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Pain Medication Management Processes Used by Oncology Outpatients and Family Caregivers Part II: Home and Lifestyle Contexts

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Pain Medication Management Processes Used by Oncology Outpatients and Family Caregivers Part II: Home and Lifestyle Contexts

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Abstract

Context—Despite the increasing complexity of medication regimens for persistent cancer pain, little is known about how oncology outpatients and their family caregivers manage pain medications at home.

Objectives—To describe the day-to-day management of pain medications from the perspectives of oncology outpatients and their family caregivers who participated in a randomized clinical trial (RCT) of a psycho-educational intervention called the Pro-Self[®] Plus Pain Control Program. In this article, we focus on pain medication management in the context of highly individualized home environments and lifestyles.

Methods—This qualitative study was conducted as part of a RCT in which an embedded mixed methods research design was used. Audio-recorded dialogue among patients, family caregivers, and intervention nurses was analyzed using qualitative research methods.

Results—Home and lifestyle contexts for managing pain medications included highly individualized home environments, work and recreational activities, personal routines, and family characteristics. Pain medication management processes particularly relevant in these contexts included understanding, organizing, storing, scheduling, remembering, and taking the medications. With the exception of their interactions with the intervention nurses, most study participants had little involvement with clinicians as they worked through these processes.

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Conclusion—Pain medication management is an ongoing multidimensional process, each step of which has to be mastered by patients and family caregivers when cancer treatment and supportive care is provided on an outpatient basis. Realistic patient- and family-centered skill-building interventions are needed to achieve effective and safe pain medication management in the contexts of individual home environments and lifestyles.

Keywords

cancer pain management; analgesics; medication management; self-care; self-management; family caregivers; medications; home; lifestyle; qualitative research; randomized clinical trial

Introduction

Cancer patients with persistent pain and their family caregivers play key roles in outpatient pain management, including management of their medication regimens (1–3). Yet little is known about how they manage pain medications on a day-to-day basis. Clinicians in busy outpatient practices may have little time to conduct comprehensive assessments of patients' pain medication management behaviors. Thus, issues with pain medication management at home may not come to light in outpatient clinical settings.

The pain medication regimens patients and family caregivers manage today are extremely complex. They often include multiple analgesics, some of which are prescribed for around-the-clock use for persistent pain and others for use as needed for breakthrough pain. Medication administration may include oral, transdermal, parenteral, and/or rectal routes. Pain medication regimens may include both opioid and non-opioid analgesics, plus co-analgesics, such as anti-depressants, anti-convulsants, or corticosteroids. In addition, patients have prescription and/or over-the-counter medications for analgesic side effects, such as constipation and nausea. This array of medications is not needless poly-pharmacy. Rather, it is guideline-based, state-of-the-art practice for management of persistent cancer pain (4–8).

The dynamic nature of cancer pain management adds to the complexity of medication regimens, as needs change and patients try different combinations of medications in an effort to achieve optimal pain management. Likewise, concomitant medications for analgesic side effects may be introduced or discontinued as side effects come and go. The result is an outpatient pain medication management challenge that is not well described.

In our randomized clinical trial (RCT) of a psycho-educational intervention called the Pro-Self[®] Plus Pain Control Program, participants brought many pain medication management issues to the intervention nurses' attention. Audio-recordings of the dialogue between the intervention nurses and study participants (both patients and family caregivers) provided a wealth of data on practical, day-to-day experiences with pain medication management. We conducted a qualitative analysis of these data, with the purpose of describing pain medication management from study participants' perspectives. Pain medication management was found to be a multidimensional process that included getting prescriptions and obtaining the prescribed medications and then understanding, organizing, storing, scheduling, remembering, and taking them at home. These processes took place in the contexts of

multiple complex health systems and highly individualized home environments and lifestyles. We previously reported on processes that occur primarily in the context of health systems, namely getting prescriptions and obtaining medications (9). The purpose of this follow-up article is to describe the processes particularly relevant to home and lifestyle contexts.

Research Design and Methods

Our research design and methods were described in detail previously (9). Briefly, this qualitative study was conducted as part of a randomized clinical trial (RCT) in which an embedded mixed methods research design was used (10,11). The RCT compared two doses of the Pro-Self[®] Plus Pain Control Program, a 10-week psycho-educational pain management intervention grounded in self-care/self-management theories (12). The qualitative study was embedded within the RCT to better understand pain management issues and strategies from study participants' perspectives, as revealed in audio-recorded dialogue with the intervention nurses.

