

Cancer-related pain management in hospice settings in Sri Lanka: adequacy, perceptions of patients and experiences of nurses

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Abstract

Pain debilitates over 75% of patients with advanced-stage cancers and its management is a primary palliative care objective¹. This study aimed to assess the adequacy of cancer-related pain management and identify related patient-perceptions and nursing-experiences at Shantha-Sevana and Sathya-Sai Hospices, Sri Lanka. This was a descriptive study which used expert-developed questionnaires, Brief Pain Inventory, Focus Group Discussions to collect patient data and in-depth interviews to collect nursing data. Adequacy of analgesia was assessed using Pain Management Index [PMI]. Relevant ethical clearance was obtained. Twenty terminally-ill cancer patients and nine nurses took part in the study. Assessment of analgesic adequacy in patients revealed that negative, zero and positive PMI were 40%, 35% and 25% respectively. All patients with negative PMI had moderate-severe pain with none being treated with strong opioids. Adverse patient-perceptions emerged in cognitive and emotional aspects, with pain-related depression being dominant [n=14]. Key patient-perceptions on pain-management were decrease in pain after hospice admission [n=9] and satisfaction with the pain-management provided [n=10]. None of the nurses had received structured training on pain-management for palliative care at basic or recruitment stages. No grading of pain was performed during pain-management. Conclusively, cancer-related pain is undertreated in hospices and room for improvement exists.

Keywords: Pain. Palliative care. Pain control. Cancer. Patient perceptions.

Introduction

Pain is a symptom that is experienced by 90% of cancer patients throughout the course of their disease [2]. Apart from the unpleasant sensory experience it creates, it is also associated with other medical problems such as depression, anxiety and fatigue, thus compounding the problem list associated with cancer [2].

Cancer pain is said to combine both inflammatory and neuropathic mechanisms, which thereby makes it a very difficult type of pain to treat [2]. Guidelines to be followed when managing cancer pain do exist, the most accepted of which has been formulated by the World Health Organization. Despite the existence of such guidelines, however, under-treatment of cancer pain has been found to be a common problem. In fact in certain instances, under-treatment of cancer pain can be as high as a shocking 40% [3]. However, no formal studies have assessed the adequacy of cancer-related pain management in any Sri Lankan onco-palliative settings.

With regard to patient perceptions on cancer-related pain management, a study carried out in Sri Lanka in 2015 among cancer patients admitted at National Cancer institute, Maharagama (NCIM) revealed that out of 124 cancer patients, 68% reported their most common need to be pain relief [4]. Studies from other countries have shed light on patient expectations associated with cancer-related pain relief and some of these are the need for emotional support, need for sufficient information and the timely recognition of pain by their health-care workers [5]. Studies have also identified the level of pain-related information and associated pain-communication from health care workers to be unsatisfactory as perceived by cancer



patients [6]. However, once again, there is a seeming lack of evidence from the Sri Lankan setting with regard to the perceptions of local patients on cancer-related pain management.

With regard to experiences of nurses in relation to this, a study in 2015 conducted among nurses in four onco-palliative settings including NCIM and Shantha Sevana Hospice, highlighted that Sri Lankan nurses have poor cancer pain management practices and that they tend to work in task-oriented settings where pain management is not a priority [7].

It is evident therefore, that there is obvious progress to be made in the management of cancer-related pain, which is a problem that affects a significant proportion of the Sri Lankan patient population. However, for progress to be made, research-backed evidence is necessary about the adequacy of cancer-related pain management at present. Perceptions of patients and nurses in this respect are necessary to identify gaps, barriers and expectations that generally go unnoticed.

Identifying the sore lack of information on the matter, the present study aimed to shed new light to bridge the gap in information. It is hoped that the evidence generated from this study would be used to refine cancer-related pain management and palliative care services in Sri Lanka.

This study aimed to assess the adequacy of cancer-related pain management in two hospice settings in Sri Lanka and elicit the perceptions of patients and experiences of nurses on cancer-related pain management.

Methods

This was a descriptive study with quantitative and qualitative components carried out at Shantha Sevana Hospice, Maharagama and Sathya Sai Hospice, Hanwell. Ethical approval to conduct the study was obtained from the Ethics Review Committee of National Hospital of Sri Lanka. All patients admitted for palliative care at these two hospices and all nurses employed in these hospices were recruited for the study with the exception of patients without pain and not on analgesics, patients who have been in the hospice for less than one week, patients unable to talk, patients unable to be mobilized for the purpose of focus group discussions and nurses employed for less than one month at the hospice.

