

Patients with Advanced Cancer: the Access to Opioids and other Pain Control Medication

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Pacientes com Câncer Avançado: o Acesso aos Opioides e demais Medicamentos para Controle da Dor

Pacientes con Cáncer Avanzado: el Acceso a los Opioides y otros Medicamentos para el Control del Dolor

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Abstract

Introduction: Pain is the worst and most frequent symptom of cancer patients causing suffering and inabilities. **Objective:** To describe how family relatives of patients with advanced cancer perceive the difficulties of accessing opioids and other pain medication. **Method:** This research adopts a Qualitative "Approach". Fourteen informal caretakers, family members of people diagnosed with advanced cancer, were interviewed through semi structured interviews. **Results:** All participants reported that they bought pain medication, including opioids and other drugs for cancer symptoms, for their relatives with advanced cancer, which had some impact on the family income. The relief of extreme suffering related to health must be a priority. It must be an ethical imperative that cuts across the assistance to patients with advanced cancer and other life threatening diseases. **Conclusion:** Public Health Programs for patients with advanced cancer must be enhanced in order to prioritize the easy access to opioids and other pain control drugs. Nonetheless, the guarantee of access must be held at medical discretion, with the accurate evaluation and prescription of pain control methods, considering the available resources. Only then it will be possible to ease suffering, ensuring equity and promoting human dignity for the ones who experience pain.

Key words: Palliative Care; Neoplasms; Pain; Analgesics, Opioids; Human Rights.

Resumo

Introdução: A dor é o sintoma mais frequente e grave vivenciado pelos pacientes com câncer, acarretando sofrimento e incapacidades. **Objetivo:** Descrever a percepção dos familiares de pacientes com câncer avançado quanto às dificuldades no acesso aos opioides e a outros medicamentos para dor. **Método:** A pesquisa se insere na perspectiva da abordagem qualitativa. Foram entrevistados 14 cuidadores informais, familiares das pessoas com diagnóstico de câncer em estágio avançado com potencial de finitude, sendo utilizadas entrevistas semiestruturadas. **Resultados:** Todos os participantes relataram comprar os medicamentos para dor; entre eles, os opioides e outros medicamentos para demais sintomas dos seus familiares com câncer avançado, impactando na renda familiar. O alívio do sofrimento severo relacionado à saúde deve ser prioritário, um imperativo ético que transversalize a assistência aos pacientes com câncer e demais adoecimentos que ameaçam ou limitam a vida. **Conclusão:** É necessário o avanço no Programa de Políticas Públicas para os pacientes com câncer, no qual seja prioritário o eficaz controle da dor, pautado na facilitação do acesso, na dispensação dos opioides e demais medicamentos para controle da dor. Contudo, a garantia do acesso deve ser alicerçada para a formação médica e avaliação eficaz, e adequada prescrição no controle da dor, de acordo com os recursos disponíveis. Somente desse modo, se intervirá no sofrimento, garantindo a equidade e a promoção da dignidade humana para os que vivenciam a dor.

Palavras-chave: Cuidados Paliativos; Neoplasias; Dor; Analgésicos Opioides; Direitos Humanos.

Resumen

Introducción: El dolor es el síntoma más frecuente y grave vivido por los pacientes con cáncer, acarreando sufrimiento e incapacidades. **Objetivo:** Describir la percepción de los familiares de pacientes con cáncer avanzado en cuanto a las dificultades en el acceso a los opioides y otros medicamentos para el dolor. **Método:** La investigación se inserta en la perspectiva del Enfoque cualitativo. Se entrevistaron a 14 cuidadores informales, familiares de las personas con diagnóstico de cáncer en estadio avanzado con potencial definición, siendo utilizadas entrevistas semiestruturadas. **Resultados:** Todos los participantes relataron comprar los medicamentos para el dolor, entre ellos los opioides y otros medicamentos para los demás síntomas de sus familiares con cáncer avanzado, impactando la renta familiar. El alivio del sufrimiento severo relacionado a la salud debe ser prioritario, un imperativo ético que transversaliza la asistencia a los pacientes con cáncer y demás adoecimientos que amenazan o limitan la vida. **Conclusión:** Es necesario el avance en el Programa / Política Pública para los pacientes con cáncer donde sea prioritario el eficaz control del dolor, pautado en la facilitación del acceso, la dispensa de los opioides y demás medicamentos para control del dolor. Sin embargo, la garantía del acceso debe ser establecida a la formación médica para una evaluación eficaz y adecuada prescripción en el control del dolor, de acuerdo con los recursos disponibles. Sólo de este modo se intervirá en el sufrimiento, garantizando la equidad y promoción de la dignidad humana para los que experimentan el dolor.

