Attitudes and Beliefs Regarding the Role of Interventional Pain Management at the End-of-Life Among Caregivers: A 4-Year Perspective

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Abstract: Intrathecal and epidural opioid analgesia represents a major advance in the management of cancer pain, adding a new dimension to opioid therapy by allowing prolonged analgesia through the use of significantly lower doses than those required for systemic administration. However, myths, misconceptions, and apprehension continue to serve as major barriers to effective cancer pain management, and concerns regarding safety, efficacy, and relative ease of utilization still prevail. This, in turn, results in unnecessary suffering, depression, diminished cognitive function, sleep disturbance, functional disability, and compromised quality of life. We conducted a survey to systematically explore medical and paramedical attitudes prior to and 4 years after the introduction an interventional pain program and attempted to qualitatively analyze what appeared as main facilities or difficulties following end-of-life clinical experiences.

In general we found that all caregivers were satisfied from using interventional pain relief techniques at the end-of-life; more so among caregivers directly involved in patient care. Although nearly half of the responders initially found “technical manipulations” moderately difficult to difficult, after a simple hands-on instruction all found these techniques to be “helpful, simple and feasible.” “When all went well,” caregivers found implantable devices as a useful tool to relieve pain, to increase the ability of patients to complete personal endeavors, notably mobilization, but also noted an increased patient anxiety at the end-of-life. “When all went wrong,” caregivers evoked the paradoxical attitude of patients to having a “high-tech” treatment at the end-of-life, causing them eventually to have “false hope,” as well as the phenomenon of “interdisciplinary hyperactivity,” creating what was referred to as therapeutic futility. In summary, this study suggests the importance on insisting to introduce novel techniques into practice despite initial apprehension, however, quality improvement by detecting and overcoming attitudinal barriers remain primordial and requires narrative research.

Key Words: pain, cancer, attitudes, end-of-life, epidural, intrathecal pumps
INTRODUCTION
Professional caregivers have a fundamental responsibility to relieve pain, particularly when patients are at the end-of-life and the time to alleviate suffering is literally running out. Despite the ubiquity of pain at the end-of-life and the multitude of minimally invasive techniques now available for the treatment of intractable cancer pain, interventional procedures are underutilized.\(^1,2\) These result in unnecessary suffering, depression, diminished cognitive function, sleep disturbance, functional disability, and compromised quality of life.\(^3\)

Barriers to effective pain management are multiple and involve physicians, nurses, caregivers, patients, and third party payers,\(^4,5\) as well as the lack of adherence to analgesic guidelines.\(^6\) Medical personnel underestimate the intensity and impact of pain on activities of daily living\(^7\) and patients fear to be labeled “bad” or become overly dependent on healthcare providers.\(^8\) Also, concerns regarding the role of interventional pain management in palliative care prevail, questioning the cost benefit ratio of “high-tech” procedures.\(^9\)

In June 2001 in concert with our colleagues in the Departments of Oncology and Geriatrics, we decided to utilize implantable devices for the treatment of refractory pain in patients at end-of-life. All patients prior to treatment were consented after clarifying goals of treatment (pain relief, comfort, quality of life), trialed with a 7-day epidural catheter with fentanyl and bupivicaine and then implanted with drug delivery systems (epidural port-a-caths® systems attached to external programmable CADD® (Smith Medical, Watford, UK) pumps or totally implanted programmable intrathecal SynchroMed® (Medtronic, Tolochenaz, Switzerland) pumps) in accordance to common practice and guidelines\(^10,11\) which have been shown to be superior to conventional medical management.\(^12\)

The purpose of this survey was to systematically explore medical and paramedical attitudes and beliefs prior and 4 years after the introduction an interventional pain program. We attempted to observe what appears as main facilities or difficulties following these experiences.

METHODS
2002 Survey
An 11-point questionnaire survey was conducted during December 2002 on medical and paramedical personnel dedicated to end-of-life treatment. Excluded were personnel not involved in patient care (administration and maintenance) and those who refused to participate. As privacy and confidentiality issues did not arise from this audit, institutional review board approval was not required.

