



Original Article

Impact of Establishing a Pain Clinic in a Rural Cancer Centre Based on the Knowledge and Experience of the Pain of Cancer Patients – A Prospective, Questionnaire-Based Study

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ABSTRACT

Objectives: Unrelieved pain significantly affects the quality of life of cancer patients. In rural settings, cancer patients do not have information or knowledge about how to control their pain because of a lack of resources or awareness. We conducted an interventional, questionnaire-based prospective study in a rural tertiary care oncological centre to look for the impact of establishing a pain clinic based on the knowledge and experience of cancer patients regarding their cancer pain.

Material and Methods: The patient pain questionnaire was filled by 380 random non-surgical patients complaining of pain who visited our centre for the treatment of cancer. The information generated was used for setting up a pain clinic covering all aspects of cancer pain. After 3 months of starting the pain clinic services, all these patients who visited the pain clinic at least once were again surveyed similarly. Out of 380 patients, we could only follow up with 348 patients and other patients were lost to follow-up.

Results: After visiting the pain clinic the mean value of the response for most of the questions decreased suggesting that the responses became more favourable as the knowledge improved and the experience of the pain became less distressing for the patients. The mean value of the responses to all the questions related to the overall knowledge of cancer pain before visiting a pain clinic was 4.22 ± 1.58 and after visiting a pain clinic was 3.83 ± 0.95 which was statistically significant ($P = 0.000$). The mean value of the responses to the questions related to the overall experience of the pain before visiting the pain clinic was 3.81 ± 1.42 and after visiting the pain clinic was 2.14 ± 1.05 which was highly significant ($P = 0.000$). We found out that the patients who had a higher mean value of the responses (8–10) suggesting the most unfavourable responses benefitted the most and the number of patients having the most unfavourable responses decreased after visiting the pain clinic.

Conclusion: In a rural tertiary healthcare cancer centre, the establishment of a pain clinic increased the general understanding and experience of cancer patients regarding their pain and pain management.

Keywords: Pain, Cancer, Knowledge, Experience, Rural

INTRODUCTION

Pain is one of the most distressing symptoms of cancer patients. It affects their quality of life significantly.^[1] In today's world, cancer incidence is increasing daily due to changes in lifestyle, dietary patterns and other risk factors. Hence, the prevalence of patients with cancer pain is also increasing. A systematic review of the literature published between 2005 and 2014 showed that the overall prevalence of pain in patients with all cancer stages was 51%, out of which 33% have moderate-to-severe pain.^[2] In recent years, the

whole world has made a lot of efforts in pain management. However, there are great differences in cancer pain prevalence and severity among different regions of the country.^[3] Several factors make pain management particularly challenging in rural communities. This is due to poor education status, low socioeconomic conditions and a lack of cancer hospitals and pain clinics in rural areas.

We performed an interventional, questionnaire-based prospective study to implement and improve pain services in a rural tertiary care oncological centre. The study aimed

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to evaluate the impact of the establishment of the pain clinic on the knowledge and experience of cancer pain in a rural tertiary healthcare centre. We hypothesised that gathering information about what the cancer patients in this rural area understand about pain management and then subsequently intervening and establishing a tailor-made pain clinic service will result in improved knowledge and experience of pain and pain management in cancer patients in a rural tertiary healthcare centre.

MATERIAL AND METHODS

The primary objective of the study was to examine the impact of establishing a pain clinic in a rural tertiary healthcare centre on the knowledge of how to use pain medications in cancer patients. The secondary objective was to examine the impact of the pain clinic on the cancer patient's experience of various aspects of pain such as severity, relief, distress to self and the family members and the expectations of pain to get better in the future. It was a questionnaire-based study to establish a pain clinic in a rural tertiary healthcare cancer centre and to see the impact of pain intervention on various aspects of cancer pain.

Inclusion criteria and exclusion criteria

Inclusion criteria were an age of more than 18 years, all non-surgical cancer patients visiting our rural cancer centre before setting up a pain clinic and patients having pain scores of the numeric rating scale >3 at any point in time. Exclusion criteria were patients having difficulties with listening, reading and writing and those who were unable to interpret evaluation forms/questionnaires.

Sample size calculation

In our hospital, the number of patients enrolled per day was about 150–200. Hence, we expected to see approximately 5000 patients in a period of 6–8 weeks. In a population of 5000 patients, with a confidence interval of 95% and a margin of error of 5% approximately 350 patients were recruited to look for the significant differences in the knowledge and experience of pain.

