

Addressing Pain Control in Low-Income Cancer Patients

One hospital's innovative pilot program finds pharmaceutical patient assistance programs lacking

IN BRIEF

In 2003, Albert Einstein Healthcare Network, in Philadelphia, Pa., established a pilot program to address pain control for its low-income cancer patients. The Program Manager, a trained nurse experienced in working with cancer patients, oversaw all program components, including targeted educational initiatives, counseling, and case management. All patients participating in the pilot program reported being in moderate to severe pain—despite being on a prescribed pain medication regimen. The majority reported substantial pain-related interference in many areas of life. Although nearly 40 percent of patients reported that they were unable to pay for medications, the pilot program received no support from pharmaceutical patient assistance programs.

Eliminating barriers to adequate pain control and decreasing disparities in the management of pain is a national concern. In April 2005, the National Pain Care Policy Act (H.R.1863) recognized pain as a priority health problem in the United States, calling for the establishment of a National Center for Pain and Palliative Care Research at the National Institutes of Health (NIH), and the development of six regional pain research centers throughout the country.

For the management of most cancers, pain medication is essential. Despite pharmacological therapy, between 5 to 10 percent of cancer patients still experience inadequate pain control.¹ The situation is more dire for patients with limited financial resources—even those dependent on government insurance. Purchasing pain medications often poses a financial burden on these individuals and their families. Government insurers (Medicaid and Medicare) often impose additional restrictions on patients through co-payments, limits on the quantities per prescription, and limits on the number of prescriptions filled per month.²

In response to these and other needs, pharmaceutical companies established patient assistance programs (or safety-net programs), which offer free medications for patients who are unable to afford them. Each patient assistance program has stringent eligibility requirements and procedures for patient enrollment. Community cancer centers serving patients from low-socioeconomic regions often look to these programs to assist patients who may not be able to afford necessary medications.

Who We Are

Albert Einstein Healthcare Network is an integrated healthcare delivery system located in North Philadelphia. Our primary service area includes 322,455 residents living in multicultural, inner-city neighborhoods where more than 80,000 people (25 percent) live below poverty level. Close to 80 percent of our patient population are minorities. Our cancer center patient population is 54 percent African-American, 37 percent non-Hispanic white, 4 percent Asian, 3 percent Hispanic, and 2 percent “other.” The most common cancers seen at our institution are:

- Breast—26 percent
- Prostate—17 percent
- Colorectal—12 percent
- Lung—11 percent
- Hepatic—4 percent.

Albert Einstein Healthcare Network continually strives to improve pain control for its patients. In fact, our pilot program grew out of a targeted effort to improve educa-

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tion, counseling, and case management services related to pain control. Once approval was received from our Institutional Review Board (IRB), the pilot program to address pain control in low-income cancer patients commenced.

Data Collection

Our first step was to conduct weekly chart reviews to identify patients with cancer who were scheduled to be seen that week and who reported a pain rating of a 4 or greater on a standardized 0-10 self-reported rating scale. (A zero score indicated “no pain,” while a 10 indicated “pain as bad as you can imagine.”) Scores of 4 or greater indicate moderate to severe pain.¹ The pilot program was limited to English-speaking patients and excluded patients with non-cancer diagnoses. We called every eligible patient to explain the pilot program and to obtain informed consent to participate in the program.

Next, we collected sociodemographic and income data in order to determine whether patients were eligible for enrollment in pharmaceutical patient assistance programs. For individuals deemed eligible to obtain pain medications at no cost, we contacted the appropriate pharmaceutical patient assistance program and obtained detailed information about the enrollment process. We did this for both long-acting opioids and short-acting analgesics.

Consenting patients were then interviewed about their pain and about their commonly held beliefs and attitudes towards pain and pain medication. We used the Brief Pain Inventory (BPI - Short form),³ which uses a 0-10 pain intensity scale to assess the participant's pain in the past 24 hours. Patients were asked to rate their pain at its worst, least, average, and present time using the following ratings: 0 = no pain, 1-3 = mild pain, 4-6 = moderate pain, 7-9 = severe pain, and 10 = pain “as bad as you can imagine.” The BPI also asks the patient to use a numeric (0-10) scale to report how pain has interfered with their general activity, mood, walking ability, employment, relations with other people, sleep, and enjoyment of life. A “0” score indicates pain does not interfere at all, while a score of “10” indicated complete interference.