The questionnaire was written with the advice of a pain psychologist as well as a member of the Unit for Medical Education and Research (UDREM) and registered in our quality database (ref. PEC.QST-1-V1.0; 22.08.2002) (Appendix I), covering the follow domains:

- Determining personnel’s role (question 1);
- Previous clinical experience in interventional pain in order to ascertain the existence of any attitude bias (question 4);
- Attitudes and beliefs toward the role of minimally invasive procedures in these patients in an attempt to assess knowledge, myths, conceptions, and misconceptions regarding “high-tech” pain medicine (questions 5, 7, 8, 9, 10, open-ended);
- Quality of training in order to determine difficulties in teaching for future courses (questions 2, 6);
- Satisfaction from the program (question 3) analyzing each component of the course (distributed handouts, theoretical teaching, discussion, hand-on);
- Future suggestions to improve training program (question 11 open-ended).

Statistical Analysis
We analyzed the results of the survey among physicians and nurses (“first-line caregivers”) who maintain intensive patient contact, vs. a second group of caregivers consisting of chief nurses, noncertified nurses, social workers, psychologists, physiotherapists (“second-line caregivers”). Groups were compared for nonparametric order with Fisher’s Exact Test for response rate, quality of training and attitudes and beliefs. A value of \(P < 0.05\) was considered significant. For satisfaction a Likert scale was used and groups were compared by Mann–Whitney test. Other results were expressed in percents.
2006 Interviews

A psychologist not involved directly in pain management performed a pilot semistructured interview on two participants (not included in the data). Then interviewees, doctors, and nurses involved in cancer care who participated in the 2002 survey were informed about the aim of study and were asked to speak about their experiences ("according to you . . .") in regard to interventional pain management through open-ended questions. The psychologist prompted interviewees to clarify their responses and explore their views, carried out each interview, lasting for 45 to 60 minutes. A hermeneutic phenomenological approach as described by Van Manens was used, specifically by "conversational interviews," in order to elicit experiential narratives from the research participants. All interactions took place in a quite room located near the workplace, a familiar setting where participants felt comfortable. Only one conversation was conducted with each participant and the psychologist explored deeper meanings of expressed items, rather than using a fixed set of questions. She also made field notes after each encounter to serve as a reminder of the context of the interaction, the environmental setting, and any nonverbal language used by the interviewee. Answers were recorded, verbatim fully transcribed and then coded by two researchers independently, a psychologist and a pain nurse, for material structuring. Participants were ensured that special efforts were made to render transcribed interviews anonymous to guarantee confidentiality.

Data Analysis

Data analysis consisted in a nontheoretical reading, in order to search for principal thematic representations, then each text segment was sorted by topic and analytical categories were derived inductively from the data. A recurrent list of topics was identified across each category and was constantly compared to the rest of the data trying to preserve as many of the nuances as possible. Finally, substantive refined themes emerged on the bases of this analysis and were discussed. Because of the limited objectives of our study, neither narrative strategies nor linguistic articulation of discourse was performed.

RESULTS

2002 Survey

All personnel (n = 32) consented to participate. Among "first-line caregivers" (group 1), 77% responded (four doctors and nine certified nurses), whereas among “second-line caregivers” (group 2), only four of 19 (21%) responded (nine noncertified nurses, two physiotherapists, two social workers, two psychologists, and four administrative nurses) (P < 0.003). No difference in prior experience, which may explain this discrepancy, was found between the groups.

When analyzing competency and preparedness, 57% of personnel participated in technical workshops, 85% received documentation, and 72% received continuous ongoing training. Workshops and continuous training satisfied both groups equally, but group 1 participated more in the PCA (patient controlled analgesia) training, obtained documentation prior to our course, and sought more supervision on the hands-on sessions (Table 1). In total, 43% found that technical manipulations were initially difficult, but 92% said that they witnessed a significantly improved pain control and improved relationships with patients with interventional pain management. These positive attitudes did not differ between groups.