Participant recruitment took place in eight outpatient cancer settings in Northern California. The sample consisted of patients with somatic and visceral pain from a variety of cancer diagnoses. Family caregivers were invited to participate also. The sample for the RCT as a whole included 222 patients and 139 family caregivers.

A subsample of 42 patients, 20 of whom participated with a family caregiver, was selected for the qualitative study. Purposeful sampling was used to achieve gender, racial/ethnic, and socioeconomic diversity. Later in the study, theoretical sampling was used to select participants with pain experiences not yet well-represented in the qualitative data set. Sampling continued until data became redundant and the coding categories were judged to be "saturated" (13–15).

The study was approved by the University of California San Francisco Committee for Human Research (UCSF CHR), the Protocol Review Committee of the Helen Diller Comprehensive Cancer Center, and the institutional review board at each clinical site. Oversight of the qualitative analysis was provided by the UCSF CHR and the institutional review board at the University of Nebraska Medical Center, where the qualitative analysis was conducted. Once written informed consent was provided, patients were randomized to intervention groups and an appointment was made for the first home visit.

Verbatim transcripts of audio-recorded intervention sessions and nurses narrative notes comprised the qualitative data (9). The data were organized by case in MAXQDA[®] (16), with a "case" consisting of all qualitative data for an individual patient or a patient-family caregiver dyad. The qualitative data analysis was conducted by two researchers (KS & VPC), proceeding concurrently with implementation of the RCT. An interpretive approach was used with themes and coding categories emerging from the data rather than from an *a priori* coding scheme. The set of transcripts for each case over the 10-week intervention was read in its entirety to get an overview of participants' pain experiences. Line-by-line coding, categorization of codes, memo-writing, tabular displays, and diagrams were used to inductively identify and develop major themes (15,17).

As the qualitative analysis progressed, pain medication management emerged as a prominent theme, mentioned by every patient and patient/caregiver dyad in our sample. We therefore selected “pain medication management” for further in-depth analysis. Peer debriefing was used to insure the rigor and thoroughness of the qualitative analysis (15,18). Emerging results were shared periodically with the principal investigator (CM), project director (CW), and intervention nurses during research team meetings. Strategies for purposeful and theoretical sampling were devised during these meetings.

In the data references below, all names are pseudonyms. Extensive verbatim quotes are included to convey participants’ experiences in their own voices. (FC) indicates that the speaker is the family caregiver. “Week” refers to the week of the intervention in which the dialogue took place. Medication trade names are used only in verbatim quotations or when needed to make sense of a data-based example.

Results

Sample Characteristics

Sample characteristics were described in detail previously (9). Briefly, patients’ mean age was 64 years (s.d. = 10.9). They were primarily male (60%) and white (74%). Years of education ranged from 7 to more than 22. Twenty-one were in the high-dose group. Two received hospice services at some point in the 10-week study. Family caregivers mean age was 63 years (s.d. + 7.5). There were primarily female (70%) and white (80%). Eighty-five percent were spouse/partners of patients. Years of education ranged from 12–19.

Overview

The qualitative analysis led to interpretation of pain medication management as a multidimensional process that involved both patients and family caregivers and took place in the context of multiple complex health systems and highly individualized home environments and lifestyles. The processes of getting prescriptions and obtaining medications, described previously (9), took place primarily in the context of multiple complex health systems. Here we describe the pain medication management processes that took place primarily within participants’ home and lifestyle contexts, namely understanding, organizing, storing, scheduling, remembering, and taking the medications that were prescribed and obtained (Figure 1).

Participants used their home environments for pain medication management in highly individualized ways. Countertops, drawers, tables, windowsills, cabinets, boxes, bags, dishes, alarm clocks, whiteboards, computers, and mobile devices were all used. Individuals and pets living in the home were taken into account. Visitors were a consideration, especially visiting grandchildren. A few participants mentioned concerns about family members who had a history of substance abuse or addiction.

Many participants in our outpatient sample lived active lifestyles made possible by good disease and symptom management. Patients and family caregivers were involved in work, hobbies, routine leisure activities, vacations, visits with extended family, and various

appointments and errands. They played golf, participated in retreats, went on cruises, and refereed ball games.

Patients varied in terms of the extent that others were involved in their pain medication management. Many had spouses/partners in the home who were actively involved, and at least one had support of a family member who lived separately. Others lived alone or with individuals who were not involved with managing their pain medications. With the exception of their interactions with the intervention nurses, and in two cases with hospice nurses, participants had little interaction about medication management with clinicians after they obtained their pain medications.

