

Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment

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Abstract

This large scale computer-assisted telephone survey was undertaken to explore the prevalence, severity, treatment and impact of chronic pain in 15 European countries and Israel. Screening interviews identified respondents aged ≥ 18 years with chronic pain for in-depth interviews. 19% of 46,394 respondents willing to participate (refusal rate 46%) had suffered pain for ≥ 6 months, had experienced pain in the last month and several times during the last week. Their pain intensity was ≥ 5 on a 10-point Numeric Rating Scale (NRS) (1 = no pain, 10 = worst pain imaginable) during last episode of pain. In-depth interviews with 4839 respondents with chronic pain (about 300 per country) showed: 66% had moderate pain (NRS = 5–7), 34% had severe pain (NRS = 8–10), 46% had constant pain, 54% had intermittent pain. 59% had suffered with pain for two to 15 years, 21% had been diagnosed with depression because of their pain, 61% were less able or unable to work outside the home, 19% had lost their job and 13% had changed jobs because of their pain. 60% visited their doctor about their pain 2–9 times in the last six months. Only 2% were currently treated by a pain management specialist. One-third of the chronic pain sufferers were currently not being treated. Two-thirds used non-medication treatments, e.g., massage (30%), physical therapy (21%), acupuncture (13%). Almost half were taking non-prescription analgesics; ‘over the counter’ (OTC) NSAIDs (55%), paracetamol (43%), weak opioids (13%). Two-thirds were taking prescription medicines: NSAIDs (44%), weak opioids (23%), paracetamol (18%), COX-2 inhibitors (1–36%), and strong opioids (5%). Forty percent had inadequate management of their pain. Interesting differences between countries were observed, possibly reflecting differences in cultural background and local traditions in managing chronic pain. *Conclusions:* Chronic pain of moderate to severe intensity occurs in 19% of adult Europeans, seriously affecting the quality of their social and working lives. Very few were managed by pain specialists and nearly half received inadequate pain management. Although differences were observed between the 16 countries, we have documented that chronic pain is a major health care problem in Europe that needs to be taken more seriously.

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Keywords: Chronic pain; Survey; Treatment of pain; Impact of pain; Europe

1. Introduction

Chronic pain is common, but there are currently no published robust pan-European epidemiological data.

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Previous surveys in European countries have focused on primary care, individual countries, and/or specific conditions or diseases that cause chronic pain (Bowsher et al., 1991; Hillman et al., 1996; Leboeuf-Yde et al., 1996; Gureje et al., 1998; Andersson et al., 1999; Zondervan et al., 1999; Elliott et al., 2002). The present large-scale survey had a main objective of demonstrating the prevalence of chronic pain, but also sought to explore how individuals perceive their pain, the impact it has on their lives, their perception of the attitudes of others towards their pain, treatments received and the adequacy of treatment. It addressed the following aims: (a) estimating the prevalence of chronic pain in 15 European countries and Israel, (b) quantifying causes of chronic pain, (c) exploring the demographics of chronic pain, (d) exploring the impact of chronic pain on individuals' quality of life and daily activities, (e) understanding current treatment practices and levels of satisfaction with treatment, (f) exploring the attitudes of individuals towards their pain and their experiences of pain, (g) exploring how individuals with chronic pain perceive the attitudes of their families, friends, colleagues and doctors.

2. Methods

This large scale computer-assisted telephone interview study was performed during the spring and early summer months of 2003 in 15 European countries and Israel.

2.1. Questionnaires

The two questionnaires used in this study were developed with the support of NFO WorldGroup, a market research company (See Appendix for details).

2.1.1. Screening questionnaire

The initial questionnaire was a screening interview that lasted approximately 5 min and consisted of 12 questions to assess the prevalence of chronic pain within each country, age and gender of respondents, the duration of pain, frequency of pain during last week, intensity of pain during last episode of pain, location of the pain, and the cause of the pain.

2.1.2. Structured in-depth-interview questionnaire

The respondents were considered to suffer from long lasting pain if they (a) had suffered from pain for at least six months, (b) had experienced pain in the last month, (c) experienced pain at least two times per week, and (d) rated their pain intensity when they last experienced pain as at least 5 on a 10-point Numeric Rating Scale (NRS) with 1 = no pain at all and 10 = the worst pain imaginable.

Respondents who fulfilled these screening criteria of the initial screening questionnaire were then interviewed in-depth using the second questionnaire of 44 questions. This in-depth interview lasted approximately 23 min. The respondents to the in-depth questionnaire were offered a small amount of money in appreciation for their time.

Questions in the in-depth interview assessed: (a) demographics, (b) frequency, duration and intensity of pain (c) the impact of pain on respondents' work and quality of life, (d) attitudes of respondents to their pain and its treatment, (e) respondents' perceptions of the attitudes of their family, friends, colleagues and doctors to their pain and its treatment, (f) respondents' interaction with healthcare professionals, including how many doctors respondents had seen, how often they had seen them and how long they had been seeing them, (g) treatments, including prescription and non-prescription medicines and non-medication strategies.

2.1.3. Translation of questionnaires into 16 European languages

Translators with four to 30 years' experience in medical or pharmaceutical translation translated the English language versions for other countries. All the regional language questionnaires were back-translated into English to confirm their accuracy.

2.2. Computer Assisted Telephone Interview (CATI) method

2.2.1. Standard CATI methodology was used to perform the survey

Interviewers used listed residential telephone numbers to contact respondents in Austria, Belgium, Denmark, Finland, France, Germany, Ireland, Israel, Italy, the Netherlands, Norway, Poland, Spain, Sweden, Switzerland and the UK. The interviewers stratified the telephone numbers by region within a country to control regional bias, but drew numbers randomly within the regions and used CATI. Interviewers mainly contacted respondents on Monday to Thursday between 4 p.m. and 10 p.m. or on Sunday between 10 a.m. and 6 p.m. to allow potential access to the widest variety of householders.

Once the interviewers had spoken to at least 300 respondents fulfilling the criteria for in-depth questionnaire-based interviews, they stopped carrying out in-depth interviews in that country.

2.2.2. Sample survey methodological considerations

This survey was conducted according to the methods of broad-scale market research and we recognize the well-established biases created in any telephone interview. The prevalence rate could have been affected by limitations in capturing all pain populations. For exam-

ple, cognitively impaired and nursing home residents could not be included. Only those people listed in telephone directories were included. Women are both more likely to answer the telephone and more willing to cooperate and take part in a survey than men, and there is also a greater likelihood that an older person is at home and is a land-line telephone user than a younger person.

To overcome some of these disparities, sample data were weighted by appropriate determinants of importance. Our goal was to create representative samples from countries that are widely disparate in size and obtain enough sample to determine differences between certain groups (e.g., age and gender) in a stable model that did not change in a substantial way as additional sample was collected.

The weighting procedures within each country used a cell-based weighting scheme with two gender categories (male and female) and seven age categories (18–30, 31–40, 41–50, 51–60, 61–70, 71–80 and 81+ years), creating 14 cells. These were balanced to the population figures obtained from the US Census Bureau International Database, summary of demographic information, October 2002 estimates. A balancing procedure was also adopted to adjust the sample cell proportions to the population cell proportions.

Two sets of weights were created. The first set was country-specific and created as already described. The second set adjusted those weights according to the relative size of the population and was used for the total pan-European results. All the pan European data quoted in this paper are based on the weighted population.

Respondents with chronic pain who were currently involved in clinical trials were excluded to ensure that the data reflected respondents who were receiving standard treatment for their pain.

2.2.3. Sample size

NFO determined the sample size for this survey based upon the following two-step approach (Cohen, 1988):

Step 1: The number of people required to be screened from each country was calculated. With a sample of 2000 people per country, there was 99% power at the 5% significance level to find a 50% prevalence of pain, assuming a 5% deviance.

Step 2: The number of people that met the criteria for pain from each country required to detect a difference between countries was calculated. With 300 pain sufferers from each country, there was 80% power at the 5% significance level to detect a small effect size of 0.30 between countries.

3. Results

3.1. Screening questionnaire results from 46,394 respondents

The rate of refusal to answer the screening questionnaire was 46% and ranged from 20% in Finland to 62% in Germany (Table 1). Of the 46,394 people within 15 European countries and Israel who agreed to take part, 19% had moderate or severe pain of at least six months duration, had experienced pain in the last month, experienced pain at least two times per week. They rated their pain intensity when they last experienced pain as at least 5 on a 10-point NRS scale between 1 = no pain and 10 = the worst pain imaginable. Hereafter, the term 'Europe' with regards to our survey, includes the data from Israel.

The prevalence of chronic pain ranged from 12% to 30%, highest in Norway, Poland and Italy, and lowest in Spain, Ireland and the UK (Fig. 1). There were some within country regional differences, e.g., in Italy where the prevalence was above 32% in the northern part of Italy and less than 22% in the southern part.

3.2. In-depth interview data from 4839 respondents suffering from chronic pain

A total of 4839 respondents (approximately 300 per country) were interviewed in-depth. The total respondents answering the question with data available for each question is often not the same as the total number who were interviewed in-depth. This is because some respondents refused to answer some questions, did not know the answer or the question was not applicable to them. Therefore, the percentages presented reflect the percentage of respondents answering that particular

Table 1
Refusal rates to telephone survey by country

| Country/region | Initial refusal rate (%) | Screening refusal rate (%) |
|----------------|--------------------------|----------------------------|
| Finland | 18 | 2 |
| Norway | 31 | 4 |
| Sweden | 32 | 3 |
| France | 35 | 3 |
| Belgium | 39 | 2 |
| Spain | 40 | 2 |
| Italy | 42 | 3 |
| Poland | 42 | 4 |
| Israel | 43 | 5 |
| Ireland | 45 | 5 |
| Denmark | 50 | 2 |
| Netherlands | 51 | 4 |
| United Kingdom | 54 | 3 |
| Switzerland | 55 | 2 |
| Austria | 56 | 3 |
| Germany | 59 | 3 |
| Mean | 43 | 3 |

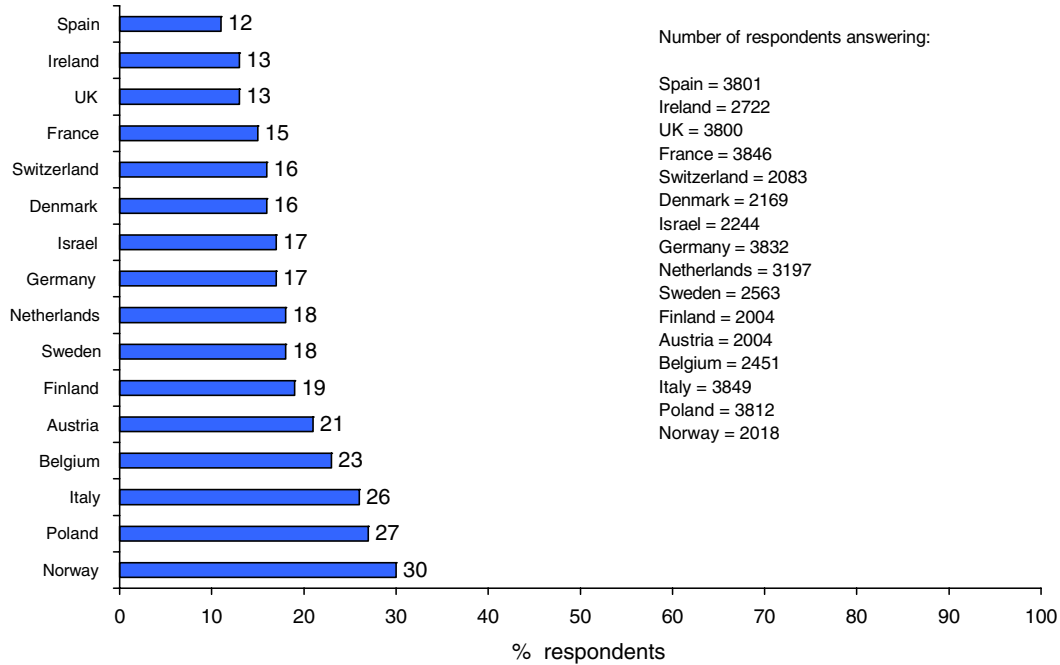


Fig. 1. Prevalence of chronic pain among 46,394 adults (>18 years) in 15 European countries and Israel responding to a computer-aided telephone screening interview. Chronic pain was defined as pain lasting more than 6 months, having pain during the last month, several times during the last week, and last experienced pain having an intensity 5 or more on a Numeric Rating Scale: 1 (no pain) to 10 (worst pain imaginable).

question, not of the total number who were interviewed in-depth.

3.2.1. Demographics

Fifty-six percent of respondents suffering from pain who were interviewed in-depth were female, which is higher than the population estimate of 52% women.

Those below 40 years of age appeared to suffer less, whereas the 41–60 age group appeared to be more likely than others to suffer from chronic pain (Fig. 2a). This telephone survey did not attempt to reach elderly persons in nursing homes etc, who often suffer from painful conditions. Pain was not more common in the oldest respondents in this survey than younger respondents.

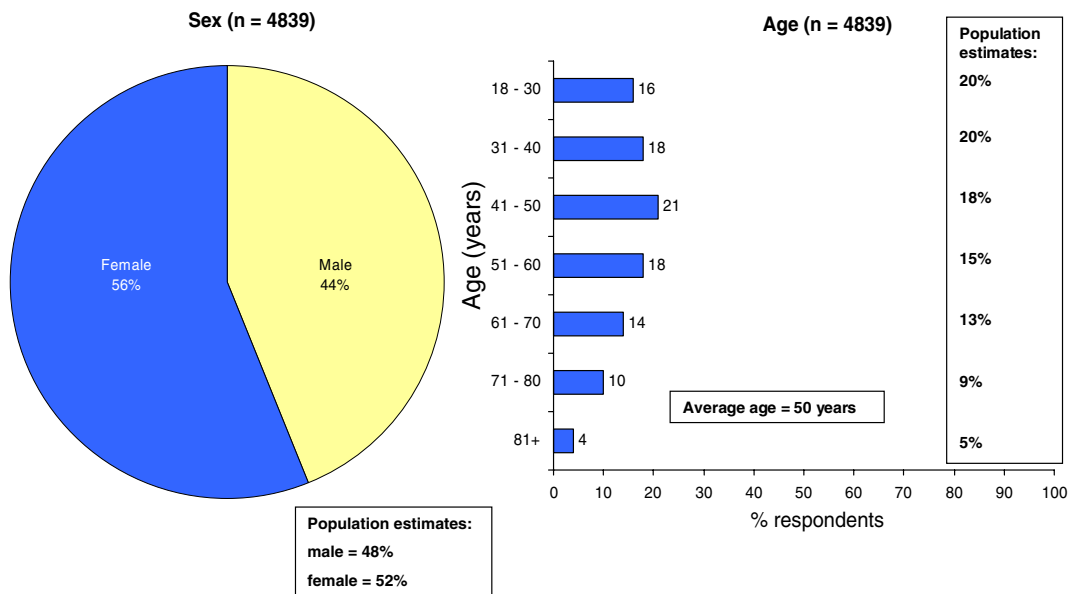


Fig. 2a. Age and sex of 4839 responders suffering from chronic pain as described under Fig. 1. Population estimates are from US Census Bureau International Database (IDB), Summary of Demographic Information. October 2002 <http://www.census.gov/ipc/www/idbnew.html>.

The mean (standard deviation) age of the respondents was 49.9 (17.4) years. The mean age and the percentage of females of the pain sufferers in the 16 countries are shown in Fig. 2b and 2c. The pain sufferers were younger in Israel, Poland and Italy, older in Germany, the Nordic countries, the Netherlands, France and Spain. There were more females among the pain sufferers in Ire-

land, France, Germany, Israel and the Netherlands (about 60%) than in the UK, Austria and Spain (about 50%) (Fig. 2c).

3.2.2. Duration of pain

The duration of pain was often prolonged (Fig. 3). Only 12% of the respondents suffered from chronic

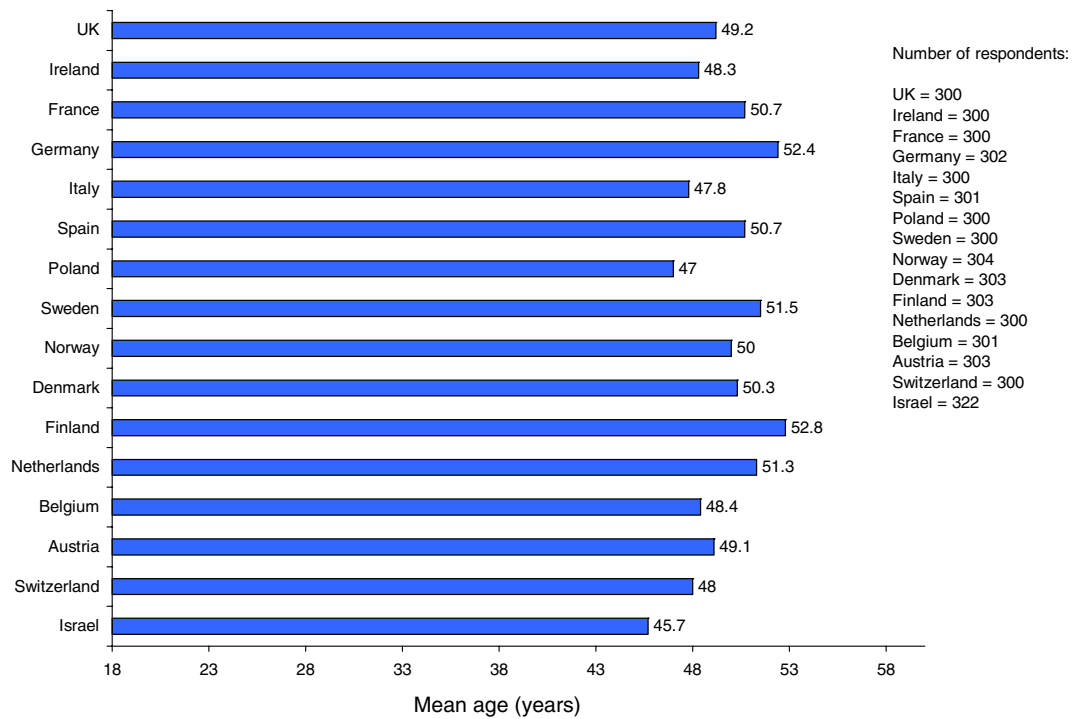


Fig. 2b. Mean age (years) of pain sufferers in the 16 countries.

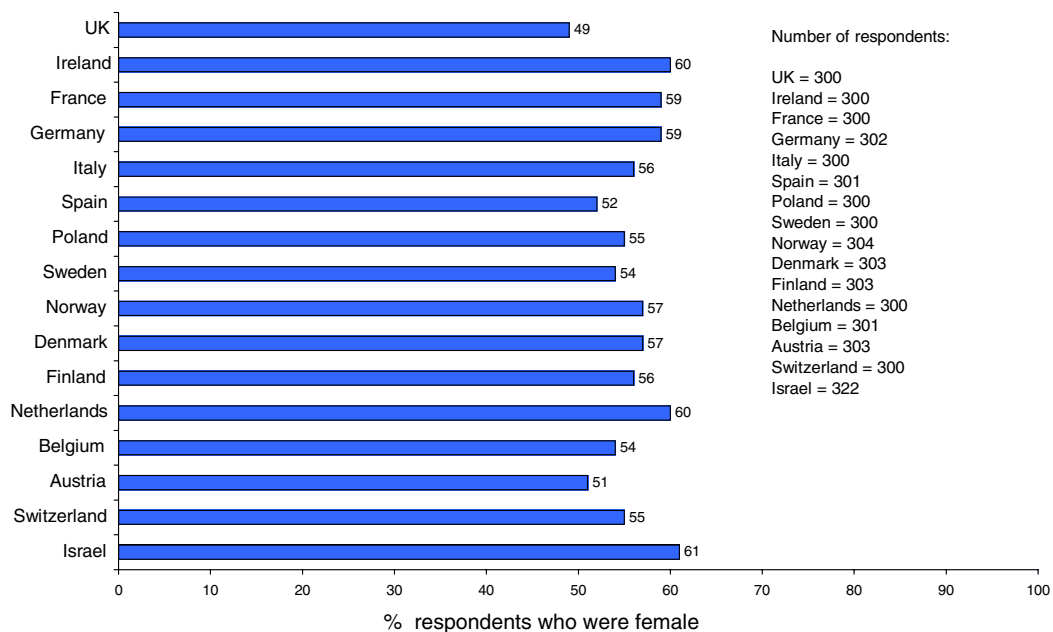


Fig. 2c. Percentage of pain sufferers who were females in the 16 countries.

