisk smärta, och 143% mer än personer med ingen eller lindrig kronisk smärta. Skillnaderna var tydligast avseende kommunala insatser och informell vård.

Ännu mer uppskattande är resultaten gällande livskvalitet för personer i olika grupperna. Genomsnittligt indexvärde utifrån EQ-5D var för personer med ingen eller lindrig kronisk smärta 0.82. För personer med måttlig kronisk smärta var motsvarande värde 0.64, och för personer med svår kronisk smärta var värdet 0.38. EQ-VAS resulterade i mindre uttalade men tydligt signifikanta skillnader.

Denna studie, som når en relativt stor andel av målpopulationen, visar att förekomst och intensitet av kronisk smärta bland personer 65 år och äldre påverkar samhälleliga kostnader och drabbade personers livskvalitet mycket tydligt.
ABSTRACT

Chronic pain among elderly people has long been a well-known problem, in terms of both societal costs and the quality of life of affected individuals. To estimate the magnitude of the problems associated with chronic pain in an elderly population, data on both costs and quality of life were gathered. A postal questionnaire was sent out to a stratified sample of 10,000 inhabitants 65 years and older in Linköping and Norrköping. The survey included questions on demographics, habits, and life situation, and different kinds of questions and instruments related to well-being (e.g., quality-of-life and pain-specific questions). In the questionnaire respondents were asked whether they were receiving any help—informal care—from a relative. If they answered yes, they were asked for permission to contact the informal caregiver and to provide contact details. The amount of informal care provided by relatives to persons with chronic pain was investigated by use of a questionnaire directed to the caregiving relatives, containing questions about time spent providing informal care.

Data on costs were collected from registers of consumption of health care, drugs, and municipal services.

The results of the study showed a very clear association between existence and severity of chronic pain and societal costs. The study population was subdivided into three groups with respect to having chronic pain or not, and a pain intensity during the last week of 0–4 (mild), 5–7 (moderate), or 8–10 (severe) on a scale of 0–10. Taking all costs (health care, drugs, municipal services, and informal care) into account, persons in the severe chronic pain group consumed on average 72% more resources than persons in the moderate chronic pain group and 143% more than those in the no or mild chronic pain group. Differences were most pronounced concerning municipal services and informal care costs.

Even more alarming are the results on the quality of life of persons in the different groups. On the EQ-5D index, the average value for persons in the no or mild chronic pain group was 0.82. For those in the moderate chronic pain group the average value was 0.64, and for those in the severe chronic pain group the average value was only 0.38. EQ-VAS resulted in less pronounced but still clearly significant differences.

It is concluded that this study, reaching a rather large part of the target population, shows that existence and severity of chronic pain among people 65 years and older affects costs to society and the quality of life of affected individuals in a massive way.
1. INTRODUCTION

1.1 Background

The reported prevalence of chronic pain among people 65 years and older varies in the literature. The variations might depend on different techniques for gathering data, but there is considerable variation in reported prevalence also between studies using the same techniques. In a brief epidemiologic study from the county of Östergötland, not specifically focused on the elderly population, the point prevalence of pain was 53% among people 65 years and older (1). The corresponding figure for chronic pain (more than three months’ duration) was 56%. The study focused on reporting prevalence of pain and its relation to certain, mainly sociodemographic, factors, and it was found that prevalence of pain was highest in the age group just prior to retirement.

Long-term pain is associated with large societal costs. The total cost of chronic pain for the Swedish society in 2003 was calculated to be 87.5 billion SEK, of which 7.5 billion SEK consisted of direct health care–related costs and 80 billion SEK consisted of indirect costs related to production loss due to illness-related sick leave. The study described here is focused on persons 65 years and older, which makes the significance of sick leave marginal. On the other hand, costs related to informal care and care performed by municipalities may be important in this age group.

This report is mainly focused on costs and quality of life associated with the prevalence of chronic pain among people 65 years and older. It is the first report of a study program aiming to investigate this population in a broader sense, with respect to prevalence, intensity, variability, and frequency of pain. The aim is also to analyze how pain correlates with sociodemographic factors, comorbidities, activities, and health.

1.2 Aim

The aim of this study was to quantify the societal cost of chronic pain in the population of elderly people 65 years or older. The impact of chronic pain on quality of life was also investigated.
2. SUBJECTS AND METHODS

2.1 Design

Data from three registers and two surveys were used in the study. The first survey was a cross-sectional postal questionnaire used to collect data from a stratified sample of the population 65 years and older residing in the two largest cities of a county (Östergötland) in the southeast of Sweden. The five strata consisted of inhabitants in the ages 65 to 69 years, 70 to 74 years, 75 to 79 years, 80 to 84 years, and 85 years or older. A questionnaire was mailed in October 2012 and was followed by 2 postal reminders, if necessary. The first reminder was mailed approximately two weeks after the questionnaire was sent out and the second reminder after approximately another two weeks. The collection of questionnaires closed in January 2013.

The study was approved by the Regional Ethics Research Committee in Östergötland, Sweden (D.nr. 2012/154-31). The sample population consisted of approximately 49 320 persons in the age group 65 years and older. A random sample of 2000 subjects was selected in each strata from the national population register by Statistics Sweden (SCB), making a total of 10 000 selected subjects.

The second survey was a postal questionnaire to collect data regarding relatives of elderly individuals who had reported in the first survey that they needed help from their relatives due to pain.

2.2 Subjects

A total of 10 000 inhabitants were selected from the sample population and 3261 of these did not participate or did not return the questionnaire; 58 of these subjects were not reachable. The net response rate was 67.3%; however, some respondents failed to answer a number of vital questions, leaving a total of 66.6% (6618) valid responses.

For analytical purposes the population was subdivided into three groups with respect to having chronic pain or not, and a pain intensity during the last week of: 0–4 (mild), 5–7 (moderate), and 8–10 (severe) on a scale of 0–10 (2, 3).
2.3 Methods

2.3.1 The elderly subjects’ questionnaire

In this section the questionnaire distributed to the almost 10 000 randomly selected subjects is briefly described. For a detailed description, see Appendix 2.

