Ars Moriendi – The art of dying

– Is it painful to die of cancer?

VERSION 2

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Abstract

INTRODUCTION: Pain is one of the toughest challenges within palliative care. The majority of palliative patients suffer from a cancer diagnosis, which often is accompanied by a large burden of pain. In Sweden there are three main methods for assessing pain and these are NRS (Numeric Rating Scale), VAS (Visual Analogue Scale) and APS (Abbey Pain Scale).

AIM: To investigate if palliative cancer patients more often suffer from pain than non-cancer patients during the last seven days in life, and to analyse if there are any differences in the use of pain rating scales and degree of pain relief between the two groups.

METHODS: Retrospective record review of patients receiving palliative care at the Department of Geriatrics at Örebro University Hospital between the 1st of January and 31st of August 2016.

RESULTS: In the study, 123 patients were included, of whom nine were excluded because they died in their homes. Thus, 114 patients were found eligible for this study. Significantly more cancer patients suffered from pain compared to the non-cancer patients. There was no significant difference between the groups in the use of pain rating scales or how often the patients were relieved from their pain. Compared to when pain rating scales were not used, a greater proportion of the patients that were assessed with pain rating scales achieved full pain relief.

CONCLUSION: Compared to non-cancer patients, a greater quantity of the cancer patients did suffer from pain. It seems that regardless of diagnose, the use of pain rating scales play an important role in whether the patients achieve full pain relief or not. This implicates the need for increased use of pain rating scales in palliative care.
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Introduction

PALLIATIVE CARE

Humans have practiced palliative care in the settings of Hospice care for a long time, which can be traced back to medieval times [1]. It was back then the Latin expression, “Ars Moriendi” was established, which means “The art of dying”. With the industrial revolution people started to see dying as a failure and the hospice movement gradually faded out. The modern Hospice movement started in the 1950s, by the physician Dame Cicely Saunders and in Sweden the first hospice unit appeared in Stockholm in 1987 [2]. Palliative care is a unique approach for patients and their families when suffering from life-threatening and incurable diseases. It focuses primarily on improving quality of life and on symptomatic relief. This includes physical, psychosocial and spiritual burden [3]. Palliative care do not only account for patients in a terminal phase of their disease; it can be applied considerably earlier [4]. There are three fundamental components in palliative care; pain relief, psychological support and involvement of the family.

There are several ways of practicing palliative care and principally they can be divided into three main subgroups; specialized palliative care, general palliative care and hospice care. Specialized palliative care includes both hospitalized care and advanced home care [2]. The first advanced home care in Sweden appeared in Linköping in 1962 [5] but it took until 2012 for the first national care program for palliative care to appear in Sweden [6]. Palliative medicine became a subspecialty in Sweden in 2015 and at the end of June 2016 there were 22 Swedish doctors whom had specialized in palliative medicine [7].

The Swedish Register of Palliative Care (SRPC) was established in 2005 as a national quality register with an ambition to improve the quality of end-of-life care [8]. A register study from 2012 showed that the symptomatic management of palliative care is different for patients suffering from cancer and patients suffering from other diseases. Pain relief was achieved to a lower extent among the cancer patients [9]. In 2015, 91 002 people died in Sweden [10], the most common causes of death were cardiovascular diseases (35%) followed by tumours (24 %). Within specialized palliative care, the most common cause of death is cancer with 87 % in total [11].
MANAGING PAIN

Freeborne et al reviewed symptom burden during the last three days of life amongst patients with different life-limiting diseases and showed that 34-45% of the patients suffered from moderate to severe pain [12]. A study from the SRPC showed that 78% of cancer patients suffer from any kind of pain [13]. Pain relief is one of the greatest tasks for palliative care, therefore the World Health Organization (WHO) created a Ladder for cancer pain in 1986 [4]. It has three steps: 1) non-opioid, 2) weak opioid and 3) a combination of strong opioid and non-opioid. The ladder is still being used, but it has been widely questioned for its effectiveness [14] [15] [16].

