Cancer-related pain: a pan-European survey of prevalence, treatment, and patient attitudes

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Background: The European Pain in Cancer survey sought to increase understanding of cancer-related pain and treatment across Europe.

Patients and methods: Patients with all stages of cancer participated in a two-phase telephone survey conducted in 11 European countries and Israel in 2006–2007. The survey screened for patients experiencing pain at least weekly, then randomly selected adult patients with pain of at least moderate intensity occurring several times per week for the last month completed a detailed attitudinal questionnaire.

Results: Of 5084 adult patients contacted, 56% suffered moderate-to-severe pain at least monthly. Of 573 patients randomly selected for the second survey phase, 77% were receiving prescription-only analgesics, with 41% taking strong opioids either alone or with other drugs for cancer-related pain. Of those prescribed analgesics, 63% experienced breakthrough pain. In all, 69% reported pain-related difficulties with everyday activities; however, 50% believed that their quality of life was not considered a priority in their overall care by their health care professional.

Conclusions: Across Europe and Israel, treatment of cancer pain is suboptimal. Pain and pain relief should be considered integral to the diagnosis and treatment of cancer; management guidelines should be revised to improve pain control in patients with cancer.

Key words: cancer pain, chronic pain, Europe, impact of pain, survey, treatment of pain

Introduction

Pain is a common and devastating symptom of cancer affecting patients’ lives sometimes more than the cancer with which they are diagnosed. Cancer pain can be managed with the various pharmacological and nonpharmacological methods currently available [1], but this is not always effective and many patients continue to suffer pain. The impact of untreated or poorly treated pain can be overwhelming as it affects physical functioning, psychological well-being, and social interactions [2]. Persistent pain is devastating for the quality of life (QoL) of those suffering from cancer: as a result patients may fear pain more than potential death from their cancer and this fear has aided the drive for the agenda for physician-assisted suicide [3].

Guidelines to assist in the management of cancer pain were developed by the World Health Organization (WHO) >20 years ago [4]; based on these, other guidelines were developed at both a national and international level [5–7]. The degree to which these guidelines have been effective in changing practice and improving patient care remains contentious.

There is substantial evidence that management of cancer pain is often suboptimal [8–11], and this is particularly true in elderly patients [12] or those from ethnic minorities [13]. A UK survey undertaken by the UK charity Cancerbackup highlighted that cancer pain was often inadequately managed [14]. Similar surveys have found deficient care and outcomes in France [15], the United States [8, 12], Canada [16], and Asia [17].

Currently, however, there are no published robust pan-European epidemiological data that profile the prevalence and management of cancer pain specifically. A recent European study focussed on the prevalence and treatment of chronic pain as a whole, including cancer pain and noncancer pain [18]. However, that study, cancer pain accounted for only 1% of the patients in the study sample [18]. Previous surveys have evaluated the pain experience either from retrospective analysis of medical records or from the views of health care professionals [8–11]. This survey was designed to specifically explore the experience of pain from the patient’s perspective;
consequently it gives a more direct insight into the impact of pain on patients, their families, and carers.

**objectives**

The goals of this study—the European Pain in Cancer (EPIC) survey—were to increase understanding of cancer-related pain and treatment in all cancer types (excluding skin cancer, which was excluded by the steering committee on the basis that the prevalence of skin cancer had the potential to skew the overall dataset), and all cancer stages, across Europe. The study aimed to determine prevalence and severity of cancer pain among patients with cancer and to obtain descriptive data regarding how it is evaluated, treated, and the outcomes of therapy. The survey reviews all forms of pharmacological treatment, but also focuses specifically on the use and impact of weak opioids—those on step II of the WHO analgesic ladder—and strong opioids (WHO step III).

**setting**

The EPIC survey was conducted in 11 European countries: Czech Republic, Denmark, Finland, France, Ireland, Italy, Norway, Romania, Sweden, Switzerland, and the UK, and Israel in 2006 and early 2007.

In accordance with advice given from the National Health Service ethics committee, the survey was designed such that ethical approval across the participating countries was not required. As is standard practice in health care market research, patients were entitled to an honorarium for participating in recognition of their time. In all cases honorarium was offered either at point of screening or after participants had been screened. The honorarium was sufficiently small as not to be an inducement to participate and in some countries patient participation was only recognised by a donation to a relevant cancer charity. In letters to patients who wished to participate, face-to-face interviews were offered; however, no face-to-face interviews took place and the survey was conducted wholly by telephone.