The subjects answered a questionnaire composed of the following variables and instruments:

- **Demographic and anthropometric data** (age, sex, residence, etc.)
- **Satisfaction with aspects of life** using LISAT-11 (4)
- **Exercise habits** using Godin Leisure-Time Exercise Questionnaire (5)
- **Nicotine and alcohol habits** (6)
- **Perceived state of health** using the EuroQol instrument (7, 8)
- **Comorbidities** (12 items covering different common comorbidities)
- **Aspects of pain** (presence, duration, intensity, frequency, localization of pain, health-care seeking, consumption of pain killers) (9-15)
- **Consumption of drugs** (prescribed) last 2 weeks
- **Consumption of drugs** (non-prescribed) last 2 weeks
- **Working situation** (currently working to any extent? when last gainfully employed?)
- **Highest education**
- **Social support** using the Oslo-3 Social Support Scale (OSS-3) (16, 17)
- **Financial resources and social support** (two questions)
- **Participation aspects** using the West Haven-Yale Multidimensional Pain Inventory (WHY) (18, 19)
- **The Pain Catastrophizing Scale (PCS)** (20, 21)
- **Distress** using the General Well-being Schedule (GWBS) (22)
- **Happiness** using two internally developed questions
- **Vitality** (internally developed question)
- **Sleeping problems** using the Insomnia Severity Index (ISI) (23, 24)
- **Help from relatives**

2.3.2 The relatives’ questionnaire

To identify informal caregivers, persons responding to the main questionnaire were asked whether they were receiving help and support from a relative. If they were, we asked their consent for us to contact their main caregiver, together with that relative’s contact details. Consumption of informal care, that is, care provided by persons related to those in need of support, was retrieved by use of
a questionnaire directed towards relatives. In the questionnaire they were asked about what kind of support they provided and how many hours they spent caring for their relative.

The relatives’ questionnaire was also intended to get information on the situation and well-being of informal caregivers.

2.3.3 Health care costs

Data on inpatient (hospital days and treatments) and outpatient (visits to various categories of personnel) care were retrieved from the Health Care Register in Östergötland (HCRÖ) (Swedish: Vårddatalagret, VDL). The HCRÖ is an administrative register containing information on all health care provided by the county council. For all visits or hospitalizations records include date, name, personal ID number, and diagnosis (main diagnosis and secondary diagnosis according to ICD-10).

All health care consumption related to the persons participating in this study was retrieved from the HCRÖ by matching the personal ID numbers to the database. The health care consumption retrieved from the HCRÖ was priced by use of the Cost Per Patient (CPP) database, containing diagnosis-related costs per patient. The detailed costs in the CPP database are administered by the Swedish association of local authorities and regions and (Sveriges kommuner och landsting, SKL).1

2.3.4 Register on prescription of drugs

The National Board of Health and Welfare (Socialstyrelsen)2 maintains a register on drug prescription. The register contains information on prescribed medications that have been retrieved by patients. The register can be merged with other registers in order to connect prescribed and retrieved drugs to specific diagnoses or individuals.

For each prescription the drug register contains information on the patient, prescribed drug, relevant diagnosis, cost, and profession and workplace of the prescriber.

Information on all prescribed and then retrieved drugs related to the participants in our study was gathered by matching the personal ID numbers to the register.

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1 https://stat.skl.se/kpp/index.htm
2 http://www.socialstyrelsen.se/statistik/statistikdatabas/lakemedel
2.3.5 Municipal costs

Information on costs incurred by the municipalities for home help services and special housing was retrieved from registers held by the municipalities in the study. In the registers all consumption of the different home help services is registered, with hours and prices attached to each service. Also the number of days in special housing is registered, and total cost can be calculated by use of the standard cost per day.

The municipal registers also contain personal ID numbers, which were used to match the data to persons participating in our study.

2.3.6 Quality of life

In the main questionnaire the instrument EuroQol-5D (EQ-5D) for measuring health-related quality of life was included. The EQ-5D instrument contains five questions concerning the dimensions mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. There are three alternative answers to each question/dimension: no problems, moderate problems, and severe problems. Five dimensions with three different levels yield 243 possible combinations. Each combination can be transformed into an index value, corresponding to a quality-adjusted life-year (QALY) weight. The transformation is made using a value set created from a population study in the UK in which a large number of persons were asked to value different combinations by use of a direct valuation method (the time trade-off technique). The index value is on a scale where zero equals dead and 1 equals perfect health. Negative values (<0), that is, worse than dead, can be obtained when using this value set.

The EQ-5D also contains a visual analogue scale (VAS) between 0 and 100, where zero is the worst imaginable health state and 100 is the best imaginable health state. The VAS is an alternative, direct method for eliciting an index value.

2.4 Statistics

All data files, and analysis of data, were handled with SPSS version IBM Statistics 20.

The outcome in costs for the three chronic pain groups was tested with ANOVA, and the result was adjusted for sex and age. The age component, in particular,
should be adjusted for when testing the different costs across the groups. ANOVA was used for the statistical analysis of costs for health care, drug acquisition, and municipal home services. The limit of significance was set to the probability of 5% (p being less than or equal to 0.050).

Stepwise regression analyses were undertaken to investigate whether chronic pain is a significant determinant of costs when controlling for other variables that can be suspected to influence costs.
3. RESULTS

Results on costs, that is, resource consumption, and quality of life are presented and summarized in this chapter. Results are presented for subgroups of the population studied.

The valid study population consisted of 6618 subjects. The study population consisted of 54% women and 46% men. Average age was 76.2 years, stretching from 65 to 102 years. Of the study population 76.9% were categorized as having no or mild chronic pain, 18.9% as having moderate chronic pain, and 4.2% as having severe chronic pain.

3.1 Cost of chronic pain

3.1.1 Health care costs

All costs are expressed as costs per year (2012 prices). Cost data were gathered over one year, from November 2011 to October 2012.

Consumption and costs of health care resources are presented in Table 1.

Table 1. Health care costs (SEK) per person per year, for persons with different grades of chronic pain.