We used the *Pain Management Barriers Questionnaire*,⁴ to determine the patient's attitude about pain and to identify any barriers to effective pain management. Patients were asked to respond to eight statements related to beliefs and attitudes towards pain and pain medication, indicating how much they agree with each statement using a 6 point Likert scale (0= Do not agree at all to 5=Agree very much).

To better differentiate between patients reporting “moderate to severe” pain and “less than moderate to severe pain” or interference due to pain, we collapsed

responses in two categories. Brief Pain Inventory scores between 0 and 3 were put in one category, indicating little to no distress. Responses between 4 and 10 were put into a separate category, indicating moderate to severe distress. We also collapsed the scores for the Pain Management Barriers Questionnaire. Responses of 0 to 2 were collapsed to indicate the patient did not agree with the statement; responses of 3 to 5 were collapsed to indicate that the patient did agree with the statement. Statistical analyses were performed using SPSS 10.0 (Chicago, Ill.).

Data Analysis

Forty patients were enrolled in the pilot program (see Table 1). The median age of patients was 59 years (range 23-81). More than half of the patients were female; the majority were African American. One-third of the patients did not complete high school. All patients were taking some form of analgesic for pain. The majority of patients (80 percent) rated their pain in the last 24 hours as 5 or greater (on a scale of 0 to 10), indicating a substantially high pain experience. More than half of the patients indicated that pain substantially interfered with all of their activities (see Table 2). Although all patients had some form of health insurance—primarily Medicaid or Medicare—15 (38 percent) responded that they were not financially able to afford their pain medication.

When we questioned patients further about their pain experience, here's what we found. Twenty-five patients (63 percent) agreed to the comment “people get addicted to pain medicine easily.” Twenty-two patients (55 percent) agreed that the experience of pain is a sign that the illness has gotten worse. Fifteen patients (38 percent) agreed that their pain medicine cannot really control pain. Nine patients (23 percent) found it “easier to put up with pain than the side effects that come from pain medicine” and nine patients (23 percent) agreed that pain medicine should be “saved” in case the pain worsens (see Table 3).

The Pilot Program

All patients enrolled in the pilot program received targeted counseling and education about pain management. The Program Manager, a trained nurse experienced in working with cancer patients and with pain management, addressed specific barriers, problems, or misconceptions reported by patients. We documented all pain-related issues reported by patients in the patient charts. We also encouraged patients who reported being “reticent” about talking with their physicians to do so at their next visit. Counseling and information regarding the management of side effects was provided, with the recommendation to contact their physician for any necessary prescriptions.

In addition, patients received relevant educational material on pain from NIH and the National Cancer Institute (NCI). Patients who reported problems with their insurance were referred to the Cancer Center's social worker.

Safety-Net Programs *Not* the Answer

The original intent of the pilot program was to enroll low-income patients into appropriate pharmaceutical company patient assistance programs. Although all patients had some form of health insurance, which included some level of prescription drug benefits, coverage was often inadequate—particularly when compared with the patient's financial needs. Medicaid patients had coverage for all their pain medications and no co-pay; however, Medicare limited quantities, which necessitated more frequent refills. Patients covered by private payers had prescription plans with variable co-pays. Not surprisingly, patients with the highest co-pays reported increasing financial difficulty as dosages for pain medication were increased with disease progression.

In an effort to match each patient with the appropriate patient assistance program, we gathered patient data on insurance and prescription drug coverage, income level, type of analgesic being used, and monthly cost (or co-pay). After reviewing application requirements for the patient assistance programs, we found many of them were either restricted to uninsured patients or that programs had been discontinued entirely. In the end, none of the patients enrolled in our pilot program were deemed eligible for patient assistance programs (see Table 4).

Meeting our Patients' Needs

Not being able to enroll any patients into patient assistance programs presented us with a unique challenge—identifying *how* we might provide patients with a low-cost treatment option for pain management. The end result was an attempt to use a highly effective, low-cost analgesic (methadone). The drug presented additional challenges, however, including a need for close supervision and dosage adjustment.