**participants**

Cancer patients were identified from a broad cross section of the population using a multimodal approach. Cancer patients were recruited to participate in a survey, the specific nature of which (the focus on cancer pain) was not disclosed until patients had been included. Five approaches were used to recruit patients:

(i) Advertisement of the survey of cancer patients on the Internet.
(ii) Identification of cancer patients by market research of randomised populations.
(iii) Advertisement of the survey in consumer publications, e.g. newspapers.
(iv) Advertisement of the survey to local support groups and patient associations.
(v) Professional referral of cancer patients by oncology institutes, oncology clinics or cancer centres, day centres for patients with cancer, cancer wards, hospitals, or health care professionals.

These recruitment methods ensure that patients volunteer to be included in the survey. All included patients proactively approached the market research company to request inclusion and survey screening. At the point of recruitment, patients did not know that the survey was to explore the parameter of pain, rather they were recruited on the basis of exploring symptoms of cancer and their impact on their lives. Specialist pain units and palliative care centres were not approached to avoid bias in the collection of data. However, six patients were recruited who were referred from a pain specialist and these recruitments were achieved through a general approach to a hospital. Table 1 shows the recruitment methods employed in each country.

Across all countries, except Italy, more than one recruitment approach was employed. In Italy, only referral from health care professionals was used, and in Nordic countries national advertising predominated as a recruitment strategy. Figure 1 shows the letters sent to health care professionals and patients. From the perspective of the health care professional and the patient, the survey was positioned to explore the experiences of patients with cancer and not pain specifically.

All patients were questioned by highly experienced market researchers from an International Market Research agency experienced in conducting health care and patient surveys, rather than health care professionals, to determine their experience of pain and its impact, in an attempt to reduce any questioner bias.

**design**

The survey was conducted in two phases, the first a screening phase to identify patients experiencing pain at least once a week and a second phase to conduct in-depth telephone interviews (Appendix 1, available as supplementary data at *Annals of Oncology* online) with patients randomly selected from the screening phase population. Patients were interviewed by telephone by trained market research interviewers with experience of speaking with patients with cancer. All interviews were carried out in the patient’s native language using a standard set of questions that had been translated and back translated for accuracy. All scoring parameters used within the survey, e.g. pain scoring systems, utilised recognised and revised versions of pain scales.

Table 1. Recruitment methods by country

<table>
<thead>
<tr>
<th>Country</th>
<th>Primary and secondary care physicians</th>
<th>Patient groups and associations</th>
<th>Advertising in national media</th>
<th>Panels of consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Czech Republic</td>
<td>✔</td>
<td></td>
<td>❌</td>
<td>✔</td>
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<tr>
<td>Denmark</td>
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<td></td>
<td>❌</td>
<td>✔</td>
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<td>France</td>
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</tr>
<tr>
<td>Italy</td>
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<td>Switzerland</td>
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<tr>
<td>UK</td>
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</tr>
</tbody>
</table>
validated numerical rating scales (NRSs) for pain on a scale of 0–10, where 0 = no pain and 10 = worst pain ever.

screening phase
In the screening interview, patients were told that ‘We are currently carrying out a study with cancer patients into the pain associated with cancer and are therefore interested in the views of people with cancer’. In this way, prevalence of cancer pain, among a cohort of patients with cancer, could be evaluated, and eligible participants for the second phase of the survey could be identified. As a result of the recruitment methods employed across the countries involved, all patients willing to participate proactively approached the researchers to register their interest to be included.

survey phase
The eligibility criteria for progression to the survey phase included age 18 years and over; pain at least for the last month at a frequency of several times per week; and a pain intensity of 5 or more on a NRS of 0–10, where 0 is no pain at all and 10 is the worst pain imaginable. This pain intensity was chosen as it had been used in previous surveys of chronic pain [18] and in other studies of pain in cancer [13], and results would therefore be comparable to these earlier data. Patients were excluded if

(i) they were suffering from skin cancer;
(ii) they reported pain intensity of <5 on NRS;
(iii) they were linked to a pharmaceutical or market research company or were currently involved in any clinical studies for pain medication.

Patients with a wide range of cancers were included (all solid tumours and haematological cancers) and all stages of cancer were included (early, locally advanced, advanced, and metastatic).