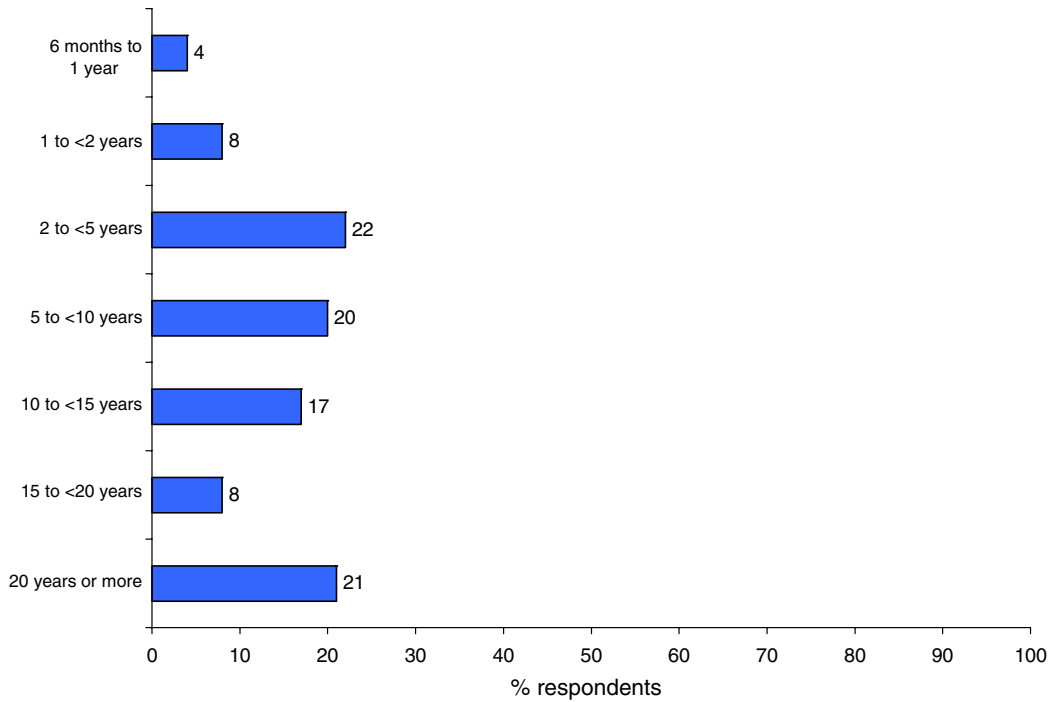


Fig. 3. Duration of chronic pain of intensity 5 or more on a 1–10 NRS pain intensity scale.

pain for less than two years, almost 60% had pain from two to 15 years and many respondents (21%) had suffered with pain for ≥ 20 years. Fig. 4 indicates that pain sufferers in Spain (9.1 years) and Finland (9.6 years) had the longest, in Ireland the shortest (4.9 years) duration of chronic pain at the time of

the interview. Median for all 16 countries was 7.0 years.

3.2.3. Body locations of pain

Fig. 5a demonstrates the most commonly reported body locations and causes of pain. The causes given

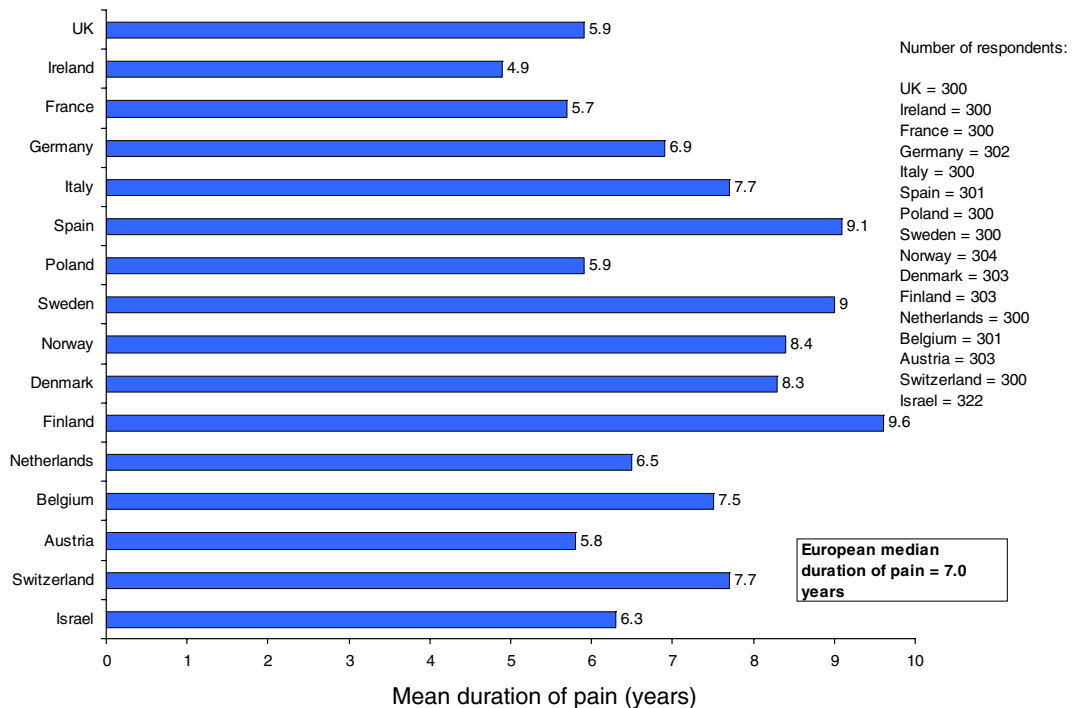


Fig. 4. Duration of pain in the 16 countries surveyed.

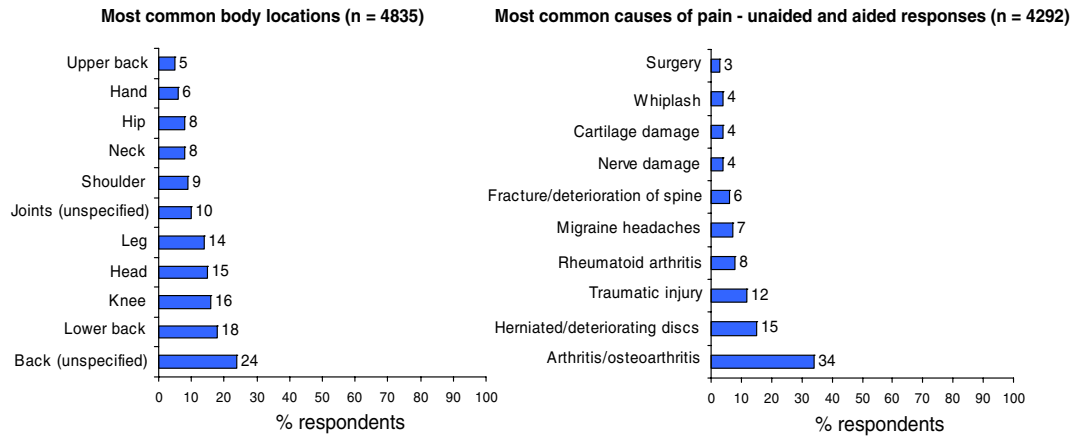


Fig. 5a. Body locations and respondents' opinions of the cause(s) of their chronic pain. Answers to reading lists of possible answers after screening questions: "Where is your pain located?" and "Please tell me the illness or medical condition that is the cause of your pain" and structured interview question: "Is your pain caused by...?".

were in answer to the general question and aided by the interviewer reading a list of possible causes. Close to half of the patients had pain in the back, more

than 40% had joint pain, most frequently knee-pain. One in 5 had head or neck pain, the same number had hand or leg pain.

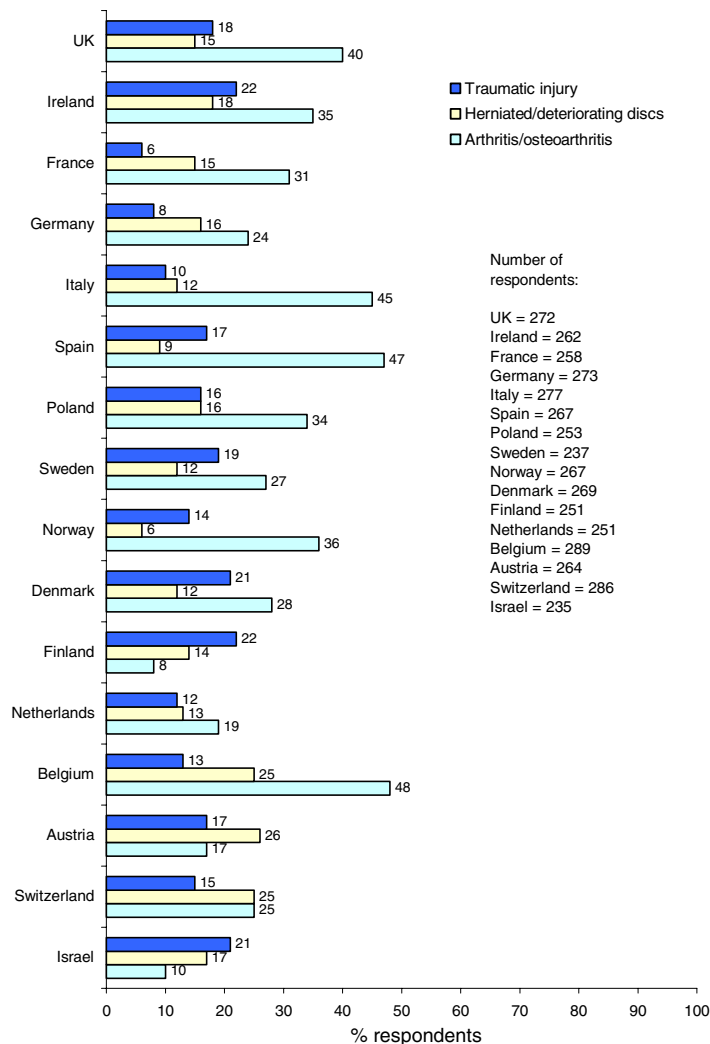


Fig. 5b. Categories of most common causes of pain cited by pain sufferers in the 16 countries.

3.2.4. Causes of pain (Fig. 5a and 5b)

Osteoarthritis and rheumatoid arthritis combined was the most common cause of pain (42%). One in five reported chronic pain from deteriorated or herniated discs, degeneration or fractures of spine. Trauma or surgery caused chronic pain in 15%. Rheumatoid arthritis and migraine headaches occurred in less than 10%. Nerve damage or whiplash was given as causes in 4% each. A number of less frequently listed causes are not shown. Only 1% of respondents gave cancer as a cause of their pain. Twelve percent of respondents did not know the cause of their pain.

Osteoarthritis/arthritis and rheumatoid arthritis were given as causes for pain more often (35–48%) in the UK, Ireland, Italy, Spain, Norway and Belgium than in Finland and Israel (8–10%) and Austria, Germany, France (17–31%) (Fig. 5b). More traumatic (about 20%) and diabetic neuropathy (5%) were reported as causes in Israel. Herniated or deteriorating intervertebral discs were more common in Austria, Switzerland, Belgium (25%) than in Norway, Sweden, Finland and Denmark (6–14%) (Fig. 5b). Headaches and migraine appear to be more common in France, Germany, Poland, Belgium, Austria and Switzerland than in other countries.

3.2.5. Intensity of pain, tolerance to pain, and time course of pain

Sixty-six percent were suffering moderate pain when they last experienced pain (i.e. reported a pain score of 5–7 on a 1–10-point NRS scale (Breivik et al., 2000))

and 34% were suffering severe pain (i.e., reported a pain score of 8–10 on a 1–10-point NRS scale (Breivik et al., 2000)) (Fig. 6a). Prevalence of severe pain was lower in the Netherlands (18%), Norway and Sweden (24%), and Austria (26%). Prevalence of severe pain was clearly higher in Israel (50%), in Italy and Spain (43–44%), and Denmark, Belgium and Finland (35–37%) (Fig. 6b). Thus in Norway where the overall prevalence of pain was 30%, less than one in four pain sufferers experienced severe pain, whereas in Spain with the lowest overall prevalence of pain, almost half of the pain sufferers had severe pain. In Israel, the overall prevalence of chronic pain was 17%; 50% of the relatively young pain sufferers in Israel, 61% of whom were women, suffered from severe pain (Fig. 6b).

This pain rating is reflected in the results regarding respondents' attitudes to the severity of their pain. In 31% of cases, the pain at its worst was so severe that they could not tolerate any more; 47% said that they could tolerate only a little more, and 18% said that they could tolerate somewhat more pain (Fig. 6a).

Forty-six percent had constant pain and 54% had intermittent pain.

3.2.6. Impact of pain on activities of daily life

To gauge the impact of chronic pain on respondents' lives, the interviewers read out a list of activities and asked respondents to rate their ability to do the activities on a 3-point scale, i.e., as just as able, less able, or no longer able to take part. Many respon-

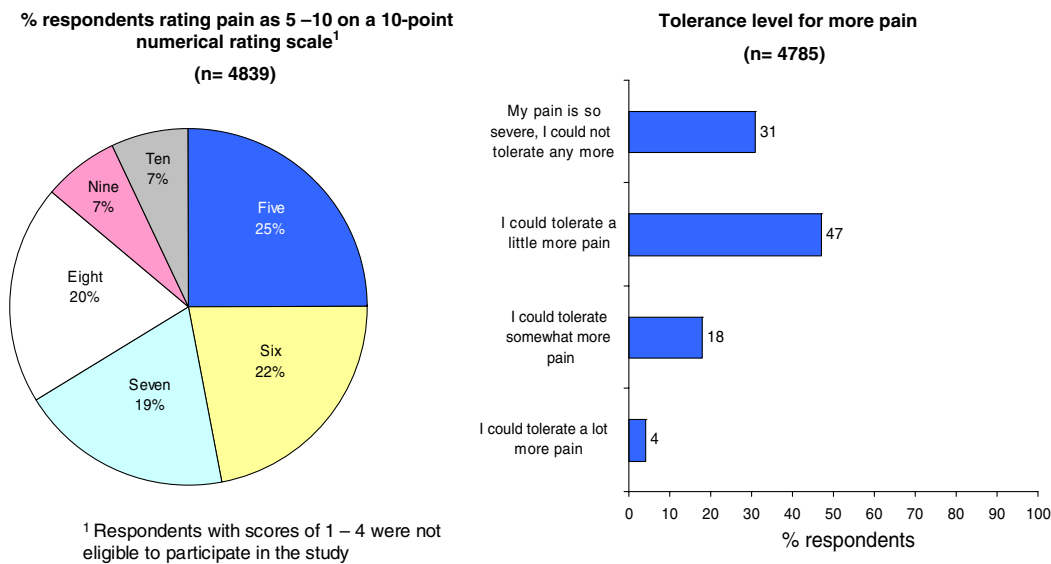


Fig. 6a. The intensity of pain experienced at the most recent episode of pain in 4839 respondents who suffered from chronic pain and their tolerance level for more pain when pain was at its worst. These data are from the responses to the screening question: “Thinking about the last time you experienced pain, please give me a number from 1 to 10 to indicate the intensity of your pain. Please use a 10-point scale where 1 means “no pain at all” and 10 means “the worst pain imaginable”.” And the structured interview question: “Thinking about the intensity of your pain when it was at its worst, which of the following statements best describes your tolerance level of this pain?”.

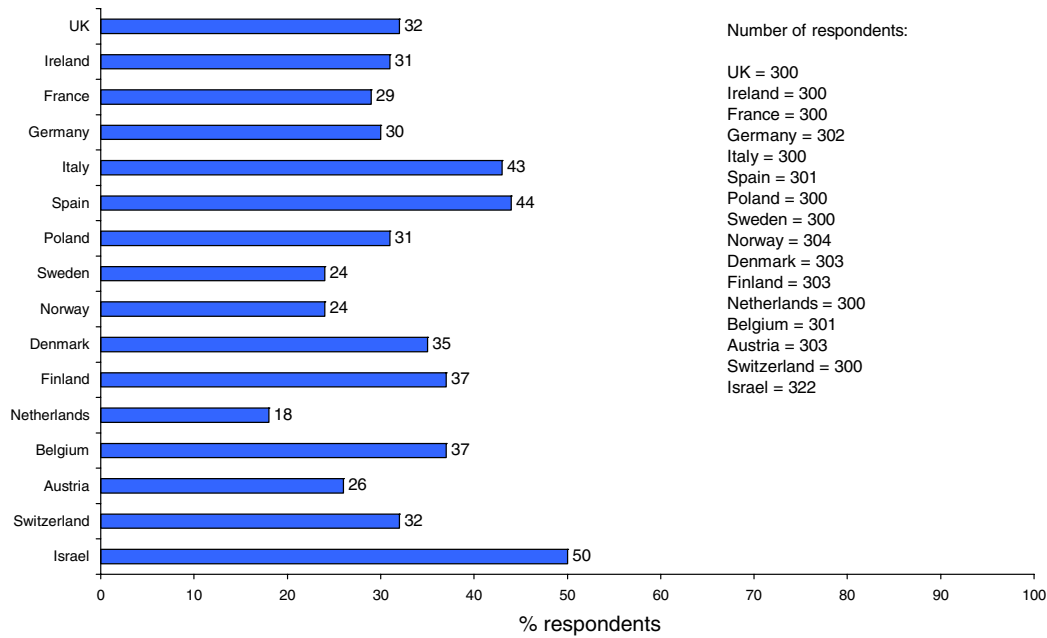


Fig. 6b. Percent of patients in the 16 countries reporting severe pain, i.e., pain intensity of 8, 9, or 10 on the 1–10 NRS as described in legend of Fig. 6a.

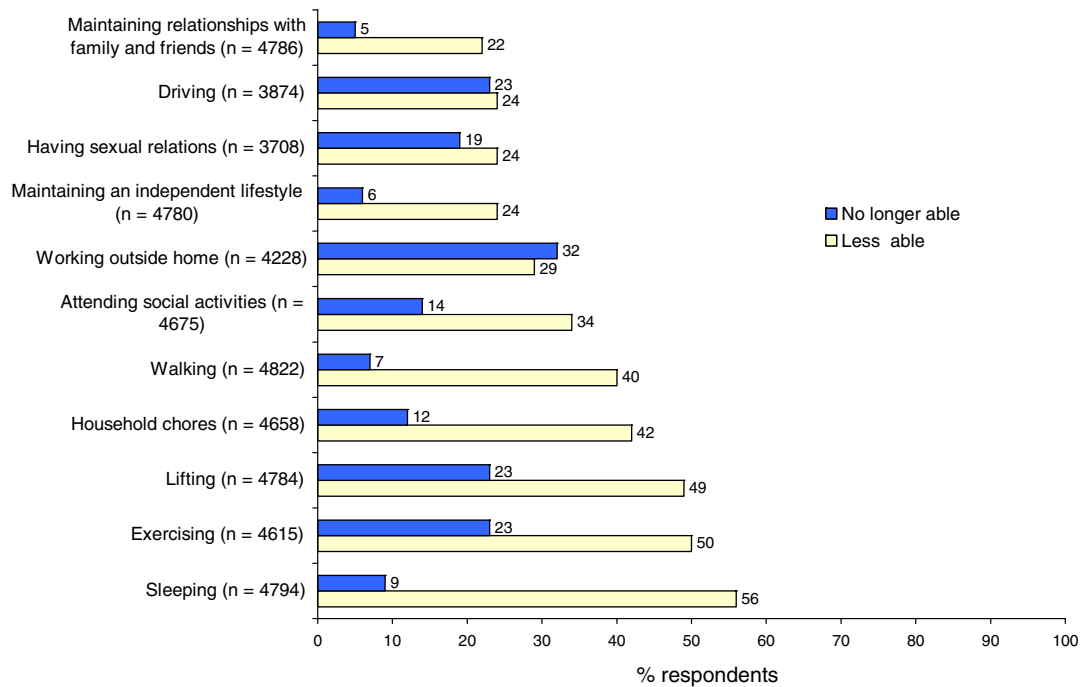


Fig. 7. The impact of chronic pain on daily activities. The graph shows percentage of respondents who were less able or unable to carry out the activities read out by the interviewers.

dents were less able or no longer able to take part in various activities (Fig. 7). It should be noted that 79% said that their pain increased during the day as a result of their activity. Fig. 7 illustrates clearly how chronic pain in a majority of the sufferers severely affects sleep, ability to exercise, walk, do household

chores, attending social activities, and maintaining independent lifestyle. Even ability to have sexual relations and maintaining family relationships are reduced in a quarter to almost half of the pain sufferers. The same proportion is less able to or unable to drive a car (Fig. 7).

3.2.7. Impact of pain on employment status

When questioned about their current employment status, 31% of the respondents with pain were employed full time, 13% were employed part time, 34% were retired and 22% were unemployed (Fig. 8). One in four said that their pain had impacted on their employment status (Fig. 8).

The interviewers then asked those respondents who were working how many days in the last six months they had lost from work because of their pain. The mean time lost from work due to pain was 7.8 days in this period. Fifty-five percent had lost no days at all, 11% had lost one to three days, 12% had lost four to nine days, 9% had lost 10 to 15 days, and 13% had lost at least 16 days.