There are three main methods for measuring pain in Sweden, APS (Abbey Pain Scale), NRS (Numeric rating scale) and VAS (Visual Analogue Scale) [17]. VAS and NRS are subjective scales from 0 to 10 where the patients themselves answer and grade their pain. VAS is a psychometric scale, originally designed as a flat line ranging from “no pain” to “pain as bad as it could possibly be” [18]. NRS is simply a numeric scale of the pain sensation, where 10 stand for worst possible pain. Ferreira-Valente et al compared four pain assessment tools, among them VAS and NRS, and it showed strong support for the validity of all four scales [19]. APS is an objective scale from 0-18 where the caregivers study and score the following items; vocalizations, facial expressions, changes in body language, behavioural changes, physiological changes and physical changes [20].

Objective

The purpose of this study was mainly to evaluate the palliative care at the Department of Geriatrics at Örebro University Hospital as a quality management for the clinic. A great sample of data was collected from the records and from this a selected sample was analysed further for this paper.

Pain is one of the greatest challenges within palliative care; therefore this was chosen to be the primary area of focus. One of the major concerns expressed by patients and their families within palliative care is the fear of experiencing severe pain during their last days of life. How good are we at managing pain within specialized palliative care?

Since reports have shown that palliative care can be different for cancer patients and non-cancer patients this paper also aimed to investigate if there is any difference between these patient groups regarding pain management? Is it more painful to die of cancer?
AIM
The main purpose of this study is to
• investigate if palliative cancer patients more often suffer from pain than non-cancer patients
• analyse if there is any difference in the use of pain rating scales and degree of pain relief between the two groups.

Material and Methods

STUDY SUBJECTS
At the palliative section at the department of Geriatrics at Örebro University Hospital there are twelve hospital beds plus one extra for ASIH (advanced care at home) patients that are listed at the care unit. Inclusion criteria were patients enrolled at the palliative section whom had died between the 1\textsuperscript{st} of January and 31\textsuperscript{st} of August 2016. This included all patients that were enrolled at the hospital care unit, which also included the patients that were listed within ASIH. It did not include patients that were a part of regular palliative home care only connected to a Community Health Center and not the hospital. The International Classification of Diseases (ICD) code describing the cause of death in the patients’ records was used to define the cancer patients and the non-cancer patients. [21]. Patients having ICD between C00-D48 were categorized as cancer patients, and the remaining patients as non-cancer patients [22].

STUDY DESIGN
This study was performed as a retrospective record review and all the data was obtained from electronic journals at the Örebro University Hospital. All collected data was assembled in Excel.

DATA COLLECTION
All records were reviewed using a standardized template. Many questions were copied from the Event of Death Questionnaire used for the Swedish Register of Palliative Care [23]. More questions were added as a request from the clinic concerning areas they sought to be investigated. When looking at pain during the last seven days of life, it was the highest rated or worst experienced pain-event that was noted.

The grading of pain followed the structure of other studies and established guidelines. NRS and VAS were performed as in a cross-sectional multicenter study of cancer patients [24] and the
guidelines for palliative care in Örebro was used for grading with APS [25], see table 1. When pain appeared and no pain rating scale had been applied, a valuation was made based on the words written in the records.

**Table 1.** Description of the evaluation with the pain rating scales.

<table>
<thead>
<tr>
<th>No pain</th>
<th>Mild pain</th>
<th>Moderate pain</th>
<th>Severe pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1-4</td>
<td>5-6</td>
<td>7-10</td>
</tr>
<tr>
<td>1-2</td>
<td>3-7</td>
<td>8-13</td>
<td>14+</td>
</tr>
</tbody>
</table>

**VAS: Visual Analogue Scale; NRS: Numeric Rating Scale; APS: Abbey Pain Scale.**

**STATISTICAL METHODS**

The difference in age was analyzed by using two-tailed Student’s t-test. The level of statistical significance was set at $p \leq 0.05$. The differences in proportions for dichotomized variables were calculated with the method described by Newcombe & Altman [26] using the program Confidence Interval Analysis (CIA). Results are reported using 95% confidence intervals (CI) for the difference in proportions. The result will be significant if the 95% CI does not include zero.

**ETHICAL ASSESSMENTS**

According to Swedish law, an ethic review is demanded when research include sensitive personal data [27]. This study was carried out by a student within the medical programme at Örebro University. Therefore it is not classified as research and not enclosed within the law of ethics review [28]. This study was made in agreement with Helsinki Declaration [29]. All patients were given a given a code number to keep the confidentiality and the results are presented at group level.