From the screening phase, each participating country opted to recruit 50 patients into the in-depth survey phase. Some countries recruited slightly >50 and some countries with small patient cohorts recruited <50 patients to the survey phase.

results
screening phase
Across Europe and Israel, 5084 adult patients were contacted for screening interviews (Figure 2). Of these, 56% (2864 of 5084) completed the screening interview, rated the intensity of their pain to be ≥5 (NRS 5–10), had experienced recurrent pain several times a month or more in the last month, and were not excluded for other reasons (Figure 2). Demographic information for 35 patients was not gathered during screening interviews; demographics of the remaining 5049 patients within the screening phase are available and are shown in Table 2. The number of patients screened per country is shown in Table 2.

demographics. Patient demographics including sex and tumour type are shown in Table 2. The most commonly represented age range was 50–59 years. The most commonly represented cancer types included breast cancer.
Values are numbers (percentages) of respondents.

Table 2. Demographics of patients screened by country and total

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Czech Republic</th>
<th>Denmark</th>
<th>Finland</th>
<th>France</th>
<th>Ireland</th>
<th>Israel</th>
<th>Italy</th>
<th>Norway</th>
<th>Romania</th>
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<td>282</td>
<td>373</td>
<td>383</td>
<td>642</td>
<td>61</td>
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<td>457</td>
<td>302</td>
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<td>1051</td>
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<td>33</td>
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<td>42</td>
<td>134</td>
<td>46</td>
<td>58</td>
<td>36</td>
<td>136</td>
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<td>59</td>
<td>69</td>
<td>257</td>
<td>68</td>
<td>356</td>
<td>262</td>
<td>41</td>
<td>191</td>
<td>63</td>
<td>584</td>
<td>55</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Bowel/CRC</td>
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<td>37</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
<td>(1)</td>
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<td>Breast</td>
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<td>(28)</td>
<td>101</td>
<td>(2)</td>
<td>139</td>
<td>(2)</td>
<td>125</td>
<td>(2)</td>
<td>274</td>
<td>(5)</td>
<td>21</td>
<td>(1)</td>
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<tr>
<td>Lung</td>
<td>414</td>
<td>(8)</td>
<td>20</td>
<td>(1)</td>
<td>32</td>
<td>(1)</td>
<td>10</td>
<td>(1)</td>
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<td>4</td>
<td>(1)</td>
<td>8</td>
<td>(1)</td>
<td>27</td>
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<td>Prostate</td>
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<td>(12)</td>
<td>12</td>
<td>(1)</td>
<td>18</td>
<td>(1)</td>
<td>26</td>
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</tr>
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<td>3</td>
<td>(1)</td>
<td>1</td>
<td>(1)</td>
<td>9</td>
<td>(1)</td>
<td>31</td>
<td>(1)</td>
<td>3</td>
<td>(1)</td>
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<td>Brain</td>
<td>135</td>
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<td>6</td>
<td>(1)</td>
<td>3</td>
<td>(1)</td>
<td>1</td>
<td>(1)</td>
<td>26</td>
<td>(1)</td>
<td>0</td>
<td>(1)</td>
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<tr>
<td>Blood borne*</td>
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<td>(1)</td>
<td>17</td>
<td>(1)</td>
<td>4</td>
<td>(1)</td>
<td>15</td>
<td>(1)</td>
<td>6</td>
<td>(1)</td>
<td>2</td>
<td>(1)</td>
</tr>
<tr>
<td>NHL</td>
<td>61</td>
<td>(1)</td>
<td>2</td>
<td>(1)</td>
<td>2</td>
<td>(1)</td>
<td>11</td>
<td>(1)</td>
<td>0</td>
<td>(1)</td>
<td>0</td>
<td>(1)</td>
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<tr>
<td>Lymphoma</td>
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<td>(2)</td>
<td>3</td>
<td>(1)</td>
<td>15</td>
<td>(1)</td>
<td>8</td>
<td>(1)</td>
<td>17</td>
<td>(1)</td>
<td>7</td>
<td>(1)</td>
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<tr>
<td>Leukaemia</td>
<td>123</td>
<td>(2)</td>
<td>2</td>
<td>(1)</td>
<td>4</td>
<td>(1)</td>
<td>5</td>
<td>(1)</td>
<td>13</td>
<td>(1)</td>
<td>3</td>
<td>(1)</td>
</tr>
<tr>
<td>SCCHN</td>
<td>213</td>
<td>(4)</td>
<td>14</td>
<td>(1)</td>
<td>21</td>
<td>(1)</td>
<td>25</td>
<td>(1)</td>
<td>19</td>
<td>(1)</td>
<td>3</td>
<td>(1)</td>
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<tr>
<td>Gynaecological</td>
<td>409</td>
<td>(8)</td>
<td>27</td>
<td>(1)</td>
<td>15</td>
<td>(1)</td>
<td>37</td>
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<td>41</td>
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<td>(1)</td>
</tr>
<tr>
<td>Other</td>
<td>682</td>
<td>(13)</td>
<td>30</td>
<td>(1)</td>
<td>50</td>
<td>(1)</td>
<td>81</td>
<td>(1)</td>
<td>57</td>
<td>(1)</td>
<td>6</td>
<td>(1)</td>
</tr>
</tbody>
</table>