Finally, the palliative care team emphasized the importance of a 24-hour hotline in order to solve technical problems. Similar concerns have been described in the literature where relatively young and inexperienced staff was working in a hospital under enormous pressures of workload, staff shortages, and without experienced role models from whom to learn the complexities of palliative care.13

2006 Interviews

Fourteen (three doctors, nine nurses, two noncertified nurse) out of 16 caregivers who participated in the 2002 survey agreed to be interviewed. Responses were

<table>
<thead>
<tr>
<th>Table 1. Participation in Training Sessions</th>
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<tr>
<td>First-Line Caregivers (Group 1)</td>
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<tr>
<td>Information sessions</td>
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<tr>
<td>PCA training</td>
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<td>Gripper® training</td>
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<td>Hands-on coaching</td>
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Nb, number; NS, not significant; PCA, patient controlled analgesia.
grouped according to experience (positive vs. negative) and professional expertise: acute care and palliative care in oncology care. The emerged thematics are summarized in Tables 2 and 3.

DISCUSSION

In December 2002, 18 months after initiating interventional pain treatments, we set to identify which attitudes of medical staff might serve to perpetuate persistent pain, by interfering with its detection and treatment implementation. We audited our activity in order to assess its qualities, deficiencies, as well as impact on attitudes that prevailed prior to its conception. We found that although patients were followed up by our interventional pain team, implementation of this program remained controversial and its dissemination difficult, even among patients suffering from terminal cancer with intractable pain and unacceptable side effects. In general, all caregivers were satisfied from this program; however, caregivers directly involved in patient care were significantly more motivated to respond to our survey and more inclined to actively obtain documents and seek coaching during the hands-on sessions, when compared to “second-line” caregivers. In the qualitative analysis of our survey, workshops were evaluated as “extremely interesting” and although nearly half found initial manipulations of epidural and intrathecal pumps “moderately difficult to difficult,” after the hands-on instruction all survey responders found these techniques “helpful, simple and feasible.”

We then proceeded to semistructured interviews. Unfortunately, none of the unregistered nurses from 2002 was available for this interview; thus, only doctors and registered nurses participated. The fact that no non-registered nurses were available for this interview may introduce an interpretation bias. However, as “first-line” caregivers were shown to be more implicated in patient care, the themes expressed by this group were assumed to be more valuable and relevant to the study.

Specifically we found that two emerging categories were perceived among caregivers regarding these clinical situations: namely, “all went well” or “all went wrong” (Tables 2 and 3).

“When all went well,” caregivers found implanted devices as a useful tool to relieve pain.

... the patient died without suffering, lucid and calm ... she was much better with the epidural

... I don’t know how he would be without the pump, but he seemed comfortable ... 

A second theme that emerged was the ability of patients to complete personal endeavors, notably mobilization:

... with the pump the patient could move, and that was important ...

... the patient could say many things to the family, he saw his kids, and everything was calmer

... I think with the epidural he could enjoy some extra precious time with his family ... 

Finally, caregivers noted an increase in anxiety parallel to pain relief.

... when there is no more pain and you’re going to die, I can understand why you start to get scared ... I don’t have pain, but I am terribly sick and I am going to die, very strange thought ... will there be a tomorrow? ... 

“When all went wrong,” caregivers evoked the paradoxical attitude of patients to the “high-tech” investment at the end of life, causing them eventually to have “false hope.”

... patient’s expectations were unreal, this is not a miracle ...

They also expressed the complexity of some patients’ attitudes toward their end-of-life situation ...
Attitudes to Interventional Pain at the End of Life

these patients are really difficult. They have no more pain, but still they suffer, sometimes even more... they are more afraid to die, they hold on more to life as compared to the other patients.

Finally, caregivers mentioned the phenomena of “interdisciplinary hyperactivity,” where a plethora of personnel (anesthesiologists, oncologists, pharmacologists, palliative care specialists) follow up a single patient.

...who is he, the king?... there are so many caregivers... it’s useless that 15 people pass to see one patient...