**Results**

A total of 123 patients were enrolled at the palliative section at the department of Geriatrics, Örebro University Hospital, and died during the study period. Of these, nine patients died at home and were excluded due to lack of documented information. This left 114 patients to be included. See the flow chart in figure 1. The patients that died at home were significantly younger (mean age 63 years, range 42-86 compared to 73 years, range 41-97, $p = 0.01$) A larger proportion of them were women.
The difference in proportion was 29%, although the difference was not significant (95% CI -5; 47). There was no significant difference regarding the proportion that had a cancer diagnosis, eight of the nine excluded patients, 89 % compared to 88% of the patients at the care unit (95% CI -32; 13).

![Flow chart](image)

**Figure 1.** Flow chart describing the study design

*ASIH = Advanced care at home, specialized palliative home care.

Of the 114 patients, a majority (89 %) lived in ordinary housing, most commonly with a partner (58 %). Regarding services at home, 39 % of the patients had a safety alarm, 32 % had home care and 33 % had home assistance on a regularly basis. Of the 114 included, 100 had cancer and 14 had a non-cancer diagnosis, see table 2 for baseline characteristics. The patients with cancer were significantly younger (mean age 72 years SD 10, compared to 85 years SD 10, \( p < 0.001 \)).
Table 2. Patient characteristics, \( n = 114 \)

<table>
<thead>
<tr>
<th></th>
<th>mean (SD)</th>
<th>range</th>
<th>( n (%) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>73 (11)</td>
<td>41 - 97</td>
<td></td>
</tr>
<tr>
<td>Length of stay, days</td>
<td>16 (17)</td>
<td>0 - 87</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td></td>
<td></td>
<td>56 (49)</td>
</tr>
<tr>
<td>Ordinary housing</td>
<td></td>
<td></td>
<td>102 (89)</td>
</tr>
<tr>
<td>Living with spouse/cohabiting</td>
<td></td>
<td></td>
<td>66 (58)</td>
</tr>
<tr>
<td>Admitted to the care unit from</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>other unit</td>
<td></td>
<td></td>
<td>65 (57)</td>
</tr>
<tr>
<td>home</td>
<td></td>
<td></td>
<td>40 (35)</td>
</tr>
<tr>
<td>emergency ward</td>
<td></td>
<td></td>
<td>9 (8)</td>
</tr>
<tr>
<td>Diagnosis as cause of death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer, ICD C00-D48</td>
<td></td>
<td></td>
<td>100 (88)</td>
</tr>
<tr>
<td>Other diseases</td>
<td></td>
<td></td>
<td>14 (12)</td>
</tr>
</tbody>
</table>

SD: Standard Deviation; ICD: The International Classification of Diseases.
C00-D48: the ICD diagnoses that are classified as tumors according to ICD-10.

The mean number of drug ordinations was 17 (range 6-37) for cancer patients and 11 (range 6-25) for non-cancer patients. Compared to non-cancer patients, the number of cancer patients who had a daily ordination for pain drugs were significantly higher, 87 % (\( n = 87 \)) and 50 % (\( n = 7 \)) respectively, difference 37 %, 95%CI 13; 61. The most common analgesic in both groups was transdermal opioids, which 71 % (\( n = 71 \)) of the cancer patients and 43% of the non-cancer patients (\( n = 6 \)) received. A significantly larger proportion of cancer patients compared to non-cancer patients had a daily ordination of two or more analgesics (\( n = 32 \) and 0, respectively, 95%CI 9; 42). Only in the cancer group, ordinations for various kinds of advanced pain medications appeared, such as Intrathecal Anesthesia, Patient Controlled Analgesia, Epidural Anaesthesia etc.
During the last 7 days of the patients’ lives, compared to the non-cancer patients, a statistically significant larger proportion of the cancer patients did suffer from pain; see figure 2 and table 3.
Figure 2. The proportion of the cancer patients and the non-cancer patients who suffered from any kind of pain during the last seven days of their lives.

There was no significant difference in the registered use of pain rating scales in the two groups, 85% of the cancer patients were pain rated and 100% of the non-cancer patients, see table 3. When the patients had recorded but unrated pain, a significant number of the cancer patients compared to the non-cancer patients were not assessed using pain rating scales, see table 3.