Values are numbers (percentages) of respondents.

*Blood-borne cancers include NHL, lymphoma, and leukaemia and represent those patients who understand they have a blood-borne cancer, but cannot articulate their precise cancer type.

CRC, colorectal cancer; NHL, non-Hodgkin's lymphoma; SCCHN, squamous cell cancer of the head and neck.

(n = 1415; 28%), prostate (n = 615, 12%), bowel and colorectal cancer (CRC) (n = 500; 9%), and lung cancer (n = 414; 8%).

**Analysis of pain by cancer and country.** The prevalence of pain among the screening population, excluding those patients with skin cancer, was 72% (3597 of 4947). Of patients who currently experienced pain several times a month or more, 93% (2873 of 3066) rated their pain as moderate-to-severe, i.e. NRS 5–10, 44% (1349 of 3066) rated their pain as severe (NRS 7–10) and 3% (110 of 3066) regarded it as the 'worst pain imaginable' (NRS 10).

When the analysis was weighted for cancer prevalence by country, gender, and cancer type using weights from the GLOBOCAN database [19, 20], the overall prevalence of pain was 84% (standard error (SE) 0.7%). Among patients who experienced pain several times a month or more, pain prevalences were moderate-to-severe pain, 94% (SE 0.5%); severe pain, 43% (SE 1.8%); and worst pain imaginable, 2% (SE <1%). Pain prevalence was substantially different among different cancer types. Patients with the highest prevalence of pain (>85%) were those with cancers of the pancreas, bone, brain, lymphoma, lung, and head and neck (Figure 3). Lower
pain prevalence (<75%) was reported among patients with prostate cancer or leukemia. It is not known from patient questioning whether patients reported primary or secondary sites of cancer and data regarding cancer type was not independently verified. Samples of patients in different countries were not well matched for cancer types. Cancer types with the highest prevalence of pain were over-represented in Switzerland, Israel, Italy, UK, France, and Ireland (Table 3). This observation may explain intercountry differences in the percentages of patients reporting pain (Figure 4). Pain was the presenting symptom for cancer in 30% of the screened population, excluding patients with skin cancer (Figure 5).

Questions regarding analgesic management in those respondents reporting a pain rating of NRS 5 or more indicated that almost a quarter of patients (23%) were not receiving analgesic medication and that this was also true for 19% (123 of 647) of those with daily pain or more frequent pain of this severity.

**in-depth telephone interview—phase II**

**pain assessment and recognition.** Demographic data for 573 patients randomly selected for phase II in-depth interview are presented in Tables 4 and 5. Each country aimed to recruit 50 patients from the screening phase into phase II. For all countries, apart from the Republic of Ireland, 50 patients or slightly more were recruited. A sample for this phase of 50 patients was chosen as previous surveys had indicated this to be a robust population size for in-depth analysis [18]. In this sample the most commonly patient-reported cancer types were breast (27%, 155 of 573) and bowel/CRC (11%, 68 of 573), followed by gynaecological (9%, 53 of 573), lung (8%, 47 of 573), prostate

![Figure 3](https://example.com/figure3.png)

**Figure 3.** Incidence of pain due to cancer type. CRC, colorectal cancer; NHL, non-Hodgkin’s lymphoma; SCCHN, squamous cell cancer of the head and neck.