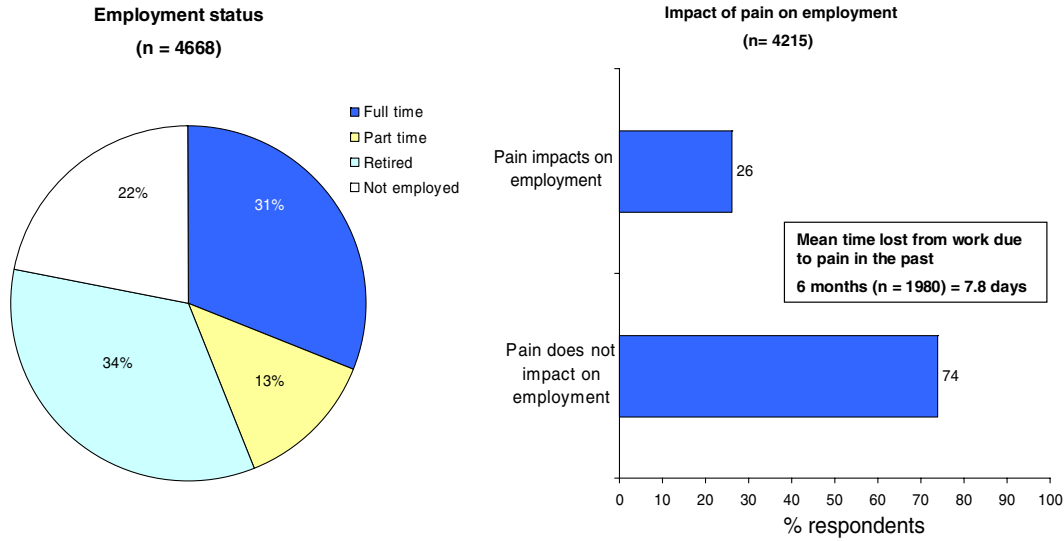


Fig. 8. Employment status of respondents with chronic pain, impact of pain on their employment status and lost days from work during the last 6 months for those who were full time or part time employed. From the structured interview questions: “Are you currently...? Employed full-time, Employed part-time, Retired, Not employed” and “In the past six months, how many days in total have you lost from work because of your pain?” and “Does your current employment status or the hours you work have anything to do with the pain that you experience?”.

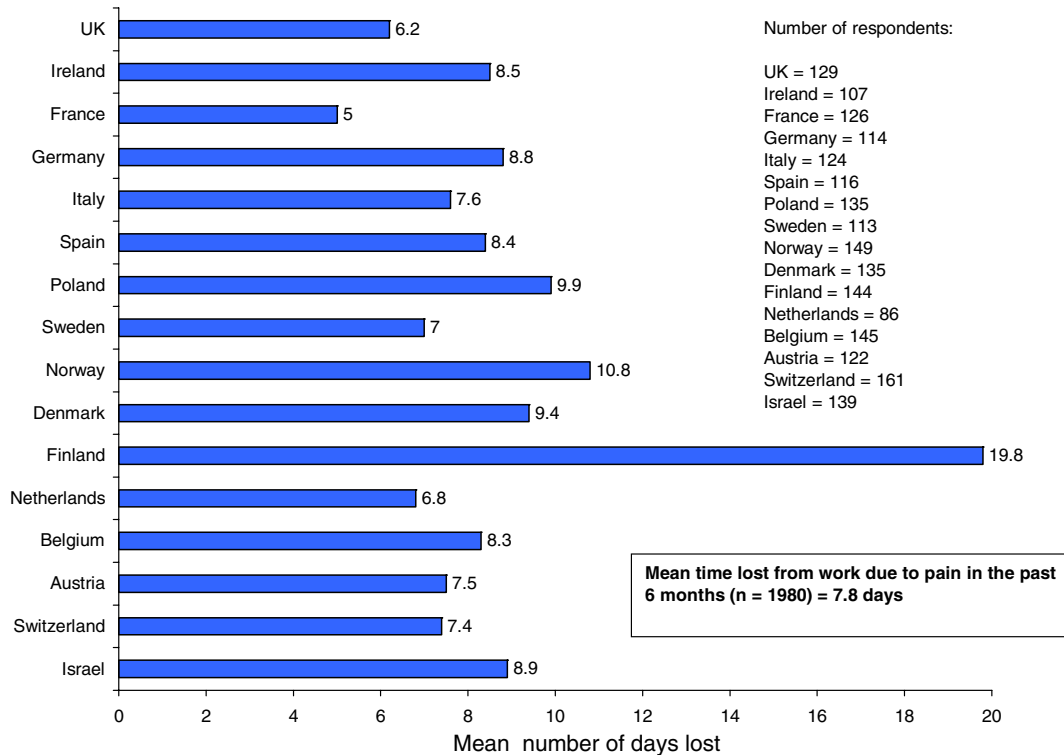


Fig. 9. Mean number of days lost during the last 6 months of full or part time employment in the 16 countries.

The country specific data show that more days are lost due to pain in Finland (almost 20 days), the least in France (only 5 days) during the last 6 months (Fig. 9). When asked whether their employment status or hours they worked had anything to do with their pain, 32% who were not retired said yes.

A total of 19% had lost their job because of their pain, 16% had changed job responsibilities and 13% had changed jobs entirely because of their pain (Fig. 10).

Differences between the 16 countries in the impact of chronic pain on employment status are shown in Tables 2a and 2b. In the Netherlands, Denmark, UK, Israel, Sweden, and Norway chronic pain sufferers more often (24–29%) lose their jobs (and probably most often go to sickness retirement) than in Ger-

many, Poland, Belgium, Ireland and France (14–15%). In Italy, Sweden, Norway, and Ireland change of job responsibilities or change of job because of pain occurs more often than in other countries, such as Spain, Belgium, Germany, Austria, Denmark, and France (Tables 2a and 2b).

3.2.8. Impact of pain on emotional status

When asked whether they had ever been diagnosed with depression because of their pain, 21% of respondents said yes (Fig. 10). Spain had the highest rate of depression among chronic pain sufferers (29%), followed by Norway (28%), Sweden and UK (24%). The lowest rate was reported in Denmark (11%) and Poland (14%) (Tables 2a and 2b).

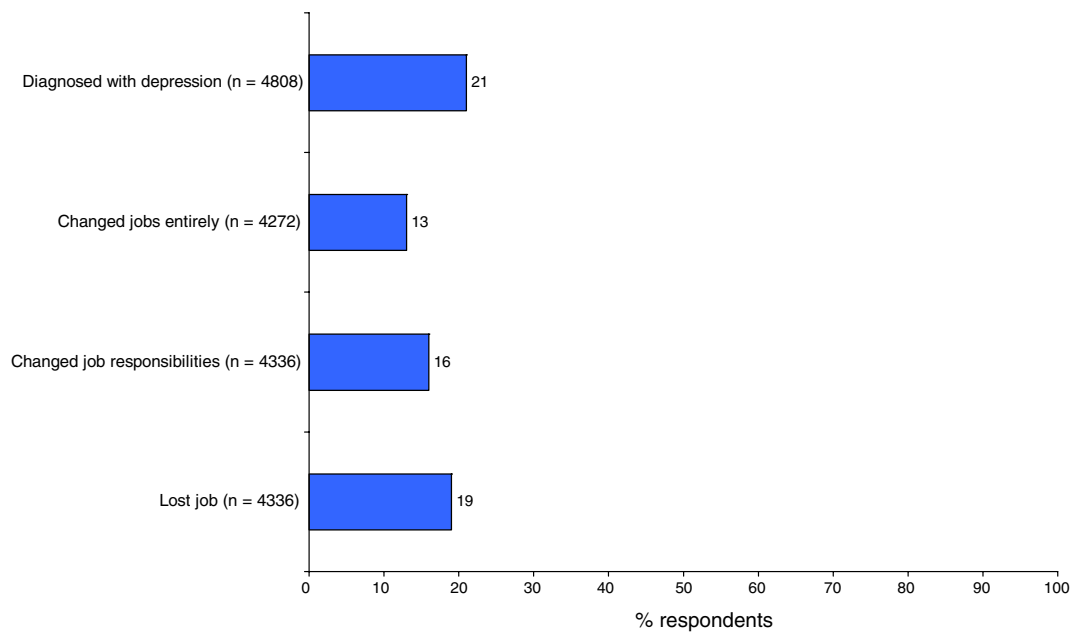


Fig. 10. Changes in employment situation and depression caused by chronic pain.

Table 2a
Job and emotional changes due to pain by country

| | % Respondents | | | | | | | | |
|------------------------------|---------------|------------------|-------------------|-----------------|-----------------|------------------|------------------|------------------|-------------------|
| | UK (n = 243) | France (n = 232) | Germany (n = 232) | Italy (n = 233) | Spain (n = 255) | Poland (n = 220) | Sweden (n = 292) | Norway (n = 289) | Denmark (n = 298) |
| Lost job | 25 | 15 | 14 | 17 | 22 | 14 | 24 | 24 | 29 |
| Changed job responsibilities | 16 | 12 | 11 | 28 | 8 | 19 | 28 | 28 | 21 |
| Changed jobs entirely | 18 | 12 | 8 | 20 | 4 | 13 | 25 | 22 | 11 |
| Diagnosed with depression | 24 | 18 | 20 | 22 | 29 | 14 | 24 | 28 | 11 |

Source is answers to questionnaire questions: “Have any of the following ever happened as a result of your pain...? (Read list)” and: “Have you ever been diagnosed with depression by a medical doctor as a result of your pain?”
Statistical testing at the 95% confidence level where: U, greater than UK; F, greater than France; G, greater than Germany; T, greater than Italy; S, greater than Spain; P, greater than Poland; W, greater than Sweden; Y, greater than Norway; D, greater than Denmark; L, greater than Finland; N, greater than

Table 2b
Job and emotional changes due to pain by country

| | % Respondents | | | | | | |
|------------------------------|--------------------------|----------------------|----------------------|----------------------|--------------------------|----------------------|---------------------|
| | Netherlands (n = 294) | Belgium (n = 286) | Finland (n = 290) | Ireland (n = 272) | Switzerland (n = 274) | Austria (n = 279) | Israel (n = 299) |
| Lost job | 29 IFGTPLBAZ | 15 | 22 GP | 15 UFGSBZ | 16 SB | 20 FGSB | 25 IFGTPBZ |
| Changed job responsibilities | 20 | 9 | 19 | 24 | 15 | 20 | 17 |
| Changed jobs entirely | 16 | 9 | 14 | 23 | 12 | 11 | 14 |
| Diagnosed with depression | 19 D | 19 D | 22 PD | 19 D | 18 D | 21 PD | 16 |

Source is answers to questionnaire questions: “Have any of the following ever happened as a result of your pain. . .? (Read list)” and: “Have you ever been diagnosed with depression by a medical doctor as a result of your pain?”

Statistical testing at the 95% confidence level where: U, greater than UK; F, greater than France; G, greater than Germany; T, greater than Italy; S, greater than Spain; P, greater than Poland; W, greater than Sweden; Y, greater than Norway; D, greater than Denmark; L, greater than Finland; N, greater than Netherlands; B, greater than Belgium; A, greater than Austria; Z, greater than Switzerland and E, greater than Israel.

3.2.9. Visits to doctors

The interviewers asked respondents how many times in the last six months they had visited their current doctor about the illness or medical condition that caused their pain. Sixteen percent had not seen their doctor at all, 14% had seen their doctor once, 60% had seen their doctor two to nine times and 11% had seen their doctor at least 10 times.

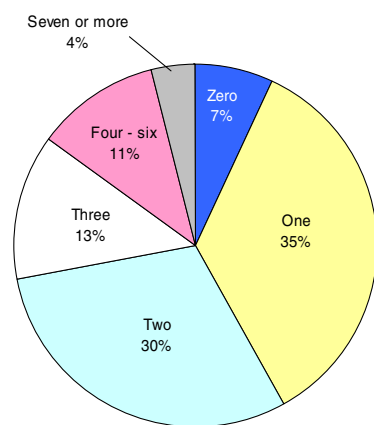
Thirty-five percent of respondents had consulted one doctor and 54% had consulted two to six different doctors (Fig. 11). The reasons for seeing more than one doctor was most often that their primary physician had referred the patients to a specialist (Fig. 11).

3.2.10. Type of doctor or health carer currently treating their chronic pain

Respondents were asked to describe the types of doctors they were currently seeing *specifically for their pain*. Most (70%) were seeing their general practitioner (GP) and 27% were seeing an orthopaedic specialist. Only 2% were currently treated by a pain management specialist (Fig. 12). Most respondents (69%) had been seeing the doctor that was currently treating their pain for one to 15 years.

When asked specifically whether they *had ever been to* a “pain management specialist”, as many as 23% said yes. The differences between the 16 countries are large,

How many doctors respondents report seeing
(n= 4780)



Reasons why respondents see more than one doctor
(based on respondents seeing more than one doctor)
(n= 2696)

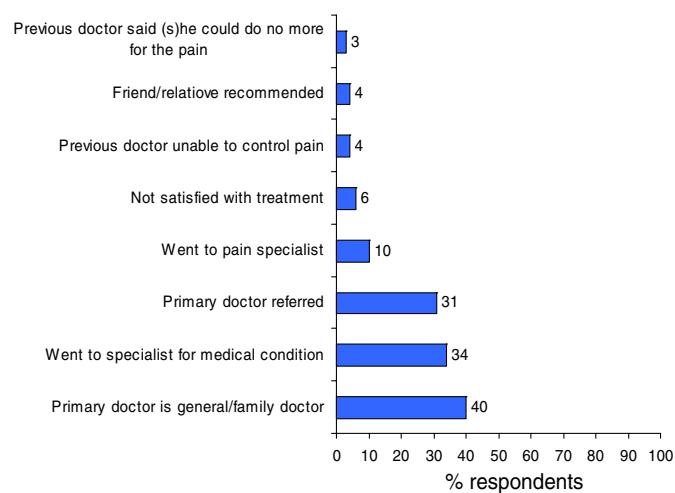


Fig. 11. The number of different doctors the chronic pain patients see and why they see more than one doctor. Answers to structured interview questions: “How many different doctors (including your current doctor) have treated you for your pain?” and “Please tell me your reasons for seeing more than one doctor for pain treatment.”

from 8% in Norway to 40–43% in France, Israel and Italy; clearly what the respondents mean by a “pain management specialist” must vary from country to country (Fig. 13).

3.2.11. Assessment of pain by doctors

When asked how often their doctor determined how much pain they were experiencing, 61% said at every visit, but 12% said never.

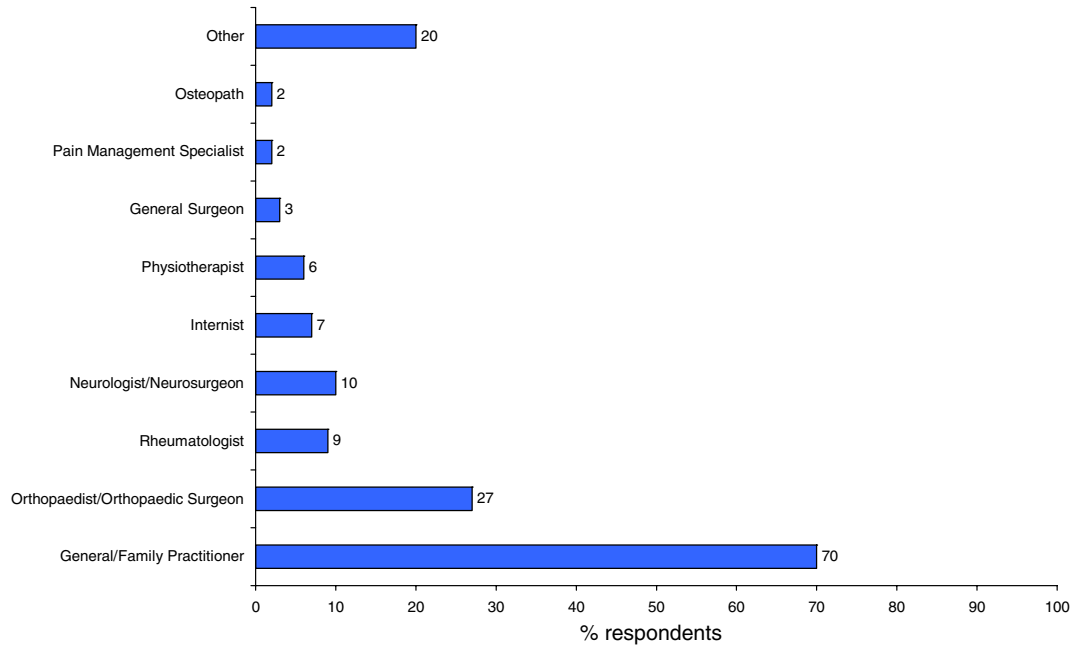


Fig. 12. Most common types of health care professionals currently treating the pain of the respondents with chronic pain * Other includes: Alternative Medicine/Homeopathy, Anaesthesiologist/Anaesthetist, Cardiologist, Chiropractor, Ear Nose Throat, Gastroenterologist, Gynecologist, Hematologist, Infectious Disease, Oncologist, Ophthalmologist, Physical Medicine, Plastic Surgeon, Psychiatrist, Pulmonologist, Radiologist, Sports Medicine, and Urologist. Based on answers to structured interview question: “What kinds of doctors are you currently seeing specifically for your pain?”.

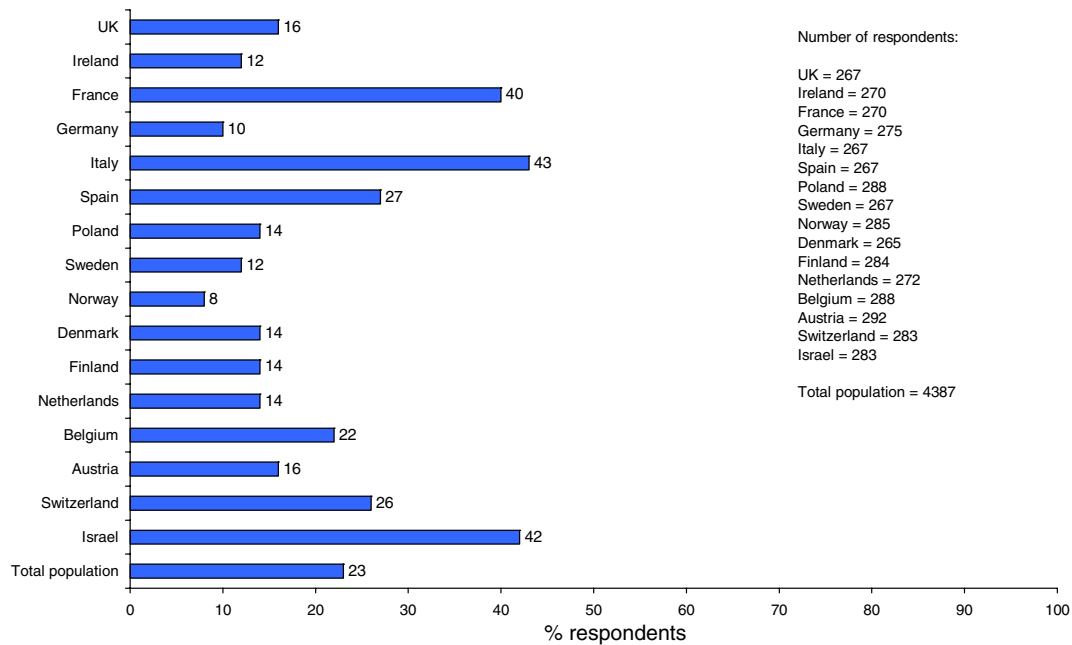


Fig. 13. Percent of those suffering from chronic pain who have seen a pain management specialist in the 16 countries. Answer to structured interview question: “Have you ever been to see a pain management specialist?”.