Palabras clave: Cuidados Paliativos; Neoplasias; Dolor; Analgésicos Opioides; Derecho Humano.

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INTRODUCTION

The Lancet recently published the results of a three-year study by the Lancet Commission on alleviating the abyss in access to palliative care and pain relief. The report reveals the neglected burden of suffering in the world. Worldwide, an estimated 61 million individuals a year are affected by health-related suffering, including those who die and those living in health conditions that threaten or limit their lives; 2.5 million of these are children¹.

According to the report, 45% of those who die experience severe suffering. Of these, more than 80% fail to receive pain relief and palliative care, comprising “A Sea of Suffering”².

The neglect of severe health-related suffering “is a medical, public health, and moral failure and a parody of justice”. Palliative care and pain relief should be essential components of universal health coverage (p.1391)¹.

The need for pain relief and palliative care has been neglected worldwide. Great value is now placed on extending life expectancy and productive years, with little weight assigned to interventions to relieve pain and suffering or increase dignity at the end of life.

The Latin American Association of Palliative Care (ALCP), based on World Health Organization (WHO) guidelines, recommends that the public health model for the development of palliative care should consist of appropriate public policies based on education, training in palliative care, and access to opioid analgesics and other essential medicines³. These two essential components (education and access to medicines) are the basis for implementing palliative care at all levels of care in the health system.

The WHO defines palliative care as:

an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual⁴.

The principles of palliative care are to promote quality of life and human dignity, where correct assessment and treatment of pain is indispensable.

According to the Brazilian National Cancer Institute José Alencar Gomes da Silva (INCA), pain is the principal symptom in cancer patients in progression, leading to suffering and incapacity⁵. It is one of the most frequent and severe symptoms in patients that require palliative care. Opioid analgesics are essential for relieving the pain, in addition to treating other distressing symptoms

such as breathlessness. The WHO estimates that 80% of patients with cancer or AIDS will suffer moderate to severe pain at the end of life, and the use of opioid analgesics is indispensable⁴. However, according to the WHO, symptomatic control is not limited to the end of life; it is an ethical obligation to alleviate suffering and ensure respect for human dignity and to control symptoms starting at diagnosis, whether in the initial or advanced stages of the disease.

In the Brazilian Consensus on Cancer-Related Pain Management, effective pain relief should be a priority in cancer treatment, since it helps improve and extend the patient’s tolerance of the cancer treatment, besides its positive impact on quality of life and survival⁶.

According to INCA, team preparedness is the main strategy for the treatment of pain and other symptoms in the care for patients with advanced cancer.

It is indispensable for the healthcare professionals to know how to control pain in patients with advanced cancer, to counteract myths and prejudices related to the available drugs, and to remain up-to-date with a focus on adequate treatment of pain with the available resources⁵⁽⁶⁾.

A key point in the quality of palliative care is to guarantee access to opioid analgesics⁷. In the last decade, Brazil has taken measures to facilitate access to opioid analgesics, including: simplification of prescription and ease in use of prescription forms for opioid analgesics; revision of the National List of Essential Medicines (RENAME) via Ruling GM/MS 1.587 of September 3, 2002; inclusion of morphine, methadone, and codeine in the Exceptional Circumstance Drug Dispensing Program, guaranteeing the availability (free of cost) for the population in need and expanded access (Ruling GM/MS 1.318 of July 23, 2001); and establishment of a Clinical Protocol and Therapeutic Guidelines for the Use of Opioid Analgesics in the Relief of Chronic Pain⁸.