### Table 3. Representation of most painful cancers by country

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Total</th>
<th>Czech Republic</th>
<th>Denmark</th>
<th>Finland</th>
<th>France</th>
<th>Ireland</th>
<th>Israel</th>
<th>Italy</th>
<th>Norway</th>
<th>Romania</th>
<th>Sweden</th>
<th>Switzerland</th>
<th>UK</th>
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</thead>
<tbody>
<tr>
<td>Mean pain score</td>
<td>6.4</td>
<td>6.1</td>
<td>6.9</td>
<td>6.5</td>
<td>6.7</td>
<td>6.1</td>
<td>7.0</td>
<td>6.3</td>
<td>5.8</td>
<td>6.7</td>
<td>5.6</td>
<td>6.5</td>
<td>6.4</td>
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<td>Total cancer</td>
<td>5084</td>
<td>282</td>
<td>373</td>
<td>383</td>
<td>642</td>
<td>96</td>
<td>287</td>
<td>457</td>
<td>302</td>
<td>327</td>
<td>1051</td>
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<td>617</td>
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<tr>
<td>Percentage of patients per cancer (%)</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pancreatic</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>10</td>
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<td>1</td>
<td>&lt;1</td>
<td>5</td>
<td>&lt;1</td>
<td></td>
</tr>
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<td>Bone</td>
<td>1</td>
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<td>1</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>3</td>
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<td>1</td>
<td>1</td>
<td>7</td>
<td>&lt;1</td>
</tr>
<tr>
<td>NHL</td>
<td>1</td>
<td>&lt;1</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>&lt;1</td>
<td>&lt;1</td>
<td>4</td>
<td>&gt;1</td>
<td></td>
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<tr>
<td>Lung</td>
<td>8</td>
<td>7</td>
<td>2</td>
<td>6</td>
<td>11</td>
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<td>3</td>
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<td>16</td>
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<tr>
<td>Bowel/CRC</td>
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<td>13</td>
<td>15</td>
<td>5</td>
<td>9</td>
<td>6</td>
<td>19</td>
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<td>8</td>
<td>9</td>
<td>8</td>
<td>13</td>
<td>6</td>
</tr>
</tbody>
</table>

NHL, non-Hodgkin’s lymphoma; CRC, colorectal cancer.
(6%, 36 of 573), and squamous cell carcinoma of the head and neck (SCCHN) (5%, 33 of 573).

Among this sample, pain was principally managed by medical oncologists (42%, 242 of 573) or a general practitioner (19%, 110 of 573). For a small minority of patients, their pain was managed by either a palliative care specialist or a pain specialist (5%, 32 of 573) after being referred to them by their principal health care professional (Figure 6).

Most (72%, 415 of 573) patients reported that their clinician asked them about their pain either at most consultations (16%, 95 of 573) or every consultation (55%, 320 of 573). A minority (22%, 128 of 573) reported that their health care professionals never, or only occasionally, asked their patients about their pain. There were substantial intercountry differences in the frequency with which physicians enquired about pain (Figure 7).

Half of patients (55%, 317 of 573) reported that they proactively describe their pain to their treating clinician at each consultation ensuring that pain is on the agenda.

On spontaneous recall, only 15% (88 of 573) of patients reported that their clinician measured their pain using a pain scale; however, with prompting this figure rose to 33% (191 of 573). Again there were major differences in the prevalence of the use of pain scales between countries (chi squared = 161 with

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Figure 4. Percentage of patients reporting pain per country during the screening phase.

Figure 5. Criteria leading patients to seek out a health care professional on which a diagnosis of cancer was made.
Patients from Italy (70%), France (52%), and Ireland (40%) reported the highest prevalence (Figure 8). In this sample, all of whom had moderate-to-severe pain; 11% of patients (67 of 573) were not receiving analgesia at all (Table 6). Similar proportions of women and men did not receive any analgesic medication for their pain (11%, 41 of 372 versus 12%, 26 of 201). Intercountry differences were observed and the prevalence rate for no analgesic medication ranged from 0% to 28% (Table 7).