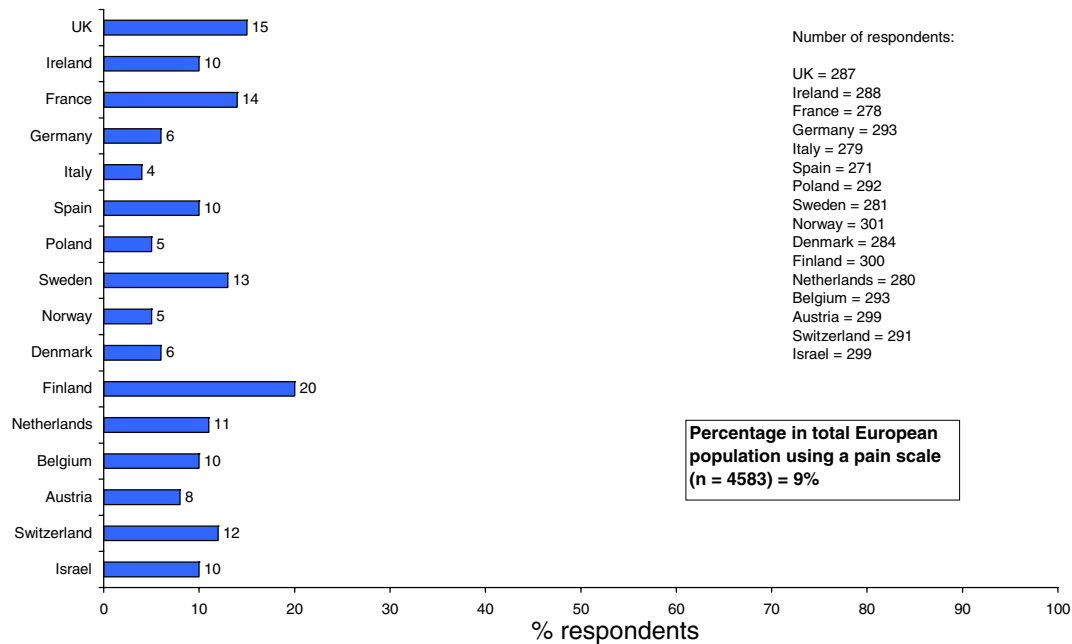


Fig. 14. The use of pain intensity scales of any kind to evaluate pain in the 16 countries. Answer to the structured interview question: “Has any doctor or medical professional ever scored you on a pain scale?”.

The interviewers then asked respondents how the doctor determined how much pain they were experiencing. The most common methods were for respondents to tell the doctor (71%) or the doctor to examine the respondent (52%); only 9% of respondents said that their doctor used a pain scale. In Finland as many as 20% of doctors used pain scales, 15% in the UK, and 14% in France, whereas only 4% used pain scales in Italy, 5% in Norway and Poland (Fig. 14).

3.2.12. Treatment

The interviewers asked respondents whether their pain was being treated in any way. A total of 69% said yes.

3.2.12.1. Currently not receiving any treatment. Those who were not currently receiving treatment were asked to give their reasons why not (Fig. 15). The most common reason given was that respondents could manage the pain on their own, pain was not bad enough, or the pain condition was better now. However, many patients disliked taking medication, had side effects from treatment, had experienced that nothing more can be done, or had decided to live with their pain.

3.2.12.2. Non-drug treatment. Sixty-nine percent of respondents had used non-drug methods, remedies or treatments for their pain. This varied from 91% in Finland to 56% in Spain. The most common being massage (30%), physical therapy (21%) and acupuncture (13%), whereas relaxation therapy and counselling was used

infrequently (Fig. 16). Thirty-eight percent of respondents felt that they had been extremely or very helpful.

The differences between the 16 countries were large, e.g. acupuncture had been tried by 41% in Sweden, around 25% in Austria, Switzerland, Norway, Denmark and the Netherlands, but only 5% in Finland, 6–7% in Spain, Poland, and Italy (Fig. 17).

Physical therapy also varied from high of 55% in Sweden, 52% in the Netherlands and 47% in Norway, to as little as 2% in France and 6% in Spain (Fig. 18).

Massage, may be a form of physical therapy: Austrians, Germans, and Poles try massage more often (47%, 46%, and 41%) than the British (15%) and the Irish (14%) pain sufferers (Fig. 19).

3.2.12.3. Currently taking non-prescription medicine. Most respondents (53%) had not taken any non-prescription oral pain medicines in the last six months and 36% had taken one or two. Most were taking NSAIDs (55%), varying from high in Finland (91%) and Austria (87%), Germany and Italy (72–79%), Israel, Belgium, Poland, Spain and UK (63–47%) to as low as 13% in Denmark and Norway.

Non-prescription paracetamol (average 43% for all 16 countries) also varied widely from 92–71% in Denmark, the Netherlands, Poland, Sweden, Norway, to only 3% in Italy, 8% and 12% in Germany and Austria.

An average of 13% were taking weak opioid analgesics, mostly low dose of, e.g., codeine or dihydrocodeine combined with paracetamol or an NSAID in countries such as France (40%), Ireland (28%), Poland (24%),

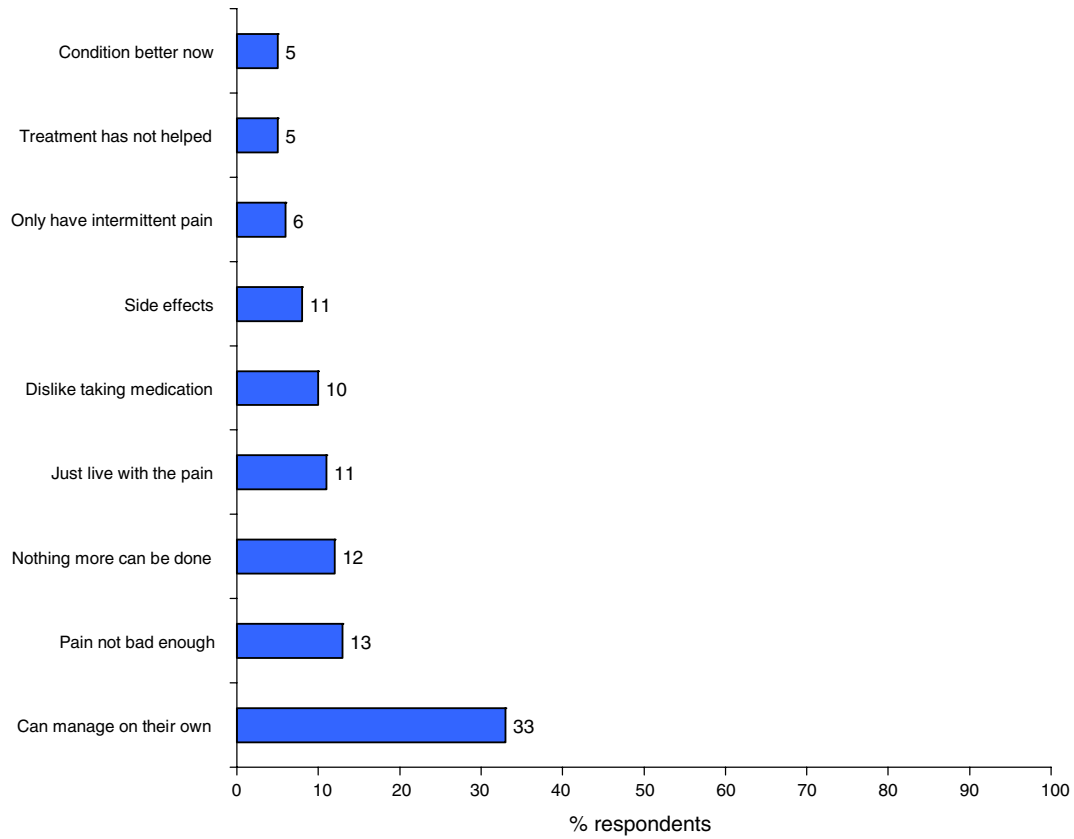


Fig. 15. One third of those suffering from chronic pain were currently not treated for their pain. These are the most common causes given for not receiving pain treatment. The graph shows only responses given by $\geq 5\%$ of respondents.

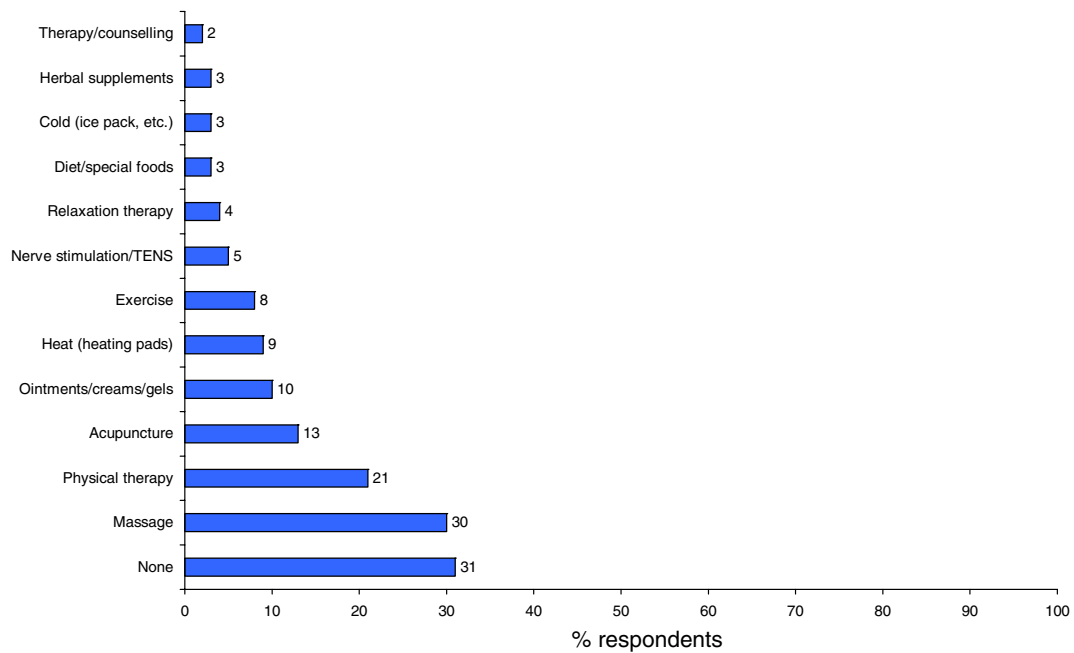


Fig. 16. The most frequently tried non-drug treatments of chronic pain in Europe. Answers to the structured interview question: “What other methods, remedies or treatments, apart from medications have you ever tried to relieve your pain for the medical condition or illness we have been discussing?”.

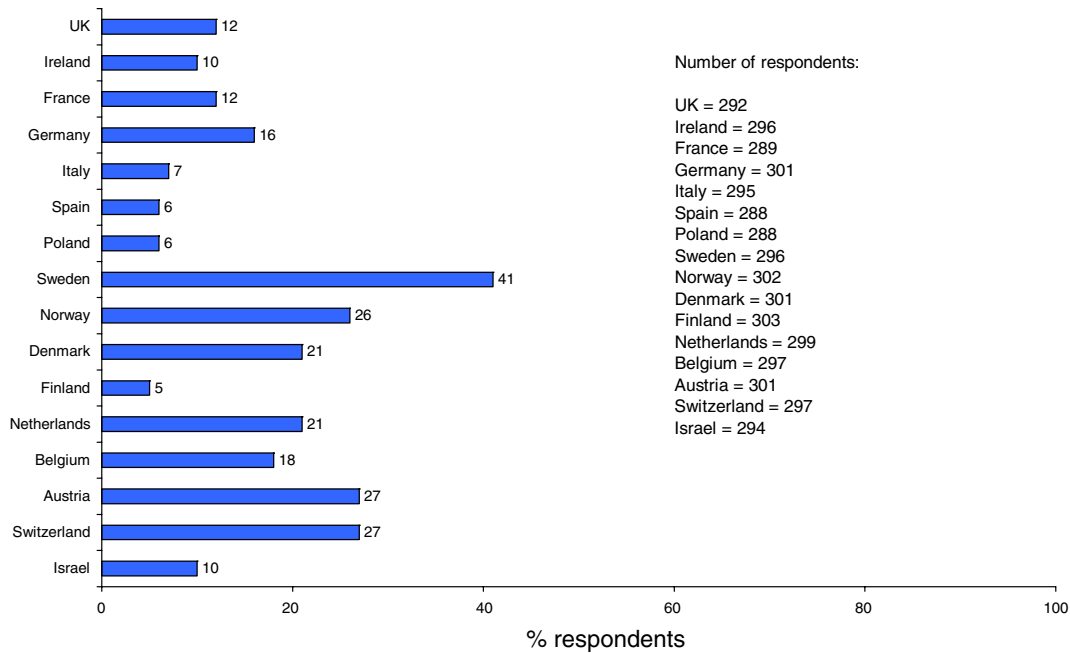


Fig. 17. Percentage of chronic pain sufferers who had tried acupuncture for their pain in the 16 countries.

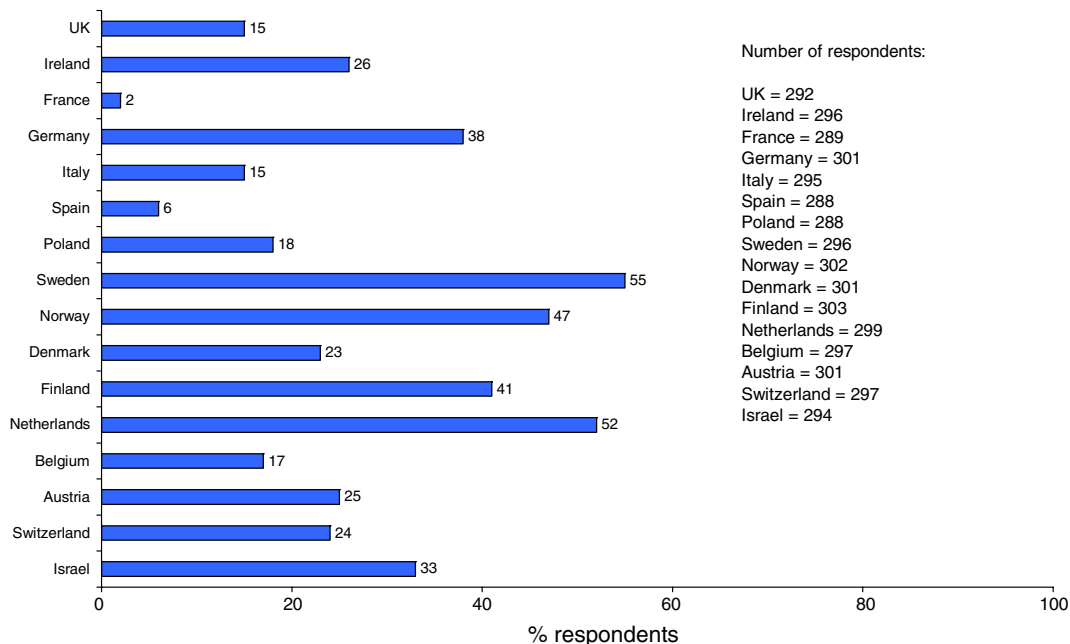


Fig. 18. Percentage of chronic pain sufferers who had tried physical therapy in the 16 countries.

UK (9%), and Israel (6%). Most of the other countries do not have non-prescription analgesics containing weak opioids.

A total of 32% of those taking non-prescription medicines felt that current non-prescription medicines were completely or very effective, 49% felt that they were somewhat effective, and 20% felt that they were not very or not at all effective.

3.2.12.4. Currently taking prescription medicine. It should be noted that 21% of the 4 839 respondents had never taken a prescription medication for their pain. Twenty-six percent (634) had taken, but stopped taking prescription medicine. When asked for their reasons, 19% of respondents said that they managed or lived with the pain, 15% said that the pain was not bad enough, and 14% thought that there were too many side effects

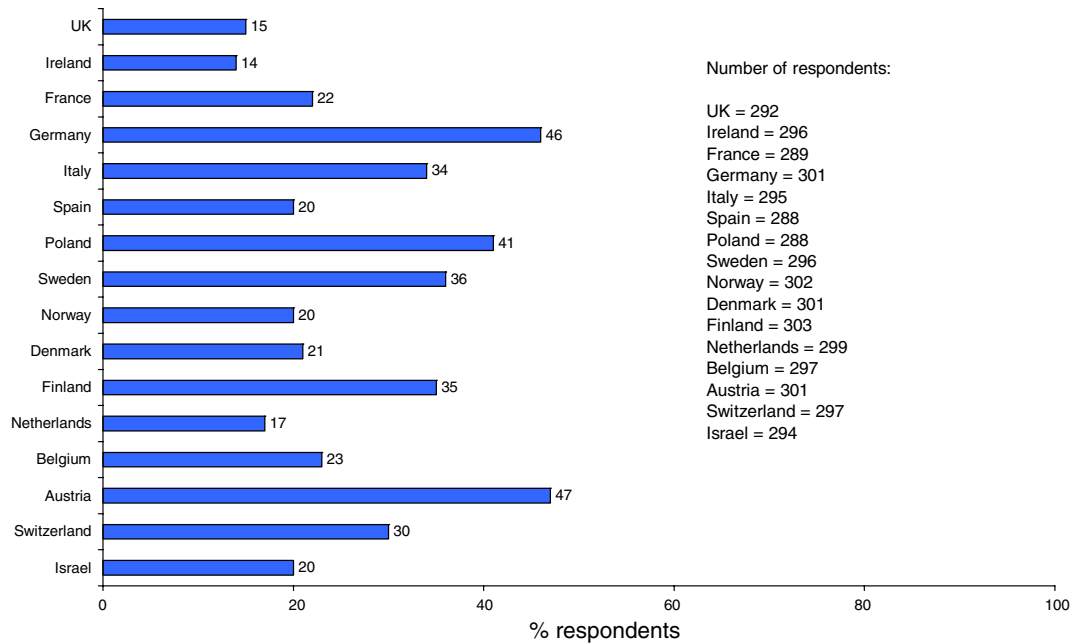


Fig. 19. Percentage of chronic pain sufferers who had tried massage for their pain in the 16 countries.

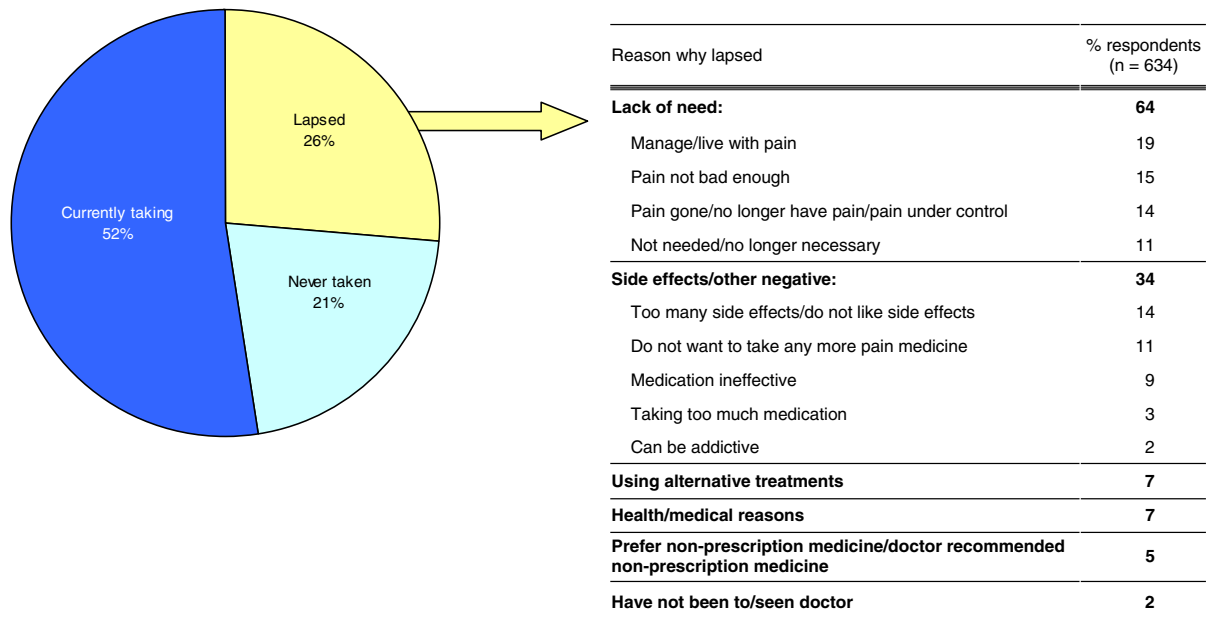


Fig. 20. Chronic pain sufferers taking, who had never taken, or who had taken and stopped taking prescription medicines and the reasons given for discontinuing prescription medicines. Answers to the structured interview questions: “Have you ever taken prescription medicine for your pain?” and “Are you currently taking prescription pain medicine?” and “Why not?”.

and/or did not like the side effects. Only 2% worried about the medicine being addictive (Fig. 20).

Most of the respondents who had taken prescription medication (3774), had taken one or two different prescription medications (65%), but over 10% had taken four or more.

3.2.12.5. *Types of prescription medication currently used for chronic pain.* The most common prescription medicines that were currently being taken by respondents were NSAIDs (44%), weak opioid analgesics (23%) and paracetamol (18%). Five percent were taking a strong opioid analgesic (Fig. 21).