Table 3, Description of the pain burden the last seven days of live, n = 114.

<table>
<thead>
<tr>
<th></th>
<th>Cancer patients n = 100</th>
<th>Not Cancer n = 14</th>
<th>Difference (95% CI)</th>
<th>Significant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any pain during the last 7 days, n (%)</td>
<td>90 (90)</td>
<td>10 (71)</td>
<td>19 (0.2; 45)</td>
<td>Yes</td>
</tr>
<tr>
<td>Moderate to severe pain</td>
<td>36 (36)</td>
<td>2 (14)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain, not fully eased</td>
<td>31 (31)</td>
<td>2 (14)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of pain rating scales, n (%)</td>
<td>85 (85)</td>
<td>14 (100)</td>
<td>-15 (-23; 7)</td>
<td>No</td>
</tr>
<tr>
<td>Pain, rated n (%)</td>
<td>68 (68)</td>
<td>8 (57)</td>
<td>11 (-13; 37)</td>
<td>No</td>
</tr>
<tr>
<td>Moderate or severe pain</td>
<td>40 (40)</td>
<td>2 (14)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain, not fully eased, n (%)</td>
<td>11 (11)</td>
<td>1 (7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain, unrated, n (%)</td>
<td>82 (82)</td>
<td>5 (36)</td>
<td>46 (19; 67)</td>
<td>Yes</td>
</tr>
<tr>
<td>Pain, not fully eased, n (%)</td>
<td>20 (20)</td>
<td>1 (7)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Moderate pain: >APS 7 or >VAS 4. Severe pain: >APS 13 or >VAS 6.

VAS: Visual Analogue Scale; NRS: Numeric Rating Scale; APS: Abbey Pain Scale
When looking at how often the patients were fully pain relieved with analgesics, no statistical difference was found between the cancer patients and the non-cancer patients, see figure 3. Patients were also analysed concerning pain relief in relation to the use of pain rating scales, regardless of the type of diagnose they had. Patients in pain that were not assessed with pain rating scales, achieved full pain relief to a lesser extent than patients whom were assessed, see table 4.

Figure 3. The amount of pain and grade of pain relief the patients achieved during the last seven days of the patients’ lives. Ca = cancer patients.

Table 4. Description of pain sensation and pain relief for all patients, in relation to when pain rating scales were used, n = 186

<table>
<thead>
<tr>
<th>Pain, not fully eased</th>
<th>Unrated pain n = 87</th>
<th>Rated pain n = 99</th>
<th>Difference (95% CI)</th>
<th>Significant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not eased at all</td>
<td>21 (24)</td>
<td>12 (12)</td>
<td>12 (1; 23)</td>
<td>Yes</td>
</tr>
<tr>
<td>Partially eased</td>
<td>3 (3)</td>
<td>0 (0)</td>
<td>3 (-1, 10)</td>
<td>No</td>
</tr>
<tr>
<td>Pain, fully eased</td>
<td>66 (76)</td>
<td>87 (88)</td>
<td>-12 (-23; -1)</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Rated pain: Mild, moderate or severe pain
CI: Confidence Interval
Discussion

The original aim with this study was to investigate if more palliative cancer patients suffer from pain than palliative patients with non-cancer diagnoses. Also, to analyse if there is a difference in how we assess and treat the pain in the two patient groups. An expected result was that a larger number of the cancer patients experienced pain compared to the non-cancer patients. There was no difference in the use of pain rating scales in general but when experiencing pain, the cancer patients were assessed less frequently with pain rating scales than the non-cancer patients. There was no significant difference regarding relief from pain between cancer patients and non-cancer patients. However, among the cancer patients there was a tendency towards a lower grade of pain relief.

When pain appeared without being assessed with pain rating scales, it was less likely to get fully eased with analgesics compared to if the patient would have been assessed. This result was regardless of the patients’ type of diagnosis. This is an important finding which support the value of pain rating scales. Cancer patients were assessed with rating scales to a lower extent and at the same time they also showed a tendency towards not achieving full pain relief.

