

Patient Barriers to Adequate Analgesia among Irish Palliative Care Patients

Geraldine McDarby*, David S. Evans, Regina Kiernan

Department of Public Health, Health Service Executive West, Merlin Park Hospital, Galway, Republic of Ireland

*Corresponding author: Dr. Geraldine McDarby, Department of Public Health, HSE West, Galway, Ireland,
E-mail: Geraldine.mcdarby@hse.ie

Abstract

Background: Cancer pain is associated with significant costs. Uncontrolled cancer pain impairs physical and psychological functioning while also being associated with increased resource utilization and healthcare costs. Patients continue to report high levels of cancer pain despite the presence of effective guidelines, shown to produce highly significant and sustained reductions. These guidelines are based on the WHO analgesic ladder with opiate analgesics as the mainstay of treatment for moderate to severe pain regardless of its etiology. This study aimed to examine patient barriers to cancer pain control among Irish palliative care patients by examining patient reported pain, prescribed analgesics and patient concerns about reporting pain and using analgesics using internationally validated tools.

Methods: A cross sectional survey was undertaken of all eligible patients attending a regional specialist palliative care centre over a four month period. Patients completed the Barriers Questionnaire II (BQII) to assess pain barriers to reporting pain and using analgesics. Patient records were examined to determine the adequacy of prescribed analgesics as defined by the WHO's Pain Management Index PMI where adequacy of analgesia relates to the congruence between the level of analgesic prescribed according to the WHO ladder and patients reported pain intensity. Ethical approval was granted by the NUIG Research in Ethics Committee and the Research Ethics Committee of the Royal College of Physicians, Ireland. Anonymised data was analyzed using SPSS

Results: The majority (76.6%) of patients surveyed reported some level of pain in the preceding week, with the majority (91.5%) being prescribed the appropriate level of analgesic for their pain level. Moderate to high levels of concern were reported for three of the four BQII factors with fatalism, concern with addiction and the masking effects of analgesics given the highest subscale ratings.

Conclusions: Despite being prescribed adequate analgesics, three quarters of cancer patients reported pain. High levels of misconceptions and fears are present which have the potential to interfere with appropriate cancer pain management. Patient concerns represent areas for treating physicians to target when assessing cancer pain and control.

Background

Pain is one of the symptoms most commonly associated with cancer, with prevalence increasing with the stage of disease^[1,2]. It impairs both physical and psychological functioning and has a significant impact on quality of life^[3-6]. The World Health Organisation (WHO) developed guidelines for cancer pain relief in the 1980's which have remained unchanged in principle since that time^[7]. These are based on a 'three step analgesic ladder approach in which the severity of pain, as report-

ed by the patient, determines the choice of analgesic^[7,8]. Under these guidelines, it is pain severity and not the underlying etiology or disease stage that determines the analgesic choice. This approach has been shown to produce significant and sustained reductions in pain and has been adopted worldwide^[4,9,10].

Although cancer pain can be controlled, studies consistently demonstrate high levels of uncontrolled pain^[1,4,5]. In 2008 a systematic review found that pain prevalence ranged from 33-64%, with patients with advanced, recurrent or terminal disease reporting the highest prevalence^[1]. In Ireland studies among

Received Date: December 27, 2016

Accepted Date: February 14, 2017

Published Date: February 16, 2017

Citation: McDarby, G., et al. Patient Barriers to Adequate Analgesia among Irish Palliative Care Patients. (2017) J Palliat Care Pediatr 2(1): 40- 45.



palliative care patients have reported pain prevalence's of 66-68%^[11,12]. Uncontrolled cancer pain is associated with significant impairments in both physical and psychological functioning while also intensifying the experience of other symptoms^[3,4]. Apart from these human costs, uncontrolled cancer pain is also associated with higher health service costs in terms of increased hospital admissions and longer inpatient stays^[13,14].

The problem of inadequately controlled cancer pain is multi-factorial, with patient, healthcare provider and system barriers recognized. Patients experience pain and must communicate that experience to their healthcare provider, who must assess this information and respond appropriately. The system in which the healthcare provider operates must support this process through access to appropriate analgesics. System barriers, including the regulatory environment and opioid access, do not pose a significant problem within the Irish context^[15,16]. Healthcare barriers, including knowledge of cancer pain and analgesics and attitudes and behaviour relating to the assessment of cancer pain and prescribing practice, were beyond the scope of this study^[17]. Patient barriers include beliefs and behaviours that lead to a reluctance to accurately report their pain experience^[18-20]. In Ireland, there have been no studies to date that have investigated reasons for poor pain control among cancer patients. This study aimed to examine patient barriers to cancer pain control among Irish palliative care patients by examining patient reported pain, prescribed analgesics and patient concerns about reporting pain and using analgesics using internationally validated tools.