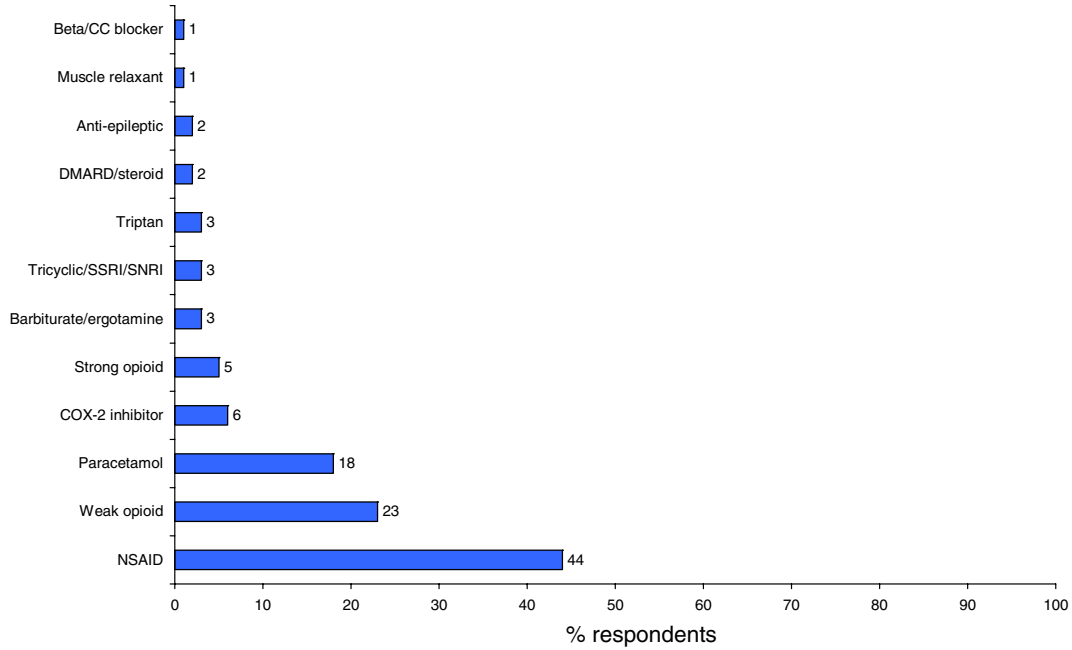


Fig. 21. Percentage of various classes of prescription medicines being used by those who report currently using prescription medicine. Answers to the structured interview question: “Which prescription pain medicines are you currently taking for the specific pain we have been discussing?” CC, calcium channel blockers. DMARD, disease modifying anti-rheumatic drugs.

When the data are broken down by country (Fig. 22; Tables 3a and 3b), it is clear that use of strong opioids varied widely from 0% in certain South-European coun-

tries to 12–13% in the UK and Ireland. Weak opioids varied even more: from 50% in UK and Norway, 36% in Sweden, 28% in Poland, between 18% and 22% in

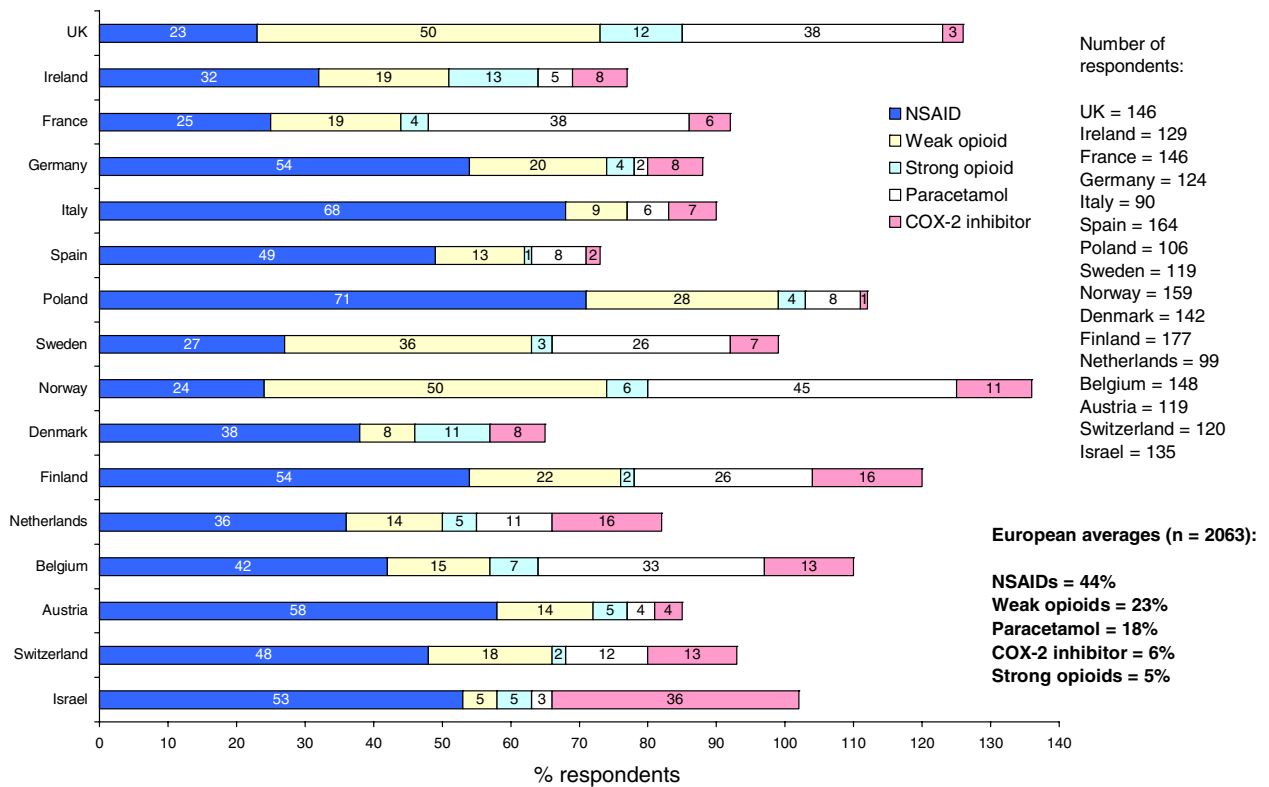


Fig. 22. Current use of prescription medicines in the 16 countries by respondents currently taking such medications. Answers to the structured interview question: “Which prescription pain medicines are you currently taking for the specific pain we have been discussing?”.

Table 3a
Currently used prescription pain medicines

| | % Respondents | | | | | | | | |
|------------------|-----------------|---------------------|----------------------|-------------------|--------------------|---------------------|---------------------|---------------------|----------------------|
| | UK (n = 146) | France (n = 146) | Germany (n = 124) | Italy (n = 90) | Spain (n = 164) | Poland (n = 106) | Sweden (n = 119) | Norway (n = 159) | Denmark (n = 142) |
| NSAIDs | 23 | 25 | 54 | 68 | 49 | 71 | 27 | 24 | 38 |
| Weak opioids | 50 | 19 | 20 | 9 | 13 | 28 | 36 | 50 | 8 |
| Paracetamol | 38 | 38 | 2 | 6 | 8 | 8 | 26 | 45 | 0 |
| COX-2 inhibitors | 3 | 6 | 8 | 7 | 2 | 1 | 7 | 11 | 8 |
| Strong opioids | 12 | 4 | 4 | 0 | 1 | 4 | 3 | 6 | 11 |
| | FGTSPWLZ | | | | | | | TS | FGTSPWLZ |

Answers to the structured interview question: "Which prescription pain medicines are you currently taking for the specific pain we have been discussing?"
 Statistical testing at the 95% confidence level: U, greater than UK; F, greater than France; G, greater than Germany; T, greater than Italy; S, greater than Spain; P, greater than Poland; W, greater than Sweden; Y, greater than Norway; D, greater than Denmark; L, greater than Netherlands; B, greater than Belgium; A, greater than Austria; Z, greater than Switzerland and E, greater than Israel.

Switzerland, Ireland, France, Germany, and Finland to between 5% and 13% in Israel, Denmark, Italy, and Spain.

The percentage of respondents taking COX-2 inhibitors ranged from 1% to 16%, except in Israel, where they were taken by 36% of respondents (during spring-summer of 2003).

Adjuvants, such as anti-epileptics and tricyclic anti-depressants were not commonly used, with <5% of respondents saying that they were currently receiving these drugs (Fig. 21).

3.2.12.6. *Effectiveness of prescription medication currently used for chronic pain.* Regarding the effectiveness of their current prescription pain medicines, 45% of respondents felt that they were completely or very effective, 41% felt they were somewhat effective, and 15% felt they were not very or not at all effective. Moreover, 64% of respondents said there were times when their pain medicines were not adequate to control their pain, apparently when activity causes breakthrough pain (Fig. 23a).

The country-specific data on inadequate pain control from medication are shown in Fig. 23b: Sweden had the lowest percentage of inadequate pain control by medication (30%), whereas 71–79% reported that pain medication at times were inadequate in Ireland, Israel, Denmark, Switzerland and the Netherlands.

3.2.13. *Overall effectiveness of treatment for chronic pain*

Sixty percent of respondents thought that their pain was being adequately controlled.. Around one-third (31%) had achieved pain control within six months from the time when they first experienced pain, but almost as many respondents (28%) had been in pain for over five years before they received effective treatment.

A pan-European average of 40% of pain sufferers were not satisfied with the effect of the treatment they were receiving for their long lasting pain. The country-specific data for overall inadequate pain control are shown in Fig. 27: This ranged from 27–33% in Finland, Ireland, Germany, Austria, and Spain to 40–45% in Israel, Italy, Norway and Sweden, and to as high as 54–61% in Switzerland, the Netherlands, Denmark and Belgium.

3.2.14. *Satisfaction with doctors*

Twenty-six percent of respondents were extremely satisfied with the doctor who was currently treating their pain, 36% were very satisfied and 28% were somewhat satisfied. Thus, 38% were not satisfied or only somewhat satisfied with the doctor treating their pain.

Table 3b
Currently used prescription pain medicines

| | % Respondents | | | | | | |
|------------------|-------------------------|----------------------|----------------------|----------------------|--------------------------|----------------------|---------------------|
| | Netherlands (n = 99) | Belgium (n = 148) | Finland (n = 177) | Ireland (n = 129) | Switzerland (n = 120) | Austria (n = 119) | Israel (n = 135) |
| NSAIDs | 36 | 42 | 54 | 32 | 48 | 58 | 53 |
| | UY | UFWY | UFY | | UIFWY | UIFWYDNB | UIFWYDN |
| Weak opioids | 14 | 15 | 22 | 19 | 18 | 14 | 5 |
| | E | E | TSDE | TDE | DE | E | |
| Paracetamol | 11 | 33 | 26 | 5 | 12 | 4 | 3 |
| | GDE | IGTSPDNAZE | IGTSPDNAZE | D | GDAE | E | |
| COX-2 inhibitors | 16 | 13 | 16 | 8 | 13 | 4 | 36 |
| | UFSPWA | UFSPA | UFTSPWDA | USP | UFSPA | | UIFGTSPWYDLNBAZ |
| Strong opioids | 5 | 7 | 2 | 13 | 2 | 5 | 5 |
| | TS | TSLZ | | FGTSPWYNLAZE | | TS | TS |

Answers to the structured interview question: “Which prescription pain medicines are you currently taking for the specific pain we have been discussing?”

Statistical testing at the 95% confidence level: U, greater than UK; F, greater than France; G, greater than Germany; T, greater than Italy; S, greater than Spain; P, greater than Poland; W, greater than Sweden; Y, greater than Norway; D, greater than Denmark; L, greater than Finland; N, greater than Netherlands; B, greater than Belgium; A, greater than Austria; Z, greater than Switzerland and E, greater than Israel.

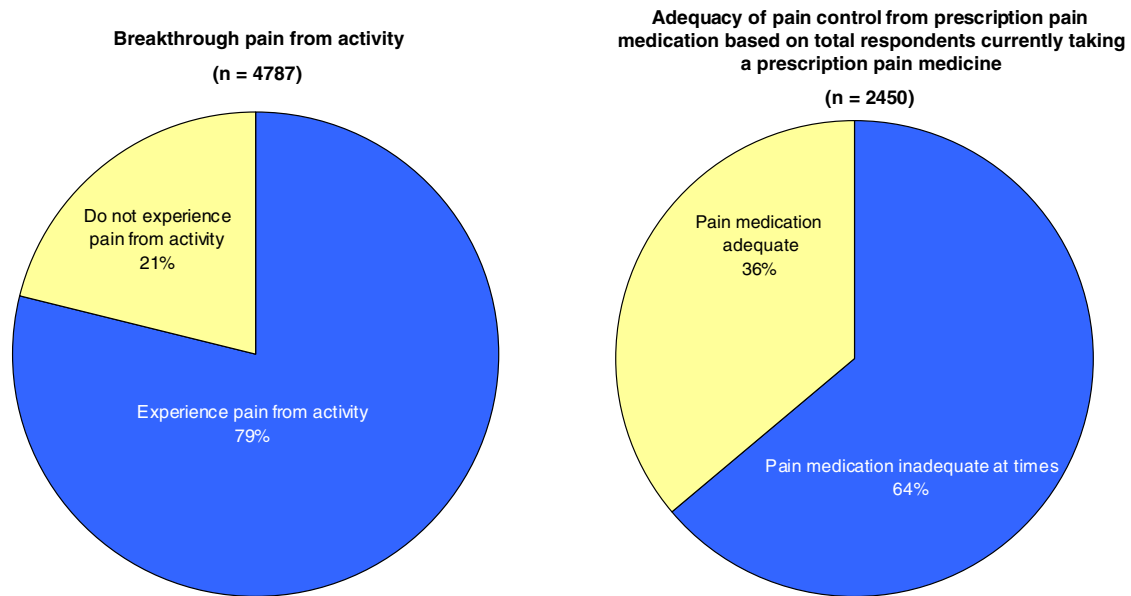


Fig. 23a. Pain provoked by activity and percentage of inadequate pain relief from medications. Answers to the structured interview questions: “Do you ever experience an increase in pain during the day as a direct result of an activity you did?” and “Are there ever times when your pain medicines are not adequate to control your pain?”.

3.2.15. Respondents' attitudes and beliefs about pain treatment

The interviewers read a list of statements to respondents to determine their attitudes and beliefs about pain treatment (Fig. 24). Nearly two-thirds of respondents said that they worried about the side effects of medicines, over half said that they would rather take medication for their illness than their pain, around 40% were afraid of becoming addicted to pain medicine, and around 40% said that they would spend all their money on pain treatment if they knew it would work.

3.2.16. Respondents' attitudes and beliefs about their pain

The interviewers read a list of statements to respondents to determine their attitudes and beliefs about their pain (Fig. 25). Three-quarters of respondents considered their pain to be just part of their medical condition, half felt tired all the time, and around 40% felt that their pain prevented them from concentrating, made them feel helpless and meant that they could not function normally. Over one-third of respondents said that they could not remember what it was like not to be in pain. As many as 16% some days feel that their pain is so bad that they wanted to die.

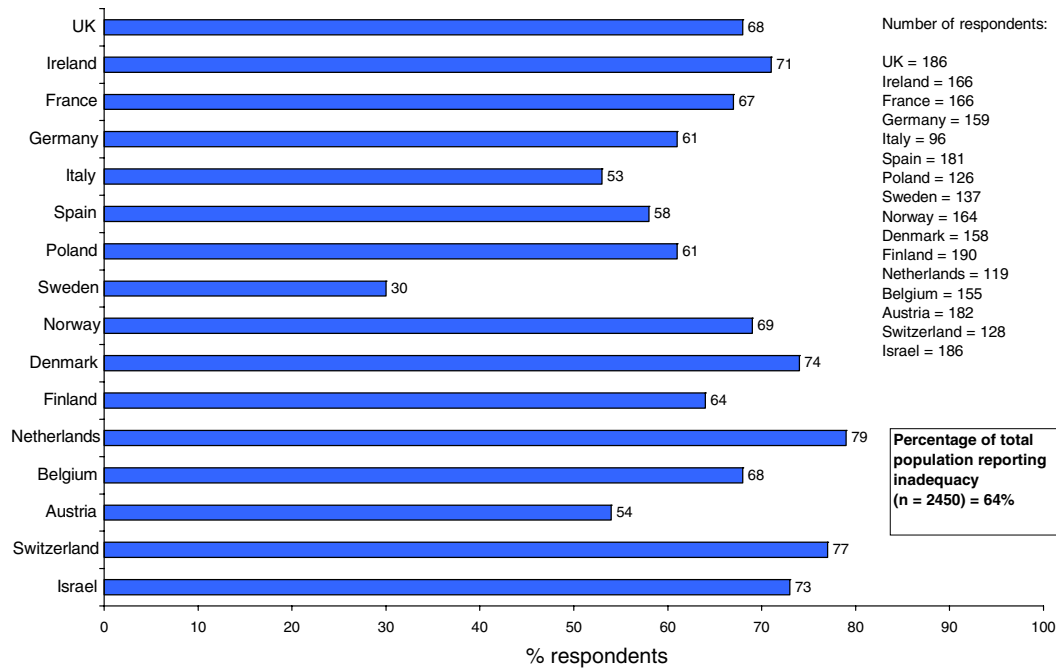


Fig. 23b. Percentage of inadequate pain control from medication in the 16 countries. Answers to the question: “Are there ever times when your pain medicines are not adequate to control your pain?”.

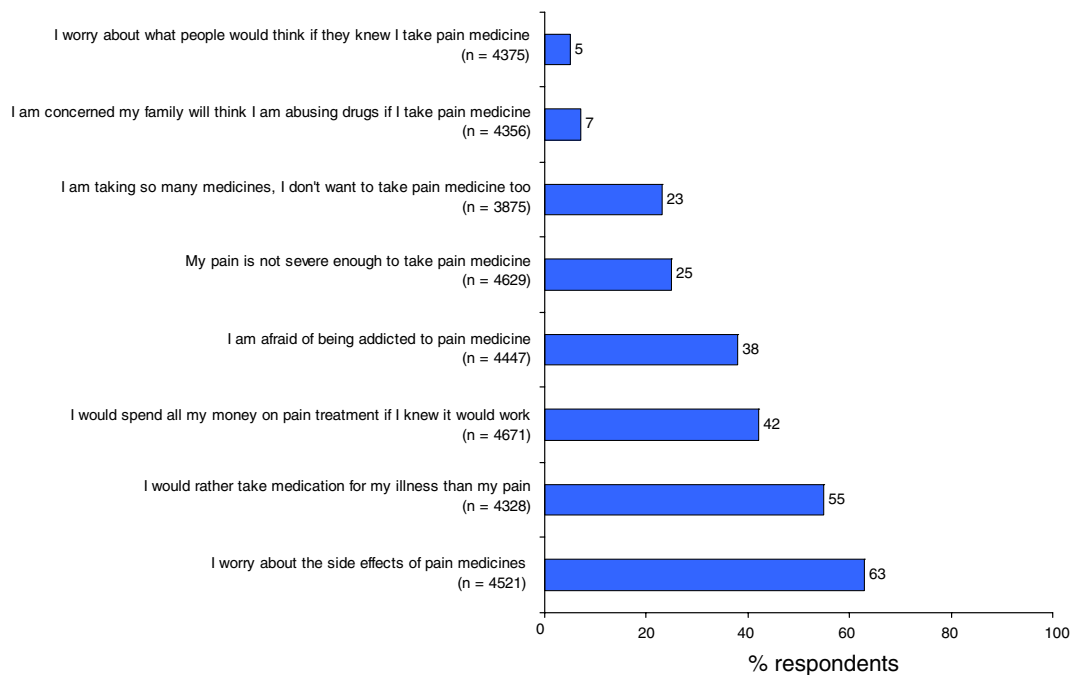


Fig. 24. Most frequently stated attitudes and beliefs of respondents about pain treatments. Percentage of respondents saying that they agreed somewhat or completely with the statements read out by the interviewers.

3.2.17. Respondents’ perception of the attitudes of others to their pain

Around 40% of respondents said that they felt their doctor would rather treat their illness than their pain and around 30% felt that their doctor did not know how to control their pain. Around 30% also felt that

no one believed how much pain they were experiencing. About one in four to one in five felt that colleagues, employers, family and doctors were unsympathetic to the respondents’ pain, did not think the pain was a problem, and did not understand how the pain affects the sufferers (Fig. 26).

