

*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;■:■-■.  
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**Key Words**

*Instructional films and videos, caregivers, pain management, cancer*

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**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.<sup>1</sup> Commonly, myths and fears about medication are barriers to caregiver pain management,<sup>2,3</sup> and complex instructions can create caregiver anxiety.<sup>4</sup> Hospice and palliative care providers report that they often experience difficulties teaching caregivers about pain medications,<sup>5</sup> and education for caregivers can be challenging because of the variance in availability of social support resources among caregivers.<sup>5,6</sup> Although having additional resources has been shown to lower caregiver stress,<sup>7</sup> cancer caregivers do not currently receive enough information to support the caregiving role.<sup>2,8</sup> Caregivers of cancer patients report informational and support needs and could benefit from additional resources on pain management.<sup>2,5</sup>

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,<sup>9</sup> greater likelihood to complete advance directive documentation,<sup>10</sup> and were less likely to opt for cardiopulmonary resuscitation.<sup>11</sup> 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.<sup>12</sup> 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.<sup>12</sup> 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.<sup>13</sup>

Caregiver education has been identified as a core intervention necessary to meet the ongoing needs of oncology caregivers,<sup>14</sup> and video-sharing Web sites such as YouTube have been used as an educational tool for viewing and learning medical techniques.<sup>15</sup> 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.<sup>16</sup> YouTube as an active learning strategy has been used in nursing education to engage learners, teach skills, and promote discussion.<sup>17</sup> Prior research has found enhanced student learning, increased creativity, and critical awareness as a result of using a YouTube instructional method.<sup>18</sup> Medical preceptors also have had students create videos for others as a pedagogical tool.<sup>19</sup>

With high Internet use among family caregivers,<sup>20</sup> the quality of information provided via the Internet or other social media outlets is a concern for providers,<sup>21</sup> 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)

pain and cancer, 2) pain and hospice, and 3) pain and palliative care. The number of videos available to users under any search term is a dynamic process controlled by YouTube as videos are constantly uploaded to the site. Regardless of the amount of videos that match the search phrases, YouTube only makes the first 500 available to users.

To qualify for inclusion in the study, videos had to be in English, have a primary topic on pain or pain management, and fit the definition of an instructional video. Instructional videos were defined as having content that included instructions or suggestions as to what a person should say or how to do something.<sup>22</sup> The elements of an instructional video include forecasting goals and steps, content in which steps are both performed and explained or elaborated, and an easily identifiable instructional message.<sup>22</sup> Video-recorded lectures that were included in the sample had to have explicit “how to” steps or “what to do” information steps (e.g., here’s what you should say, here’s what you should do). Additionally, infomercials, commercials, recorded introductions of speakers, general introductions, overviews and definition of hospice and palliative care, and lectures that did not include how-to steps or process explanation were excluded from the study.

Video characteristics from the YouTube site were collected as summary information about the video and viewership. This included the video category, date posted, length (minutes and seconds), and funding information (in print or verbalized). YouTube also collects and provides information to indicate the popularity of video viewing, measured by the number of views, number of “like” ratings, number of “dislike” ratings, and number of comments.

To analyze the design of videos, we coded for instructional design and make of content, two elements of educational video format. Instructional design was assessed using a three-part coding scheme derived from Morain and Swarts,<sup>23</sup> which takes into consideration the frame of instruction within the video. The three instructional frames include explanation (instructional talk, i.e., not accompanied by actions taken to complete the step), demonstration (any movement intended to illustrate a step, accompanied by explanation), or doing (any movement intended to illustrate

a step, not accompanied by explanation). The make of the content of the video and its audio tracks also was coded using the categorization by Weaver et al.<sup>24</sup> (user-generated amateur, user-generated professional, recording of mainstream media without user editing, and user manipulation of mainstream media content). Mainstream media is the inclusion of a movie or television clip.

To analyze whether the design of videos were inclusive of a caregiver audience, we coded for the use of appropriate literacy instruction tools and whether caregivers appeared in videos. Given that caregivers are not professional providers with medical knowledge and background, we coded for the use of literacy tools to explain complex pain management instructions. The Federal Plain Language Guidelines published by Plain Language in March 2011<sup>25</sup> were used to identify the use of literacy tools in the videos. According to the Federal Plain Language Guidelines, communication aids that assist with ensuring clarity include using examples, lists, tables, illustrations, and highlighting important concepts. Coders were instructed to choose all that applied to each video. Additionally, videos were coded for the participants present in the video, including patient, caregiver, clinician, and other professionals. Voice-overs with identified and credentialed speakers were coded as being present in the video and categorized accordingly. For patients and caregivers, coders noted if they were real or simulated.