Methods

A cross sectional survey and an examination of patient records was undertaken on all eligible patients attending a regional specialist palliative care centre in Ireland over a four month period. Sample size calculations (using Epi-Info version 3.5.3) were performed using an expected pain prevalence range of 50 - 80% from Irish and international literature^[11,12,21,22]. Based on a total eligible patient population of 96 for the region, a sample size of 50 was required (10% minimum detectable difference, 95% confidence level).

Eligibility included age greater than 18 years, a malignant diagnosis, a life expectancy of greater than one month and the capacity to provide informed consent. Ethical approval was granted by the NUIG Research in Ethics Committee and the Research Ethics Committee of the Royal College of Physicians, Ireland.

Patients were asked to complete a 28 item questionnaire, the Barriers Questionnaire II (BQII). The BQII is a validated 27 item tool designed to assess concerns about reporting pain and using analgesics among cancer patients^[20-23]. Items on the BQII are rated on a five point Likert scale ranging from DO NOT AGREE AT ALL to AGREE VERY MUCH. Questions are grouped into four factors (Fatalism, Harmful Effects, Physiological Effects, and Communication) and presented in the form of means. In line with international practice, means between zero and 1.5 are considered to represent low levels of concern, means between 1.5 and 2.5 represent moderate levels of concern, while means greater than 2.5 represent high levels of concern^[23]. Patient pain was assessed in line with international application of the BQII using a single item from the Brief Pain Inventory (BPI), a validated tool used to assess pain intensity^[20]. Patients

were asked to report their worst level of pain over the preceding week on an 11 point Likert scale^[20,24-26].

The medical records of each participant were examined to elicit socio-demographic and medical information including age, marital status, gender, disease characteristics, treatment status, and current prescribed analgesics. In addition, the principle investigator determined the adequacy of prescribed analgesics using the Pain Management Index (PMI), a tool developed by the WHO to approximate adequacy of analgesia for a population^[20,27]. A patient's reported pain intensity (0 - 10) is recorded into no pain (0), mild pain (1-3), moderate pain (4 - 6) and severe pain (7+). It is then compared to the most potent analgesic prescribed for that patient, obtained from the patients records and given a numeric score based on the WHO analgesic ladder (paracetamol/NSAID = 1, weak opiates = 2, strong opiates = 3). Analgesic score is then subtracted from pain intensity. Pain management is considered adequate when there is congruence between the patients reported pain intensity and the potency of the analgesic prescribed, equating to a PMI score of zero or greater^[20].

During the study, all patients received the on-going multidisciplinary care provided by the specialist palliative care team including medical and specialist nursing input, physiotherapy, complementary therapies including aromatherapy and massage and psychosocial support. This centre has adopted the WHO's analgesic ladder as part of its pain control guidelines. Patients in this region have access to palliative services 7 days a week and are reviewed by the team on an as needed basis. During periods of acute or uncontrolled pain, patients are often reviewed daily, with regular liaison with the patients General Practitioner.

All statistical analyses were performed on anonymised data with SPSS version 21.0 (SPSS Inc., Chicago, IL). One way ANOVA was used to examine any associations between BQ means and socio-demographic, disease and pain characteristics including PMI, containing more than two categories. Those variables with only two categories were examined using independent t-tests. Homogeneity of variance was assessed using Levene's test and post hoc analysis was undertaken using Turkey HSD in the case of equal variances and Tamhane's procedure in the case of unequal variances. Pearson's correlation coefficient was used to compare mean pain scores and BQ subscale and total means.

Results

Profile

The median age of participants was 69 years (range 35 - 85). The majority of participants were female (57.1%) with 51.5% married or co-habiting. Over three quarters (76.0%) were day care patients with inpatients representing 24.0% of participants. The most common sites of primary cancer were gastrointestinal (34.7%), breast, (20.4%), and lung (18.4%). Over two thirds (69.4%) had metastatic disease with 71.4% receiving active treatment in the form of either radiotherapy or chemotherapy at the time of participation (Table 1).

Table 1: Participant demographic, disease and pain characteristics.