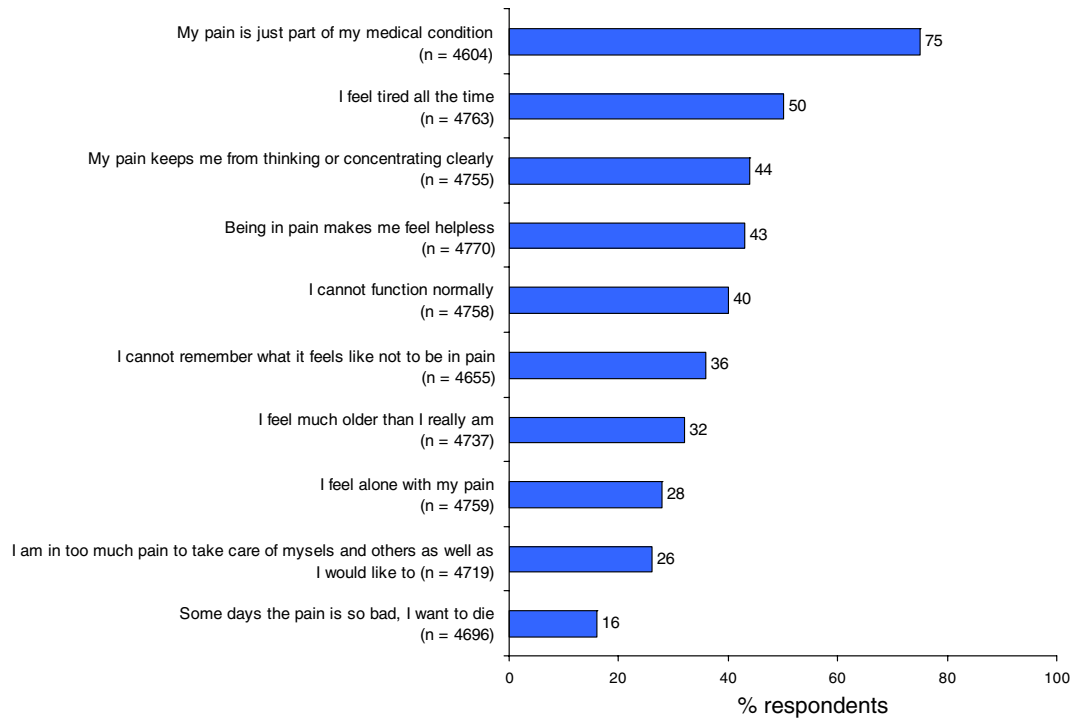


Fig. 25. Most frequently stated attitudes and beliefs about their pain given by the respondents with chronic pain. Percentage of respondents who agreed somewhat or completely with the statements read out by the interviewers.

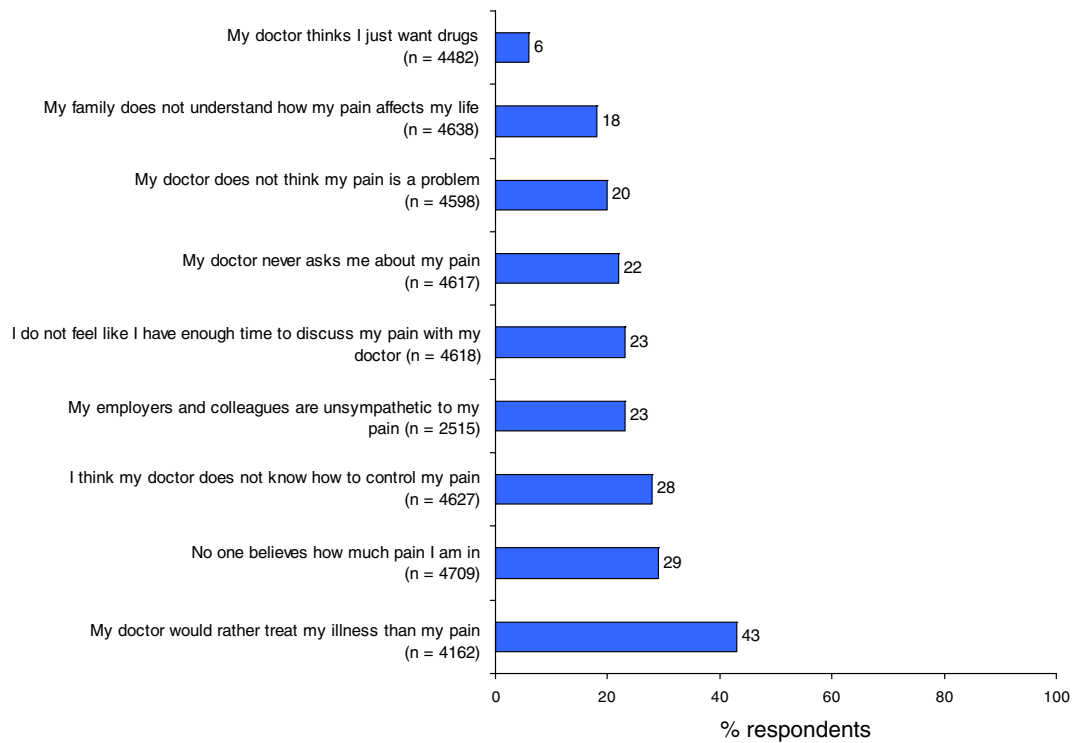


Fig. 26. The most frequently stated opinions of the respondents of the attitudes of their friends, family-members, colleagues, and doctors. Percentage of respondents who agreed somewhat or completely with the statements read out by the interviewers.

4. Discussion

Our survey of 46,394 respondents in 16 countries shows an overall prevalence of moderate to severe chronic pain in the general adult population of 15 European countries and Israel of 19%. Although about 60% of the respondents suffering from chronic pain were satisfied with the effect of treatment, 40% were not. Many aspects of everyday life, working life, somatic, emotional and social wellbeing and quality of life were clearly affected in most of the 4839 respondents with chronic pain. This survey documents that chronic pain is a major health care problem in Europe.

4.1. Validity of the observed prevalence data for chronic pain in Europe

From this large scale survey of almost 50,000 respondents we are confident that on average one in five adult Europeans suffer from chronic pain, which is moderate in 2/3 of the cases and severe in 1/3 of the cases. With random samples of 2000 to almost 4000 respondents in each of the 16 countries surveyed, we are confident that the documented country specific prevalence data for chronic pain are valid.

Our data agree with those of other large scale surveys. In a computer-assisted telephone survey of 17,543 individuals in the Australian general adult population, which defined chronic pain as pain every day for three months in the six months before the interview, the prevalence was 18.5% (Blyth et al., 2001).

In a recent survey of 12,333 respondents aged over 16 years in the general population of Denmark, the overall prevalence of chronic pain lasting at least six months was 19% (Eriksen et al., 2003). This supports the validity of our study in which the prevalence in Denmark was 16%. Unlike our survey, the survey in Denmark did not exclude mild pain and excluded cancer patients. However, cancer was cited as the cause for chronic pain by only 1% of respondents in our survey.

The prevalence in Norway was documented to be 30% in our study, which agrees well with the 25% reported in a postal questionnaire study of 4,000 adult Norwegians performed by Rustoen et al. (2004).

However, telephone-interview-surveys have well known biases: the oldest, the sickest, those living in nursing homes, those in lower socioeconomic strata will not be reached by telephone interviews. Prevalence of long-lasting pain is higher in such groups, a fact which would tend to underestimate the overall pain prevalence when using a telephone interview. On the other hand, women are more willing than men to respond to telephone interviews. Women have higher pain rates than men (Moulin et al., 2002).

Those with a pain problem in their household could be expected to be more willing to take part in an inter-

view about pain than those without pain problems among their family members. The refusal rates varied from country to country, and this may have caused selection bias: The most obvious would be that in countries with a high refusal rate, a possible tendency for more persons with a pain problem to be willing to respond, would falsely increase the prevalence. However, the country with the highest reported prevalence of chronic pain (30%) had one of the lowest refusal rates (35%) (Table 1). If there is a selection bias in the Norwegian sample, it is probably not caused by a lower willingness to participate by those without pain problems. And Germany had prevalence close to the overall mean for the 16 countries, but had the highest refusal rate (62%).

In a systematic review Harstall and Ospina (2003) concluded that the prevalence of chronic pain, as defined by IASP, i.e., pain without apparent biological value that has persisted beyond the normal tissue healing time, usually taken to be 3 months, ranges from 11.5% to 55.2%, with a mean of 35.5% when pain intensity is not specified. However, they estimated the prevalence of *severe chronic pain* in the general population to be 11% among adults. In our survey, we considered people to have significant chronic pain if they had suffered for at least six months, had experienced pain in the last month and at least twice per week, and rated their most recent experience of pain as at least moderate in intensity, i.e., 5 or higher on a 1–10 NRS. In our study 2/3 of the chronic pain sufferers had moderate pain (NRS = 5, 6, or 7 (Breivik et al., 2000)), whereas 1/3 had severe pain (NRS = 8, 9, or 10 (Breivik et al., 2000)). Thus, prevalence data on chronic pain depend on the degree of pain intensity and pain duration included in the definition of chronic pain. We feel confident that our definition excludes those with mild pain that most people would consider more a nuisance than a chronic disability.

4.2. Variation of prevalence between the 16 countries

The observed prevalence of chronic pain varied from 12% in Spain and 13% in the UK and Ireland to 26% and 27% in Italy and Poland and 30% in Norway. A variation across different countries was also seen in the rating of the intensity of pain and the causes given for their chronic pain by respondents. Apart from random variation in samples of 300 pain sufferers, these country differences are likely to be multifactorial, e.g. differences in the perception of pain and pain treatment, age stratification of the population and lifestyle. An older population may explain in part the higher rate of osteoarthritis and joint pain in some countries. Gunzelmann et al. (2002) and Eriksen et al. (2003) have documented a higher prevalence of pain in older people. Unfavourable climatic conditions may influence musculoskeletal pain. It is interesting that in Italy the prevalence was

above 32% in the northern part of Italy and less than 22% in the southern part. Many wonder why Norway has a prevalence of 30% while the neighbouring countries to the east and south range from 16% to 19%. However, a recent questionnaire survey in Iceland, Norway's closest neighbour to the west, 31% of the respondents suffered from chronic pain that had lasted more than 3 months (Gunnarsdottir, 2005).

It is interesting that only one in four of persons with chronic pain in Norway suffered from severe pain, compared to 44–50% in countries with lower overall prevalence, such as Spain and Israel. Does this mean that the Norwegians complain more easily of pain, or does it in fact mean that more people suffer from moderately severe pain in the north-western part of Europe?

4.3. Chronic pain sufferers' opinion of the impact of chronic pain on quality of life

The survey showed that approximately one-third of the persons with chronic pain are in severe pain and approximately half had constant pain. Most have had pain for at least two years and one-fifth have had pain for 20 years or more. Many people with chronic pain are less able or unable to do a range of daily activities. Perhaps the most notable results were that around two-thirds of people were less able or unable to sleep because of their pain, and about half found walking and household chores difficult because of pain. Approximately two-fifths of people have difficulty with sexual relations, one-third said that they were less able or unable to maintain an independent lifestyle and two-fifths of people said that their pain made them feel helpless and they could not function normally. One-fifth felt inadequate as a spouse or partner and a similar proportion of people said that they had been diagnosed with depression as a result of their pain.

Low self-esteem is engendered by the serious impact of chronic pain on peoples' lives. This was vividly documented by the chronic pain sufferers' opinion of the attitudes and beliefs of their doctors, their colleagues, friends and families about their pain (Fig. 26). These findings illustrate important aspects of the immense burden of chronic pain on the individual sufferers. These aspects of long-lasting pain have not been well documented before.

4.4. Implications for economy of the individual and of society

Approximately 60% of people said that they were less able or unable to work outside of home and around one-fifth had lost their job because of pain. Around one-third of people who were not retired said that their current employment status or hours that they worked was affected by their pain.

The effect of chronic pain on the ability to work has implications for the economy of society. As well as the cost related to the loss of productivity due to time off work and reduced work effectiveness, there is also the cost in loss of skills if people are forced to reduce their hours or stop working altogether (Blyth et al., 2003).

Moreover, it is well-known that social compensations, retirement pensions and other so-called indirect costs represent a burden to the economy that is much higher than direct healthcare costs (Jensen et al., 2004). The marked differences between countries in Europe in the effect of chronic pain on employment status reflect differences in the health care, sickness-retirement, and social welfare systems in these countries.

The impact of pain on healthcare resource utilisation in terms of visits to physicians is also evident in our data. Sixty percent of people had visited their doctor about their pain two to nine times in the last six months and 11% had visited at least 10 times.

4.5. Opinion of chronic pain sufferers of evaluation and management of chronic pain

One-fifth of people felt that their doctor did not see their pain as a problem; approximately the same proportion said that their doctor had never asked them about their pain, and over 40% said that their doctor would rather treat their illness than their pain. Thus, it is striking that patients often do not think that their doctor considers the pain as a problem. Respondents with conditions that are a source of chronic pain reported having an important symptom overlooked. Whilst it is clearly important to treat the patient's underlying condition, it is equally important to tackle the chronic pain resulting from it. Forty percent of those with long lasting or recurring pain in the present pan European survey reported that their pain was not managed well. This varied markedly between the 16 countries, from 27% to 29% in Finland and UK, Ireland and Germany, to 40–45% in Israel, Italy, Norway, Sweden, and to as high as 54–61% in Switzerland, the Netherlands, Belgium and Denmark (Fig. 27). In 2001, the *European Federation of Chapters of the International Association for the Study of Pain (EFIC)* declared that while acute pain may reasonably be considered a symptom of underlying disease or injury, chronic pain, with its many consequences for physical activities, socio-economic burdens and quality of life, could be viewed as a disease in its own right (www.efic.org; Niv and Devor, 2004). This is emphasised by Siddal and Cousins (2004).

Formal pain scales were rarely used, a finding that is supported by a recent survey of UK General Practitioners (Stannard and Johnson, 2003). Pain scales provide a recognised and validated method for tracking changes in pain intensity and the effectiveness of treatments, and will signal to the patient that pain is taken seriously.

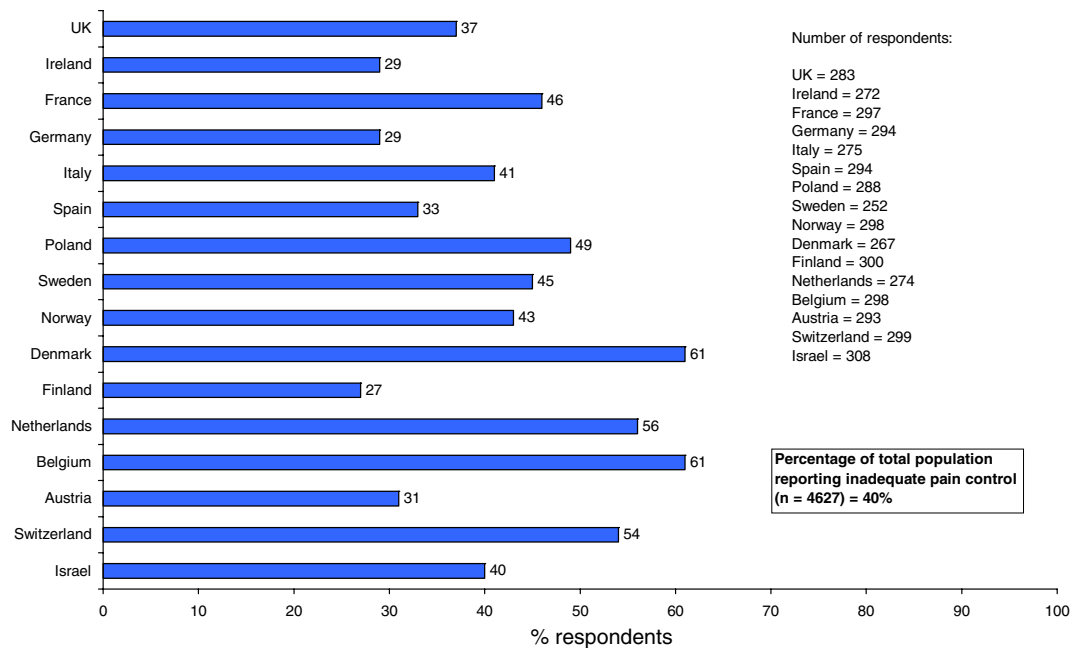


Fig. 27. Percentage of chronic pain sufferers who report that their pain is inadequately controlled in the 16 countries: Answers to the structured interview question: “Would you say your pain is being adequately controlled?”.

It must be emphasized that that 28% of respondents with pain believed their doctor does not know how to control their pain. Although 23% had at some time been to a pain specialist, only 2% were managed by a pain specialist. This suggests that specialist pain services are unavailable to a majority of chronic pain sufferers who could have benefited from specialised care. This is supported by data collected during the survey of GPs in the UK in which the doctors reported that only 14% of their patients in pain were referred to hospital for any specialist treatment (Stannard and Johnson, 2003).

4.6. Non-drug treatment of chronic pain

Seventy percent of the chronic pain sufferers were being treated with various non-drug treatments, most often physical therapy, massage and acupuncture. Thus large resources are used on such therapies with only meagre evidence base for their effects. Multidisciplinary and cognitive-behavioural approaches to management of chronic pain conditions are well documented to have significant and lasting effects. It is therefore an important finding that very few respondents in our survey reported having been exposed to these effective pain management strategies.

4.7. Drug treatment of chronic pain

Eighty percent of chronic pain sufferers reported that they experience breakthrough pain from activity, a phe-

nomenon recently emphasized by Svendsen et al. (2005), and 64% of those currently using prescription pain medications reported that their pain medications were inadequate at times to control their pain. The very marked differences in the use of non-prescription and prescription drugs of the weak and strong opioid classes of analgesics between the 16 countries clearly indicate that guidelines for appropriate use of these drugs in Europe are needed. The chronic pain sufferers' opinion of the adequacy of pain management did not seem to correlate to the drug usage-profiles of the countries surveyed (Figs. 22, 23 and 27; Tables 3a and 3b). Recently published guidelines (Kalso et al., 2003; The Pain Society, 2004) provide guidance on the use of opioids to non-cancer-related pain. They stress that these analgesics should be used with the utmost care, but that appropriate and responsible use of strong opioids should be considered when NSAIDs, paracetamol and weak opioids, as well as available non-drug treatments, have failed to provide relief and improve quality of life.

Over one-third of respondents worry about becoming addicted to pain medication and two-thirds were concerned about other side effects. Side effects of drugs were also cited as a major barrier to pain control by 74% of GPs in the UK (Stannard and Johnson, 2003).

All analgesics have side effects, the recent focus on cardiovascular and gastrointestinal adverse effects of coxibs and traditional NSAIDs, the risks of hepatotoxicity of paracetamol in accidental or intentional overdose, all must be balanced against the well known side effects of opioids. Most physical side effects of opioids

decrease over time and those that do not, including constipation, can usually be managed. However, the risk of opioid drug abuse is a reality. The challenge is to find best practice, a sensible ‘middle way’ between opiophobia and opiophilia with appropriate and responsible use of potent as well as weak opioid analgesics when the non-opioid analgesics do not suffice and alternative pain management is not available or fail to help the patient to better quality of life.

The approach to the management of chronic non-cancer pain should be one of mutual partnership between the patient and their practitioner, with valuable and frequent input from other health professionals who are part of a multidisciplinary care team. Primary and secondary care services need to work closely together to ensure good communication regarding the management of patients suffering with chronic non-cancer pain. Chronic pain should be recognised as an important disease-entity, a health care problem in its own right, and not only a symptom, and treated with the same priority as any underlying disease.

5. Conclusions and perspectives

The present survey has documented that chronic pain is common in Europe, that chronic pain affects negatively many aspects of quality of life, and that patients with long lasting pain experience a multitude of negative attitudes and distrust from health care providers, from colleagues, families and acquaintances. Chronic pain of moderate to severe intensity occurs in 19% of adult Europeans, seriously affecting their daily activities, social and working lives. Most respondents

had not received pain specialist treatment and 40% had inadequate management of their pain. We have documented that chronic pain is a major health care problem in Europe. This needs to be taken more seriously by health care providers and those responsible for health care policies and allocations of resources.

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Appendix

Int. Initials: _____ Project #: 25-02-3404
 Start Time: _____ Date: 04 November 2002
 Stop Time: _____ **FINAL** Approved: 04 November 2002

Structured Telephone Interviews on Chronic Pain
 –Patients–

| |
|--|
| ID: _____ |
| Name: _____ |
| Phone: _____ |
| Date of Interview: _____ Time: _____ am/pm |

Hello, my name is _____ of _____. We are conducting important health care research on issues related to pain, and we would like to include your opinions. May I ask you some background questions to determine if you qualify for our study? It should take only 3-4 minutes.