Understanding

Once prescriptions were written and the medications obtained, patients and family caregivers were immediately faced with understanding the medications that they brought home. Patients usually received some basic information about their medication, but not to the extent needed or in a form that was helpful. As Jim and Barbara said:

Barbara (FC): They just gave him a prescription and handed it to him and that was it. **Jim:** I thought that was the way it was. I didn't know better. I didn't know what questions to ask. [Week 3]

Jerry's physician told him what to take, but did not provide any further information. Jerry noted, "He (physician) answers elegant, well-articulated questions." When Jerry couldn't formulate such a question, the physician did not proactively offer any explanation about the prescribed medications. Laura noted that the label on her pain medication bottle said, "take as directed," yet she had received no directions. Alan said that he received his first pain medication prescription "in a vacuum" without any further explanation about how to take it.

Lack of understanding about how to use prescribed medications led to uncontrolled pain. For example, Robert was prescribed a long-acting opioid, but noted:

Robert: We did not have much of a conversation about it, frankly. He said, "You could use this if you need to." I wasn't very clear on what that meant to be honest with you. So I tried it once or twice for breakthrough pain, just one tab." [Week 1]

As a result of irregular use and dissatisfaction with the results, Robert stopped taking the prescribed medication and was in pain that he described as "terrible" prior to entry into the RCT.

Many areas of confusion were evident in participants' discussions with nurses. Keeping the purposes and names of medications straight was one such point of confusion. Derrick thought ibuprofen was a blood thinner. Hal thought ibuprofen and aspirin were the same medication and that the purpose of acetaminophen was to cause sweats. The use of generic preparations meant that patients had to master long, polysyllabic names with no intuitive link to the medication's purpose. Thus, patients developed their own language to talk about their medications. For example, Chuck noted that medication names were "not in English," so he made up his own names, such as "fungus amongus," or referred to individual medications as "whatchacallits". Jack kept oxycodone and OxyContinTM (Purdue Pharma

LP) straight by dose, rather than by name: “It’s the 5 milligram one.” Jim knew his medications for constipation by function, rather than by name, i.e. “the stool softener,” and “the laxative.” Others referred to their medications by appearance, i.e. “the little white one.” Patients’ difficulty in articulating medication names in a language meaningful to prescribing clinicians posed safety risks. For example, Derrick was on morphine and “a little white one.” When he asked his primary care provider for a refill of “the little white one,” he instead was prescribed “great big horse pills.”

The use of abbreviations was confusing. For example, did “SA” stand for short-acting or sustained action? Differences between single versus dual agent preparations (e.g. the difference between oxycodone and oxycodone with acetaminophen) could be confusing. Patients’ idiosyncratic ways of referring to single and dual agent preparations made it difficult to determine exactly what they were taking:

Hal: I haven’t taken the Percocet without the, ah...I’ve had trouble with that... what’s the other medication that’s in Percocet? **Nurse:** Well it’s oxycodone and Tylenol. **Hal:** Tylenol. I can never remember Tylenol for some reason, but anyway, I’m taking my regular one with Tylenol right now... These are the 2. This is the Percocet without Tylenol and the morphine. [Week 6]

The difference between medications with similar-sounding names, such as oxycodone and OxyContin™ (Purdue Pharma LP), was confusing. For example, Ellen was taking 20 mg of OxyContin™ and 5 mg of oxycodone, but reported that she was taking 25 mg of Oxycontin.™

Lack of understanding about maximum daily dose limits was common. Some patients initially did not know that acetaminophen and non-steroidal anti-inflammatory drugs have maximum daily limits nor did they realize how easily the limit could be exceeded when they used an over-the-counter preparation in combination with a prescription medication. Pete learned that he was taking too much acetaminophen when his pharmacist refused to fill a prescription for acetaminophen with codeine. On the other hand, some patients did not know that opioids do not have a dose ceiling and worried about increasing the dose as tolerance developed.

Analgesic patches presented another source of confusion, especially when combining patches of different doses to cover waning effectiveness toward the end of a dose period. Where to affix analgesic patches to the body was another area of confusion. Tony and Marie explained that they had read the instructions on the package insert, but did not understand what “flank” meant:

Tony: It gives you all the different places you can put it. **Marie (FC):** It was funny. **Tony:** We were amazed. One place they said was the flank. It’s like “where’s the flank?” **Marie (FC):** What’s the flank? I know where the flank is on a dog or a horse, but where’s my flank? [Week 1]

Understanding the meaning of intervals was an issue for some. For example, Keiko misunderstood what “every 3 days” meant. She reasoned that every three days meant Monday, Tuesday, and Wednesday, and applied a new fentanyl patch on Monday and