Despite the progress resulting mainly from the above-mentioned rulings, pain management is still precarious in Brazil. The main obstacle is lack of information and gaps in training on palliative care for healthcare professionals and local health system administrators⁸.

The Organization for the Prevention of Intense Suffering (OPIS), in an official side event to the 37th Regular Session of the United Nations Human Rights Council, addressed the devastating situation of intense suffering due to denial of access to morphine. With the title “Ending the Agony: Access to Morphine as an Ethical and Human Rights Imperative”⁹⁽¹⁾, the movement led by OPIS focuses on addressing the difficulty in access to morphine and similar opioids⁹. According to

the organization, the difficulty “is largely due to overly strict government regulations based on disproportionate concerns related to dependence and diversion, and a historical neglect of suffering within many medical systems”⁹.

At the global level, the WHO identified various obstacles to overcoming unmet needs in palliative care, including the population’s insufficient access to opioid analgesics, failing to comply with international conventions on access to essential medicines⁴.

METHOD

The current study adopted a qualitative approach, where the aim was to describe the perceptions of families of patients with advanced cancer concerning access to opioid analgesics and other pain relief drugs.

The choice was made for a qualitative approach due to its potential for exploring unquantifiable aspects, using the meanings assigned by subjects to practices, aspirations, values, and attitudes¹⁰.

We interviewed 14 informal caregivers of persons diagnosed with advanced-stage cancer. Informal caregivers included family members, persons with kinship ties to the patient, and persons with affective ties with the patient other than family members. Inclusion criteria were: age 18 years or older, being the patient’s reference caregiver, have been the patient’s caregiver for at least a month, and agreeing to participate in the study. The number of participants met the criterion of discourse saturation, when the inclusion of new participants was stopped based on observation of the repetition of the resulting narratives¹¹.

The study was approved by the institutional review boards of the René Rachou Research Center/Oswaldo Cruz Foundation, under case review number 2.360.868 (CAAE: 76425617.9.0000.5091) and the Hospital de Clínicas, Universidade Federal do Triângulo Mineiro (HC/UFTM), number 2.430.351 (CAEE: 76425617.9.3001.5154).

Fourteen semi-structured interviews were held, lasting an average of 50 minutes. The technique was chosen because it allows collecting objective and subjective data and facilitates the relational aspects and greater rapport between interviewer and interviewee, allowing to expound in depth on the proposed theme¹², given the study’s complex target: experiences and perceptions of principal caregivers concerning access to opioid analgesics and similar pain relief drugs. The interviews were held at the university hospital (HC/UFTM) in the outpatient clinic or ward, at a time chosen by the participant (family caregiver).

For inclusion of participants, the research project was explained to the teams at the university hospital

(HC/UFTM) that care for cancer patients, and these professionals were asked to suggest potential participants that met the inclusion criteria. Potential participants were approached personally by the researcher, who explained the study, its objectives, and the informed consent form and verified their potential interest in participating.

Participants were assured of the interview’s confidentiality and were advised that they would only be identified in the study by their family tie to the patient, as specified in the free and informed consent form.

The semi-structured interviews were based on the following questions: Has your family member (the patient) experienced pain recently? If yes, was the pain treated? In your opinion, did the treatment help relieve the pain? Does your family member take, or has he or she taken, any medication for the pain, such as morphine, codeine, or others? Do you purchase these medicines, or do you get them through the Unified Health System (SUS)?

The interviews for data collection were performed from December 2017 to January 2018. All the interviews were recorded and transcribed. Data analysis from the 14 interviews was based on content analysis¹³.

RESULTS AND DISCUSSION

Pain is considered one of the main symptoms that impacts cancer patients’ quality of life. In our sample, 71% of the caregivers reported that the patients had experienced pain. It should be pointed out, however, that if the participants had been the patients themselves rather than their family members, this result might have been different, since according to a classic study, 70% of family members overestimate the patient’s pain¹⁴.