Data was collected in October 2017 using four pre-tested interviewer-administered study instruments. These were an expert-developed questionnaire to gather patient-related information, disease-related information and pain-related information [developed

with the opinion of a consultant oncologist and public health specialist], Brief Pain Inventory, which is a WHO-developed tool for the assessment of clinical pain, expert-developed Focus Group Discussion guide and in-depth interview guide [developed with the opinion of a consultant oncologist and public health specialist]. Utilizing the information of the Brief Pain Inventory, the Pain Management Index (PMI) was calculated to assess the adequacy of pain management.

Quantitative data collected by the expert-developed questionnaire and Brief Pain Inventory was entered and analysed by the investigators using the computer package SPSS 23. Descriptive statistics were used for analysis. Qualitative data collected through the in-depth interviews and Focus Group Discussions was analysed using content analysis.

Results

Twenty terminally-ill cancer patients and nine nurses took part in the study. The response rate was 100%. The socio-demographic characteristics, disease characteristics and pain-related characteristics of the sample population are shown in Table 1.

Table 1
The socio-demographic characteristics of the sample population [n=20]

	Frequency (n)	Percentage (%)
<u>Socio-demographic characteristic</u>		
<u>Gender</u>		
Male	7	35.0
Female	13	65.0
<u>Age category</u>		
51-60	6	30.0
61-70	9	45.0
71-80	4	20.0
81-90	1	5.0
<u>Mean Age</u>	64.8 years	
<u>Race</u>		
Sinhalese	14	70.0
Tamil	4	20.0
Muslim	2	10.0
<u>Religion</u>		
Buddhism	10	50.0
Christianity	7	35.6
Hinduism	1	5.0
Islam	2	10.0
<u>Civil Status</u>		
Married	7	35.0
Single	4	20.0
Divorced	7	35.0
Widowed	2	10.0
<u>Highest educational qualification</u>		
Grades 1-5	7	35.0
Grades 6-11	8	40.0
Passed O/L	2	10.0
Passed A/L	3	15.0

	Frequency (n)	Percentage (%)
<u>Former Employment status</u>		
Employed	13	65.0
Unemployed	4	20.0
Retired	3	15.0
<u>Disease characteristic</u>		
<u>Primary diagnosis</u>		
Oropharyngeal cancer	10	50.0
Rectal cancer	2	10.0
Gynaecological cancer	3	15.0
Thyroid cancer	1	5.0
Carcinoma of Unknown Primary	1	5.0
Don't know/ in denial	3	15.0
<u>Time since diagnosis of cancer</u>		
<1 year	1	5.0
>1 year	17	85.0
Don't know	2	10.0
<u>Metastasis</u>		
Yes	6	30.0
No	7	35.0
Don't know	7	35.0
<u>Cancer treatment received</u>		
No treatment	2	10.0
Radiotherapy	4	20.0
Multiple	13	65.0
Alternate/Complementary therapy	1	5.0
<u>Problems experienced currently</u>		
<u>Physical</u>		
Pain	18	90.0
GIT symptoms	7	35.0
Insomnia	8	40.0
<u>Mental</u>		
Social	11	55.0
Spiritual	9	45.0
Financial	4	20.0
<u>Comorbidities</u>		
Diabetes mellitus	3	15.0
Hypertension	3	15.0
<u>Pain related characteristic</u>		
<u>Time since pain</u>		
< 6 months	3	15.0
< 1 year	4	20.0
> 1 year	10	50.0
Unable to comment	3	15.0
<u>Time since treatment of pain</u>		
< 1 month	1	5.0
< 6 months	2	10.0
< 1 year	4	20.0
> 1 year	6	30.0
Don't know	7	35.0
<u>Time spent in hospice</u>		
< 1 month	3	15.0
< 6 months	3	15.0
< 1 year	3	15.0
> 1 year	11	55.0
<u>Change in pain after admission to hospice</u>		
Decreased	8	40.0
Increased		
Similar	6	30.0
Unable to comment	6	30.0

	Frequency (n)	Percentage (%)
<u>Trajectory of pain</u>		
Steady	3	15.0
Increasing	1	5.0
Decreasing	4	20.0
Intermittent	12	60.0

The Brief Pain Inventory (BPI) showed that the most common site of pain (30%) was in the throat which may be due to the fact that 50% of the study population had oro-pharyngeal carcinoma. One quarter of patients (25%) claimed 10 to be the level of worst pain experienced in the past 24 hours and only 30% of patients confirmed 100% of relief from the analgesia given. The BPI also revealed that 30% of patients were receiving level 1 analgesics, 25% level 2 analgesics, 40% level 3 analgesics while 5% received only adjuvants such as gabapentin.

Assessment of analgesic adequacy in patients was done by calculating the PMI. Negative, zero and positive PMI levels were revealed to be 40%, 35% and 25% respectively. This means that 40% of participants were undertreated and 25% of participants were over-treated with only 35% being adequately and correctly treated. All patients with negative PMI indicating under-treatment, had moderate-severe pain with none being treated with strong opioids.