Protocol

A well-validated patient pain questionnaire (PPQ) was used for assessing the knowledge of cancer pain and the psychosocial experience of pain in cancer patients in our study. PPQ is a 16-item ordinal scale that measures the knowledge and experience of a patient in managing chronic cancer pain.^[4] The patient was asked to read each question thoroughly and decide if he/she agreed with the statement or disagreed. The patient was then instructed to circle a number to represent how much, on a scale of 0–10, he or she agreed or disagreed with the statement. The PPQ includes 9 items that measure knowledge about pain and 7 items that measure the patient's experience with pain. All of the items

have been formatted such that 0 is the most positive outcome and 10 is the most negative outcome. The PPQ was filled by 380 random non-surgical patients complaining of pain who visited our centre for the treatment of cancer. The negative aspect of the questionnaire-based study, that the patients may sometimes not understand the meaning of the questions, was negated by the fact that a healthcare worker helped the patients in filling up and understanding the questionnaire. The questionnaires were analysed by the researchers to assess the knowledge and experience of the pain. The severity of pain, distress to the patient and family due to pain; and the patient's knowledge of how and when to use the pain medications were assessed. The information generated was used for setting up a pain clinic covering all aspects of cancer pain including standard pain management and counselling. The WHO analgesic guidelines for the management of pain with a stepwise escalation from anti-inflammatory analgesics to strong opioids were done as per the symptoms of the patients.^[5-7]

After 3 months of starting the pain clinic services, all these patients who visited the pain clinic at least once were again surveyed similarly. The PPQ was filled out by these patients after a visit to the pain clinic. Out of 380 patients, we could only follow up with 348 patients and other patients were lost to follow-up. The response to the questions of the questionnaire was assessed and compared to the previous response in the initial evaluation. The impact of establishing the pain clinic was assessed from the change in the response to the questions.

Statistical analysis

Data were analysed using the SPSS version 20.0. About 348 patients were analysed for the results. Student *t*-test was applied to compare the response of the patients before and after visiting the pain clinic. A Chi-square test was applied for the subgroup analysis of the questions related to the experience of pain before and after visiting the pain clinic.

RESULTS

After visiting the pain clinic, the mean value of the response for most of the questions decreased suggesting that the responses became more favourable as the knowledge improved and the experience of the pain also became less distressing for the patients [Table 1]. The difference in the mean value of the responses to the questions before and after visiting the pain clinic was statistically significant ($P < 0.05$) for questions 1, 2, 6–8, 10 and 12–16 [Table 2]. Only questions 4 and 10 showed an increase in the mean value of the response [Table 2]. The mean value of the responses to all the questions related to the overall knowledge of cancer pain before visiting a pain clinic was 4.22 ± 1.58 and after visiting a pain clinic was 3.83 ± 0.95 which was statistically significant ($P = 0.000$). The mean value of the responses to the questions related to the overall experience of the pain before visiting the pain clinic was

Table 1: Mean scores of the questions before and after visiting the pain clinic.

Question	Mean (Mean±SD)		Number	Correlation	Significance
	Pre-intervention	Post-intervention			
Q1. Cancer pain can be effectively relieved.	0.687±1.25	0.41±0.87	348	-0.008	0.883
Q2. Pain medicines should be given only for severe pain	7.43±5.88	5.79±2.94	348	0.020	0.711
Q3. Pain medications cause addiction over time	5.26±3.59	4.87±3.42	348	0.080	0.136
Q4. To give the lowest amount of medicine possible to save larger doses for later when the pain is worse	6.93±3.91	9.06±4.97	348	-0.084	0.116
Q5. It is better to give pain medications around the clock (on a schedule) rather than only when needed	2.26±2.93	1.96±3.14	348	0.036	0.502
Q6. Treatments other than medications (such as massage, heat and relaxation) can be effective in relieving pain	3.37±2.90	2.27±2.90	348	-0.032	0.556
Q7. Pain medicines can be dangerous and can often interfere with breathing	5.09±3.19	3.31±2.61	348	0.039	0.464
Q8. Patients are often given too much pain medicine.	3.32±3.51	1.09±1.72	348	-0.110	0.040
Q9. If pain is worse, the cancer must be getting worse	3.63±3.51	5.76±3.35	348	-0.012	0.829
Q10. How much pain over the last 1 week?	2.91±1.98	2.20±2.06	348	-0.007	0.897
Q11. How much pain at present?	2.17±1.56	1.98±1.46	348	-0.054	0.317
Q12. How much pain relief receiving currently?	3.97±3.02	2.20±1.71	348	-0.056	0.300
Q13. How distressing is the pain to you?	4.11±3.51	2.75±1.76	348	0.063	0.239
Q14. How distressing is your pain to your family members?	5.12±3.61	2.91±1.81	348	-0.058	0.282
Q15. To what extent do you feel you are able to control your pain?	4.74±2.82	2.35±1.80	348	-0.051	0.346
Q16. What do you expect will happen with your pain in the future?	3.69±3.1	0.60±1.01	348	0.020	0.705