Overall, 50% (289 of 573) of the patients believe that their health care professional does not consider their QoL as an important aspect of the overall care plan and a smaller overall percentage believe their health care professional does not understand that pain is a problem (12%, 72 of 573). A substantial minority of patients indicated that they believe that their clinician would rather treat their cancer than the accompanying pain (38%, 220 of 573), that their clinician does not have time to discuss pain within a consultation (33%, 191 of 573), and that their treating clinician did not know how to treat moderate-to-severe cancer pain (26%, 150 of 573) (Figure 9). Considerable differences were reported between countries (Table 8). Overall, patient perceptions of physician interest in pain as a legitimate focus of therapy was least favourable in the Nordic countries (Table 8).

22 df, P < 0.0001). Patients from Italy (70%), France (52%), and Ireland (40%) reported the highest prevalence (Figure 8).

**pain treatment—medications.** Clear responses to survey questions were recorded for 437 of 441 patients who reported that they used prescription medications to treat pain. Of these, 24% were taking a step III opioid alone, 12% were taking a step II opioid alone, 7% were taking step II, and step III opioids, either together or in combination with nonopioid drugs [step II and step III medications, as defined by the WHO analgesic ladder (WHO 1986)], and 8% received nonopioid analgesics alone (Table 9).

Of patients reported to be receiving prescription medicine, 84% (371 of 441) rated their medication as ‘quite effective’ or ‘very effective’. Prescribed medication was rated at these levels of effectiveness by 87% (159 of 183) of patients receiving step III opioids.
Breakthrough pain or inadequate pain relief was common among those receiving prescription medicine and occurred in 63% (281 of 441) of the patients. Of these patients, 58% (165 of 281) reported inadequate pain relief all the time, every hour, several times daily, daily, or several times per week. Only a third of patients experiencing inadequate pain control are treated with additional analgesic medication (33%, 93 of 281), primarily strong or step III opioids (10%, 29 of 281).

There were large intercountry differences in prescribing step III opioids (Figure 10). Prescribing of these medications was highest in Italy, where patients were recruited into the survey from cancer institutions only.

The most common adverse effect reported by patients taking a prescription opioid medication (n = 266) was constipation (37%, 100 of 266). Of patients taking prescribed opioids who experienced constipation, a quarter had not been coprescribed a laxative, and a very small percentage used over-the-counter medications for constipation. The other frequently reported adverse effects among opioid-treated patients were nausea and vomiting (33%, 89 of 266) and sedation (20%, 55/266). However, 26% (71 of 266) reported no adverse effects at all.

The overall prevalence of patients reporting a good QoL was 48% (280 of 573). Substantial proportions of patients, including some with a good QoL,
reported that pain stops them concentrating or thinking (51%, 294 of 573), that pain creates difficulty in performing normal activities in daily life (69%, 396 of 573), and that cancer pain made them an increased burden to others (43%, 251 of 573). Almost a third of patients (30%, 177 of 573) are in too much pain to be able to care sufficiently for themselves or for others, and of those still in employment, 52% (72/136) stated that their pain impacts their work performance.
Pain associated with cancer was described as distressing by 67% of patients, as an intolerable aspect of their cancer by 36% and 32% reported that they feel so bad they want to die.

**discussion**

**principal findings**

The aim of this pan-European 12-country survey was to explore the burden of cancer pain, current pain treatment practices across Europe, and their effects in all cancer types and cancer stages. Sadly, the results of this survey challenge the belief that cancer pain is usually well managed. Despite more than two decades of education in Europe regarding the importance of pain assessment and rational use of analgesics based on pain severity [4], the results indicate that assessment is often poor and suboptimal treatment and outcomes are frequent. Poor care of cancer pain is clearly unacceptably commonplace in Europe.

Many patients feel that their treating clinicians prioritise the treatment of cancer over the treatment of pain and that this is reflected in lack of assessment or time devoted to the issue in consultations. Consequently, many patients report feeling disempowered, that their QoL is not a consideration for their treating clinician, and that their clinicians do not understand their pain or how to treat it.