<table>
<thead>
<tr>
<th>Cost Item</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 5088)</th>
<th>Persons with moderate chronic pain (5–7) (n = 1249)</th>
<th>Persons with severe chronic pain (8–10) (n = 281)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital days</td>
<td>Consumption Cost</td>
<td>Consumption Cost</td>
<td>Consumption Cost</td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>0.97</td>
<td>1.40</td>
<td>1.97</td>
<td>0.012</td>
</tr>
<tr>
<td>Total care cost</td>
<td>10 391</td>
<td>13 951</td>
<td>17 836</td>
<td>0.012</td>
</tr>
<tr>
<td>Visits, outpatient and primary care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>Consumption Cost</td>
<td>Consumption Cost</td>
<td>Consumption Cost</td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>2.60</td>
<td>10 609</td>
<td>3.75</td>
<td>15 216</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>0.54</td>
<td>417</td>
<td>0.95</td>
<td>682</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>0.21</td>
<td>438</td>
<td>0.32</td>
<td>842</td>
</tr>
<tr>
<td>Other</td>
<td>4.84</td>
<td>3156</td>
<td>7.06</td>
<td>4863</td>
</tr>
<tr>
<td>Total, outpatient</td>
<td>8.19</td>
<td>14 619</td>
<td>12.08</td>
<td>21 603</td>
</tr>
<tr>
<td>Total health care</td>
<td>25 010</td>
<td>35 554</td>
<td>44 959</td>
<td></td>
</tr>
</tbody>
</table>
differences. Persons in the group with the most severe chronic pain consume on average almost double compared to persons in the no or mild chronic pain group. The additional health care consumption is evenly distributed between inpatient and outpatient care.

Average costs for persons in the moderate chronic pain group are almost exactly midway between the mildest and the most severe groups.

### 3.1.2 Costs for prescribed drugs

Costs for prescribed and retrieved drugs are presented in **Table 2**.

**Table 2.** Costs for prescribed and retrieved drugs (SEK) per person per year, for persons with different grades of chronic pain.

<table>
<thead>
<tr>
<th>Drug</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 5088)</th>
<th>Persons with moderate chronic pain (5–7) (n = 1249)</th>
<th>Persons with severe chronic pain (8–10) (n = 281)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analgesics</td>
<td>107</td>
<td>416</td>
<td>1039</td>
<td>0.000*</td>
</tr>
<tr>
<td>Anti-inflammatory, antirheumatics, and 5 other drugs**</td>
<td>46</td>
<td>167</td>
<td>410</td>
<td></td>
</tr>
<tr>
<td>Antidepressants, tranquilizers, and sleeping pills</td>
<td>66</td>
<td>122</td>
<td>218</td>
<td></td>
</tr>
<tr>
<td>Other drugs</td>
<td>3644</td>
<td>4880</td>
<td>6366</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>3863</strong></td>
<td><strong>5585</strong></td>
<td><strong>8033</strong></td>
<td><strong>0.000</strong></td>
</tr>
</tbody>
</table>

*Significance test undertaken for the two items together.

**pregabalin, gabapentin, duloxetine, venlafaxine, amitriptyline

As seen in **Table 2**, a pattern similar to that of health care costs emerges concerning costs for prescribed drugs. Average costs increase with the severity of chronic pain for all drug groups presented. Significance tests undertaken again indicate highly significant differences. Total costs for prescribed drugs are more than twice as high for persons with severe chronic pain compared to those in the no or mild chronic pain group.

Average costs for persons in the moderate chronic pain group are a little closer to those for the mildest group, that is, the most severe group stands out a little more clearly concerning prescribed drugs than health care.
3.1.3 Costs for municipal services

Costs incurred by the municipalities are presented in Table 3.

**Table 3. Municipal costs (SEK) per person per year for persons with different grades of chronic pain.**

<table>
<thead>
<tr>
<th>Cost item</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 5088)</th>
<th>Persons with moderate chronic pain (5–7) (n = 1249)</th>
<th>Persons with severe chronic pain (8–10) (n = 281)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home help services</td>
<td>3991</td>
<td>5386</td>
<td>15 470</td>
<td>0.000</td>
</tr>
<tr>
<td>Special housing (days)</td>
<td>5585</td>
<td>5407</td>
<td>13 376</td>
<td>0.136</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>9576</td>
<td>10 793</td>
<td>28 846</td>
<td></td>
</tr>
</tbody>
</table>

In Table 3, concerning municipal costs, it can be seen that costs increase with the severity of chronic pain. Average costs for persons in the most severe group are three times those for persons in the no or mild chronic pain group. When costs are separated according to home help services and special housing, significance tests indicate significant differences concerning home help services but not special housing, although a clear trend towards higher costs for the severe chronic pain group can be discerned.

For municipal costs the most severe group stands out very clearly, as average costs in the moderate chronic pain group are only slightly higher than those for the mildest group. This might depend on the fact that the persons in the study are on average quite old and in certain need of municipal services, even if not affected by chronic pain. When experiencing severe chronic pain, a care recipient’s need of help and services seems to rise steeply.

3.1.4 Informal care cost

In the elderly subjects’ questionnaire respondents were asked to state whether they were receiving help from a relative to manage their everyday life. Respondents receiving help were also asked for permission for us to contact the relative, and to state the name and contact information of the relative. Of all respondents 249 stated that they received help, and the relatives’ questionnaire was answered by 128 relatives. Of these, 38 (30%) were relatives of persons with no or mild chronic pain, 55 (43%) were relatives of persons with moderate chronic pain, and 35 (27%) were relatives of persons with severe chronic pain.

The relatives answering the questionnaire reported their time spent to help/support with different chores, as reported in Table 4.
Table 4. Average number of hours used for different chores during a 28-day period for the 128 respondents (hours per day within parentheses).

<table>
<thead>
<tr>
<th>Activity/chore</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 38)</th>
<th>Persons with moderate chronic pain (5–7) (n = 55)</th>
<th>Persons with severe chronic pain (8–10) (n = 35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shopping</td>
<td>7.6 (0.3)</td>
<td>13.7 (0.5)</td>
<td>18.1 (0.6)</td>
</tr>
<tr>
<td>Cooking</td>
<td>36.7 (1.3)</td>
<td>15.0 (0.5)</td>
<td>22.4 (0.8)</td>
</tr>
<tr>
<td>Cleaning</td>
<td>5.2 (0.2)</td>
<td>11.6 (0.4)</td>
<td>10.9 (0.4)</td>
</tr>
<tr>
<td>Washing clothes</td>
<td>4.6 (0.2)</td>
<td>4.7 (0.2)</td>
<td>6.0 (0.2)</td>
</tr>
<tr>
<td>Getting around outside the home</td>
<td>6.0 (0.2)</td>
<td>7.6 (0.3)</td>
<td>12.3 (0.4)</td>
</tr>
<tr>
<td>Taking medication</td>
<td>1.0 (0.0)</td>
<td>1.7 (0.1)</td>
<td>4.9 (0.2)</td>
</tr>
<tr>
<td>Handling finances</td>
<td>1.4 (0.1)</td>
<td>1.6 (0.1)</td>
<td>2.0 (0.1)</td>
</tr>
<tr>
<td>Miscellaneous*</td>
<td>9.0 (0.3)</td>
<td>10.8 (0.4)</td>
<td>11.6 (0.4)</td>
</tr>
<tr>
<td>Being available</td>
<td>146.1 (5.2)</td>
<td>123.4 (4.4)</td>
<td>183.7 (6.6)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>71.5 (2.6)</td>
<td>66.9 (2.4)</td>
<td>88.3 (3.2)</td>
</tr>
</tbody>
</table>

*Miscellaneous domestic chores
**The sum of all chores, except “being available”

Costs for production loss related to informal care, that is, worktime spent by relatives in caring activities, are presented in Table 5.
Table 5. The number of workdays during the last 4 weeks that the respondent could not work due to helping their relative.