The following narratives indicate that opioid analgesics are still inaccessible via the Unified Health System (SUS) for the study population:

We didn’t even try [to obtain the opioid analgesics through the SUS]. It’s not easy through the SUS. So, we scrimp and save. Sometimes we don’t have enough, so we find a way somehow (P10, daughter). She was only taking Buscopan and this other drug called Panadeine [paracetamol + codeine] which I don’t know if it’s the same thing. I bought it, because the SUS doesn’t have it (P1, daughter).

Now she’s taking another drug that we can afford, codeine. We buy it, because were told we wouldn’t be able to get it [from the SUS]. It’s really affordable. And she receives a social benefit, so we can afford to buy it (P8, daughter).

Some of the medicines are from the SUS, and some we buy, because she purchases them at the pharmacy

monthly, when she receives her monthly benefit, so she goes there and buys her medicines. All I know is that it's expensive (P13, son).

Although the government rulings guarantee free access to medicines through the public health system (SUS) for patients with chronic pain, according to the family caregivers this access is not guaranteed in practice, and it is up to family members and patients to purchase the medicines, impacting their family income.

Another obstacle to access is to find pharmacies that sell morphine and similar opioids. As shown in the following narrative by a family caregiver, a difficulty in smaller towns is that the drugs are not available in the pharmacies.

She takes several drugs, and they're expensive. Even today I'm going to have to buy them to take with me [from the large city], because many of the drugs aren't available [in the home town] (P14, father).

Marketing of controlled-use medicines in Brazil is subject to intense inspection and overly strict bureaucratic procedures, causing difficulties for private pharmacies, which often prefer not to supply such drugs, thereby hindering access by the population¹⁵.

As voiced by the caregiver, the difficulty in purchasing morphine becomes even more complex for patients living outside Brazil's state capitals and other large cities. The distance from the town where "P14" lives and the city where she is able to purchase the medicine is approximately 310 km, about a five-hour trip.

Participants identified difficulties with the bureaucratic procedures for accessing the medicines, as shown in the following narrative.

In the beginning, there was all this paperwork we had to do. She was taking Ultram [tramadol]. It took a long time [to get the medication], I think it was about three weeks after she came home. You go to the city government, and you talk to the social worker, and the drug really is expensive. So, they went to our house and interviewed us. It was this whole procedure to approve [the tramadol] (P8, daughter).

In Brazil, the management of funding for opioid analgesics is decentralized, depending on the health structure in the states and municipalities⁸. Most local administrators lack specific programs for enrolling patients that use the medication, which would facilitate the distribution. A prescription thus requires special prescription forms and additional paperwork.

Disinformation in the healthcare units that dispense these drugs further hampers the process.

Among the participants, 14% reported that they manage to obtain the medicines through donations:

I'm able to obtain them in the pharmacies that receive donations. Just like Hospital X has a pharmacy there in our community that has one of his medicines, and sometimes I manage to get it there free. But we always have to buy the other drugs. Dipyron is the only drug I can get for him from the SUS. I go to the local pharmacy and I get nothing. I don't need to buy Dimorf [morphine sulfate], I can get it from the pharmacy when I have to (P5, wife).

It's not exactly an NGO, but there's a pharmacy that donated some drugs for her, that she needed. Those drugs for vomiting. Near the hospital. It was the hospital staff that told us. Real close by, where they told us. We went there and got the medicine she needed for her nausea (P8, daughter).

A study published in *The Economist* highlights the importance of nongovernmental organizations' role in supporting and providing palliative care¹⁶.

Donation of medicines, according to the participants, is a possible path for obtaining medicines and alleviating the impact on the family budget:

So, we spend on medicine at least, if I'm able to get the morphine free, and the dipyron, I spend about \$40 a month on the other two. And when I don't get them free and have to buy everything, I spend about \$80. Because the morphine is expensive, and the dipyron is too, so I spend more because of those two (P5, wife).

One of the issues in country assessment of the development of palliative care is government funding. The absence of such funding places a financial burden on patients and family members⁷. Although Brazil has laws that guarantee access to pain relief drugs, in practice there are gaps in access for the population studied here.