Gender	% (n)
Female	57.1%(28)
Male	42.9%(21)
Location	
Day care (home)	76%(38)
In-patient Unit	24%(12)
Marital Status	
Single	20%(9)
Married/co-habiting	51.1%(23)
Widowed	24.4%(11)
Divorced/separated	4.4%(2)
Site of Primary Tumour	
Gastrointestinal	34.7%(17)
Breast	20.4%(10)
Lung	18.4%(9)
Gynaecological	8.2%(4)
Haematological	6.1%(3)
Melanoma	6.1% (3)
Prostate	4.1% (2)
Renal	2% (1)
Pain characteristics	
Level	% (range)
No pain (0)	23.4% (12.8 - 36.2)
Mild (1 - 3)	25.5% (12.8 - 38.3)
Moderate (4 - 6)	27.7% (14.9 - 42.6)
Severe (7+)	23.4% (12.8 - 36.2)

Prevalence of Pain (BPI)

Table 1 shows the rating of patient’s worst level of pain in the previous week (taken from the BPI). Three quarters (76.6%) experienced some form of pain, with over half (51%) reporting moderate or severe pain (table 1). No demographic characteristics were found to be associated with pain intensity.

Prescribed Analgesics and Adequacy of Analgesia

The vast majority of subjects (78%) were prescribed a WHO level III analgesic (strong opioid) and 64% were prescribed it regularly, as per WHO guidelines. Almost all participants (91.5%) were prescribed adequate analgesics based on their reported level of pain as evidenced by a PMI greater than zero. (table 2)

Table 2: Prescribed Analgesics and Adequacy of Analgesia.

Prescribed analgesics and schedule	% (n)
Level I regularly	14.0 (7)
Level I as required	24.0 (12)
Level II regularly	8.0 (4)
Level II as required	14.0 (7)
Level III regularly	64.0 (32)
Level III as required	14.0 (7)
Adequacy of Analgesia	
Adequate (PMI > 0)	91.5%
Inadequate (PMI < 0)	8.5%

Patient Concerns about Reporting Pain and Using Analgesics (BQII)

Patients reported moderate to high levels of concern for three of the four factors on the BQII. The highest mean was for fatalism (3.47) followed by Harmful Effects (2.25) and Physiological Effects (1.85). The lowest mean was for Communication (1.54). The mean rating of BQ items overall was 2.20.

In comparing differences in the level of concern about reporting pain by demographic and disease characteristics, age was associated with Fatalism, with those over 70 years having higher fatalism scores than those in the 53 - 70 age group (p = 0.01; 0.17 - 1.44). Patients who reported they were receiving active treatment also had higher means for Communication (t47 = 2.04; p = 0.05).

No relationships were found between pain intensity scores and BQII items or between location and BQII items or pain intensity.

Table 3: Means for Factor Items on BQII (1 - 1.5 = low level of concern, 1.6 - 2.5 = moderate level of concern, > 2.5 = high level of concern)

Factor and sub scale means	Mean (0 - 5)	SD
Fatalism		
Fatalism	3.47	0.86
Harmful effects		
Harmful effects	2.25	1.27
Addiction	2.30	1.27
Immune effects	2.01	1.50
Physiological effects		
Physiological effects	1.85	0.90
Masking effects	2.24	1.41
Side effects	1.70	1.24
Communication	1.54	1.26
The good patient	1.59	1.51
Distract	1.47	1.33
BQ total	2.10	0.77

Discussion

The patients involved in this study were similar with respect to age, gender and site of primary cancer to the population of patients referred to the regional specialist palliative care centre^[28]. The most common diagnoses of study respondents were also similar to the most common causes of cancer death in the Irish population^[2]. The majority were undergoing some form of active treatment.

The reported prevalence of pain in the preceding week was high at 76.6%, but broadly similar to the only previously reported pain prevalence in a similar Irish palliative care population (68%)^[11]. This level of pain is also on a par with what has been observed internationally in patients with advanced or recurrent cancer^[21]. Just over half (51%) reported pain of moderate to severe intensity, pain levels known to have a significant impact on quality of life, functional status and resource utilisation^[6]. Such high levels of pain could be seen to reflect poorly on standards of medical care were it not for the PMI scores. Almost all patients in this study had a PMI of greater than or equal to one, meaning that the level of analgesic prescribed was congruent with the intensity of pain reported, indicating adequacy of

analgesia. While reassuring, the PMI can only provide a rough estimate of how pain is treated in a population, if patients are non-compliant or prescribed doses inadequate, the adequacy of analgesia will still be considered acceptable by the PMI^[20]. Unfortunately no measure of compliance was used in this study.

