

Review Article

YouTube as a Tool for Pain Management With Informal Caregivers of Cancer Patients: A Systematic Review

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Abstract

Context. Cancer caregivers have information and support needs, especially about cancer pain management. With high Internet use reported among caregivers, YouTube may be an accessible option when looking for information on cancer pain management.

Objectives. The purpose of this study was to explore the availability and characteristics of instructional cancer pain management videos on YouTube and determine to what extent these videos addressed the role of informal caregivers in cancer pain management.

Methods. A systematic review of videos on YouTube resulting from search terms “pain and cancer,” “pain and hospice,” and “pain and palliative care” was conducted in May 2013. If the video addressed pain management, was in English, and was instructional, it was coded for the scope and design of instructional content that included caregivers.

Results. The search terms yielded 1118 unique videos, and 43 videos met the inclusion criteria. Overall, 63% of videos were viewed 500 times or less, and half of the videos received “like” ratings by viewers. Video instruction was primarily talk without any onscreen action (65%), user-generated amateur video (79%), and had poor quality sources of information. Videos were mainly clinician centered (77%). Although most videos addressed the need for caregiver pain assessment (35%) and caregiver education (23%), few actually addressed specific caregiver pain management barriers.

Conclusion. Most videos were primarily directed toward a clinical audience. Future research is necessary to determine if the platform is feasible and beneficial as a support tool for oncology caregivers. *J Pain Symptom Manage* 2014;48:1200–1210. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

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Key Words

Instructional films and videos, caregivers, pain management, cancer

Introduction

Home-based cancer care, which can include the provision of hospice and palliative care when disease is advanced, places day-to-day oversight of patient care in the hands of informal caregivers (often family or friends) who have little experience with pain management, symptom control, and use of medical equipment.¹ Commonly, myths and fears about medication are barriers to caregiver pain management,^{2,3} and complex instructions can create caregiver anxiety.⁴ Hospice and palliative care providers report that they often experience difficulties teaching caregivers about pain medications,⁵ and education for caregivers can be challenging because of the variance in availability of social support resources among caregivers.^{5,6} Although having additional resources has been shown to lower caregiver stress,⁷ cancer caregivers do not currently receive enough information to support the caregiving role.^{2,8} Caregivers of cancer patients report informational and support needs and could benefit from additional resources on pain management.^{2,5}

Research on patient and caregiver education shows promise for the effectiveness and usefulness of providing health-care resources and information in video format. Patients exposed to video decision support tools had a greater likelihood to choose comfort goals,⁹ greater likelihood to complete advance directive documentation,¹⁰ and were less likely to opt for cardiopulmonary resuscitation.¹¹ A randomized controlled trial of cancer patients found that an educational video on cancer pain improved outcomes associated with the Brief Pain Inventory and the Patient Pain Questionnaire.¹² The same study indicates promising benefits of video educational tools for caregivers as well. Caregivers who participated in video-based educational intervention on cancer pain with the patient also had improved knowledge about cancer pain, especially regarding beliefs about addiction and saving medicine for when the pain is worse.¹² A recent study on video discharge instructions in pediatric emergency care found improved

caregiver knowledge and satisfaction, with caregivers reporting that video instructions were extremely helpful.¹³

Caregiver education has been identified as a core intervention necessary to meet the ongoing needs of oncology caregivers,¹⁴ and video-sharing Web sites such as YouTube have been used as an educational tool for viewing and learning medical techniques.¹⁵ YouTube is the most popular video-sharing Web site with an international audience, availability on any mobile device, and linked to other Web sites and used in social networking.¹⁶ YouTube as an active learning strategy has been used in nursing education to engage learners, teach skills, and promote discussion.¹⁷ Prior research has found enhanced student learning, increased creativity, and critical awareness as a result of using a YouTube instructional method.¹⁸ Medical preceptors also have had students create videos for others as a pedagogical tool.¹⁹

With high Internet use among family caregivers,²⁰ the quality of information provided via the Internet or other social media outlets is a concern for providers,²¹ and there is a need to determine the availability of videos that address the caregiving role. In light of the increasing popularity and easy accessibility of YouTube, coupled with caregivers' need for information, an analysis of cancer pain videos on YouTube was undertaken to determine whether and to what extent materials and resources about pain management are available. Specifically, we aimed to evaluate the availability of instructional videos related to managing cancer-related pain through instructional videos on YouTube. As a secondary goal, we aimed to assess whether the scope and design of instructional content included the caregiver's role.

Methods

A systematic review of YouTube videos was conducted on May 9, 2013. Three different searches were entered into YouTube's search engine using the following key phrases: 1)

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