Wednesday. Thus, she changed the patch every 48 hours, instead of every 72. Hal used his fingers to be sure he was explaining medication intervals correctly:

Hal: I'm doing one every 4, but I'm skipping a 4 hour section... And that seems to work out all right. But what I'll do is I'll take...let's see I guess...when I got back in here I took one about 4:00...and so...4:00, 5:00, 6:00, 7:00, 8:00. I'll take one at 8:00, 9:00, 10:00, 11:00, 12:00...about 1:00, and then I'll skip that one after one o'clock. ... from that 1...1:00, 2:00, 3:00, 4:00...I've got to count on my fingers.
[Hal, Week 2]

Participants used a wide variety of information sources, including written information from physicians, nurses, and pharmacists, and information printed on pill bottles or package inserts. Popular media, the internet, and personal acquaintances were other sources of information. Despite the amount of medication information available, patients didn't always know how to use it or even what was reliable and useful information. A strategy some patients used to better understand their medications was taking a family member, or even a group of family members, to clinic appointments. For example, Frank brought his wife, son, and daughter to appointments to hear information directly from his physician.

Even when patients acquired information about their medications, barriers to understanding existed. Written information could be hard to understand. As Jack said:

Jack: I read instructions on this last medicine I got at the ER. It says you take with a meal or without. You got to do one or the other. Is that...Have you ever heard that? [Week 6]

Information printed on pill bottles and package inserts was too small for some to read. Chuck used a magnifying glass to read the small print on his medication bottles. Dee found the information printed on pill bottles less than useful because it did not indicate what the medication was for:

Dee: The medications...I mean, you say, oh God. You come home and you have the medication and you can't remember what she said. And there were times when I was getting 3 and 4 different medications in one fell swoop, so that's very tough to remember. Well a lot of these, they don't say what they're for. And that's a problem. I mean we get home, it's like, "What is this?" [Week 3]

Duane commented that printed information provided by their pharmacy was more for legal purposes than anything else. Some patients simply chose not to use the information available. For example, Hal chose not to read printouts from the pharmacy so as not to predispose himself to the side effects.

Clearly, having information was not the same as having an understanding of a prescribed pain medication. Understanding developed over time. It was an experiential process that involved more than getting information, although information was required for understanding. Also required was an explanation of how to take the prescribed medication, given a patient's unique needs. However, except for the Pro-Self[®] Plus intervention, little evidence indicated that participants received the explanations they needed.

Organizing

Organizing pain medications at home presented a host of issues, because of the sheer number and various forms of medications prescribed for regular use, for use as needed, or both. Organizing these different types of pain medications required a different mindset than medications taken on a fixed schedule, such as oral chemotherapy or medications for other chronic conditions, such as high blood pressure. Multiple analgesic formulations compounded organization challenges. While most analgesics came in pill or capsule form, pain management regimens also included transdermal patches, lozenges, and liquids.

Participants used a wide range of highly individual strategies to set up workable organizational systems. Some found a pillbox to be an effective organizing tool. For others, the compartments were not large enough for all their pills, or the medication schedule didn't match the number of compartments. When a medication was not in pill form, such as a liquid or patch, a pillbox did not help. Some patients expressed concern that once the pills were out of their original containers, they were no longer sure what they were or how they should be taken, so they preferred not to use a pillbox. Others filled the pillbox incorrectly, leading to adverse outcomes. For example, Chuck had loose stools when the following dialogue took place about the senna in his pillbox:

Nurse: So are those little pillbox things working for you? **Chuck:** I did. Look at this, I got to show you so you don't think I'm lying. I filled it all out. See. **Nurse:** I see. You've got four senna in here for Tuesday evening. **Chuck:** Yeah, that's it. Wait, no. Let me see. **Nurse:** You do. You've got four senna in there. **Chuck:** Wait a minute. Now, one of them isn't senna... I do have four senna. You're right about that. [Week 6].

Patients who chose not to use a pillbox had various other strategies for organizing their medications. Bob's daily routine was to put his pills in two ziplock bags—one for morning and one for evening. He then differentiated the medications by color. Dee put her pills on the kitchen counter each morning, decided what she absolutely had to take that day, and “nibbled” away at them:

Duane (FC): She'd put a pile of pills out there and throughout the day she'd nibble away at them. **Dee:** (chuckle) Yeah, I'd put a pile...okay. I'd just look at what the pills are every day and I'd try to do an overview of what I have to take. I just look at all the pills and say, okay, what do you absolutely have to take today? Because I hate pills and that's kind of how I manage it. [Week 1].

