Original Article

# Integration of Specialized Pain Control Services in Palliative Care: A Nationwide Web-based Survey

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## Abstract

**Introduction:** Pain control is an important part of palliative care (PC), and conventional analgesics do not provide adequate pain relief to all patients. Many patients present with complex pain syndromes that require interventional pain control measures usually deployed by pain specialists. There is adequate integration of specialized pain control services with PC elsewhere, but information about the same in our country is lacking. **Materials and Methods:** An internet survey was conducted among palliative specialists regarding the need and availability of pain specialists for their patients suffering from complex pain syndromes. Their attitude toward integrating specialized pain control services in their practice was also explored. **Results:** Majority of palliative physicians came across situations where specialists in pain would control the patients' pain better. There was a poor availability of such services, and when available, the cost was significant. It is heartening to note that though there is poor integration of specialized pain control services with palliation, palliative physicians acknowledge the need for pain specialists and their techniques for providing pain relief for their patients. **Conclusions:** Effective pain control is needed in palliation, barriers however exist, and there is a need to make pain specialists and interventional techniques more freely available.

**Keywords:** Pain management, pain specialist, palliative care, survey

## Introduction

Many patients today live with chronic pain, but living with pain is not their choice, it is fate. One of the roles of medicine is to provide succor to those who are condemned by fate to suffer. Pain control though historically the role of the family physician has shifted to the anesthesiologist in the surgical setting[1] and to palliative physicians in palliative care (PC).[2] With the rise of the superspecialty of interventional pain physicians, pain relief has its own specialists.[3] It is axiomatic that pain physicians can control pain better since they are adept at interventional techniques.

Patients suffering from a variety of terminal diseases would benefit from PC, but those of cancer are the ones who seek palliation maximally.[4] Keeping the need for spreading the scope of PC for other diseases aside, there is a need to ensure that a greater number of cancer patients receive PC. The component of pain in the symptomology of these patients is so large that often PC is erroneously equated with pain control.[5,6]

Relief from pain is believed to be a basic human right.[7] It is unfortunate that in cancer patients, pain control is incomplete.[8]

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In addition, a large number of people worldwide are in need of PC at the end of life, and very few of them actually have access to it.[9] Since interventional pain control is a new superspecialty, there is a relative shortage of these practitioners all over. The Indian Society for Study of Pain formed by interventional pain physicians in 1984 reportedly has 1700 members but contact details of its members are not available on their website[10] while the Indian Association of Palliative Care established in 1994 has over 1300 members.[11]

There are many factors responsible for the poor accessibility of PC for patients. The first being the paucity of PC centers. In a vast country such as India, there are only 223 centers,[12] of which 182 are in the state of Kerala.[13] Many large states have just one or two centers and Patients have to travel large

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distances to reach a center. The second hurdle has been the availability of opioids, there has been a severe shortage all over the country but this is now improving.[14] Another important factor that interferes in the pain control programs is the lack of a multidisciplinary approach among health-care professionals.[15]

At present, in India, efforts are going on to make PC services available more widely in the country.[16] Recently, the Supreme Court of India concluded the Public Interest Litigation that it was hearing since 2007 demanding free availability of morphine across India for cancer patients. The court observed "the present petition does appear to have served its purpose and led to an improvement in the system that was earlier prevailing."[17] The issue that remains unexplored is the attitude of PC physicians and their willingness to work in close collaboration with pain physicians.

Given the limitation of pain control in palliation, integration of specialized pain control services with PC may help. Elsewhere, an integration of these services is seen, but there is little information about the situation in our country. This survey was conducted to find out the following:

1. The need for pain specialists in the care of patients under palliation
2. The barriers in integrating interventional pain control methods in palliation
3. The attitude of palliative physicians toward pain specialists and interventional techniques.

## Materials and Methods

The aim of the study was to enhance pain control in palliation. The objectives were to identify the needs and barriers for integration of specialized pain control services with PC and the attitude of PC physicians toward this. Toward this end, we conducted an anonymous nationwide survey among PC physicians using Google forms. A questionnaire was developed to elicit this information. The questionnaire was based on the one used earlier in another country.[15] The questionnaire was validated by sending it to 10 PC physicians. Based on the replies, it was concluded that the questionnaire was suitable for use in the survey. The survey was conducted using census method in which Google forms were distributed among members of the Indian Association of Palliative Care by E-mail. The survey contained 14 close-ended questions, most with multiple choice answers.