Lack of access to opioid analgesics and other essential medicines for treating symptoms of cancer patients has a huge impact on their families' income, already largely committed to basic needs such as food, as illustrated in this quote:

I'm telling you, my budget was already tight and it's even tighter now, because just my medication alone is \$45.00 a month [the participant has Chagas cardiopathy]. For that, I've already spent \$120.00. So, for somebody that only makes the minimum wage, and having to pay \$30 for the water bill and

another \$25 for the light bill, there isn't much left for food. Sometimes there's none left for bread, or vegetables, and some days there's none for meat, either, because you can't afford that every day. So, you have to control the expenses (P7, husband).

One participant reported that they had to purchase the patient's essential medicines, which adds to the basic cost of living and has a heavy impact on the monthly budget, preventing the family from spending on healthy food:

We live on just \$320 a month, and there's his food, too, because he needs a lot of vegetables, and there's no way for us to make that kind of money. I have to buy them, and we often have to go without, because we can't afford them, because he needs to eat, and we have to go without. So, we can't follow a very good diet, because we're worried about bills, because there's water and electricity that we can't do without. And I need the LPG to cook the meals, and we live off his earnings. So, most of his money goes for basic expenses. And I have to get by somehow with what's left over for the medication. I usually do some odd jobs, and that's how I'm able to buy some fruit and vegetables (P5, wife).

The drugs for pain relief and other symptoms, plus food, were main concerns voiced by the study participants, as expenses covered by the families.

Another issue reported by family caregivers was the numerous return visits to the health services (emergency department, health post, etc.) due to the patient's constant pain.

Look, there were nights when I'd bring her in three times to the emergency ward, because they'd give her the painkiller and it would relieve the pain, and they'd send her home. So, I'd take her home, and she'd doze off and then wake up again in pain. And I had nothing to give her, no painkiller at home. I'd bring her back that same night. There was one night when I brought her to the emergency ward three times (P7, husband).

She went to the health post, and from the health post they sent her to city X [where the cancer treatment is performed]. And then she'd go home, and later come back here, and by now it's been three times that she's been hospitalized with this same pain. Hardly a week would go by after she'd come home and she already had to go back to the hospital (P4, sister).

I went with him twice to the Emergency Medical Unit. And the pain would come back as soon as the medication wore off, and the pain was back. The other times I didn't even take him to the

Emergency Unit, because it wasn't doing any good. So, it was better to just stay home and wait for his appointment (P5, wife).

They gave her an injection [at the hospital in the patient's home town]. The pain got better right then, but it wore off. It got better then. She was discharged. The next day she woke up in pain again. So, I brought her here [the cancer hospital] (P13, son).

The repeat visits to the emergency department at short intervals for pain relief reveals the weaknesses in treatment of this symptom. Studies are thus needed to address adequate care for effective pain relief.

A comprehensive literature review on the efficacy of WHO guidelines for the treatment of cancer pain highlights that such guidelines help physicians to alleviate cancer pain for most patients¹⁷. Although the WHO guidelines are recent (first published in 1986 and revised in 1996) and simple to apply, one may wonder whether they are implemented adequately. We suggest that studies be done to investigate this issue.

Two male caregivers, husbands of patients, reported that the most difficult moment in the treatment was when their wives were in pain, with no medication at home to relieve it, as voiced here:

She's been in pain for five months. She'll feel better, but when she gets home it hurts again. It's just the medication. The hardest part [of the cancer treatment] is now. She complains of the pain (P9, husband).

Effective pain relief is one of the neglected phenomena in the care offered by health professionals, although pain relief at home is one of the essential points for patients, to promote their dignity and reclaim their autonomy¹⁸.

In the absence of effective pain relief, the following quote illustrates how sleep is compromised along with the quality of life of patients and their families:

She couldn't sleep, and neither could I. There was one day when I don't know if I fell asleep or simply passed out. All I know is that I woke up, and it was high noon. I don't know if I had slept or blacked out (P9, husband).