Eight patients at Sathya Sai and eight patients at Shantha Sevana participated in two focus group discussions which aimed to identify patient perceptions on cancer-related pain management. Patient perceptions related to pain were identified in sensory, cognitive and emotional aspects. Both positive and negative themes emerged when exploring psychological effects experienced due to pain, with negativity being more dominant. Negative themes were identified along the three themes of depression, anger and problems with adjustment. Feelings of depression identified were feeling that death is preferable to living in pain (25%, n=4), feeling worthless and burdensome to society (25%, n=4), hopelessness about future (25%, n=4), feeling like there is only death to look forward to now (18.8%, n=3) and feeling that pain has to be tolerated with no other way out (12.5%, n=2). Feelings of anger that were identified were feeling that pain is restrictive and interfering with their life (18.8%, n=3) and feelings of anger towards spiritual forces (12.5%, n=2). Feelings related to an adjustment problem followed the thought of 'Why did this happen to me?' (37.5%, n=6). No feelings of anxiety about their future were identified through the focus group discussion. Contrastingly, positive themes that emerged were a state of



acceptance (12.5%, n=2) and the will to be happy despite the pain (6.25%, n=1).

The majority felt that pain decreased (56.3%, n=9) after coming to the hospice. Some felt that there was no change (25%, n=4) and some stated that pain started after admission (12.5%, n=2). At Sathya Sai, 100% of patients were happy with the care given. All felt that the staff provided timely and adequate care and that the staff was giving them the maximum care possible. At Shantha Sevana, only 25% (n=2) was completely satisfied with the care given. A certain proportion (37.5% (n=3)) was only partly happy with the care being given because their pain had not completely disappeared and 25% (n=2) were not happy. The unhappy proportion felt that more drugs needed to be given since the pain is intractable. Two patients (25%) said that satisfaction is only temporary because pain re-emerges when drugs wore down. However, all felt that the staff was giving them the maximum care possible. All patients were satisfied by the emotional support that is given by the healthcare workers by way of listening to their needs, verbal consolation and timely attendance to their needs.

Only one patient at Sathya Sai said that their medication was explained to them. The rest in both hospices said that no pain and analgesic related education is provided to them. However, 100% of patients said that they have no desire to know about their medication and that they had complete trust in the health care workers to do what is best for them.

With regard to the nurses, there were 3 working at Sathya Sai and 6 working at Shantha Sevana, all of whom underwent in-depth interviews. The basic training received by nurses varied with a few (33.33%) having undergone the basic government training of three/four years and majority (66.66%) having received basic training of one year from a private nursing school. The years of service as a nurse varied from 3 months to 40 years. A few nurses (33.33%) had a service of just three months, whereas 22.2% had a service of 1 year, 11.1% had a service of 3 years and 8 years each and 22.22% had a service of more than 30 years.

None had received any special training in the field of oncology and none had any prior work experience in oncology except one senior nurse (11.1%) who had worked at NCIM for 25 years. None had received any special training in palliative care prior to working at the hospice. After joining the hospice, there had been no structured training on palliative care, but there have been ad-hoc trainings provided by the senior nurses and other workshops/seminars conducted by National Cancer Institute Maharagama (NCIM), Nurses' Training School etc. (8-10 times per year). None had prior experience of working in palliative care. For 33.3% of

the nurses, working at the hospice was their first practical training as a nurse. Experience of working at the hospice ranged from 3 months to 8 years.

The majority of nurses (77.77%) had chosen to work in the hospice setting due to reasons of convenience such as lower work load, close proximity to home and residence and meals being provided. Some (11.11% (n=1)) said that they had chosen to work in palliative care due to better work satisfaction and a further 11.1% said that they had chosen the field due to a personal experience of a loved one having died in need of palliative care.

The healthcare worker hierarchy for pain management is organized from doctor to nurse and nurses only provide medication as per the doctor's prescriptions. At Sathya Sai Hospice, there was a voluntary medical officer who visits the hospice once a week, but he was contacted thrice daily on a schedule to provide updates. At Shantha Sevana Hospice, there was a voluntary medical officer who visits the hospice thrice a week.

All nurses claimed that they had been given some theoretical input on pain management during their basic training, but most of what they practice as pain management had been learnt on the job. Work involved in pain management was mainly said to be the administration of pain medication. However, at times sedatives were given alongside analgesics. All nurses said that they give emotional support to patients by way of verbal consolation and sometimes attendants are delegated to massage areas of pain. Of note, no assessment or grading of pain was done when administering medication.

None of the nurses were able to identify any challenges to pain management directly, however one nurse at Shantha Sevana stated that the process involved in obtaining morphine is cumbersome, due to the rigorous documentation and auditing involved. With regard to feelings of adequacy and satisfaction with the pain management being provided, nurses at Shantha Sevana felt completely satisfied stating that adequate pain management is being provided, but the nurses at Sathya Sai found it difficult to comment on this. Furthermore, all nurses at both hospices felt that they need further education and training on pain management. They found it difficult to identify the areas in which they would like to receive said knowledge.