E-mail addresses of PC physicians sourced from the website of the Indian Association of Palliative care, which is in public domain. The replies received did not reveal the name or the E-mail of the respondent, thus maintaining confidentiality. The questionnaires were mailed to 652 members whose E-mails were available on the site. Of these, 422 mails bounced since the E-mails were incorrect and only 230 are assumed to have reached the members. Since the number of replies were small, a census method was deemed most appropriate for the study.

## Results

### Response rate

In all, 230 inquiries were sent out and we received the filled forms from 73 doctors, thus the overall response rate was 31.7%.

### Respondents' characteristics

The largest group of respondents (35.6%) were from government hospitals, physicians from private hospitals, and PC centers formed the next largest group (24.7% each), 4.7% were from hospices, while the balance 11% had other affiliations. Almost half of our respondents (47.9%) had <5 years practice in the field of PC, 28.2% had between 5 and 10 years' experience, and 23.9% had over 10 years' experience in the field.

### Complex pain syndromes

Most of the respondents had encountered patients with complex pain syndromes, 53.4% did so often, while 43.8% encountered them sometimes, and only 2.7% had never come across such syndromes.

Almost half of the physicians (47.9%) could manage these patients sometimes, 35.6% could mostly manage them, but 16.4% could not really manage such patients. Overall, 64.3% of the respondents could do with help to manage such patients. Nearly 58.9% felt that a pain specialist could have handled the job better, while 34.2% were ambiguous. Only 6.8% of the respondents did not feel that a pain specialist would do a better job.

Massive, i.e., 97.2% of the physicians felt that the main responsibility of pain specialists was either to do interventional pain control, assess and prescribe analgesic or both. Interestingly, 62.5% felt that the role of the pain specialist was to do both. Almost 64.4% physicians believed that interventional pain control should be used in PC, while 21.9% were unsure. Only 13.7% physicians felt that these techniques had no role in palliation.

### Pain services

A large percentage felt the need for pain services (65.8%) while 24.7% were unsure. Almost half said that pain services should be available continually while the other half felt that they should be available on demand. However, 35.6% said that pain services were available continually while 39.7% had these services on demand; unfortunately, 24.7% reported that pain services were not available to them at all. Nearly 95% physicians believed that integration of pain and PC services would be interest of the patients. Nonavailability of pain specialists was claimed to be the leading cause of the absence of integration (41.2%), while 16.2% quoted nonaffordability.

The perceived need and actual use of pain services in the past 12 months is shown in Figure 1. It may be noted that the perceived need was always more than the actual use of specialized pain services.

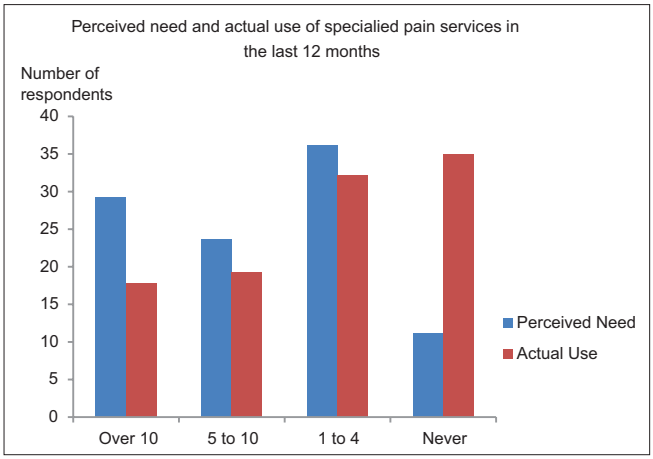


**Figure 1:** Perceived need versus actual use of specialized pain services.

## Discussion

The response rate to our internet-based E-mail survey was 31.7%; this is quite in line with the observation of the Canadian group that investigated responses to web-based surveys.[18] Similar to Canadians, we too used reminders and personalized mails, but we stopped short of giving them gifts, due to a resource crunch. The web has emerged as an important resource for information, to the extent that Richard Smith suggests a scientific world sans science journals.[19] Web-based surveys can be customized, are economic, fast, and have a widespread reach, but low response rates and inadequate question comprehension threaten the validity of survey results.[20] Yet the net can take you, where you could hardly hope to go.