Another strategy was to line up the original pill bottles in a particular way, rather than putting a week's supply in a pillbox. This approach had the advantage of keeping pills in their original bottles until needed, so patients could check the directions with each dose. Chuck had an elaborate daily ritual for organizing his medications. He lined up all the pill bottles, read the label instructions with his magnifying glass, took out the pills for the day, and put them in a glass. He was satisfied with his approach. However, medication safety was an issue with medications sitting out in a glass.

In addition to organizing pain medications at home, patients with active lifestyles needed a complementary system for use when they were away from home. Whether away for a brief or extended time, patients needed a separate system for medication organization that they could carry with them. They used a variety of strategies to organize their pills when away from home, including small boxes or cases, plastic bags, envelopes, and pillboxes. Chuck and Patty both used a pillbox when away from home, even though they did not use it at home. Jack used different pillboxes for home and travel.

Lack of an organizational system presented safety risks, like those evident when Derrick showed the nurse the container in which he kept his pills:

Nurse: I'm just wondering, with your pills all jumbled up this way, how you keep track of what's what. These look like herbal medications. These look like fish oil capsules. **Derrick:** Those are flax. **Nurse:** Flax oil and way down here is a little white pill and that looks like some kind of a prescription medication. **Derrick:** That's the morphine 15 mg. [Week 3]

Storing

In addition to organizing pain medications, study participants had to safely store them. Organizing and storing were interrelated processes for some patients, in that their medications were organized in a place that provided safe storage. In other instances, storage issues weren't considered, even though the medications were well-organized. For example, medications could be well-organized on the kitchen counter, but this strategy did not provide safe storage. We defined storing as putting pain medications safely away, in contrast to organizing, which was defined as the orderly arrangement of medications so they could be easily remembered and kept track of. Howard and Betty illustrate the interrelated processes of organizing and storing. Howard first organized his medications in a pillbox. Then he took the next scheduled dose out, put it in a dish, and set an alarm. However, when grandchildren visited, he skipped the step of placing the next dose in the dish:

Howard: I have my little white dish. I put it right there. Set my alarm clock for 5:00 and that's it. **Betty (FC):** (When) the baby's over, we don't leave the little dish down...but when the children aren't here, we just put the next one in there and then he knows the time to take it. **Howard:** When the alarm goes off, I take it. [Week 1]

Storage of old medications was another issue. Patients described keeping out-dated prescription medications on hand, with no particular plan to dispose of them. Dee had "a zillion dollars worth of medicine in that drawer." Paul said:

Paul: I have a whole shelf of drugs I don't take anymore (chuckle) that didn't work...tried that, didn't work, you know. I should get rid of them. [Week 3]

Howard also had many old medications on hand:

Nurse: Oh, look at that. You have a whole bucket of medicine. **Betty (FC):** Yeah. In case he needs them. **Howard:** These are things I thought I would throw away. [Week 3]

And Chuck used a box to hold all of his old medications:

Chuck: I do have some stuff here. I think some of this stuff is old. I think that's why I threw them in here. **Nurse:** Okay. The other thing I suggest doing, is don't hold on to old medication. **Chuck:** Yeah. I should get rid of some of this stuff.

Nurse: Yeah. Take it to the hospital. **Chuck:** I don't know what it is. I just put it in there. They've been there a long time. [Week 10]

Storage occasionally involved hiding medications. Sometimes pain medications were hidden from patients by family caregivers. At other time patients and family caregivers hid them from other family members. Hiding medications from patients, was a strategy undertaken by family caregivers when they feared that the patient would get confused and take too much. However, if the family caregiver was not available or unaware that the patient was in pain, the patient had to do without a needed dose. For example, Betty was afraid Howard would take too much and stored his medications where he could not find them:

Nurse: Did you take any extra strength Tylenol or any Tylenol or anything?

Howard: No. I almost did last night and I didn't know where it was and I didn't want to wake her up because she gets...cause maybe I might... **Betty (FC):** Oh, Pumpkin. I'm gonna take it out right now and put it in your box here. [Week 3]

Another issue in storing medications was consideration of who else was in the home beside the patient and family caregiver. Children, youth, visitors, and even pets needed to be taken into account. A few participants' families included an individual with a history of drug abuse or addiction, which presented another layer of issues related to storing medications over and above preventing accidental ingestion by curious youngsters. The presence of an individual with past or current substance abuse made it imperative to store medications where they could not be found even if the individual was actively seeking to find them. In other words, storing medications involved hiding them and locking them up.