<table>
<thead>
<tr>
<th>Persons without (or with mild) chronic pain (0-4)</th>
<th>Persons with moderate chronic pain (5-7)</th>
<th>Persons with severe chronic pain (8-10)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persons working</td>
<td>9</td>
<td>23</td>
<td>8</td>
</tr>
<tr>
<td>Whole workday</td>
<td>2</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Part of workday</td>
<td>1</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Any work</td>
<td>3</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>Days, total</td>
<td>Whole workday</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Part of workday</td>
<td>20</td>
<td>14</td>
<td>34</td>
</tr>
<tr>
<td>Sum, full-time equivalent</td>
<td>14</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td>Hours, total</td>
<td>112</td>
<td>144</td>
<td>56</td>
</tr>
<tr>
<td>Production loss (SEK)</td>
<td>Total</td>
<td>29 232</td>
<td>37 584</td>
</tr>
<tr>
<td>Average (128 persons)</td>
<td>769</td>
<td>683</td>
<td>418</td>
</tr>
</tbody>
</table>

*Assumption that “part of day” = 50%

The cost of a workday was calculated as average wage (Sweden, 2012) plus taxes, in accordance with the human capital method. The average wage was 29 800 SEK and taxes were 40%, making the value of a workday SEK 2066 and the value of a work hour SEK 261.

A method, based on neoclassical economic theory, for valuing leisure time (on the margin) is to use the average wage minus income taxes, as this is the compensation that an employee gets for working a day or an hour. Income tax is here approximated to be 25%, which makes the cost of an hour of leisure time equal to 29 800 * 0.75 / 160 = SEK 140. As most of the informal caregivers in this study were retired, the value of an hour of leisure time is halved, that is, set to SEK 70.

Subtracting work hours from the total number of hours spent helping/caring gives the leisure time hours used; see Table 6.
Table 6. Leisure time hours spent on helping relatives, and the associated costs.

<table>
<thead>
<tr>
<th>Persons without (or with mild) chronic pain (0–4) (n = 38)</th>
<th>Persons with moderate chronic pain (5–7) (n = 55)</th>
<th>Persons with severe chronic pain (8–10) (n = 35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leisure time, hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2605</td>
<td>3535</td>
<td>3034</td>
</tr>
<tr>
<td>Hours per person</td>
<td>69</td>
<td>64</td>
</tr>
<tr>
<td>Cost per person (SEK)</td>
<td>9660</td>
<td>8960</td>
</tr>
</tbody>
</table>

In the elderly subjects’ questionnaire 249 respondents reported that they received help from a relative. Of these relatives 128 responded to the relatives’ questionnaire. The 121 relatives not responding were distributed as follows: 73 relatives of persons with no or mild chronic pain, 32 relatives of persons with moderate chronic pain, and 16 relatives of persons with severe chronic pain. The average hours and costs for the 128 respondents are assumed to be valid for all 249 receiving help. Extrapolating results to the group of 249 persons yields hours and costs according to Table 7.

Table 7. Hours of work time and leisure time spent helping, and the associated costs.

<table>
<thead>
<tr>
<th>Persons without (or with mild) chronic pain (0–4) (n = 111)</th>
<th>Persons with moderate chronic pain (5–7) (n = 87)</th>
<th>Persons with severe chronic pain (8–10) (n = 51)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work hours per person</td>
<td>2.95</td>
<td>2.62</td>
</tr>
<tr>
<td>Work time, hours</td>
<td>327</td>
<td>228</td>
</tr>
<tr>
<td>Cost of work hours (SEK)</td>
<td>85 347</td>
<td>59 508</td>
</tr>
<tr>
<td>Leisure hours per person</td>
<td>69</td>
<td>64</td>
</tr>
<tr>
<td>Leisure time, hours</td>
<td>7659</td>
<td>5568</td>
</tr>
<tr>
<td>Cost of leisure hours (SEK)</td>
<td>536 130</td>
<td>389 760</td>
</tr>
<tr>
<td>Cost, total (SEK)</td>
<td>621 477</td>
<td>449 268</td>
</tr>
</tbody>
</table>

From Table 7 the conclusion might be drawn that persons with severe chronic pain consume less informal care than persons with less severe chronic pain. It must be remembered, however, that the proportion of persons in the most severe group that receive help from relatives (51/281) is much higher than for the less severe groups (87/1249 and 111/5088, respectively). So, looking at the entire study population, the average consumption of informal care is highest in the most severe group.
In Table 8 the above results are translated into figures for the whole population of the study. The results for the subgroup of receivers of help are averaged over the whole study population of 6618 persons. The group of 249 persons constitutes 3.76% of the total study population.

Costs related to informal care are summarized in Table 8.

**Table 8. Informal care costs per person (SEK) over 28 days, for persons with different grades of chronic pain (whole study population).**

<table>
<thead>
<tr>
<th>Cost item</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 5088)</th>
<th>Persons with moderate chronic pain (5–7) (n = 1 249)</th>
<th>Persons with severe chronic pain (8–10) (n = 281)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Consumption</td>
<td>Cost</td>
<td>Consumption</td>
</tr>
<tr>
<td>Working hours</td>
<td>0.06</td>
<td>17</td>
<td>0.18</td>
</tr>
<tr>
<td>Leisure time</td>
<td>1.51</td>
<td>105</td>
<td>4.46</td>
</tr>
<tr>
<td>Total</td>
<td>122</td>
<td>360</td>
<td>1181</td>
</tr>
<tr>
<td>Per year*</td>
<td>1586</td>
<td>4680</td>
<td>15 353</td>
</tr>
</tbody>
</table>

*As the period studied was 4 weeks, the totals are multiplied by 13 to get annual costs.