When asked how long he and his wife had been unable to sleep because of her inadequate pain relief, he replied:

About two months. Because sometimes she'll be sleeping and wake up in the middle of the night, and there's no medicine [for the pain], so we just have to wait (P9, husband).

According to the Brazilian Consensus on Cancer-Related Pain Management, assessment of pain should focus on the intensity, location, factors that exacerbate or relieve the symptom, and previous and current treatments⁶. A highly relevant factor is understanding that pain assessment should take into account its impact on sleep and performance of daily activities. The goals of pain management thus focus on improving the patient's comfort and performance of everyday activities.

Despite the undeniable potential gain in the patient's quality of life and the family members' comfort, pain is still largely overlooked, often considered "an inherent symptom in the natural history of the disease"⁶⁽¹³⁷⁾.

As a result of this view, pain is often taken for granted as an inevitable consequence of cancer, about which nothing can be done, reproducing the idea that "it's just the way it is, because of the advanced cancer", contextualizing the ignorance among many health professionals as to adequate pain assessment and the possibilities for intervention. This scenario leaves patients and family members in an endless search to relieve the pain and suffering, where all they are able to do is "carry the burden".

The patient is left to withstand the pain, while the family witnesses the intense suffering caused by the lack of effective assessment and adequate medication for pain relief.

Brazil needs to make progress on two key issues: access to pain relief drugs and intensive training for physicians¹⁵, since investment in access alone does not guarantee effective pain management. Physicians need knowledge for proper assessment of the symptom and adequate prescription.

CONCLUSION

The study aimed to describe the perceptions of family members of patients with advanced cancer concerning the difficulties in access to medicines for treating pain.

Studies in Brazil on cancer pain generally take a clinical approach, namely assessing the pain and the use of opioid analgesics and other drugs. There is little in the literature on the narratives of people that actually experience the pain (patients and family caregivers) concerning the obstacles to accessing analgesic drugs. The study thus aimed to reveal the limitations in access to opioid analgesics and other pain relief drugs in the study population.

We opted to conduct the study with family caregivers rather than with the patients with advanced cancer due to the specificities in this stage of cancer, with pain and other distressing symptoms, repeated hospital admissions, and emotional vulnerability, in which case the study would have been an additional source of stress for the patients.

Importantly, the study's main focus was to describe difficulties in access to pain relief, where family caregivers could properly supply such information, since they are often in charge of managing and conducting such processes.

It is important to note, however, that the perceived intensity of pain might have been different if the patients themselves had reported it.

All the participants, family members of patients with advanced cancer, voiced difficulty in access to opioid analgesics and other pain relief drugs. The following obstacles were identified: difficulty in dispensing the drugs through the public health system (SUS) due to the excessive bureaucracy; delays in releasing the medication, an average of three weeks in the SUS; and difficulty purchasing the drugs in small towns. All the participants reported purchasing the pain relief drugs, thereby straining their family income. Another avenue reported for obtaining the medicines was through donations by nongovernmental organizations or other charitable institutions. Participants reported that donation of the medicines had been extremely important for mitigating the impact on their family budget, allowing them to spend on the patients' other needs such as healthier diet.

Palliative care, including effective pain management, is an essential element of universal health coverage. It is thus crucial for Brazil to make progress with a public policy for cancer patients in which a key priority is effective pain management based on facilitating access to opioid analgesics and other analgesic drugs.

Future studies could use a mixed qualitative and quantitative approach to populations with different sociodemographic characteristics, associating them with access to opioid analgesics and other pain relief drugs, besides data collection techniques that select patients with diverse types and stages of cancer and different durations in the use of medication for pain.

Training should prioritize the approach to pain as an ethical imperative permeating the care provided by all health professionals. Only thus will it be possible to intervene in the "sea of suffering", abandonment, and inequity and promote human dignity for those experiencing the pain and suffering of a disease that threatens life itself.

CONTRIBUTIONS

Francine Rosa Portela was responsible for the study conception, fieldwork and writing of the article. Celina Maria Modena oriented the research and revised the manuscript.

CONFLICT OF INTEREST:

None.

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