Next, quality of sources, the nature of provider communication, and acknowledgment of caregiver pain management barriers in the videos were coded to evaluate the scope of videos. Given that the YouTube platform offers access to amateur videos, we were interested in capturing the accuracy of information presented. The Health on the Net Foundation<sup>26</sup> Web site criteria were adapted for videos and used to code for the quality of sources used within the video. Coding of this variable included the presence or absence of source information for a) qualifications of speakers, b) cited sources of information, c) balanced evidence, d) contact information, e) advertising, and f) transparency regarding funding and sponsorship. To ascertain if caregivers were included in the perspective of information presented, communication depicted in the video

also was coded as patient centered, patient/family centered, family centered, or clinician centered. Finally, given extensive research on caregiver, myths, and barriers about pain management, we assessed whether caregiver pain management barriers were addressed in the instructional scope of videos.<sup>27,28</sup> Specifically, the dimensions of the Caregiver Pain Medicine Questionnaire were used as coding categories. These categories are detailed in Table 4.

All the videos from our key phrase searches were linked to a coding Web site that allowed coders to watch the video and simultaneously complete a coding form. Three coders, two medical students and the first author, coded the videos. Both medical students had completed one year of coursework and were guided by the first author, who has conducted extensive research with hospice and palliative caregivers. Three training sessions were held. Training sessions involved watching and coding videos and then discussing them to refine approach and consensus. To develop inclusion criteria, 12% of the data (150 videos) were used and 96% coder agreement reached. The remaining videos ( $n = 968$ ) were split so that each coder applied inclusion criteria to approximately half of the sample. All videos that met inclusion criteria were double coded. Half of the videos were used to help coders become familiar with coding definitions and

to calculate reliability assessment (84%). The first author reviewed coding for the overall sample as an additional reliability check, and agreement of two among three coders ensured consistency of the evaluation. Data were entered into SPSS (SPSS Inc., Chicago, IL) for frequency distributions of the variables.

## Results

Figure 1 is a flow diagram of the sampling process, and Table 1 identifies and summarizes the videos that were analyzed. From the three key phrase searches, a total of 1500 videos were made available, and after duplications were removed, there were a total of 1118 unique videos. Of the 1118 videos pulled from searching YouTube, the average time for the videos was 8 minutes 45 seconds, with the median time at 3 minutes 35 seconds. Of the 1118 videos, 1075 (96%) were not coded because they did not meet inclusion criteria. As a result, 43 videos were left to code, a total of 13 hours, 6 minutes, and 32 seconds of content, which comprised the data set for the following analysis. Videos were published between June 19, 2008 and May 1, 2013.

The information on the individual videos used in the study is summarized in Table 1. Detailed in this table are the category assigned

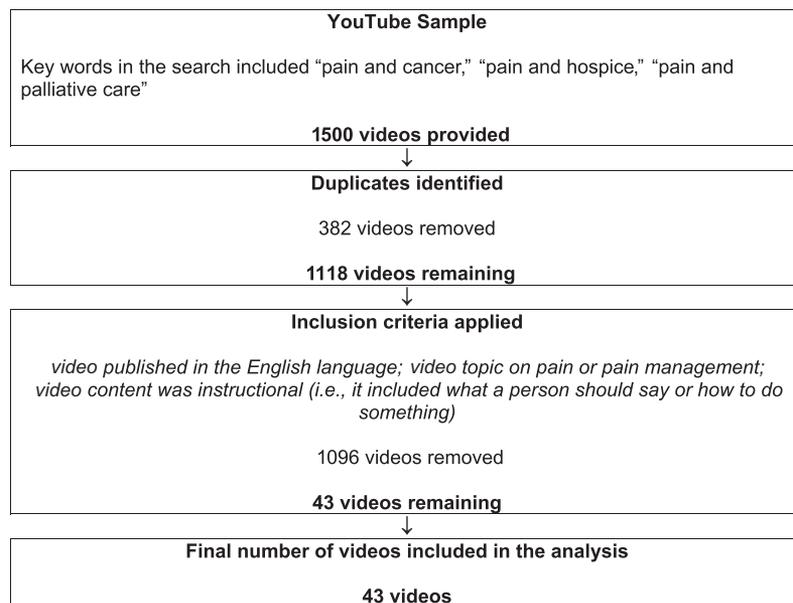


Fig. 1. Flowchart of sample.