When extrapolated to the whole study population the pattern is very clear that increased severity of chronic pain is associated with increased informal care costs. Persons in the most severe group consume more than three times as much formal care as persons in the moderate chronic pain group, and almost ten times as much as persons in the no or mild chronic pain group.
3.1.5 Total societal cost

In Table 9 the costs presented in Tables 1, 2, 3, and 8 are summarized. Table 9 presents costs per person averaged over the whole study population.

**Table 9. Summary of annual costs (SEK) per person with different grades of chronic pain.**

<table>
<thead>
<tr>
<th>Cost type</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 5 088)</th>
<th>Persons with moderate chronic pain (5–7) (n = 1 249)</th>
<th>Persons with severe chronic pain (8–10) (n = 281)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health care</td>
<td>25 010</td>
<td>35 554</td>
<td>44 959</td>
<td>0.000*</td>
</tr>
<tr>
<td>Drugs</td>
<td>3863</td>
<td>5585</td>
<td>8033</td>
<td></td>
</tr>
<tr>
<td>Municipal services</td>
<td>95.76</td>
<td>10 793</td>
<td>28 846</td>
<td></td>
</tr>
<tr>
<td>Informal care</td>
<td>1586</td>
<td>4680</td>
<td>15 353</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>40 035</strong></td>
<td><strong>56 612</strong></td>
<td><strong>97 191</strong></td>
<td></td>
</tr>
</tbody>
</table>

*Significance test undertaken for the two items together.

The societal costs summarized follow the same pattern as the included cost items. On average, persons in the most severe group cost 72% more than persons in the moderate group, and 143% more than persons in the no or mild chronic pain group. The significance test for health care and drug costs combined indicates highly significant differences.

3.2 EQ-5D

The health-related quality of life of persons with different grades of chronic pain is presented in Table 10. Results on both the EQ-5D profile and EQ-VAS are presented.

**Table 10. Health-related quality of life measured by EQ-5D.**

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Persons without (or with mild) chronic pain (0–4) (n = 5040)</th>
<th>Persons with moderate chronic pain (5–7) (n = 1235)</th>
<th>Persons with severe chronic pain (8–10) (n = 280)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>76.0%</td>
<td>45.4%</td>
<td>24.7%</td>
</tr>
<tr>
<td>Self-care</td>
<td>95.8%</td>
<td>90.5%</td>
<td>77.5%</td>
</tr>
<tr>
<td>Usual activities</td>
<td>92.1%</td>
<td>78.2%</td>
<td>59.3%</td>
</tr>
<tr>
<td>Pain/discomfort</td>
<td>40.9%</td>
<td>1.7%</td>
<td>1.5%</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>75.7%</td>
<td>58.2%</td>
<td>43.7%</td>
</tr>
</tbody>
</table>

| Index                   | 0.812 (CI 0.806–0.818)                                          | 0.629 (CI 0.617–0.641)                             | 0.385 (CI 0.360–0.410)                          |
| VAS score 0–100         | 75.6 (n = 4 917)                                                | 61.5 (n = 1 213)                                   | 48.0 (n = 276)                                  |
As can be seen in Table 10, differences are very clear between people with different degrees of pain for the index value and the VAS score, and for each of the five dimensions. The least evident difference concerns the dimension of self-care. The differences detected clearly show the association between existence and degree of chronic pain and the health-related quality of life experienced.

### 3.3 The relation between chronic pain and costs

Stepwise regression analyses were undertaken to investigate whether chronic pain is a significant determinant of costs when controlling for other variables that can be suspected to influence costs. Total health care costs and the parts making up health care costs, that is, outpatient care, inpatient care, and drugs were all analyzed using the following variables as determinants:

- Chronic pain (>4) (yes/no)
- Chronic pain (>7) (yes/no)
- Comorbidity (at least one)
- Comorbidity (at least three different)
- Comorbidity (at least five different)
- Traumatic accident (yes/no)
- Rheumatic arthritis and arthritis (yes/no)
- Diseases of heart and vessels (yes/no)
- Diseases of airways and lungs (yes/no)
- Low mood and depression (yes/no)
- Anxiety (yes/no)
- Diseases of the gastrointestinal organs (yes/no)
- Diseases of the nervous system (yes/no)
- Diseases of the urogenital organs (yes/no)
- Diseases of the skin (yes/no)
- Tumors and cancer (yes/no)
- Metabolic diseases (yes/no)
- Sex (male?)
- Age (years)
- Education, more than elementary (yes/no)
- Education, more than secondary (yes/no)
- Finances, able to solve pinch (yes/no)
- Home help service (yes/no)
- Special housing (yes/no)

The explanatory power was low throughout all regression analyses undertaken. The important finding, however, was that chronic pain (>7) remained a
significant explanatory variable in all analyses except in the regression explaining inpatient costs.

In the regression analysis explaining total health care costs, chronic pain (>7) was significant. We also divided the patients into a normal cost group and a high cost group and ran a logistic regression. In this analysis chronic pain (>7) remained a significant explanatory variable.

In the regression analysis explaining outpatient care costs, chronic pain (>7) was a significant explanatory variable.

In the regression analysis explaining inpatient care costs, chronic pain did not enter the regression model as an explanatory variable.

In the regression analysis explaining costs for prescribed and retrieved drugs, chronic pain (>7) was a significant explanatory variable.
4. DISCUSSION

In this study of the societal cost of chronic pain in an elderly population, postal questionnaires were sent to 10,000 random persons in the municipalities of Linköping and Norrköping, both situated in the county of Östergötland in the southeast of Sweden. The target population, that is, those 65 years and older who resided in the two municipalities, was approximately 50,000 persons. The response rate to the questionnaire was 66.6% after two postal reminders. A number of registers were used to obtain data on consumption of health care, drugs, and municipal services of individuals in the study population.

The results of the study show that costs are clearly associated with the existence and severity of chronic pain. This relation is evident for all kinds of resource use studied. Health care costs differed significantly for the three groups having no/mild, moderate, and severe chronic pain. Outpatient care costs are underestimated due to the fact that data from private caregivers were not included in the data capture. A possible bias concerning the municipal costs relates to the fact that we could only get usable data from one of the two included municipalities (Linköping). Concerning the municipal costs, the group with the most severe chronic pain stands out as a large consumer of resources. Differences between the group with no or mild chronic pain and the group with moderate chronic pain are in some cases surprisingly small, especially concerning costs related to municipal services. This might be due to the fact that the study population was elderly, implying a rather high consumption of care-related resources irrespective of the existence or not of chronic pain. It might be that resources consumed due to problems with chronic pain become really notable only for the group with the most severe chronic pain. This, of course, depends on how sharp the division into no/mild, moderate, and severe chronic pain. We chose rather strict criteria to include persons in the severe chronic pain group (8–10 on a scale of 0–10). If less strict criteria for inclusion in the most severe group had been used, the differences in costs between groups would most certainly have been smaller.