Scheduling

Scheduling medications according to the best time to take them in relation to daily lifestyles was another aspect of the pain medication management process. Effective scheduling required patients to understand which medications provide maximum benefit with a fixed schedule and which could be flexibly tailored according to changing needs. Some patients used the gold standard for persistent pain management, namely a scheduled, around-the-clock analgesic with a short-acting preparation for breakthrough pain. However, others used increasing pain as a cue for taking their next dose, even for medications prescribed on a fixed, around-the-clock schedule. This approach fit with the mindset of taking medications only when pain is present. Some patients made a game of stretching the intervals between doses, challenging themselves to see how long they could hold out. Others scheduled their medications at easy-to-remember times, such as 8:00 AM and 8:00 PM.

Participants described a great variety of ways in which medications were scheduled in relation to individual lifestyles. Some patients linked their medication schedule to activities such as meals or getting up in the morning. Pete took his controlled-release oxycodone at

3:00 AM so that his pain was well-controlled when he got up and prepared for work. This schedule gave him the best start to his work day:

Pete: Then I'll take the 40 at 3:00 in the morning. **Nurse:** So that's your new schedule, 3 p.m. and 3 a.m.? **Pete:** Yeah. That seems to work really well. The reason that works well is that I'm under good pain management when I have to get up in the morning at 6:00 and dress and go to work. Then I don't have to worry about crossing that threshold of getting the pain medicine to work. It was nice this morning when I got to work because I got there about 7:20 and by 7:30 I was deep into work. [Week 3]

Ellen had a very different routine for her first analgesic dose of the day. After awakening, she ate something and waited a while to take her controlled-release oxycodone, because her "stomach juices needed time to get going." Otherwise, she became nauseated. Weekly, as well as daily, routines were taken into account in scheduling, such as planning to start a new medication on a Monday to minimize the impact of side effects over the weekend.

Remembering

Once medications were obtained, understood, organized, stored, and scheduled, patients still had to remember to take them. Many participants lived active lifestyles and their systems for remembering medications were at risk for breaking down when the daily routine changed. For example, Diane forgot to take her pain medications for three days during a family visit. As she said, "I fell off my good system" and she suffered increasingly severe pain. Not realizing that she had forgotten to take her controlled-release oxycodone, she began taking extra acetaminophen with hydrocodone at 90 minute intervals, thus chasing pain that could not be optimally controlled with this medication. The use of a pillbox facilitated remembering, but was not fail-safe. Patients had to remember to go to their pillbox. When a routine changed, such as during a family visit, the pillbox itself could be forgotten.

Several patients described mild cognitive impairment, resulting from chemotherapy, fatigue, or role overload, which affected remembering. Patty felt overwhelmed by work, family responsibilities, and fatigue. She described several instances of forgetting her medications. One day she came to the realization that she was "tapped out...I'm usually pretty good, but my brain sockets died."

Family caregivers often played a key role in reminding patients to take their pain medications, providing a back-up for patients' remembering strategies. For example, Morgan and his caregiver daughter Mona described elaborate strategies to ensure that he remembered his medications. He used two pillboxes: "I have a pill box that has AM and PM and I fill them up two weeks at a time, so I'm always two weeks ahead of the schedule." Mona also called him at bedtime to make sure he took his evening medications:

Mona (FC): With the juggling of things recently, I will always before I go to bed at night, call my dad and just have him repeat what he's doing, so that we double check, double check. And he knows I'm not doing it to annoy him. I'm doing it to help him because we don't want anything slipping through the cracks. [Week 1]

Taking

After accomplishing all the other steps in the pain medication management process, taking them was a straightforward, unremarkable behavior for most study participants. However, some experienced challenges even with this last step in the process. For example, Greg had trouble swallowing large pills. They tended to stick in his throat and he had to cough them up and try again. Once his throat was burned when a pill lodged there. Patty developed hand and foot syndrome and because of the unfamiliar clumsiness of her hands, she dropped her pills one time. They scattered on the floor and she wasn't sure she found them all. Diane had trouble managing a large, heavy bottle of liquid morphine because of pain and weakness in her arms.

Taking (or almost taking) medications incorrectly was an issue for some. Jim's family caregiver, Barbara, forgot that sustained-release pills should not be cut in half. As Jim's pain decreased with palliative radiation treatment of his bone metastases, Barbara suggested that he cut his controlled release oxycodone in half. When Jim reminded her that controlled release pills shouldn't be split, she became frightened that her suggestion might have resulted in a fatal overdose. In subsequent discussions with the intervention nurse, Barbara expressed an ongoing lack of confidence in her ability to help Jim manage his pain without the nurse's guidance.