SD: Standard deviation

Table 2: Mean difference in the scores before and after visiting the pain clinic.

Paired differences (Pre-intervention question score post-intervention question score)	Mean	SD	Standard error mean	Significance (2-tailed)
PRE Q1-POST Q1	0.2787	1.5349	0.0823	0.001
PRE Q2-POST Q2	1.644	6.530	0.350	0.000
PRE Q3-POST Q3	0.391	4.761	0.255	0.127
PRE Q4-POST Q4	-2.135	6.578	0.353	0.000
PRE Q5-POST Q5	0.305	4.223	0.226	0.179
PRE Q6-POST Q6	1.098	4.171	0.224	0.000
PRE Q7-POST Q7	1.776	4.052	0.217	0.000
PRE Q8-POST Q8	2.228	4.083	0.219	0.000
PRE Q9-POST Q9	-2.133	4.887	0.262	0.000
PRE Q10-POST Q10	0.712	2.873	0.154	0.000
PRE Q11-POST Q11	0.187	2.204	0.118	0.114
PRE Q12-POST Q12	1.761	3.564	0.191	0.000
PRE Q13-POST Q13	1.362	3.833	0.205	0.000
PRE Q14-POST Q14	2.2083	4.1326	0.2215	0.000
PRE Q15-POST Q15	2.394	3.431	0.184	0.000
PRE Q16-POST Q16	3.089	3.241	0.174	0.000

SD: Standard deviation

3.81 ± 1.42 and after visiting the pain clinic was 2.14 ± 1.05 which was highly significant ($P = 0.000$) [Table 3]. Sub-group analysis of the response to the experience of pain was done. We found out that the patients who had a higher mean value of the responses (8–10) suggesting the most unfavourable responses benefitted the most and the number of patients having the most unfavourable responses decreased after visiting the pain clinic [Table 4].

DISCUSSION

Cancer pain is one of the most common, debilitating symptoms among cancer patients worldwide. Unrelieved pain greatly affects a patient's work, activities, comfort, motivation, mood and overall quality of life. In rural settings, patients do not have much knowledge about how to control their cancer pain.^[8] Many patients continue to live with pain as they think that it is part of their illness and cannot be cured. These patients may view pain medications as inherently dangerous and many of them have social stigma related to opioid use,^[9] which is particularly more in rural communities which have been disproportionately affected by the current opioid crisis.^[10,11] In rural areas, it is challenging to maintain privacy about own health.^[12] The news that someone is receiving cancer pain medications may signal to others the likely presence of opioids in the home, introducing both security concerns and the potential for negative reactions from others.^[13] Professional personnel and community services are frequently harder to access in rural locations.^[14,15] When considered collectively, these elements appear likely to cause patients to have less understanding of their pain management principles and hence worsen their experience of pain.

We attempted to evaluate the knowledge and experience of cancer patients regarding their pain using the PPQ because we are working at a rural tertiary cancer hospital that is still in its early stages of development. We evaluated the knowledge gaps in this subset of patients and their experiences with cancer pain based on the data we gathered with this questionnaire. This assisted us in opening a pain clinic in our facility. Following their visit to the pain clinic, all of these individuals were contacted once more. We discovered that when patients visited a pain clinic and received painkillers, their knowledge of and experiences with cancer pain improved.

