

Original Article

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 of a psychoeducational 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 randomized clinical trial, 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.

Conclusion. Pain medication management is an ongoing multidimensional process, each step of which has to be mastered by patients and their family caregivers when cancer treatment and supportive care are provided on an outpatient basis. Realistic patient- and family-centered skill-building interventions

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are needed to achieve effective and safe pain medication management in the contexts of individual home environments and lifestyles. *J Pain Symptom Manage* 2014;48:784–796. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

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 that the patients and their 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 nonopioid analgesics, plus coanalgesics, such as antidepressants, anticonvulsants, 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 polypharmacy. 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 psychoeducational 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 the 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 was 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 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 psychoeducational pain management intervention grounded in self-care/self-management theories.¹² The qualitative study was embedded within the RCT to better understand pain management

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