

Original Article

Pain Medication Management Processes Used by Oncology Outpatients and Family Caregivers Part I: Health Systems Contexts

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Abstract

Context. Oncology patients with persistent pain treated in outpatient settings and their family caregivers have significant responsibility for managing pain medications. However, little is known about their practical day-to-day experiences with pain medication management.

Objectives. The aim was to describe day-to-day pain medication management 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 by patients and family caregivers in the context of multiple complex health systems.

Methods. We qualitatively analyzed audio-recorded intervention sessions that included extensive dialogue between patients, family caregivers, and nurses about pain medication management during the 10-week intervention.

Results. The health systems context for pain medication management included multiple complex systems for clinical care, reimbursement, and regulation of analgesic prescriptions. Pain medication management processes particularly relevant to this context were getting prescriptions and obtaining medications. Responsibilities that fell primarily to patients and family caregivers included facilitating communication and coordination among multiple clinicians, overcoming barriers to access, and serving as a final safety checkpoint. Significant effort was required of patients and family caregivers to insure safe and effective pain medication management.

Conclusion. Health systems issues related to access to needed analgesics, medication safety in outpatient settings, and the effort expended by oncology patients and their family caregivers require more attention in future research and health-care reform initiatives. *J Pain Symptom Manage* 2014;48:770–783. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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Key Words

Cancer pain management, analgesics, medication management, self-care, self-management, family caregivers, health systems, medication safety, qualitative research, randomized clinical trial

Introduction

Oncology patients with persistent pain treated in outpatient settings and their family caregivers have significant responsibility for managing pain medications.^{1–3} Yet despite extensive research on cancer *pain* management,^{4–7} only a few researchers focused specifically on the practical day-to-day management of pain *medications*. Given the number of patients who experience persistent pain at some point in the cancer trajectory⁸ and the fact that analgesic regimens are a mainstay of outpatient cancer pain management,^{9–11} the number of patients and family caregivers who face the challenge of pain medication management is substantial. Thus, management of pain medications by patients and family caregivers is a phenomenon that needs more attention from researchers.

Patient behaviors associated with pain medications are typically studied as “adherence,”^{12–15} narrowly defined as the “self-administration of medications in prescribed amounts and at prescribed intervals”^{13(p205)} or “nonadherence,” such as avoiding, forgetting, or stopping the medication or altering the dose.^{16–18} However, a few researchers recently examined medication management by patients and/or family caregivers as a broader and more complex activity than simply adherence. They conceptualized medication management as a whole range of behaviors required for effective and safe handling of medications. Those behaviors include teamwork, organization, routinization, decision making, and gaining access.^{19–22} Living alone, depression, physical impairments, highly complex medication regimens, and multiple prescribers place patients at risk for problems with medication management.²³

The few studies on medication management by patients and family caregivers were conducted in a wide variety of clinical populations, including caregivers of patients receiving hospice services,^{19,22} breast cancer patients treated with oral chemotherapy,²¹ and frail older adults receiving home health-care

services.^{23,24} Medication regimens differ significantly across these populations and present unique challenges. For example, medications administered in a cyclic manner, such as some oral chemotherapeutic agents, present different management challenges than medications taken on a daily basis indefinitely or medications for symptom management taken according to an individually tailored regimen. The availability of services to assist patients and family caregivers also varies across populations, ranging from no in-home services to home care by a multidisciplinary hospice team. Consideration of the particular clinical contexts for medication management is crucial as research in this area moves forward.

To our knowledge, only two studies specifically addressed pain medication management in the outpatient oncology setting. Our research team previously reported on difficulties in obtaining pain medications and accessing medication information among oncology outpatients participating in a randomized clinical trial (RCT).²⁵ Liang et al.²⁰ reported on opioid-taking skills and behaviors in an outpatient sample in Taiwan. Although these studies provided important insights, both had limitations. Ours was conducted more than 10 years ago, and the findings were serendipitous when a small qualitative component was added to an ongoing RCT.^{26,27} The study by Liang et al. evaluated only 10 participants and was situated in the Taiwanese context. In our present RCT, an expanded qualitative component yielded extensive data on pain medication management over time, allowing for a more in-depth analysis in the current U.S. context than previously reported.

The purpose of this qualitative study was to describe the day-to-day management of pain medications from the perspectives of oncology outpatients and their family caregivers who participated in an RCT of a psychoeducational intervention called the Pro-Self[®] Plus Pain

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