One other striking result is the very large impact of the existence and severity of chronic pain on the quality of life of the persons affected. Using the EQ-5D index, the average quality of life values were 0.81, 0.63, and 0.38 in the no/mild, moderate, and severe chronic pain groups, respectively. Using the EQ-VAS, differences were a little less marked but still clearly significant.

Our results indicate that the cost to society, in terms of health care, drugs, municipal services, and informal care, for the average person 65 years or older, is 45,600 SEK, as calculated from Table 9.
The municipalities studied, Linköping and Norrköping, together have approximately 50,000 inhabitants 65 years and older, which would translate into a total cost of 2.3 billion SEK. We assume that our municipalities are representative for Sweden (approximately 1.8 million inhabitants 65 years and older). This would imply that costs attributable to people 65 years and older add up to 84 billion SEK for Sweden. These costs can be seen as the cost of an aging population.

The additional cost of chronic pain that is more severe than mild, that is, for moderate and severe chronic pain, is on average 5534 SEK per person 65 years and older. This means that for Linköping and Norrköping together the additional cost of the presence of chronic pain that is worse than mild is 278 million SEK. For Sweden the additional cost of the presence of chronic pain worse than mild amounts to 10.2 billion SEK.

In a Swedish study (25) the authors estimated the direct and indirect costs of patients with a diagnosis related to chronic pain (DRCP). The mean total cost per patient and year was estimated at 6400 EUR (SEK 56,000), which should be compared to the cost of the average person 65 years or older of 45,600 SEK found in this study. The estimation of DRCP is not intended to estimate the cost of pain, as there is evident risk that the cost of pain would be overestimated, since many have the diagnosis without pain. A strength of our study is that the pain classification is based on the patients’ own evaluations.

A fact that distinguishes this study from other similar ones is that we have been able to include costs incurred by the municipalities, making this study more complete compared to its predecessors.

A possible weakness in the study lies in the gathering of data on informal care. For the purpose of estimating time spent by relatives caring for persons with chronic pain, the relatives’ questionnaire was used. Some internal loss of data was experienced, as some questions could apparently be misunderstood. A related issue is how to value the relatives’ loss of leisure time due to informal care efforts. Traditionally, on the margin, an hour of leisure time is valued at the net hourly wage, because this is what would have been earned if the hour had instead been spent on work. In our study population many of the caring relatives were retired. For those retired, the alternative use of hours spent caring was not to work but to pursue leisure activities. From a strict loss-of-production point of view it could be argued that the value of leisure time is zero. We do not agree with setting the value at zero, as many elderly people produce value, even if not through paid labor, for instance, performing babysitting, household work,

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3 Calculated as \((56,612 - 40,035) \times 0.189 + (97,191 - 40,035) \times 0.042 = 5534\) (see Table 9).
gardening, and so forth. Therefore, we decided to set the value of leisure time to half the average net hourly wage. Setting a lower value (or even zero) would, of course, affect our results, but not in a decisive way; the marked differences between the groups would persist.

In this study, reaching a rather large part of the target population, it is shown that existence and severity of chronic pain among people 65 years of age and older affects costs to society and the quality of life of affected individuals in a massive way.
5. REFERENCES

6. APPENDICES

6.1 Appendix 1. Adjustment weights for different strata regarding age, gender and loss of respondents

The total figures for respondents are not representative of figures for the population, not only because of a great loss of respondents but also because of the respondents’ deviation toward the population, regarding age and gender. To get age-adjusted figures, each respondent was weighted with the weight option in SPSS.

Weights for adjusting the number of respondents in each stratum toward the population average were made for gender and municipality, respectively. Each stratum is defined by age, where:

- Stratum 1 equal 65–69 years
- Stratum 2 equal 70–74 years
- Stratum 3 equal 75–79 years
- Stratum 4 equal 80–84 years
- Stratum 5 equal 85 years and older

The following figure shows how the proportion of respondents compares to the proportion of residents for each stratum (i.e., the populations in the two cities). Strata 2 and 5 have about equal proportions, and therefore the weight will be close to 1 for respondents in these strata. However, small variations can occur, since the weights are calculated within each stratum for sex and city of residence, respectively. A weight greater than 1 indicates that the respondents are fewer in proportion compared to the population, while a weight smaller than 1 indicates that the respondents have a greater proportion in the study compared to the population.
Adjusting weights for the respondents from Linköping

<table>
<thead>
<tr>
<th>Stratum</th>
<th>Mean</th>
<th>N</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Men</td>
<td>1.3200</td>
<td>376</td>
<td>0.00000</td>
</tr>
<tr>
<td>2</td>
<td>1.0200</td>
<td>351</td>
<td>0.00000</td>
</tr>
<tr>
<td>3</td>
<td>.7700</td>
<td>358</td>
<td>0.00000</td>
</tr>
<tr>
<td>4</td>
<td>.6600</td>
<td>296</td>
<td>0.00000</td>
</tr>
<tr>
<td>5</td>
<td>.8700</td>
<td>209</td>
<td>0.00000</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>1590</td>
<td></td>
</tr>
<tr>
<td>2 Women</td>
<td>1.4100</td>
<td>367</td>
<td>0.00000</td>
</tr>
<tr>
<td>2</td>
<td>1.0600</td>
<td>381</td>
<td>0.00000</td>
</tr>
<tr>
<td>3</td>
<td>.8500</td>
<td>374</td>
<td>0.00000</td>
</tr>
<tr>
<td>4</td>
<td>.7600</td>
<td>351</td>
<td>0.00000</td>
</tr>
<tr>
<td>5</td>
<td>1.0700</td>
<td>319</td>
<td>0.00000</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>1792</td>
<td></td>
</tr>
</tbody>
</table>