Keith and his family caregiver Keiko experienced several issues related to taking pain medications. Keiko was initially unaware of Keith's cognitive decline as he approached the end of life and that he was taking more pills than were prescribed for pain he described as "slashing". When questioned during an emergency room visit about why he had run out of his pills so quickly, Keiko became aware of the problem with cognition: "Now I control the medicine because I think he was taking two pills before the 8 hours see, and that's why it went so fast." However, Keiko herself had difficulty handling Keith's transdermal patches:

Keiko (FC): So then we went to the pharmacy to get the patch. So at the pharmacy he's going to question me. "You had 2 boxes and 10 in each box. How come it's gone so fast?" I said, "Well I'll tell you the truth. I dropped two of them," because those things are so tiny, you need to take that plastic off, and if it gets stuck on your hand then you cannot use them, that's what the box say. It's like contaminated, and I say "I messed up two." I had to tell him, "I messed up those two patches myself," you know, and I said, "I could not use those two." [Week 1]

Discussion

Analysis of dialogue between study participants and intervention nurses in the Pro-Self[®] Plus Pain Control RCT yielded the most comprehensive account to date of cancer pain medication management from the perspectives of oncology outpatients and family caregivers. Perhaps our most important finding is the complexity of pain medication management in the outpatient setting. Pain medication management is a multidimensional process, each step of which has to be mastered for effective and safe pain management. Adding to the complexity are the contexts in which pain medication management occurs, including the clinical, regulatory, and reimbursement systems (9) and unique home

environments and lifestyles. Patient and family caregiver experiences, revealed in dialogue with the intervention nurses over a 10-week period, provided a unique window into the day-to-day handling of pain medications when cancer treatment and supportive care are provided on an outpatient basis. These findings have implications for the content of future pain management interventions, as well as for further development of self-management theory.

Our findings call attention to the practical behavioral processes required for effective and safe pain medication management, and suggest that additional skill-building content in this area is needed in pain management interventions. A recent systematic review of pain management interventions indicated that skill-building content for medication management is rarely, if ever, included (19). Content pertaining to medications typically falls within the cognitive and attitudinal domains, including content on the purposes and doses of medications, misconceptions, fears, and reluctance to use strong analgesics (20–24). The use of a pillbox to facilitate organizing and remembering medications is typically the only content pertaining to practical, day-to-day behavioral skills (25,26). Our results indicate that a wide range of behavioral skills are needed, all the way from communication and coordination skills in the contexts of complex clinical, regulatory, and reimbursement systems (9) to ways to safely handle pill bottles when one's hands are clumsy from neuropathy or hand and foot syndrome.

Although experimental interventions have not systematically included comprehensive content on pain medication management, a growing body of qualitative research does address medication management in the oncology population (2). For example, researchers described key elements of medication management by oncology outpatients in Taiwan (27) and family caregivers of patients at the end of life in the United States (28,29). Medication management behaviors such as obtaining medications, communicating, coordinating, organizing, remembering, storing, and taking or administering were described in these populations. Our results support and extend these earlier findings by describing the pain medication management process multi-dimensionally, taking into account the health systems (9), home, and lifestyle contexts, and demonstrating the unrelenting effort and attention required of both oncology outpatients and family caregivers. Thus, qualitative evidence increasingly supports the need to include medication management skills in pain management interventions.

More broadly, our results contribute to self-care and self-management theory, which provides the conceptual foundation for the Pro-Self[®] Plus Pain Control intervention (12,30,31). Our qualitative analysis of pain medication management allowed us to flesh out key behavioral processes that constitute an important component of self-management of persistent pain, namely the management of pain medications. This study adds to research that “drills down” into day-to-day, real-world activities that patients and family caregivers engage in to accomplish self-management, thus permitting more precise specification of self-management concepts (32). Ongoing development of self-management theories relevant to living with cancer as a chronic condition is crucial in oncology research, given that patients and families are living with cancer for ever-longer periods of time (30). Patients' and caregivers' practical, real-world perspectives, elicited through qualitative research, make an important contribution to the ongoing development of self-management theories.

Self-management does not mean taking care of oneself in isolation from healthcare clinicians. Yet, the absence of assistance with pain medication management from clinicians other than the intervention nurses was striking. While two patients began receiving in-home hospice services during the study, most patients in our qualitative sample were active individuals who saw clinicians only intermittently for outpatient treatment or clinic follow-up. Clinicians provided the needed prescriptions, but patients and their family caregivers were essentially on their own with the practical, day-to-day aspects of pain medication management. Some developed effective and even creative strategies for managing their pain medications. Others used strategies that had a hit-or-miss quality and some strategies were clearly unsafe. Thus, routine clinical practice in today's healthcare system does not appear to provide sufficient support.