Implementation of new therapeutic programs demands extreme scrutiny. The description of various clinical effectiveness and cost-effectiveness models for pain management has been extensively reviewed. However, it is myths, misconceptions, and apprehension that continue to serve as major barriers to effective cancer pain management in hospitalized patients as well as in nursing homes. In the qualitative analysis of our questionnaire, we attempted to ascertain the reasons for this resistance. We observed that reluctance to change was usually not due to the belief that conservative treatment relieves pain in all cases, nor that theoretically epidurals or intrathecal pumps cannot achieve adequate analgesia, but rather to a personal general apprehension. Only two respondents admitted that their motivation to change was “because they want to try something new” or “I like technical procedures” and one who thought that “technical procedures in the setting of the end-of-life is inappropriate.”

Bearing in mind that the efficacy of long-term continuous neuroaxial infusion for the treatment of refractory pain has been established and that changes in the curriculum of pain and palliative improve medical practices, we conducted our survey and interview to reiterate that need for change. We attempted to quantify attitudes and beliefs that were expressed during the introduction of Interventional Pain program. Our results suggest that introduction of “hi-tech” interventions is fairly straightforward and simple in appropriately selected cases, improves patients’ quality of life, and facilitates patient–nurse and patient–doctor relationship, however, it may be perceived as futile in some cases. We witnessed that individuals who less responded to the survey, were less motivated during the workshops, and resisted change were among “second-line caregivers” who by definition were not intensively implicated in patient care and perhaps less aware for need to change.

CONCLUSION

Intrathecal and epidural opioid analgesia represents a major advance in the management of cancer pain. Acknowledging the increasing needs for acute palliative care in the hospital settings and that end-of-life care education programs are lacking, we insist on the importance of introducing novel techniques into practice despite initial apprehension. Quality improvement by detecting and overcoming attitudinal barriers remains primordial and further narrative research is of interest.

REFERENCES


### Appendix I: Sample Questionnaire

**PROJET D’AUDIT APRES L’INTRODUCTION DE TECHNIQUES INTERVENTIONNELLES DANS LE TRAITEMENT DE LA DOULEUR CANCEREUSE**

1. Quelle est votre fonction?
   - Médecin
   - Infirmier(e)
   - Aide soignant(e)
   - Autre: ...........

2. Avez-vous pris en charge, dans votre unité, un patient bénéficiant d’une technique telle le PAC® épidural ou la pompe implantable intrathécale?
   - Oui
   - Non
   *(Si Non passez à la question n° 4)*

3. La prise en charge de ces patients a-t-elle modifiée votre pratique et/ou votre comportement habituel?
   - Oui
   - Non

4. Lors de l’introduction de ces techniques, avez-vous bénéficié?
   - *Séance d’information sur les techniques interventionnelles* Oui Non
   - *Cours PCA* Oui Non
   - *Formation Gripper®* Oui Non
   - *Documents écrits* Oui Non
   *(PCA, Gripper®, Péridurale antalgique)*
   - *Suivi équipe d’antalgie interventionnelle* Oui Non

5. Vous avez trouvé:
   - **Très satisfaisant**
   - **Insatisfaisant**
   - *Séance d’information sur les techniques interventionnelles*
   - *Cours PCA*
   - *Formation Gripper®*
   - *Documents écrits*
   *(PCA, Gripper®, Péridurale antalgique)*
   - *Suivi équipe d’A.I*

6. Si vous avez rencontré des difficultés lors de la prise en charge de ces patients, de quel ordre étaient-elles?
   - *Liées à la technique: (PAC®, pompe implantée)* Oui Non
   - *PCA* Oui Non
   - *Changement de Gripper®* Oui Non
   - *Liées à relation avec le patient* Oui Non

7. A votre avis, ces techniques apportent-elles une amélioration significative dans le traitement de la douleur?
   - Oui
   - Non

8. A votre avis, ces techniques apportent-elles une amélioration significative dans la relation avec le patient?
   - Oui
   - Non

9. A votre avis, ces techniques apportent-elles une amélioration significative pour le concept de prise en charge en soins palliatifs?
   - Oui
   - Non

10. Souhaitez-vous poursuivre la prise en charge de tels patients dans votre unité?
    - Oui
    - Non

11. Quels seraient vos besoins pour améliorer celle-ci?(cours, coaching clinique, logistique . . .)