Adjusting weights for the respondents from Norrköping

<table>
<thead>
<tr>
<th>Stratum</th>
<th>Mean</th>
<th>N</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Men</td>
<td>1.5300</td>
<td>348</td>
<td>0.00000</td>
</tr>
<tr>
<td>2</td>
<td>.9400</td>
<td>372</td>
<td>0.00000</td>
</tr>
<tr>
<td>3</td>
<td>.8400</td>
<td>301</td>
<td>0.00000</td>
</tr>
<tr>
<td>4</td>
<td>.6600</td>
<td>275</td>
<td>0.00000</td>
</tr>
<tr>
<td>5</td>
<td>.8600</td>
<td>171</td>
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</tr>
<tr>
<td>Total</td>
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<td></td>
</tr>
<tr>
<td>2 Women</td>
<td>1.3700</td>
<td>397</td>
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</tr>
<tr>
<td>2</td>
<td>1.0000</td>
<td>392</td>
<td>0.00000</td>
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<tr>
<td>3</td>
<td>.8300</td>
<td>364</td>
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<td>4</td>
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</tr>
<tr>
<td>5</td>
<td>1.0900</td>
<td>280</td>
<td>0.00000</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>1762</td>
<td></td>
</tr>
</tbody>
</table>
Example of the effect of adjusting for sex and age. Outcome for the question regarding overall physical health (Question F6b)

<table>
<thead>
<tr>
<th>Unadjusted figures</th>
<th>Frequency</th>
<th>Percentage</th>
<th>Valid Percentage</th>
<th>Cumulative Percentage</th>
</tr>
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<tr>
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<td>2.2</td>
<td>2.2</td>
<td>2.2</td>
</tr>
<tr>
<td>Valid Bad</td>
<td>428</td>
<td>6.5</td>
<td>6.6</td>
<td>8.8</td>
</tr>
<tr>
<td>Valid Rather bad</td>
<td>760</td>
<td>11.5</td>
<td>11.7</td>
<td>20.4</td>
</tr>
<tr>
<td>Valid Rather good</td>
<td>2448</td>
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<td>37.5</td>
<td>58.0</td>
</tr>
<tr>
<td>Valid Good</td>
<td>2295</td>
<td>34.7</td>
<td>35.2</td>
<td>93.2</td>
</tr>
<tr>
<td>Valid Very good</td>
<td>445</td>
<td>6.7</td>
<td>6.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>6521</td>
<td></td>
<td>98.6</td>
<td>100.0</td>
</tr>
<tr>
<td>Missing</td>
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<td></td>
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<td></td>
</tr>
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<td>Total</td>
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<td>1.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
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<td></td>
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</table>

<table>
<thead>
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<th>Percentage</th>
<th>Valid Percentage</th>
<th>Cumulative Percentage</th>
</tr>
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<td>2.1</td>
<td>2.1</td>
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<tr>
<td>Valid Bad</td>
<td>409</td>
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</tr>
<tr>
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<td>2413</td>
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<td>36.9</td>
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<td>2367</td>
<td>35.8</td>
<td>36.2</td>
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<tr>
<td>Valid Very good</td>
<td>481</td>
<td>7.3</td>
<td>7.4</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
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There is a small downsizing effect of the adjustment for the group with Very bad or Bad physical health, from 8.8% to 8.4%, and a more significant upsizing effect for the group that reported Very good or Good physical health, from 42.0% to 43.6%. This can be explained by the lower weights for elderly respondents and higher weights for the youngest respondents in stratum 1, when it is plausible that the older respondents have more physical ailments compared to the younger ones.
6.2 Appendix 2. The elderly subjects’ questionnaire

The subjects answered a questionnaire composed of the following variables and instruments:

**Demographic and anthropometric data:** These included year born, sex, registered residence (Linköping or Norrköping), height (cm), weight (kg), and satisfaction with weight (a five-graded scale with the endpoints “weighs more than 10 kg too much” and “weighs more than 10 kg too little”). Body mass index (BMI) was calculated as weight/height² (Kg/m²).

**Satisfaction with aspects of life:** Three items were selected from LISAT-11 (26), which captures the patient’s estimations of satisfaction with life as a whole (LISAT-life) as well as satisfaction in ten specific domains. In the present study we chose LISAT-life, and two specific items: somatic health (LISAT-somhealth) and psychological health (LISAT-psychhealth).

**Exercise habits:** The Godin Leisure-Time Exercise Questionnaire was chosen to capture usual exercise habits (27). The instrument contains four questions where the person states how many times weekly he/she does “strenuous” “moderate,” and “mild” exercise, respectively. The different intensities are described with examples in the questionnaire. A total leisure activity score is calculated by the times per week stated for the different intensities multiplied by 9 for strenuous, 5 for moderate, and 3 for mild. A high score (here denoted as GLTEI) indicates higher intensity and higher frequency of weekly leisure-time activities (28).

**Nicotine and alcohol habits:** From the instrument the “Health Curve” (in Swedish: Hälsokurvan) (6) we chose four questions concerning smoking and taking snuff, concerning both frequency (from never to daily habit) and number of cigarettes per day (three alternatives ranging from 1–9 to 20 or more) and number of snuff boxes per week (from 1–3 per week to 7 or more per week). Five questions concerned alcohol habits.

**Perceived state of health:** The EuroQol instrument captures a patient’s perceived state of health (7, 8). A state of health is defined as combinations of five dimensions and three levels of choice (no problems, some problems, or severe problems) for each dimension: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. This descriptive system covers the first part of the instrument. The answers are coded 1–3. The codings are transformed by a table or by using an algorithm to score the findings (EQ-5D) on a scale between zero and one (negative values can be obtained)(29). A second part
concerns a self-estimation of today’s health according to a 100-point scale, a “thermometer” (EQ-VAS) with defined endpoints (high value indicates good health and low value indicates bad health). Thus, the two parts comprise different aspects of health-related quality of life. In this study, as well as the specific item values, the total score as the self-estimation scale are used.

**Comorbidities:** This aspect was captured with 12 items covering different common comorbidities: (1) traumatic accident, (2) rheumatic arthritis and arthritis, (3) diseases of heart and vessels (including high blood pressure, angina pectoris, and heart attacks), (4) diseases of airways or lungs, (5) low mood and depression, (6) anxiety, (7) diseases of the gastrointestinal organs, (8) diseases of the nervous system, including eyes and ears, (9) diseases of the urogenital organs, (10) diseases of the skin, (11) tumors and cancer, and (12) metabolic diseases (including diabetes, obesity, anorexia, bulimia, and struma). These comorbidities were reported on a five-graded scale: (a) no; (b) yes, according to both my and my doctor’s opinions; (c) yes, according to my own opinion; (d) yes, according to my doctor’s opinion; or (e) do not know.