Patients in this study expressed moderate to high levels of concern with virtually all barrier concepts presented to them, returning the highest level of Fatalism reported in any population to date. Fatalism scores among US populations have been consistently low, ranging between 1.04 and 1.29 with a similarly low 1.1 being returned in a Danish sample^[29]. Although Fatalism means are higher in populations in the East, ranging from 2.32 to 2.57, they are still significantly lower than the 3.47 found in this Irish sample^[30]. This indicates that patients in this population believe that cancer pain is an inevitable and uncontrollable consequence of cancer. This level of fatalism is both surprising and alarming. It is unclear whether this level of fatalism is a cultural norm or is a reaction to a history of poor pain management. Regardless of its origins, this level of fatalism must act as a barrier to the adequate management of pain. Its association with those in the over 70's age category in this sample is significant given that the majority of cancers are now diagnosed in those 65 and older^[1].

The Harmful Effects factor also received a moderate mean, driven primarily by moderate levels of concern for addiction. Small but significant proportions of patients (17 - 19%) have reported hesitancy to use analgesics stemming from concerns of addiction and one does not have to look far for the source of this concern^[19,30-32]. Despite the fact that countless studies have shown that the risk of addiction to analgesics among cancer patients is extremely small, the public are continually bombarded with the propensity of opioids to cause addiction and suffering in popular culture, with no distinction being made between legitimate and illegitimate use. This unbalanced and often sensationalistic view of opioids cannot help but influence the public's views of these medications, and if not countered by a credible source have the potential to represent a barrier to analgesic use.

A moderate mean was also found in relation to the Physiological Effects factor, driven primarily by moderate levels of concern with the Masking Effects subscale. This subscale represents the idea that pain is a signal that patients value, or at least fear to suppress. The moderate subscale mean indicates that this concept resonates with this Irish sample, and while the proportions of patients who have reported omitting or discontinuing their analgesics in order to maintain this valued insight have been small (5%), this concept has been linked with non-compliance in the literature^[32-35].

Limitations

While this sample size was adequate to represent the population from which it was drawn, the small sample size as well as regional differences in access to palliative care make generalization to the national level problematic. Some associations between BQ scores and demographic, disease or pain characteristics could also have been missed. Given that access to palliative care in this region is comparably high, it is possible that the reported pain prevalence may be an underestimate.

The study was further limited by some practical issues relating to the validated tools utilized to facilitate international comparison. The BQ is limited in that it measures agreement with barrier concepts only and while they have a role, these bar-

riers do not always translate into non-compliance. It is however the most widely used tool to measure patient barriers to adequate analgesia worldwide and therefore allows comparison with international data. While the BPI is the tool used alongside the BQ II to allow determination of the PMI, it only gives a measure of pain prevalence. Levels of uncontrolled pain can be more accurately determined by use of longitudinal measures. Finally, the PMI is used to reflect the adequacy of analgesia in a population but cannot determine the relative contribution of patient or healthcare provider barriers.

Conclusions

The problem of inadequate cancer pain management has been well documented on an ongoing basis since the 1980's with the first report implicating patients' knowledge and beliefs in this problem published in 1984^[36]. The findings of this study indicate that despite more than 20 years of research and a sustained international effort to raise the profile of cancer pain and its management, cancer patients remain in significant pain. This pain has implications for the individual as well as implications across society and the health sector. And while the findings further suggest that the problem of inadequate management of cancer pain is one that may rest at least in part with the patients themselves, the problem of uncontrolled cancer pain is not that simple.

The Danish population expresses levels of concern with these barriers that are in some cases even higher than those expressed by this Irish sample^[29,37]. Despite this, Denmark has the highest legal consumption of opioids worldwide, indicating that their use of opioids is not hindered by their levels of concern^[38]. In the United States we can see that low barriers do not guarantee low pain prevalence, as concern for the barrier concepts in the US has always been the lowest measured worldwide despite the US registering the same high prevalence of cancer pain^[39]. What the findings of this study do tell us unequivocally is that Irish cancer patients have high levels uncontrolled pain coupled with misconceptions and fears that have the potential to interfere with the appropriate management of cancer pain. Concerns relating to addiction, the masking effects of analgesics and fatalism in particular represent areas for treating physicians to target when assessing cancer pain and cancer pain control. Research has demonstrated that appropriate knowledge as well as sensitive physician communication translates into lower pain intensities and improved compliance^[18,40]. When physicians become aware of the misconceptions that are likely to act as barriers to adequate pain control in their cancer patients, they have the opportunity to address those concerns. This has the potential to translate into improved compliance and pain control. While the fault may lie with the patients, the solution may lie with the physician.

Conflict of Interest: The authors have no conflict of interest, financial or other interests to declare.

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