According to Freeborne et al, the amount of patients suffering from pain within palliative care is 34-45% [12]. In our results that number is higher, which is probably due to our study group only analysing patients within specialized palliative care. A registry study of palliative care from 2016 showed that cancer patients more often suffered from pain than stroke patients (78 % compared to 43 %) [13]. The study had a lower number of patients with pain in both groups compared to our study (90 % and 71 % respectively). This might be a result of not restricting the cohort to patients within specialized palliative care, but also included patients receiving palliative home care. They did however show a significant difference ($p < 0,001$). Another registry study published in 2015 showed that when compared to patients with interstitial lung disease, patients with lung cancer suffered more from pain (73 % compared to 51 %, $p < 0,001$) [30].

In 2012, a registry study comparing palliative cancer patients to patients with heart disease showed that cancer patients were pain relieved to a lesser extent (9,8 % compared to 14,9 %, $p < 0,000$). In our study, the numbers were higher (31% and 14% respectively) but we could not find a significant difference between the cancer patients and the non-cancer patients [9].
Why is it that pain-rating scales are not used every time a patient is in pain or seems to be in pain? Is it because the scales are difficult to use or is it just simply a matter of habit or lack of time? That it would be too time-consuming is unlikely since none of the scales require much time. The APS was actually created in 2004 as a 1-minute assessment of patients with end-stage dementia [31]. A case report from Japan earlier this year concluded that the application of APS assists in the relief of cancer pain [32]. If it would be the norm to always use the scales when a patient is in pain, would the pain management be better?

A descriptive study of 223 oncologic patients in 2006 showed a trend towards better pain management with a daily use of numeric pain rating scales [33]. It also concluded that a systematic pain monitoring with VAS or NRS is feasible with good patient compliance. An important aspect that was not taken into consideration in this study is the validity of different pain scales. Maybe there are scales that are better at assessing pain? In other countries than Sweden there are different scales that are considered gold standard. For example, in Italy, ABTP (Alberta Breakthrough Pain Assessment Tool) has recently been proven effective to evaluate the outcome of breakthrough pain in cancer patients [34]. The problem is that it contains multiple questions and is therefore much more time-consuming than for example VAS or NRS.

An important aspect of pain is the psychological burden, such as anxiety, depression and sleep disturbance. APS can identify some of these measures but VAS and NRS do not. Boaz et al illuminates the lack of prognostic and diagnostic tools for BTP (breakthrough pain) in cancer patients and showed that the IQ-BTP (Italian Questionnaire for BTP) effectively assessed not only the pain but also the psychometric properties [35]. In summary, the use of pain assessment is important and it seems to affect the outcome of pain treatment. In Sweden the recommended scales are NRS, VAS and APS but worldwide there is no clear consensus in what scales to use and when to use them.

This study only took the single worst sensation of pain during one day in consideration, regardless of it being assessed with scales or not. Some patients experienced pain many times during one day and therefore there is hard to assess weather the pain was eased or if it was rated during the other times. In some cases, this could be interpreted as if there were not any pain rating scales used that day even though they were in fact used but not recorded. For example, a patient may have rated VAS 0 in the morning but later during the day, the pain increased but was not at this occasion rated with a scale. It will appear as “having pain but not rated” since that was the highest pain that day.
This might have affected the results. However, the template did contain a separate question for the use of pain rating scales within the last seven days of life, regardless of the pain intensity.

In this study there is no gradation for the pain burden in total, it only considered if the patient was in any pain or not. One patient may have experienced pain 20 times a day, four days in a row, while another patient only experienced pain at one single occasion.

CONCLUSION
A larger proportion of the cancer patients at the palliative ward at Örebro University Hospital palliative ward suffered from pain than patients with a non-cancer diagnosis. Also, the cancer patients were assessed with pain rating scales to a lower extent than the non-cancer patients. When comparing pain in cancer patients and non-cancer patients, there was no difference in pain relief in relation to the use of pain rating scales.

The degree of pain relief seems to depend more on whether the patient have been assessed with pain rating scales than if they have a cancer diagnosis or not. This implicates the need for increased use of pain rating scales in palliative care.

Acknowledgements
I would like to give my special thanks to my supervisor Åsa Andersson who supported me all the way and made this paper possible. Available for proofreading and support through the weekends is not something a student expect from his or hers supervisor. But still you did. You have helped me a lot in the process but you have also pushed me into making my own decisions. Thank you.
References


Vård i Livets Slutskede - Är det smärtsamt att dö av cancer?