- 1 Yes..... **CONTINUE**
- 2 No **TERMINATE**

1. How many adults aged 18 or older live in your household?

[1-20] Adults 18+ in household

TERMINATE IF ZERO

2. How many adults aged 18 or older who live in your household experience pain from an illness or medical condition?

[1-20] Adults 18+ in household who experience pain

TERMINATE IF ZERO

3. Are you an adult aged 18 or older who suffers from pain from an illness or medical condition?

- 1 Yes..... **CONTINUE**
- 2 No **ASK TO SPEAK TO THAT HOUSEHOLD MEMBER**
 **REPEAT INTRODUCTION AND CONFIRM Q3 = YES**

CONTINUE SCREENING THE HOUSEHOLD MEMBER WHO SUFFERS FROM PAIN

4. Record sex from voice

- 1 Male
- 2 Female

5. How old were you on your last birthday?

[18-97] Years old

TERMINATE IF LESS THAN 18 YEARS OLD

6. For how long have you suffered from pain due to your illness or medical condition?

____ Years, ____ Months, ____ Weeks

TERMINATE IF LESS THAN SIX MONTHS or DK/REFUSED

7. When was the last time you experienced pain? Was it...? **(READ LIST) (ACCEPT ONE RESPONSE)**

- 1 Today CONTINUE
- 2 Not today, but within the past week CONTINUE
- 3 More than a week, but less than a month ago CONTINUE
- 4 1-3 Months ago TERMINATE
- 5 4-6 Months ago TERMINATE
- 6 More than 6 months ago TERMINATE
- 7 DK/Refused TERMINATE

8. How often do you experience pain? Do you experience it...? **(READ LIST) (ACCEPT ONE RESPONSE)**

- 1 At all times CONTINUE
- 2 Daily CONTINUE
- 3 Several times a week CONTINUE
- 4 Approximately once a week TERMINATE
- 5 Several times a month TERMINATE
- 6 Approximately once a month TERMINATE
- 7 Less often than once a month TERMINATE
- 8 DK/Refused TERMINATE

9. Thinking about the last time you experienced pain, please give me a number from 1 to 10 to indicate the intensity of your pain. Please use a 10-point scale where a “1” means “no pain at all” and a “10” means “the worst pain imaginable.” **(DO NOT READ LIST) (ACCEPT ONE RESPONSE ONLY)**

- 1 No pain at all TERMINATE
- 2 TERMINATE
- 3 TERMINATE
- 4 TERMINATE
- 5 CONTINUE
- 6 CONTINUE
- 7 CONTINUE
- 8 CONTINUE
- 9 CONTINUE
- 10 The worst pain imaginable CONTINUE
- 11 DK/Refused TERMINATE

10. Are you currently involved in any medical studies for pain medication?

- 1 Yes TERMINATE
- 2 No CONTINUE

11. Where is your pain located? **(DO NOT READ LIST) (ACCEPT MULTIPLES)**

- 1 Abdomen ASK QU. 1C and 1I
- 2 Ankle ASK QU. 1A
- 3 Arm ASK QU. 1A
- 4 Back (unspecified) ASK QU. 1D and 1F
Ask, “What part of your back?” before accepting “unspecified”
- 5 Bladder
- 6 Bones ASK QU. 1A
- 7 Chest
- 8 Colon/intestine ASK QU. 1C
- 9 Elbow ASK QU. 1A
- 10 Foot ASK QU. 1A
- 11 Groin

- 12 Hand..... ASK QU. 1A
- 13 Head ASK QU 1G
- 14 Hip ASK QU. 1A
- 15 Joints ASK QU. 1A
- 16 Knee ASK QU. 1A
- 17 Leg..... ASK QU. 1A
- 18 Lower back..... ASK QU. 1D
- 19 Muscles
- 20 Neck ASK QU. 1F
- 21 Prostate
- 22 Shoulder ASK QU. 1A
- 23 Stomach..... ASK QU. 1I
- 24 Upper back..... ASK QU. 1F
- 25 Throat ASK QU. 1I
- 26 Wrist..... ASK QU. 1A
- xx Other (Specify: _____)
- 27 DK/Refused

12. Please tell me the illness or medical condition that is the cause of your pain. (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | | Tab Nets |
|----|---|----------|
| 01 | Arthritis | 1 |
| 02 | Bursitis (ASK QU. 1B) | |
| 03 | Cancer | 7 |
| 04 | Crohn's Disease | 9 |
| 05 | Diabetic neuropathy | 5 |
| 06 | Disc problems (ASK QU. 1D) | |
| 07 | Endometriosis | 9 |
| 08 | Fibromyalgia | 6 |
| 09 | Headaches/migraine (ASK QU. 1G) | |
| 10 | Hip (bad hip, old break, hip replacement) (ASK QU. 1A) and clean back to SQ.11 | |
| 11 | HIV/AIDS | 9 |
| 12 | Interstitial cystitis | 9 |
| 13 | Joints, generally | 9 |
| 14 | Knees (bad knees, cartilage damage in knee, knee replacements) (ASK QU. 1A) and clean back to SQ.11 | |
| 15 | Lupus | 9 |
| 16 | Medication reactions (ASK QU. 1E) | |
| 17 | MS/Multiple Sclerosis | 9 |
| 18 | Muscular dystrophy | 9 |
| 19 | Neuropathy (unspecified) (ASK QU. 1H) | |
| 20 | Nerve damage/pain | 9 |
| 21 | Osteoarthritis | 1 |
| 22 | Osteoporosis | 9 |
| 23 | Poor circulation/vascular disease | |
| 24 | Post-herpetic neuralgia | |
| 25 | Rheumatoid Arthritis | 1 |
| 26 | Sciatica | |
| 27 | Scoliosis | 9 |
| 28 | Shingles | 8 |
| 29 | Shoulder (shoulder injury, shoulder replacement, torn rotator cup) (ASK QU. 1A) and clean back to SQ.11 | 9 |
| 30 | Spinal Stenosis | |
| 31 | Surgical pain/post up | |

| | | |
|----|----------------------|--------------|
| 32 | Trigeminal Neuralgia | 9 |
| 33 | Traumatic injury | |
| 34 | Tumors | 9 |
| Xx | Other (Specify) | (ASK QU. 1A) |
| 35 | DK/Refused | |

IF FOLLOW-UP QUESTIONS ARE INDICATED IN QU. 11 OR QU. 12, READ INVITATION AND START INTERVIEW WITH INDICATED SECTION(S) OF QU. 1.

IF NO FOLLOW-UP QUESTIONS ARE INDICATED IN QU. 11 OR QU. 12, READ INVITATION AND START INTERVIEW WITH QU. 2.

TABULATION NETS (Iterative and exclusive in this priority order):

- 8 = Shingles
- 7 = Cancer
- 6 = Fibromyalgia
- 5 = Diabetic neuropathy
- 4 = Traumatic injury
- 3 = Headaches
- 2 = Lower back
- 1 = Arthritis
- 9 = Other

Thank you for your responses. You qualify to complete a survey on chronic pain. It will take approximately 20 minutes, and we will mail you <currency amount> in appreciation for your time. Would you be interested in completing the survey?

- 1 Yes..... **ADMINISTER IMMEDIATELY OR SCHEDULE INTERVIEW**
- 2 No **TERMINATE**

| | |
|----------------------|----------------------------------|
| Int. Initials: _____ | Project #: <u>25-02-3404</u> |
| Start Time: _____ | Date: <u>5 November 2002</u> |
| Stop Time: _____ | Approved: <u>5 November 2002</u> |

FINAL

Structured Telephone Interviews on Chronic Pain

–Patients–

Standard script for interviews that do not immediately follow screening to be added by field vendor.

Interviewer: Read once to all respondents answering any section of Q1: “You may have already given me some of this information, so if I ask you anything you have already answered, please simply reconfirm your response.”

1a. Is your pain caused by...? (READ LIST) (ACCEPT MULTIPLES)

| | |
|---|-----------------|
| A tumor | 01 |
| Cancer | 02 (ASK QU. 1E) |
| A break or fracture that never healed correctly | 03 |
| Cartilage damage | 04 |
| Arthritis | 05 |
| Surgery that never healed correctly | 06 |
| Repetitive motion, or carpal tunnel syndrome | 07 |
| Tendonitis | 08 |
| Bone spurs | 09 |

| | |
|-------------------|----|
| Traumatic injury | 10 |
| None of the above | 11 |
| DK/Refused | 99 |

1b. **Is your pain caused by chronic bursitis?** (ACCEPT ONE RESPONSE ONLY)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 9 |

1c. **Is your pain caused by...?** (READ LIST) (ACCEPT MULTIPLES)

| | |
|--|---|
| Spastic colon | 1 |
| Crohn's Disease | 2 |
| Ulcerative colitis | 3 |
| Diverticular disease (diverticulitis, diverticulosis) | 4 |
| None of the above | 5 |
| DK/refused | 9 |

1d. **Is your pain caused by a herniated disc or deteriorating discs?** (ACCEPT ONE RESPONSE ONLY)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 9 |

1e. **Is your pain a result of radiation or chemotherapy?** (ACCEPT ONE RESPONSE ONLY)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 9 |

1f. **Is your pain caused by...?** (READ LIST) (ACCEPT MULTIPLES)

| | |
|------------------------------------|---|
| Whiplash | 1 |
| Nerve damage | 2 |
| Arthritis | 3 |
| Fracture or deterioration of spine | 4 |
| None of the above | 5 |
| DK/Refused | 9 |

1g. **Do you suffer from...?** (READ LIST) (ACCEPT ONE)

| | |
|--------------------|---|
| Migraine headaches | 1 |
| Cluster headaches | 2 |
| Both | |
| Neither | 3 |
| DK/Refused | 9 |

1h. **Is your neuropathy due to diabetes?** (ACCEPT ONE RESPONSE ONLY)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 9 |

1i. Is your pain caused by...? (**READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|------------|---|
| A tumor | 1 |
| Cancer | 2 |
| Neither | 3 |
| DK/Refused | 9 |

2. What words would you use to describe the pain you generally experience? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**) (**PROBE ONCE WITH “WHAT OTHERS?”**)

| | |
|------------------|----|
| Aching | 01 |
| Annoying | 02 |
| Bad | |
| Burning | 03 |
| Constant | 04 |
| Dull | 05 |
| Excruciating | 06 |
| Intense | 07 |
| Nauseating | 08 |
| Painful | 09 |
| Pressing | 10 |
| Pricking | 11 |
| Pulling | 12 |
| Sharp | 13 |
| Shooting | 14 |
| Stabbing | 15 |
| Throbbing | 16 |
| Tingling | 17 |
| Other (Specify:) | Xx |
| DK/Refused | 99 |

3. Would you describe the pain you generally experience as constant, on-going pain that is always there or intermittent pain that comes and goes? (**DO NOT READ LIST**) (**ACCEPT ONE RESPONSE ONLY**)

| | |
|--------------|---|
| Constant | 1 |
| Intermittent | 2 |
| DK/Refused | 9 |

4. Thinking about the intensity of your pain when it was **at its worst**, which of the following statements best describes your tolerance level for this pain? Would you say...? (**READ LIST**) (**ACCEPT ONE RESPONSE ONLY**)

| | |
|---|---|
| My pain was so severe I could not tolerate anymore, not even a little | 1 |
| I could tolerate a little more pain | 2 |
| I could tolerate somewhat more pain, OR | 3 |
| I could tolerate a lot more pain | 4 |
| DK/Refused (DO NOT READ) | 9 |

5. I am going to read to you a list of activities. As I read each item, please tell me how much your pain affects your ability to participate in that activity, whether you are “just as able”, “less able”, or “no longer able” to participate in the activity. **(READ LIST, WAITING FOR RESOPNSE TO EACH)**

| | Just as Able | Less Able | No Longer Able | DK/ Refused |
|---|-----------------|--------------|-------------------|----------------|
| Walking | 1 | 2 | 3 | 9 |
| Lifting | 1 | 2 | 3 | 9 |
| Exercising | 1 | 2 | 3 | 9 |
| Doing household chores | 1 | 2 | 3 | 9 |
| Driving | 1 | 2 | 3 | 9 |
| Attending social activities | 1 | 2 | 3 | 9 |
| Working outside the home | 1 | 2 | 3 | 9 |
| Sleeping | 1 | 2 | 3 | 9 |
| Maintaining relationships with friends and family | 1 | 2 | 3 | 9 |
| Maintaining an independent lifestyle | 1 | 2 | 3 | 9 |
| Having sexual relations | 1 | 2 | 3 | 9 |

6a. Have any of the following ever happened as a result of your pain...? **(READ LIST, WAITING FOR RESOPNSE TO EACH)**

| | Yes | No | DK/ Refused |
|------------------------------|-----|----|----------------|
| Lost job | 1 | 2 | 9 |
| Changed job responsibilities | 1 | 2 | 9 |
| Changed jobs entirely | 1 | 2 | 9 |

6b. Have you ever been diagnosed with depression by a medical doctor as a result of your pain? **(ACCEPT ONE RESPONSE ONLY)**

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 9 |

7. With whom do you generally discuss your pain? **(DO NOT READ LIST) (ACCEPT MULTIPLES)**

| | |
|----------------------------------|---|
| A doctor | 1 |
| A nurse | 2 |
| Another health care professional | 3 |
| Spouse/partner | 4 |
| Other family members | 5 |
| Friends, coworkers | 6 |
| Other (Specify): | 7 |
| Do not discuss my pain | 8 |
| DK/Refused | 9 |

9. Intentionally left blank to maintain skip patterns

10a. How many times in the past 6 months have you visited your current doctor for your pain? **(ACCEPT ONE RESPONSE ONLY. IF RANGES GIVEN ASK: “Would that be closer to _____ or _____?”)**

of Times: _____
 DK/Refused 98 – (SKIP TO QU. 10c)

10b. Intentionally left blank to maintain skip patterns

10c. Do you feel comfortable discussing your pain with your doctor? (**ACCEPT ONE RESPONSE ONLY**)

- Yes 1 – (SKIP TO QU. 11a)
- No 2
- DK/Refused 3 – (SKIP TO QU. 11a)

10d. Why do you feel uncomfortable discussing your pain with your doctor? (**RECORD VERBATIM**) (**CLARIFY VAGUE RESPONSES**) (**PROBE FULLY WITH, “WHAT OTHER REASONS?”**)

11a. Is your pain currently being treated in any way? (**ACCEPT ONE RESPONSE ONLY**)

- Yes 1 – (SKIP TO QU. 12a)
- No 2
- DK/Refused 3 – (SKIP TO QU. 12a)

11b. Why are you not currently being treated for your pain? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**) (**PROBE ONCE WITH: “WHAT OTHER REASONS?”**)

| | Yes | No | Tab Nets |
|---------------------------------|-----|----|----------|
| Pain not bad enough | 1 | 2 | 1 |
| Can manage on own | 1 | 2 | 1 |
| Condition better now | 1 | 2 | 1 |
| Non-prescription medicines work | 1 | 2 | 1 |
| Only have intermittent pain | 1 | 2 | 1 |
| Exercise helps | 1 | 2 | 1 |
| Do not need | 1 | 2 | 1 |
| Nothing more can be done | 1 | 2 | 2 |
| Treatment has not helped | 1 | 2 | 2 |
| Dislike going to doctor | 1 | 2 | 3 |
| Dislike taking medication | 1 | 2 | 3 |
| Do not want surgery | 1 | 2 | 3 |
| Too expensive | 1 | 2 | |
| Just live with pain | 1 | 2 | |
| Side effects | 1 | 2 | |
| Do not have a doctor | 1 | 2 | |
| Too busy/not enough time | 1 | 2 | |
| DK/Refused | | | |
| Other (Specify): | | | |

TABULATION NETS:

- 1 = Lack of Need (Net)
- 2 = Lack of Effective Treatment (Net)
- 3 = Dislike Treatment (Net)

- 12a. How many different doctors (including your current doctor) have treated you for your pain? (**ACCEPT ONE RESPONSE ONLY. IF RANGES GIVEN ASK: “Would that be closer to _____ or _____?”**)

of Doctors: _____
 DK/Refused 98

**(NOTE: IF 2 OR MORE IN QUESTION 12a, ASK QUESTION 12b.
 IF ONE IN QUESTION 12a, SKIP TO QU. 12c.
 IF ZERO IN QUESTION 12A AND NO IN QUESTION 11a, SKIP TO QUESTION 15a.
 IF ZERO IN QUESTION 12a, AND NOT NO IN QUESTION 11a, SKIP TO QU. 14a).**

- 12b. Please tell me your reasons for seeing more than one doctor for pain treatment? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**) (**PROBE ONCE WITH: “WHAT OTHER REASONS?”**)

| | |
|---|----|
| Primary doctor was a general practitioner or family physician | 01 |
| Primary doctor referred to another doctor | 02 |
| Another doctor was recommended to me by a friend, relative | 03 |
| Went to a specialist for my medical condition | 04 |
| Went to a pain specialist | 05 |
| Was not satisfied with the treatment I was receiving | 06 |
| Former doctor was not able to control my pain | 07 |
| Felt that my previous doctor did not believe the severity of my pain | 08 |
| Former doctor said he/she could not do anything more to treat my pain | 09 |
| Other (Specify): | 10 |
| DK/Refused | 11 |

- 12c. What kind of doctors are you currently seeing specifically for your pain (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|---|----|
| General Practitioner (GP)/Family Practitioner | 01 |
| Doctor of Osteopathy | 02 |
| Internist (Internal Medicine) | 03 |
| Anesthesiologist/Anesthetist | 04 |
| Chiropractor | 05 |
| Ears, Nose, Throat (ENT) | 06 |
| Gastroenterologist | |
| General surgeon | 07 |
| Gynecologist/Obstetrician (OB/GYN) | 08 |
| Hematologist | 09 |
| Infectious Diseases (ID) | 10 |
| Neurologist | 11 |
| Neurosurgeon | 12 |
| Oncologist | 13 |
| Orthopedist/Orthopedic surgeon | 14 |
| Pain management specialist | 15 |
| Physical medicine and rehabilitation | 16 |
| Physiotherapist | 17 |
| Plastic surgeon | 18 |
| Psychiatrist | 19 |
| Rheumatologist | 20 |
| Sports medicine | 21 |

| | |
|------------------|----|
| Other (specify:) | 22 |
| None | |
| DK/Refused | 23 |

12d. Have you ever been to see a pain management specialist? (**ACCEPT ONE RESPONSE ONLY**)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 3 |

TABULATION NOTE: IF CODE 15 (PAIN MANAGEMENT SPECIALIST) IS
 “YES” IN Q12c, EDIT Q12d TO “YES.”
 (NOTE: “NO” IN QUESTION 11a, SKIP TO QUESTION 14a.)

13a. How long have you been seeing the doctor who currently treats you for pain? (**RECORD RESPONSE**)

_____ Years, _____ Months, _____ Weeks

13b. [13b.] How often does this doctor determine how much pain you are in? Would you say...? (**READ LIST**)
 (**ACCEPT ONE RESPONSE ONLY**)

| | |
|-----------------------------------|---|
| During every visit | 1 |
| Every two visits | 2 |
| Every 3-4 visits | 3 |
| Every 5-6 visits | 4 |
| Every 7-10 visits, OR | 5 |
| Less often | 6 |
| Never → Skip to QU. 14a | |
| DK/Refused (DO NOT READ) | 7 |

13c. How does the doctor who generally treats your pain determine how much pain you are in? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|--|---|
| I tell him/her | 1 |
| Doctor examines me | 2 |
| Doctor asks me to walk | 3 |
| Doctor asks me to move the part of my body that is in pain | 4 |
| Doctor uses a pain scale | 5 |
| Doctor does not do anything to determine how much pain I am in | 6 |
| Other (Specify): | 7 |
| DK/Refused | 9 |

NOTE: IF DOCTOR USES A PAIN SCALE (CODE 5) TO QU. 13c, RECORD “YES” IN Q14a AND CONTINUE WITH QU 14b.

14a. Has any doctor or medical professional ever scored you on a pain scale? (**ACCEPT ONE RESPONSE ONLY**)

| | |
|------------|-----------------------|
| Yes | 1 |
| No | 2 – (SKIP TO QU. 14e) |
| DK/Refused | 3 – (SKIP TO QU. 14e) |

14b. What type of scale did the doctor use to score your pain? (**READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|-----------------------------|-----------------------|
| Number scale/numeric rating | 1 – (ASK QU. 14d) |
| Word or descriptive scale | 2 – (SKIP TO QU. 14e) |
| Faces scale | 3 – (SKIP TO QU. 14e) |
| Other scale (specify:) | 4 – (SKIP TO QU. 14e) |
| DK/Refused | 9 – (SKIP TO QU. 14e) |

NOTE: IF YES TO NUMBER SCALE/NUMERIC RATING (CODE 1), ASK QU. 14c. OTHERWISE, SKIP TO QU 14d.