This survey indicates that many patients with moderate-to-severe cancer pain (NRS 5–6/10) receive no analgesic medication. Among patients reporting severe pain (NRS 7–10/10), only 24% ($n=60/241$) received strong opioid...
monotherapy (WHO step III analgesics) and the use of weak opioids (step II) was prevalent. Several reasons may account for the poor care of cancer pain: inadequate appreciation by the physician of the intensity of the pain, lack of knowledge, fear of the adverse effects of step III opioids, and regulatory barriers to opioid prescription and dispensing. Breakthrough pain is shown to be prevalent and presents a significant problem to patients. Only a minority of patients were prescribed an appropriate dose of rescue medication for breakthrough pain. For a third of patients (32%), it was outlined that pain was so bad they wanted to die (see Q56 of the questionnaire in Appendix 1, available as supplementary data at Annals of Oncology online). This question was asked at the end of the survey and it was not determined if this response from these patients was a true reflection of possible depression or a figurative expression. Data from these patients were not analysed for correlation either with pain score or their expression of fear for death. Given that this represents only one question amid a large cohort of questions, it is unlikely to have influenced the survey outcomes. However, depression is clearly associated with chronic pain [18, 21]. Assessments of cognitive functioning and depression were not undertaken in this survey so it is possible, and perhaps likely, that these 32% of patients also represent those experiencing a high degree of depressive symptoms.

Side-effects present a significant issue to patients, in particular opioid-induced gastrointestinal dysfunctions such as nausea and constipation. In this survey, only a minority of patients received prophylactic laxative therapy in line with published guidelines [7], although sadly these data mirror that seen in a previous audit of care [20]. Further, it is clear that while few patients received a coprescription of laxatives with their opioid, even fewer report self-medication with over-the-counter formulations for constipation symptoms. More

<table>
<thead>
<tr>
<th></th>
<th>Total (n = 437)</th>
<th>Moderate-to-severe pain: NRS 5–6 (n = 196)</th>
<th>Severe-to-most severe pain: NRS 7–10 (n = 241)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients taking step III opioids alone</td>
<td>109 (24)</td>
<td>49 (25)</td>
<td>60 (24)</td>
</tr>
<tr>
<td>Patients taking step III and step II opioids</td>
<td>20 (4)</td>
<td>7 (3)</td>
<td>13 (5)</td>
</tr>
<tr>
<td>Patients taking step III opioids and nonopioid medication</td>
<td>40 (9)</td>
<td>14 (7)</td>
<td>26 (10)</td>
</tr>
<tr>
<td>Patients taking step III and step II opioids and nonopioid medication</td>
<td>14 (3)</td>
<td>5 (2)</td>
<td>9 (3)</td>
</tr>
<tr>
<td>Patients taking step II opioids alone</td>
<td>53 (12)</td>
<td>31 (15)</td>
<td>22 (9)</td>
</tr>
<tr>
<td>Patients taking step II opioids and nonopioid medication</td>
<td>30 (6)</td>
<td>9 (4)</td>
<td>21 (8)</td>
</tr>
<tr>
<td>Patients taking nonopioid medication alone</td>
<td>39 (8)</td>
<td>12 (6)</td>
<td>27 (11)</td>
</tr>
<tr>
<td>Not stated</td>
<td>132 (30)</td>
<td>69 (35)</td>
<td>63 (26)</td>
</tr>
</tbody>
</table>

Values are numbers (percentages) of respondents.
NRS, numerical rating scale.
that a proportion of patients may have been suffering from moderate or greater severity, indicating pain of moderate or greater severity, it is possible that a subcohort may have had depressive comorbidity that may have amplified their pain experience. Many studies have indicated a link between pain and depressive symptoms, including a very recent study in cancer pain [21] in which pain severity, pain distress, pain right now, and the Pain Interference Scores significantly correlated with the Center for Epidemiological Studies Scale Depression scores. Depressive symptoms were not evaluated in the current study and it is possible that a subcohort may have had depressive comorbidity that effected their evaluations.

Implications and conclusions. Overall, the findings of this survey indicate that there is significant opportunity to improve the management of cancer pain in all the surveyed countries in Europe. There is a need to develop effective strategies for translating knowledge into improved clinical practice.

The World Health Assembly has recently invited the WHO and the International Narcotics Control Board (INCB) to establish an Access to Controlled Medications Programme (ACMP) in order to ascertain appropriate availability of opioid analgesic drugs for the medical treatment of severe pain caused by malignant diseases, acute trauma, surgery and acute medical conditions, and chronic painful conditions. The ACMP is updating existing guidelines for cancer pain management in adults and children and will produce evidence-based guidelines for pharmacological treatment of acute and chronic noncancer pain [22].