På en palliativ avdelning vårdas patienter i livets slutskede. Majoriteten har en cancersjukdom men det finns även patienter med andra sjukdomar. Några av de viktigaste målen med palliativ vård är att öka patienters livskvalité och att lindra besvärande symtom. Smärta och smärtlindring är en av de största utmaningarna och för att kunna värdera smärta kan vårdpersonal använda sig av skattningsinstrument i form av smärtskalor. Det finns subjektiva skalor där patienten själv svarar på frågor men det finns också skalor som kan användas när patienten inte är talbar, där vårdpersonal objektivt värderar smärta.

En ny studie i form av en journalgranskning har genomförts på den Geriatriska klinikens Palliativa sektion på Universitetssjukhuset Örebro. Syftet var dels att genomföra ett kvalitetsarbete för kliniken men också för att utvärdera hur ont palliativa patienter egentligen har under sina sista dagar i livet. Har patienter med en cancersjukdom mer ont än patienter med annan sjukdom? Här jämfördes de här två patientgrupperna för att se om det var någon skillnad i användandet av smärtskalor och hur ofta man nådde en fullgod smärtlindring.

Det visade sig att, jämfört med patienter med annan sjukdom, besvärades fler cancerpatienter av någon form av smärta under de sista sju dagarna i livet. Det var ingen skillnad mellan patientgrupperna gällande hur ofta man nådde en fullgod smärtlindring. Däremot sågs ett samband mellan grad av smärtlindring och användning av smärtskattningsinstrument, oberoende av grundsjukdom. Patienter med smärta och som blev smärtskattade blev i större utsträckning fullt smärtlindrande med hjälp av läkemedel.

Den här studien visar hur viktigt det är att använda smärtskalor på palliativa patienter för att kunna uppnå en fullgod smärtlindring. Det viktigaste verkar alltså inte vara vilken sjukdom patienterna lider av utan snarare om deras smärta blev skattad eller inte.
Dear editor,

We are pleased to submit our manuscript “Ars Moriendi – The art of dying”, to be considered as an original article for publication in the Journal of palliative medicine. This is a retrospective record study, investigating pain burden and pain management in palliative cancer patients compared to palliative non-cancer patients.

In this manuscript, we show that more cancer patients experience pain than non-cancer patients. We also found that regardless of diagnosis, pain relief seems to be influenced by weather the patients have been assessed with pain rating scales or not. If a patient is pain assessed, he or she is more likely to achieve full pain relief.

We believe that this manuscript would be suitable for your journal since managing pain is one of the greatest challenges of palliative care. A great majority of palliative patients suffer from cancer diagnoses, which are often accompanied with severe pain. Pain assessment with pain rating scales is an important tool to evaluate the severity of the pain and also to evaluate treatment. Our finding of the importance of the scales could be of great importance for patients within palliative care.

This manuscript has not been published and is not under consideration elsewhere.
We have no conflicts of interest to disclose

Thank you for your consideration!

Sincerely,

Sofia Norstedt, medical student
Åsa Andersson, PhD
Department of Geriatrics, Örebro University Hospital
Ethical Considerations

An obvious problem with record reviews and registry studies is that the patient is neither asked nor informed about their participation. Informed consent is obligatory when performing medical research, as the participation must be voluntarily. A patient can normally decline to participate. It is impossible to know if the patient would have refused to participate in the study or not. Is it ethical correct to automatically assume that they would have?

There is always a dilemma regarding the confidentiality with journal reviews. Even though the results are presented unidentified at a group level to keep the patients confidentiality, it is not undisclosed for the person that collects the data. When performing record reviews, it is inevitable to not take part of more information than the specific questions that are sought.

Since record reviews and registry studies are retrospective, the patients themselves will not benefit from the research. However, one must find that the profit and knowledge it gives for the research overweighs this. The expectation is that results and findings will improve treatments and care systems and this will hopefully be of benefit for future patients.

In summary, even though the patients do not know that they are participating in these studies, they will take no harm. There is no intervention affecting their bodies or interferences with their lives so there cannot be any inconvenient or unwanted side effects for the individual patient. Since there is no risk or burden for the study subjects one must believe that if there are potential benefits that will come from research in this area, this overweighs the fact that the patients cannot give an informed consent.