What is interesting is that most cancer patients have very poor knowledge about two facts. These items were

the 'addiction risk' associated with pain medication and the 'tolerance' developed over time. Patients coming to the hospital had a belief that pain medications should be given only for severe pain (mean score 7.43 ± 5.88) as it may cause addiction over time (mean score 5.26 ± 3.59) and the larger doses should be reserved only for future use when the pain is worse (mean score 6.93 ± 3.91) due to the fear of tolerance in these patients. Out of these knowledge barriers, visiting the pain clinic improved their knowledge about addiction (mean score 4.87 ± 3.42). Only two questions related to the knowledge of pain showed more unfavourable responses even after a pain clinic visit. They continue to worry about developing a tolerance to the medications they are taking (mean score 9.06 ± 4.97) and think that increasing pain signals a worsening of their malignancy. The patients' knowledge of these two questions did not increase, which may be attributed to their incorrect interpretation of the questions as a result of their low educational standing or their strong convictions about their illnesses as a result of the lack of access to accurate information. A study in 2004 in China assessing cancer pain beliefs also found that concerns about cancer prognosis, tolerance and addiction were patients' and their family caregiver's main belief barriers.^[16] There have been many cancer pain educational programs and educational interventions which have made significant benefits to patient's knowledge and attitudes.^[17] However, as the number of cancer patients is increasing, cancer pain education programs may not meet all the knowledge needs of cancer patients. The results of the study done by Ma *et al.* in 2021 concluded that patients' pain management outcomes, patients' pain knowledge and family caregivers' pain knowledge were not satisfactory.^[18] To improve the knowledge of patients and their families, we should strengthen cancer pain education programs and take more targeted measures, such as individualised education based on cancer pain knowledge assessment. More diversified educational measures should be taken for society, such as culturally tailored videos, booklets, telephone, mini-fellowships and face-to-face consulting.^[19]

The experience of the patients toward cancer pain improved after the pain clinic visit which was reflected by significantly decreased scores on the questionnaire. The average pain score at present was 2.17 ± 1.56 in our study which was similar to the pain scores observed in a previous study (2.65 ± 2.15), however, these pain scores improved after visiting the pain

Table 3: Mean scores of overall knowledge and experience of cancer pain and the difference after visiting the pain clinic.

	Pre-intervention Score	Post-intervention Score	Pre-post-intervention Score	Standard error mean	Significance (2 tailed)
Knowledge	4.22±1.58	3.83±0.95	0.38±1.75	0.0938	0.000
Experience	3.81±1.42	2.14±1.05	1.67±1.74	0.0935	0.000

Table 4: Subgroup analysis of questions of experience of pain.

Questions	Pre-intervention scores			Post-intervention scores			Significance
	0-3	4-7	8-10	0-3	4-7	8-10	
	Q10	206	137	4	295	37	
Q11	301	42	4	304	42	1	0.901
Q12	185	104	59	287	60	1	0.417
Q13	178	76	94	238	108	2	0.58
Q14	147	79	122	220	125	3	0.017
Q15	150	118	80	274	69	5	0.447
Q16	182	110	56	338	10	0	0.101

clinic in our study.^[18] The overall knowledge and experience of the patients showed a favourable response and it improved after a visit to the pain clinic. Mean scores of the pain that the patient was having at that time, in the last week, and the relief they were getting currently improved after they visited the pain clinic. One interesting thing to note in the experience of pain was the thinking of patients that their cancer pain is more distressing to their family (mean score 5.12 ± 3.61) than to themselves (mean score 4.11 ± 3.51). This highlights the psychological impact of the pain and the patients perceive themselves as a burden on their families. The mean scores, however, improved after visiting the pain clinic. During subgroup analysis of the questions related to the experience of the pain, we found that there was a decrease in the number of patients having the most unfavourable response. It implies that there was a decrease in the number of patients for whom the pain experience was most distressing. This will also improve the satisfaction of the patients and, in turn, will lead to improved quality of life. Other psychological aspects of pain such as the patient's sense of control over their pain and the belief that their pain will improve in the future were also improved after they visited the pain clinic. These favourable outcomes of establishing a pain clinic in a rural setup have a significant impact on the mental well-being and quality of life of these patients.

CONCLUSION

Pain knowledge and experience of the patients are important indicators of pain management outcomes. This study helped in assessing the effect of establishing a pain clinic service in a rural tertiary health-care centre and it improved the overall knowledge of the patients about cancer pain and improved their overall experience in their pain management.

Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent.

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Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The author(s) confirms that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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