In our study reported ten years ago (33), patients described some difficulties obtaining medications and cognitively processing information, but other medication management issues were not prominent enough to constitute a main analytic theme. In contrast, pain medication management issues were pervasive in our current study and the intervention nurses devoted considerable time to assessment and coaching in this regard. Several possible explanations exist for the differing findings. First, the qualitative results of our previous RCT led to an expanded assessment protocol in the current study, which may have resulted in richer data on pain medication management. Also, the current study included more extended contact between intervention nurses and study participants, which may have allowed more issues to come to light.

However, our different findings may not be solely due to an enhanced assessment procedure or the more extended period of study participation. Cancer treatment has changed profoundly in the ten years since our earlier study and these changes impact pain medication management in the home setting. The increased effectiveness of standard treatment and increased availability of experimental clinical trials have resulted in longer periods of cancer survivorship and the need for longer-term management of persistent pain. Cancer is now a chronic condition for many individuals (30,34). Guidelines for cancer pain management (4–8) mean that clinicians are more likely to assess pain and prescribe medications for both pain and analgesic side effects. While these changes in clinical practice improve quality of life, they result in more medications for patients and family caregivers to manage at home. More medications mean new challenges and more risks. Unfortunately, lack of understanding about the purposes of analgesics and how to manage them apparently have not changed and safety risks may have increased. In this regard, the current study replicated and extended findings in our earlier RCT (33).

Limitations

In addition to limitations described previously (9), we note that a comprehensive examination of medication management issues, including the management of oral chemotherapeutic agents and medications taken for conditions other than cancer, was not undertaken in this study. Examination of how oncology outpatients manage all the medications they have on hand might produce different findings. Also, our sample was

limited to Northern California. Individuals living in different areas in the U.S. and around the world may experience pain medication management differently.

Summary and Conclusion

This qualitative study embedded in a RCT provided a unique window into the practical, day-to-day issues with managing pain medications experienced by patients and family caregivers. Each step of a multidimensional process had to be mastered in the contexts of multiple complex systems (9) and unique home environments and lifestyles in order to achieve effective and safe pain medication management. Yet, except for the RCT intervention, most study participants were essentially on their own with pain medication management.

As a whole, our results indicate that safe and effective pain medication management by oncology outpatients requires both health systems changes (9) and skill-building interventions at the individual and family level. At the system level, better integration, coordination, and communication are needed. For patients and family caregivers, proactive assessment and skill-building are needed for each step of the pain medication management process.

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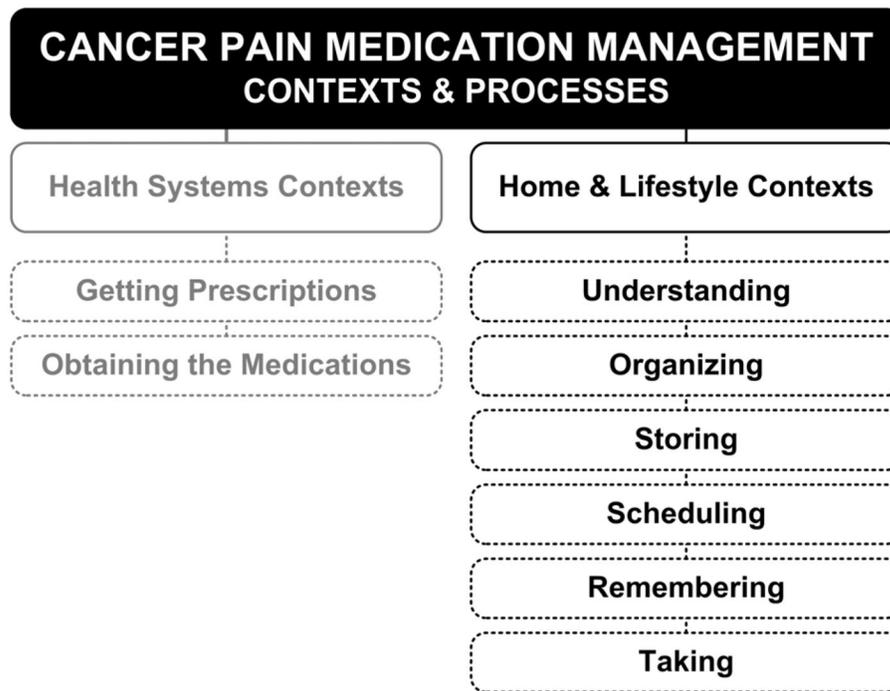


Figure 1.
Pain medication management contexts and processes.