14c. When the doctor most recently scored your pain on a number scale, what was the number that was used to describe your pain? (**IF RANGE GIVEN ASK: “Would that be closer to _____ or _____?”**)

Rating #: _____
DK/Refused 98

14d. How satisfied are you with the doctor who currently treats your pain? Would you say...? (**READ LIST**) (**ACCEPT ONE RESPONSE ONLY**)

| | |
|----------------------|---------------------|
| Extremely satisfied | 1 (skip to Qu. 15a) |
| Very satisfied | 2 (skip to Qu. 15a) |
| Somewhat satisfied | 3 (skip to Qu. 15a) |
| Not very satisfied | 4 |
| Not at all satisfied | 5 |
| DK/Refused | 6 - SKIP TO QU. 15a |

14e. Why do you say you are **not very or not at all satisfied** with the doctor that currently treats your pain? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**) (**PROBE ONCE WITH: “WHAT OTHER REASONS?”**)

| | Codes | Tab Nets |
|---|-------|----------|
| Has not helped me/has not relieved my pain | 1 | 1 |
| Just gives me prescriptions/medications | 2 | 1 |
| Not good/competent/does not know what he/she is doing | 3 | 1 |
| Not thorough/does not follow through | 4 | 1 |
| Does not care/show interest/understand | 5 | 2 |
| Do not see same doctor each time | 6 | 2 |
| Does not listen/take time to listen | 7 | 2 |
| Does not take me seriously/believe me | 8 | 2 |
| Does not keep me informed/does not explain everything | 9 | 2 |
| Dislike doctor, generally | 10 | 2 |
| Condition can't be treated/have to live with it | 11 | |
| Need to see a different type of doctor | 12 | |
| Other Negative (Specify): | 13 | |
| DK/Refused | 14 | |

TABULATION NETS:

- 1 = Treatment Provided (Net)
- 2 = Doctor/Patient Relationship (Net)

15a. Have you ever taken prescription medicine for your pain? **(DO NOT READ LIST) (ACCEPT ONE RESPONSE ONLY)**

- Yes 1 – (SKIP TO QU. 15c)
- No 2
- DK/Refused 3 – (SKIP TO QU. 21)

15b. Why not? **(DO NOT READ LIST) (ACCEPT MULTIPLES) (PROBE ONCE WITH: “WHAT OTHER REASONS?”)**

| | Codes | Tab Nets |
|---|-------|----------|
| Pain not bad enough | 01 | 1 |
| Never prescribed | 02 | 1 |
| Not needed/no longer necessary | 03 | 1 |
| Manage/live with the pain | 04 | 1 |
| Doctor does not believe I need medication | 05 | 1 |
| Pain is gone/no longer have pain/pain under control | 06 | 1 |
| Taking non-prescription medicine | 07 | |
| Do not want to take any more pain medicine | 08 | |
| Too many side effects/do not like side effects | 09 | 2 |
| Interferes with other medications | 10 | 2 |
| Can be addictive | 11 | 2 |
| Have not been to/seen a doctor | 12 | |
| Price/cost/no medical coverage | 13 | |
| Do not buy/take medication | 14 | |
| Health/medical reasons | 15 | |
| Other (specify:) | Xx | |
| DK/Refused | 20 | |

TABULATION NETS:

- 1 = No Need (Net)
 - 2 = Side Effects/Other Negative (Net)
- (Note, some rows intentionally left blank)

NOTE: IF NO (CODE 2) IN Q15a, SKIP TO QU. 21

15c. How many different kinds of prescription pain medicines have you ever taken for your pain? **(ACCEPT ONE RESPONSE ONLY) (IF RANGES GIVEN ASK: “Would that be closer to _____ or _____?”)**

- # of pain medicines: _____
- DK/Refused 98

16a. Are you currently taking prescription pain medicine? **(ACCEPT ONE RESPONSE ONLY)**

- Yes 1 – (SKIP TO INSTRUCTIONS BEFORE QU.17)
- No 2
- DK/Refused 3 – (SKIP TO INSTRUCTIONS BEFORE QU.17)

16b. Why not? **(DO NOT READ LIST) (ACCEPT MULTIPLES) (PROBE ONCE WITH: “WHY ELSE?”)**

| | Codes | Tab Nets |
|---|-------|----------|
| Pain is gone/no longer have pain/pain under control | 01 | 1 |
| Not needed/no longer necessary | 02 | 1 |
| Pain is not bad enough | 03 | 1 |

| | | |
|---|----|---|
| Manage/live with the pain | 04 | 1 |
| Too many side effects/do not like side effects | 05 | 2 |
| Taking too much medication | 06 | 2 |
| Can be addictive | 07 | 2 |
| Interferes with other medication | 08 | 2 |
| Medication ineffective | 09 | |
| Price/cost/no medical coverage | 10 | |
| Using alternative treatments | 11 | |
| Do not want to take any more pain medicine/more medication than necessary | 12 | |
| Have not been to/seen a doctor | 13 | |
| Ran out of/finished medication | 14 | |
| Health/medical reasons | 15 | |
| Prefer non-prescription medication/doctor recommended a non-prescription medication | 16 | |
| Other (specify:) | xx | |
| DK/Refused | 17 | |

TABULATION NETS:

1 = No Need (Net)

2 = Side Effects/Other Negative (Net)

(Note, some rows intentionally left blank)

(NOTE: IF 2 OR MORE MENTIONED IN QU.15c, ASK QU. 17a

**IF “ZERO OR ONE” MENTIONED IN QU.15c AND NO OR DK (CODES 2 OR 3)
IN QU.16a, SKIP TO QU.21**

17a. Has your doctor ever switched prescription pain medicines or prescribed more than one medicine for the same pain? (**READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|--|---|
| Switched prescription pain medicine | 1 |
| Taken more than one prescription pain medicine for the same pain | 2 |
| Both | 3 |
| Neither | 4 |
| DK/Refused | 5 |

NOTE: IF NO CODE 1 IN Q17a, SKIP TO QU. 18

17b. Why did you switch from one prescription pain medicine to another? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|--|----|
| Pain became worse | 01 |
| Needed a stronger medication | 02 |
| Switched doctors | 03 |
| Medication did not work | 04 |
| Had a negative reaction to medication | 05 |
| Did not like side effects | 06 |
| Effects of medication did not last long enough | 07 |
| Afraid of becoming addicted | 08 |
| Current doctor's recommendation | 09 |
| Other (Specify): | 10 |
| DK/Refused | 11 |

(NOTE: IF “NO” (CODE 2) IN QUESTION 16a, SKIP TO QUESTION 21)

18. Which prescription pain medicines are you CURRENTLY taking for the specific pain we have been discussing? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|--|----|
| NSAIDs | |
| COX-2 Inhibitors | |
| Anti-epileptic drugs | |
| Beta blockers/calcium channel blockers | |
| Tricyclic antidepressants/SSRIs/SNRIs | |
| Barbiturates/butalbitals/ergotamines | |
| Muscle relaxants | |
| Narcotic analgesics | |
| Triptans | |
| <hr/> | |
| Actiq | 01 |
| Arthrotec | 02 |
| Azathioprine | |
| Brufen | 03 |
| Celebrex | 04 |
| Dextromoramide | 05 |
| DF 118 | 06 |
| Diamorphine | 07 |
| Diconal | 08 |
| Dihydrocodeine | |
| Distalgesic | 09 |
| Doloxen | 10 |
| Duragesic | 11 |
| Equagesic | 12 |
| Etodolac | 13 |
| Fembed | 14 |
| Fentanyl | 15 |
| Hydromorphone | 16 |
| Laraflex | 17 |
| Lidifen | 18 |
| Methodox | 19 |
| Moraxen | 20 |
| Morphine | 21 |
| MST | 22 |
| MXL | 23 |
| Nalbuphone | 24 |
| Narphen | 25 |
| Neorocyn | 26 |
| Newbane | 27 |
| Oramph | 28 |
| Orudis | 29 |
| Oxycontin | 30 |
| Oxynon | 31 |
| Palladone | 32 |
| Pethidine | 33 |
| Pemidine | 34 |
| Relifex | 35 |
| Sevredol | 36 |
| Solpadol | 37 |
| Syclimorph | 38 |
| Tramadol | 39 |
| Vioxx | 40 |
| Zamadol | 41 |

| | |
|------------------|----|
| Zydo | 42 |
| Other (Specify): | xx |
| None | 97 |
| DK/Refused | 98 |

19. Overall, how effective are your current prescription pain medicines? Would you say they are...? (**READ LIST**)
(**ACCEPT ONE RESPONSE ONLY**)

| | |
|-----------------------------------|---|
| Completely effective | 1 |
| Very effective | 2 |
| Somewhat effective | 3 |
| Not very effective OR | 4 |
| Not at all effective | 5 |
| DK/Refused (DO NOT READ) | 6 |

20. Are there ever times when your pain medicines are not adequate to control your pain? (**ACCEPT ONE RESPONSE ONLY**)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 3 |

21. Do you ever experience an increase in pain during the day as a direct result of an activity you did? (**ACCEPT ONE RESPONSE ONLY**)

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 3 |

22. Intentionally left blank to maintain skip patterns

23. Intentionally left blank to maintain skip patterns

24. Intentionally left blank to maintain skip patterns

25. In the past six months, how many different kinds of non-prescription, oral medications have you taken for your pain? (**ACCEPT ONE RESPONSE ONLY**) (IF RANGES GIVEN ASK: “Would that be closer to _____ or _____?”)

| | |
|--|-------|
| # of non-prescription, oral medicines: | _____ |
| DK/Refused | 98 |

26. Which non-prescription, oral medicines are you currently taking for pain? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|-------------------|----|
| Acupan | 01 |
| Advil | 02 |
| Alka-Seltza | 03 |
| Anadin | 04 |
| Aspirin | 05 |
| Aspirin + codeine | 06 |
| Aspro | 07 |
| Brexidol | 08 |
| Capol | 09 |
| Caraflex | 10 |
| Co-codomol | 11 |
| Co-codoprin | 12 |

| | |
|--------------------------------------|----|
| Codinine | 13 |
| Codis 500 | 14 |
| Disprin | 15 |
| Disprol | 16 |
| Dolobid | 17 |
| Flexin | 18 |
| Froben | 19 |
| Headex | 20 |
| Imbosid | 21 |
| Keral | 22 |
| Ledofen | 23 |
| Migraleve | 24 |
| Miloxicam | 25 |
| Nurofen | 26 |
| Obifen | 27 |
| Panodol | 28 |
| Paracetamol | 29 |
| Paracodal | 30 |
| Paramol | 31 |
| Solpadine | 32 |
| Tylox | 33 |
| Voltarol | 34 |
| Veganin | 35 |
| Other (Specify): | Xx |
| None (SKIP TO QU. 28) | 97 |
| DK/Refused (SKIP TO QU. 28) | 98 |

27a. Overall, how effective are your current non-prescription, oral pain medicines? Would you say they are...? (**READ LIST**) (**ACCEPT ONE RESPONSE ONLY**)

| | |
|-----------------------------------|---|
| Completely effective | 1 |
| Very effective | 2 |
| Somewhat effective | 3 |
| Not very effective, OR | 4 |
| Not at all effective | 5 |
| DK/Refused (DO NOT READ) | 6 |

27b. Considering all prescription and non-prescription oral medicines you take for pain, approximately how many pills do you take each day? (**ACCEPT ONE RESPONSE ONLY**) (**IF RANGES GIVEN ASK: "Would that be closer to _____ or _____?"**)

| | |
|-------------|-------|
| # of pills: | _____ |
| DK/Refused | 98 |

28. What other methods, remedies or treatments, apart from medications, have you ever tried to relieve your pain for the medical condition or illness we have been discussing? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

| | |
|-------------------------------|----|
| Acupuncture | 01 |
| Alcohol rubs | 02 |
| Alcoholic drinks | 03 |
| Bio feedback | 04 |
| Change in diet, special foods | 05 |
| Cold (ice packs, etc) | 06 |
| Exercise | 07 |
| Heat (heating pad, etc.) | 08 |

| | |
|---------------------------------|----|
| Herbal supplements | 09 |
| Hypnosis | 10 |
| Imagery | 11 |
| Massage | 12 |
| Meditation | 13 |
| Nerve stimulation or TENS | 14 |
| Ointments/creams/gels | 15 |
| Relaxation therapy | 16 |
| Physical therapy | 17 |
| Support groups | 18 |
| Therapy/counseling | 19 |
| Vitamins | 20 |
| Other (Specify): | xx |
| None/no others (SKIP TO QU 32a) | 98 |
| DK/Refused (SKIP TO QU 32a) | 99 |

(NOTE: IF 2 OR MORE MENTIONED IN QUESTION 28, ASK QUESTION 29, OTHERWISE SKIP TO QUESTION 30)

30. In general, how successful have these therapies been in relieving your pain? (READ LIST) (ACCEPT ONE RESPONSE ONLY)

| | |
|--------------------------|---|
| Extremely successful | 1 |
| Very successful | 2 |
| Somewhat successful OR | 3 |
| Not very successful | 4 |
| DK/Refused (DO NOT READ) | 6 |

31. Intentionally left blank to maintain skip patterns.

32a. Have you been treated for pain or seen a doctor for pain in another country? (ACCEPT ONE RESPONSE ONLY)

| | |
|------------|-----------------------|
| Yes | 1 |
| No | 2 - (SKIP TO QU. 32c) |
| DK/Refused | 3 - (SKIP TO QU. 32c) |

32b. For what reasons did you see a doctor for pain or seek treatment for pain in another country? (READ LIST) (ACCEPT MULTIPLES)

| | |
|--|---|
| Better access in other country | 1 |
| Better reimbursement in other country | 2 |
| Closest clinic is in another country | 3 |
| Was traveling on holiday or business at the time | 4 |
| Other (specify:) | 6 |

32c. What is the greatest distance you have traveled for pain treatment, including doctor visits? (ACCEPT ONE RESPONSE ONLY) (IF RANGES GIVEN ASK: “Would that be closer to _____ or _____?”) Miles in UK Kilometers elsewhere.

| | |
|------------------|-------|
| # of kilometers: | _____ |
| DK/Refused | 98 |

| |
|--------------------------------------|
| Miles in uk Kilometers elsewhere. |
|--------------------------------------|

33. Intentionally left blank to maintain skip patterns.

34. Would you say your pain is being adequately controlled? (**ACCEPT ONE RESPONSE ONLY**)

- Yes 1
 No 2 – (SKIP TO QU.36)
 DK/Refused 3 – (SKIP TO QU.36)

35. How long was it from the time you first experienced pain to the time your pain was adequately controlled? (**RECORD RESPONSE**)

_____ Years, _____ Months, _____ Weeks

36. Where do you hear about new methods for treating pain? (**DO NOT READ LIST**) (**ACCEPT MULTIPLES**)

- Doctor's office (doctor, nurse, information in waiting room) 1
 Magazines/newspapers 2
 Television (health channel, news, talk shows) 3
 Internet 4
 Friends, family, co-workers 5
 Pharmacy/pharmacist 6
 None/do not hear about new methods for treating pain 7
 Other (Specify): 8
 DK/Refused 9

37. Now we would like to understand how pain affects your life. I am going to read a list of statements that could be used to describe how people who are experiencing pain think and feel about it. For each statement I read, please think about yourself and your own pain and tell me how much you agree or disagree with each statement using the following 5-point scale.

You may wish to write these down, or I can re-read them to you at any time. You can answer with numbers or the words, whichever is easier. After I finish reading the list of statements, I will have only a few more questions, and our interview will be done.

INTERVIEWER: Read the agreement scale below.

- 1 = "Disagree completely"
 2 = "Disagree somewhat"
 3 = "Neither agree nor disagree"
 4 = "Agree somewhat"
 5 = "Agree completely"

Let's start with... (READ LIST) (ACCEPT ONE RESPONSE FOR EACH) (RANDOMIZE) (REPEAT SCALE AS NECESSARY)

If respondent simply responds "agree" or "disagree" probe with: "How much do you agree/disagree? Would you say you agree/disagree completely or somewhat?"

| | Not Applicable | Disagree Completely | Disagree Somewhat | Neither Agree or Disagree | Agree Somewhat | Agree Completely |
|--|----------------|---------------------|-------------------|---------------------------|----------------|------------------|
| I would rather take medication for my illness than my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I worry about the side effects of pain medicine | 9 | 1 | 2 | 3 | 4 | 5 |
| My pain is not severe enough to take pain medicine | 9 | 1 | 2 | 3 | 4 | 5 |
| I am taking so many medicines, I do not want to take pain medicine too | 9 | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|--|---|---|---|---|---|---|
| I am afraid of being addicted to pain medicine | 9 | 1 | 2 | 3 | 4 | 5 |
| I worry about what people would think if they knew I take pain medicine | 9 | 1 | 2 | 3 | 4 | 5 |
| Some days the pain is so bad, I want to die | 9 | 1 | 2 | 3 | 4 | 5 |
| No one believes how much pain I am in | 9 | 1 | 2 | 3 | 4 | 5 |
| I cannot function normally | 9 | 1 | 2 | 3 | 4 | 5 |
| I feel much older than I really am | 9 | 1 | 2 | 3 | 4 | 5 |
| I feel inadequate as a spouse/partner because of my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I feel like people treat me differently because I have pain | 9 | 1 | 2 | 3 | 4 | 5 |
| Being in pain makes me feel helpless | 9 | 1 | 2 | 3 | 4 | 5 |
| I feel tired all the time | 9 | 1 | 2 | 3 | 4 | 5 |
| I cannot remember what it feels like not to be in pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I fear my pain will cause me to lose my job | 9 | 1 | 2 | 3 | 4 | 5 |
| I would spend all my money on pain treatment if I knew it would work | 9 | 1 | 2 | 3 | 4 | 5 |
| My doctor would rather treat my illness than my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I do not feel like I should discuss my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| My family does not understand how my pain affects my life | 9 | 1 | 2 | 3 | 4 | 5 |
| I do not feel like I have enough time to discuss my pain with my doctor | 9 | 1 | 2 | 3 | 4 | 5 |
| My employers and colleagues are unsympathetic to my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I am always willing to try a new treatment for pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I think my doctor does not know how to control my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| My doctor does not think my pain is a problem | 9 | 1 | 2 | 3 | 4 | 5 |
| My pain is just part of my medical condition | 9 | 1 | 2 | 3 | 4 | 5 |
| My doctor never asks me about my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| My doctor thinks I just want drugs | 9 | 1 | 2 | 3 | 4 | 5 |
| I am concerned my family will think I am abusing drugs if I take pain medicine | 9 | 1 | 2 | 3 | 4 | 5 |
| I feel alone with my pain | 9 | 1 | 2 | 3 | 4 | 5 |
| I am in too much pain to take care of myself and other people as well as I would like to | 9 | 1 | 2 | 3 | 4 | 5 |
| My pain keeps me from thinking or concentrating clearly | 9 | 1 | 2 | 3 | 4 | 5 |
| My pain forces me to rely too much on other people | 9 | 1 | 2 | 3 | 4 | 5 |

The next few question are for demographic purposes only

38. Are you currently...? **(READ LIST) (ACCEPT ONE RESPONSE ONLY)**

| | |
|---------------------------------|---------------------|
| Employed full-time | 1 - (CONTINUE) |
| Employed part-time | 2 - (CONTINUE) |
| Retired | 3 - (SKIP TO QU.40) |
| Not employed | 4 - (SKIP TO QU.40) |
| DK/Refused (DO NOT READ) | 5 - (SKIP TO QU.40) |

39. In the past six months, how many days in total have you lost from work because of your pain? **(ACCEPT ONE RESPONSE ONLY) (IF RANGES GIVEN ASK: "Would that be closer to _____ or _____?")**

| | |
|-------------|-------|
| # of hours: | _____ |
| DK/Refused | 98 |

40. Does your current employment status or the hours you work have anything to do with the pain that you experience? **(DO NOT READ LIST) (ACCEPT ONE RESPONSE ONLY)**

| | |
|------------|---|
| Yes | 1 |
| No | 2 |
| DK/Refused | 3 |

41. Do you live alone or with other family or household members? **(DO NOT READ LIST) (ACCEPT ONE RESPONSE ONLY)**

| | |
|------------------|---|
| Live alone | 1 |
| Live with others | 2 |
| DK/Refused | 3 |

42. Are you...? **(READ LIST) (ACCEPT ONE RESPONSE ONLY)**

| | |
|---------------------------------|---|
| Married | 1 |
| Single | 2 |
| Divorced/separated, OR | 3 |
| Widowed | 4 |
| DK/refused (DO NOT READ) | 5 |

43. How many children, under age 18 currently live in your household? **(DO NOT READ LIST) (ACCEPT ONE RESPONSE ONLY)**

| | |
|--------------|-----------------------|
| None | 1 – (SKIP TO CLOSING) |
| One | 2 – (CONTINUE) |
| Two | 3 – (CONTINUE) |
| Three | 4 – (CONTINUE) |
| Four | 5 – (CONTINUE) |
| Five or more | 6 – (CONTINUE) |
| DK/Refused | 7 – (SKIP TO CLOSING) |

44. What are their ages? **(DO NOT READ LIST) (ACCEPT MULTIPLES)**

| | |
|---------------|---|
| Under 2 years | 1 |
| 2-3 years | 2 |
| 4-5 years | 3 |
| 6-8 years | 4 |
| 9-10 years | 5 |

| | |
|-------------|---|
| 11-12 years | 6 |
| 13-15 years | 7 |
| 16-17 years | 8 |
| DK/Refused | 9 |

Those are all of the questions I have this (**MORNING/AFTERNOON/EVENING**)

Thank you very much for your help on this study. (**TERMINATE**)

Standard script to confirm address to mail incentive payment to be added by field vendor.

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