Discussion

The present study investigated a previously unexplored topic in the field of Sri Lankan palliative medicine. While two previous studies have discussed palliative care needs of cancer patients and perceptions



of nurses on cancer palliation in Sri Lanka, these studies have not focussed on pain management in cancer patients or provided an objective assessment of its adequacy.

The sample population of the present study included all patients and nurses in two of the oldest and most established hospice settings in Sri Lanka and it was hoped that the findings would provide a clear picture of the diverse aspects pain management in Sri Lankan hospice settings. The response rate was 100% for the study.

With respect to patient-perceptions on cancer-related pain management, this study revealed a plethora of insights. Firstly, with respect to cancer-related pain itself, both positive and negative themes emerged, with negative themes being more dominant. Negative perceptions reverberated the connotations of depression, anger and problems with adjustment. The dominance of depression and anger being associated with cancer patients having pain, when compared to patients without pain was corroborated by a study carried out in 1995 by Glover et al which analysed whether pain made a difference to the mood states of oncology patients [8]. This study revealed that such patients were also more likely to be anxious, although anxiety was not a feeling that was identified in any of the patients interviewed in the present study. The reason for this may be that these patients had no reason to be anxious about whether the pain is indicative of an underlying sinister cause, since they were already aware of their terminal illness. It may also be possible that the interviewers failed to uncover hidden anxieties in these patients, as some level of anxiety is to be expected despite the patients already being aware of their condition.

Secondly, with respect to pain management, three key perceptions were identified. The first of these was that most patients perceived a decrease in pain after hospice admission. The second was that most patients expressed satisfaction with pain management and 100% expressed satisfaction with emotional support provided at the hospice setting. A Sri Lankan study carried out in 2015 among cancer patients at NCIM, revealed that the majority of patients claimed pain relief to be their most common need and that out of them, 86% confirmed adequate pain relief [7]. In the same study, 70% of patients expressed satisfaction with the psychological support received [7].

The marked increase in satisfaction in the present study with all patients being satisfied with the emotional support given may be because the hospice setting is a more specialized setting for palliation when compared to NCIM. However, it may also be that the study at NCIM used more comprehensive rating scales to compute the

level of satisfaction and the present study due to its use of only content analysis may have not picked up on subtle undertones of dissatisfaction. The third perception that was identified was that although the majority did not know details of their analgesia, none of them displayed an interest in knowing. The fact that most patients had no knowledge of their pain management is a theme that repeatedly emerged in several other studies done worldwide. A systematic review carried out in 2009 revealed that the quality of pain communication was subpar in certain key areas consistently [5]. Another study carried out in the same year showed that some patients experienced a lack of information from nurses with respect to pain management [6].

Despite this drawback, most participants in the present study expressed no desire to receive the required knowledge on the matter. This could possibly be due to the fact that they feel it is purposeless given the finality of their condition or that they feel it is beyond their comprehension to know about different types of medication.

Five key themes were identified with regard to experiences of nurses. These themes were not having received any formal, structured training in palliative care, the bulk of pain management being learnt on the job, no assessment or grading of pain being performed at the hospice, satisfaction with pain management being provided and the need for further education in pain management.

A study carried out in 2015 at to assess the knowledge and perceptions on cancer palliative care among Sri Lankan nurses revealed similar findings with none of the nurses having received any special training on cancer palliative care, but expressing a desire to continue education [4]. The previously cited study carried out at NCIM revealed with respect to nurses that only 54% expressed satisfaction with the care they provided. The present study shows a marked improvement in the satisfaction levels of the nurses, quite possibly due to the more rewarding nature of the work they do by attending to terminally ill patients and also having the opportunity to get to know and interact with the patients better at the hospice setting than at a ward setting. However, a drawback worth noting is that grading or assessing the pain is not done, as part of the daily work of a nurse. The investigators feel that this is a crucial drawback at a palliative setting, where pain must be graded for proper management. A similar finding was recorded in a 2010 study carried out at community-based hospices in the United States which revealed that cancer pain is not being documented or assessed in keeping with the recommendations of evidence based practices [9].



Conclusion

Cancer-related pain is inadequately treated at Sri Lankan hospices and room for improvement exists. The investigators recommend structured training for nurses working at hospices in this regard.

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Ethics approval

Ethical approval to conduct the study was obtained from the Ethics Review Committee of National Hospital of Sri Lanka.

Informed consent

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Data sharing statement

No additional data are available.

Conflict of interest

The authors declare no conflict of interest.

Similarity check

It was applied by Ithenticate®.

Peer Review Process

It was performed.

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