At the start of the drug regimen, we provided cancer patients with detailed education regarding methadone's side effects. An oncology nurse made daily phone calls to monitor each patient's response to the medication. Our conclusion: implementation of a cost-effective regimen using methadone is feasible; however, titration of dosage requires very close medical supervision as side effects are not as predictable as with other opioids.

Lessons Learned

We found that even though concerns regarding addiction have been proven false in extensive literature, patients and

Table 1: Patient Characteristics

(N=40)

Category	N	Percent
Gender		
Female	26	65
Ethnicity		
Asian or Pacific Islander	1	2
Black, not Hispanic	32	80
White, not Hispanic	5	13
Hispanic/Latino	2	5
Marital Status		
Single, never married	12	30
Married, living with partner	10	25
Widowed	5	13
Separated, Divorced	13	32
Education		
Less than High School	13	33
High School graduate	17	43
College	10	24
Finances		
Not able to pay for medication	15	38
Has Health Insurance	40	100
Age (median, range)	59	23-81

Table 2: Pain Inventory Data

<i>In the past 24 hours, rate the following:</i>	Mean	STD
Pain on Average	5.08	2.43
Worst Pain	5.63	2.74
<i>In the past 24 hours, rate how much your pain has interfered with your:</i>	Score ≥ 4	Percent
General Activity	73	
Mood	55	
Ability to Walk	60	
Ability to Work	75	
Ability to Relate with Others	50	
Sleep	50	
Enjoyment of Life	70	

providers continue to express them.⁵⁻¹⁰ Not surprisingly, two of the primary barriers to our pilot pain management program were patient fears about addiction and concerns about what their pain meant in terms of their disease.

We also found that many of our cancer patients face financial obstacles obtaining pain medications. Unfortunately, this circumstance only contributes to the under management of their pain, as well as to a diminished quality of life.

Even more frustrating was that we were not able to enroll a single patient from our pilot program into an appropriate patient assistance program. We found the applications to be cumbersome and patient eligibility to be tightly restricted.

Table 3: Pain Management Barriers

Barrier	Score 3-5 (percent) Percent Agrees	Score 0-2 (percent) Percent Doesn't Agree
Pain medicine cannot really control pain	38	62
People become addicted to pain medicine easily	63	35
Good patients avoid talking about pain	18	82
The experience of pain is a sign that the illness has gotten worse	55	45
It is easier to put up with pain than with the side effects that come from pain medicine	23	75
Pain medicine should be "saved" in case the pain gets worse	23	75
Pain builds character—it's good for you	10	90
Complaining about pain could distract a doctor from curing my problem	13	85

Table 4: Description of Pain Medication and Safety Net Program

Drug	Safety Net
MS Contin	<i>Purdue</i> : Applications no longer accepted. Discontinued January 2004.
OxyContin	Cannot have prescription coverage
Generic Sustained-release morphine	Safety Net not available
Duragesic	<i>Janssen</i> : Income (1)<\$18,000 (2)<\$24,000 Cannot have prescription coverage for product.
Kadian	<i>Alpharma</i> : Application process easy. Cannot have prescription coverage.
Methadone	Safety Net not available
Percocet	Safety Net not available

In addition, enrollment procedures for these programs are time-consuming and burdensome for physicians, staff, and cancer patients. For example, most applications required producing copies of patients' income sources, tax records, and monthly expenses, such as rent and utility bill receipts. Some companies even charged patients small monthly fees, usually related to shipping costs. Certain application processes had to be initiated by phone from the physician's office before the application could be faxed. The form then had to be completed by the patient and the physician prior to being mailed back to the pharmaceutical company. These requirements place an extra burden on busy cancer center staff and drain the limited energy of cancer patients dealing with serious health issues. Bottom line: most pharmaceutical patient assistance programs do not provide easy access for clinicians and patients, and are heavily restricted to the most needy patients.

Until some of these challenges are addressed, it is likely that some of our cancer patients—especially those from low-income families—will continue to experience and report insufficient pain control. 📌

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Acknowledgments

This pilot project was funded by a grant from the Nathan Cummings Foundation

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