The respondents in this survey were spread across institutions controlled by the government as well as the private ones. They represent PC centers and hospices. This is where one expects PC specialists to be. PC is a relatively young specialty in India and so also our respondents had a relatively short experience in this field. A quarter of them had over 10 years' experience in the field, another quarter had 5–10 years' experience while bulk of them, almost half had <5 years' experience in the field. The relative youth of our respondents is important in view of the opiophobia that has been noted among physicians in the developing countries.[21] Retrospectively we feel, we should have collected the age of our respondents, an error we now regret.

This survey deals with the management of complex pain syndromes, which are commonly observed in cancer patients. Some of the pain is due to the primary disease,[22] while some could be due to the spread[23] and some due to the treatment.[24] Damage that takes place to the nerves is due to the disease process or chemotherapy that leads to neuropathic pain that presents a different challenge to the physician.[25,26] Pain is clearly multidimensional and one of the most distressing of all the symptoms suffered by patients in PC.

Pain is probably the oldest symptom recognized by human, and most efforts of medicine have been focused on controlling it. Pain control has been Holy Grail of medicine, all over the world, and opium was the God's own medicine.[27] However, fearing the addictive potential of opioids, the Narcotic Drugs and Psychotropic Substances Act was passed in 1985 that led to a sudden and precipitous drop in morphine supply and consumption around the country.[28] At the same time, the WHO experts published the analgesic ladder for pain control, which contained opioids in the third step of pain control. Tremendous efforts were needed on the part of activists to get the government-amend rules to make morphine available for cancer and other diseases where pain is a major problem.[29]

The WHO ladder had been recommended as a pain control guideline;[30] this was never intended to be the final answer for pain. Experts acknowledged that the ladder will help most cases of pain, but there could be a small fraction that would require more steps.[31] In fact, an additional step, consisting of interventional methods, has been added to the three-step ladder.[32] Complicated or complex pain syndromes require one to look beyond the ladder, and this is true for cancer pain.[33]

Palliative physicians are well trained to control symptoms of cancer, but despite their best efforts, cancer pain is not optimally treated.[34] Millions of cancer patients die a horrible death in severe pain and suffering, surely there is a need to bring in other modalities of pain control and specialists who are adept in the use of these modalities to provide relief to all.[35] This is where pain specialist comes in, they can provide interventional methods when conventional analgesics fail.[36] If palliative physicians alone are able to provide adequate relief, pain specialists need to be brought in for impeccable assessment and control of pain.[37]

One of the heartening results of this survey is that palliative physicians recognize that complex pain syndromes exist and that they need help to tackle them. They also acknowledge that pain specialists would do a better job doing this and that they are ready and keen to collaborate with them. There are barriers to this collaboration; first, not many pain specialists are available, this being one of the latest medical specialties to come into its own. Second, economic reasons come in the way of these collaborations. Elsewhere too barriers for collaboration have been noted, though their nature is different.[15] The higher values of perceived need compared to actual use show that though palliative physicians want to use specialized pain services, barriers to this collaboration exist.

Interventional methods of pain control require more equipment and devices, most of which are not available at primary health centers.[38] Availability of relatively aseptic conditions, imaging devices, catheters, and parenteral preparations all cost money, this makes interventional pain control more expensive and less accessible; but with a positive attitude of palliative physicians, it is hoped that these barriers will be overcome.

Palliative physicians surveyed by us recognized the need for pain specialists in their practice, they not only perceived the need for such services, but had actually used them whenever possible. They also acknowledged that pain specialists can

use interventional methods, assess pain more accurately, and use analgesics more effectively in the control of pain. Surveys among pain specialists have shown that they too are in favor of collaborating with palliative physicians to better the lot of patients.[39] With this mutual acknowledgement of each other's expertise, we are encouraged to believe that the lot of cancer patients will be better in the future than what it is today. PC that improves the quality of life is a basic human right and must be provided to all patients in need.[40]

## Conclusions

This study reveals that chronic pain syndromes are encountered by PC physicians and they would prefer to have the support of pain specialists to handle such patients. These physicians acknowledge that pain specialists have the means and techniques to provide relief to these patients though there are barriers for collaboration between these specialties. With this positive attitude, we believe that there will be more collaboration to provide comfort to patients under PC.

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### Conflicts of interest

There are no conflicts of interest.

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