**Aspects of pain:** This area was covered by several questions.

*Presence and duration of pain:* (a) no; (b) yes, with less duration than three months; or (c) yes, with a duration of more than 3 months.

*Pain in last 7 days:* (a) yes or (b) no.

*Anatomical regions with pain:* On a drawing with 45 predefined anatomical areas, the subjects marked the anatomical areas where they had had pain.

*Average pain intensity in last 7 days:* a numeric rating scale with figures between 0 (denoted no pain) and 10 (denoted the worst imaginable pain).

*Anatomical regions with most intensive pain:* On a drawing with 45 predefined anatomical areas, the subjects marked the anatomical areas with the worst pain intensities.

*Average pain intensity in last 7 days:* a numeric rating scale with figures between 0 (denoted no pain) and 10 (denoted the worst imaginable pain) for the pain areas indicated in the anatomical drawing concerning the worst pain.

*Frequency of pain:* (a) seldom, (b) sometimes, (c) often, or (d) always/nearly always.
Consumption of painkillers (prescribed and/or non-prescribed) in last 7 days: (a) no; (b) yes, but only occasionally; (c) yes, on several occasions but not every day; or (d) yes, every day.

Health-care seeking (including complementary medicine) due to pain in last 3 months: (a) no; (b) yes, traditional health care; (c) yes, complementary medicine.

Chronic pain—near relatives (parents, grandparents, siblings, or children): (a) yes, (b) no, or (c) do not know.

Chronic widespread pain—near relatives (parents, grandparents, siblings, or children): (a) yes, (b) no, or (c) do not know.

Pain in low back or pelvic region with debut in connection with pregnancy (only for women): (a) yes, intensive pain; (b) yes, moderate pain; (c) no; or (d) has not been pregnant or has not given birth.

Chronic pain grade: This scale was used for assessing severity in three dimensions: persistence, intensity, and disability (9-15). The scale was modified and concerned the last 4 weeks.

Consumption of drugs (prescribed) in last 2 weeks: (a) analgesics, (b) medications for heartburn or acid reflux, (c) laxatives, (d) hypnotics, (e) anti-anxiety medication, (f) anti-depressants, (g) anti-inflammatories, (h) medicines for heart problems, (i) drugs for circulatory problems, (j) medications for skin diseases, or (k) insulin. The possible answers were (a) no; (b) yes, occasionally; and (c) yes, more or less every day.

Consumption of drugs (non-prescribed) in last 2 weeks: (a) analgesics, (b) medications for heartburn or acid reflux, (c) laxatives, (d) anti-inflammatories, (e) medications for skin diseases, (f) asthma medication, (g) drugs for improving vitality, (h) nutritional supplements (vitamins B, C, and D, etc.), and (i) herbal remedies against certain complaints and health problems. The possible answers were (a) no; (b) yes, occasionally; and (c) yes, more or less every day.

Working situation: This aspect was covered by two questions. (1) Are you currently working to any extent? (a) yes, or (b) no, not at all); and (2) When were you last gainfully employed? Possible answers ranged between 1 week to 3 months ago and never been gainfully employed.

Highest education: This item had four possible answers—elementary school, secondary school, university 1–2 years, and university ≥3 years.
Social support: Social support was measured using the Oslo-3 Social Support Scale (OSS-3) (16, 17) with three questions. Possible raw scores were 3–14 points, with 3–9 indicating weak social support.

Financial resources and social support: Two questions from Statistics Sweden were used.

1) If you suddenly found yourself in an unexpected situation where you had to get hold of 14 000 SEK within a week, would you be able to raise that sum? (Yes or No); and
2) Do you think on the whole that one can trust most people, or do you think one should be careful in dealing with people? (Possible answers were “You can count on most people” and “One should be careful in dealing with other people”).

Participation aspects: The West Haven-Yale Multidimensional Pain Inventory (WHY–MPI) is a 61-item self-report questionnaire measuring psychosocial, cognitive, and behavioral effects of chronic pain (30, 31). In the present study, we chose 2 subscales out of 4 from part 3, which measures to what extent the patients engage in various activities.

The Pain Catastrophizing Scale (PCS): The PCS measures three dimensions of catastrophizing - rumination, magnification, and helplessness (32, 33) - based on 13 items (with five alternatives). In the present study we used the total PCS (PCS-total); 52 was the maximum score according to the original scale, and a high score represents the worse outcome. However, due to a technical failure the most negative alternative (“all the time”) was not printed in the questionnaire, so the most negative alternative was “to a great degree.” In the present study PCS-total had possible scores between 0 and 39 instead of 0 and 52.

Distress: the General Well-being Schedule (GWBS) (22) was used to capture life satisfaction and level of psychological distress. GWBS consists of 18 items, and in the present study the total score (0–110) was used. The interval 0–60 reflects severe distress, 61–72 moderate distress, and 73–110 positive well-being.

Happiness: Two internally developed questions were used: (1) Overall, how do you think your life is these days? (a) happy, (b) rather happy, or (c) not so happy); and (2) Overall, how satisfied are you with your life as a whole these days? (answers were plotted on a numeric rating scale with the endpoints 0 = very dissatisfied and 10 = very satisfied).
**Vitality:** This issue was covered by the internally developed question, “Which statement best describes your situation?” with the alternatives (a) I am energetic and have good strength, (b) I’m pretty vital and have reasonable strength, or (c) I lack vitality and strength.

**Sleeping problems:** One single question asked, “Do you have trouble falling or staying asleep?” (yes or no).

We also used the Insomnia Severity Index (ISI) to quantify perceived severity of insomnia (23, 24). Insomnia has the following diagnostic criteria: (1) the individual has difficulty falling asleep, staying asleep, or achieving restorative sleep; (2) this difficulty is present despite adequate opportunity and circumstance to sleep; (3) this impairment in sleep is associated with day-time impairment or distress; and (4) this sleep difficulty occurs at least three times/week and has been a problem for at least one month (34). The seven items of the ISI are rated on a five-point Likert scale (0–4). The scores of the seven items make up the total score of the ISI (max = 28). The score is divided into four categories: no clinically significant insomnia (ISI: 0–7), subthreshold insomnia (ISI: 8–14), moderate clinical insomnia (ISI: 15–21), and severe clinical insomnia (ISI: 22–28).

**Help from relatives:**
Do you need help in your day-to-day life from a relative? (a) no; (b) yes, from my spouse; (c) yes, from my children; (d) yes, from other relatives; or (e) yes, from acquaintances. If help is necessary, is this due to pain?
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