Data from other studies have helped highlight potential strategies that could improve pain control in routine practice [23];

- increasing the priority of pain control in health care systems—which currently focus mainly on curative disease management only;
- education to improve the assessment of pain for clinicians, nurses, and pharmacists [8, 24, 25]—current lack of education may perpetuate the notion that pain is not a priority in patient care;
- education for clinicians and health care professionals to overcome reluctance to prescribe opioids appropriately for patients in pain [8, 24, 26];
- clear communication of opioid prescribing from a regulatory perspective to overcome the fear of regulatory scrutiny for physicians [8, 27] in line with available guidelines regarding the availability of opioids from WHO and the INCB [22];
- education for patients to increase adherence to therapy [28] and help them overcome patient aversion to side-effects such as constipation and confusion or fears of addiction and tolerance [11, 29], as well as help to overcome psychological barriers patients have about cancer pain, e.g. 'pain with cancer is inevitable and intractable' or a belief that if they bother the doctor with their pain they are not being 'good patients' [30];
- improving reimbursement mechanisms—currently some reimbursement mechanisms either do not reimburse opioids for cancer pain, particularly those in outpatient situations [23], or favour high technology approaches, e.g. pumps, over oral opioid therapy [23];

Strengths and weaknesses. This was a large cross-sectional survey; >5000 patients with cancer-related pain were contacted and detailed attitudinal interviews were conducted with a randomly selected sample of 573 of those who were eligible. Patients attending specialist pain units and palliative care centres were not contacted, and patients with skin cancer were excluded. While the geographical coverage of the survey was broad, the countries included were not balanced for recruitment methods, patient-reported cancer type, or any of the common demographic considerations, and it is not possible to make reliable intercountry comparisons based on the present results.

Patients registered their interest to be included in the survey in response to advertisements or a recruitment letter from their health care professional. At this point, no patient knew the survey was to explore cancer pain specifically, rather than symptoms associated with their cancer. However, on screening it is clear that patients with a relatively high pain score, who are also relatively young (56% are aged <60 years), were recruited. From these, only patients with a pain score 5 or higher on a 0–10 NRS pain scale were included for further questioning. As a result, the survey is restricted to those with a pain score indicative of pain of at least moderate severity [2].

This survey was intended to address a current gap in knowledge of the pain experience from the patient’s perspective, as other surveys/studies have reviewed patient medical notes or captured the physicians’ perspective. By exploring the patient experience, the survey provides insight into the patients’ perspective into their cancer pain experience and its treatment. Although this may be considered a weakness of this study, it is also a strength of the study that it focuses on patients’ subjective experiences.

Within the survey cohort, no screening of cognitive function or mental health status was undertaken, as patients self-selected for inclusion. As the survey cohort represents a selected population of patients with a pain score indicating pain of moderate or greater severity, it is possible that a proportion of patients may have been suffering from anxiety or depression which may have amplified their pain experience.
• improvements in pain assessment—improved assessment of pain provides the clinician with a baseline on which to provide better pain management [31, 32], and such measurements would help to counter current observations that suggest a majority of patients with moderate-to-severe pain due to cancer do not receive analgesia appropriate for their pain [8, 9, 13].
• implementation of simple protocols for oral opioid pain control has been shown to improve the management of pain for patients although this study [33] was conducted on a small scale in only two cancer types (non-small-cell lung cancer and prostate cancer); however, patients treated according to an oral pain management protocol achieved significantly better reductions in pain (P = 0.008) compared with those treated with analgesia according to physician discretion.
• implementation of guidelines and policies from a governmental perspective to highlight pain as an imperative and actively promote or legislate that it be taken seriously.

This survey highlights for the first time that across Europe and Israel, cancer pain remains an issue, that cancer pain is far from optimally treated, and that it is misleading to assume that cancer pain is better managed than other types of chronic non-malignant pain. Cancer pain should be included in the overall perspective of diagnosis and treatment and taken seriously at all levels of society from government to clinicians. Clearly, the results of the present survey show that the major programme recently jointly initiated by the INCB and the WHO to update the cancer pain management guidelines from 1986 [4] and 1996 [34] are needed, even for developed European countries which have relatively liberal regulations on the availability of and accessibility to potent analgesic drugs. In most other parts of the world, both drug regulations and resources present very significant barriers to appropriate treatment of severe cancer pain. The INCB and WHO programme [22] is aimed at these geographical areas of the world, but is clearly also needed for western Europe.

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references