Table 1  
Summary of the Sample

Title of Video (Author) [YouTube ID <sup>a</sup> ]	Category	Views/Likes	Published Date <sup>b</sup> (Number of Days)	Mean Views (day)
Cancer and Pain#3 Space Coast Cancer Center (SpaceCoastCC) [J2Q3cdh2mJs]	Science and Technology	2 (0)	May 1, 2013 (93)	0.022
Cancer care training: a multidisciplinary approach to pain and palliative care (CChange10) [fnpHWfe1u-s]	Nonprofits and Activism	178 (1)	August 10, 2010 (1097)	0.162
Constipation: managing side effects that hinder quality of life (ProHospiceSolutions) [CRwo5cLlJE]	Education	106 (0)	February 29, 2012 (520)	0.204
Coping with chronic back pain (BupaHealth) [mHhgXZm8Lvo]	Education	681 (0)	April 21, 2011 (834)	0.817
Culturally relevant pain assessment and management in palliative care (painpallcare) [g97-AYNEIMU]	Science and Technology	173 (0)	May 4, 2012 (455)	0.380
Dementia care medications—hospice of the valley (HospiceofValleyAZ) [GEem0VJ-Tiw]	Education	230 (0)	January 7, 13 (207)	1.11
Dr Jose A. Contreras on responsible pain management (PainLiveTV) [Ou90VLqFWRU]	Science and Technology	46 (0)	August 3, 2012 (364)	0.126
Dr Russell Portenoy—OPIOID THERAPY (painpallcare) [B4V6D5gD6PE]	Science and Technology	2897 (11)	September 19, 2011 (683)	4.242
Episode 3: Communicating about pain: for people with pain (LetsTalkPain) [myZ113YZH80]	Education	134 (0)	November 2, 2009 (1369)	0.098
Family hospice, right for you (FamilyHospice) [RgBx2AMm5sM]	Nonprofits and Activism	102 (0)	December 06, 2010 (970)	0.105
FASTING: a peaceful way to avoid a prolonged dying with pain and suffering. 25 x11 (Stanley Terman) [wtD8O_uptt0]	Nonprofits and Activism	1172 (9)	October 26, 2011 (646)	1.814
Fibromyalgia: epidemiology, assessment and treatment (painpallcare) [ru9z5d428o]	Science and Technology	184 (1)	February 13, 2012 (536)	0.343
From pokes to post-op: an overview of pain prevention and management in hospitalized children (CAPHCTv) [Vm-POeZXln8]	Science and Technology	123 (1)	January 11, 2012 (569)	0.216
Get in and out of bed without aggravating your back pain (Gord McMorland) [XpB534yB2Zw]	How To and Style	1031 (2)	May 18, 2010 (1172)	0.880
GRACEcast-106_CA-Rx_Dr Stephanie Harman: managing pain (GRACE4cancerinfo) [ee6Kb-6Psdo]	Science and Technology	15 (0)	August 2, 2012 (365)	0.041
Hospice Care.wmv (AudibleRxTopics) [VK8fQ7Oq96k]	Education	5 (0)	June 12, 2012 (416)	0.012
How to convert opioids (studywithmedmnemonix) [VXNpxtEUTIU]	Education	667 (8)	May 11, 2012 (448)	1.489
Joint and bursal injections (painpallcare) [eKNS1Tm7anc]	Education	248 (0)	March 3, 2011 (883)	0.281
Late-stage Alzheimer's dementia care: how to recognize pain with teepa snow—Part 2 (PinesofSarasota) [9kSjHtHSJCw]	Education	1374 (2)	December 13, 2012 (232)	5.922
LIFE before death. What is pain? (LifeBeforeDeathMovie) [nOgMtCIL1xU]	Nonprofits and Activism	5339 (21)	June 17, 2011 (777)	6.871
Management of pain in palliative care (Jon Hilton) [JZuPvlq6xaY]	Education	34 (0)	January 16, 2013 (198)	0.172
Nausea, vomiting—Part 2 (painpallcare) [iI_FZd-3ruo]	Education	899 (1)	November 9, 2010 (997)	0.902
Nausea, vomiting—Part 3 (painpallcare) [JcDAhCMWnXA]	Education	457 (0)	November 9, 2010 (997)	0.458
Nausea, vomiting—Part 5 (painpallcare) [d9WwY9qFlkE]	Education	185 (1)	November 9, 2010 (997)	0.186
Neuraxial analgesia: epidural and intrathecal (painpallcare) [s2fR4i4k4Uo]	Education	681 (3)	April 7, 2011 (848)	0.803
Pain assessment Podcast (John Campbell) [xJHk2H7gU7A]	Education	497 (7)	March 9, 2012 (511)	0.973
Pain Didactic: fibromyalgia Pt 3 (painpallcare) [h6psmG0N5Ug]	Education	244 (4)	February 9, 2011 (905)	0.270
Pain expectations (1 of 4) (AllinaComm) [nFSYRVbhMnQ]	Science and Technology	22 (0)	February 17, 2013 (166)	0.133

(Continued)

Table 1  
Continued

Title of Video (Author) [YouTube ID <sup>a</sup> ]	Category	Views/Likes	Published Date <sup>b</sup> (Number of Days)	Mean Views (day)
Pain management (HPNAINformation) [pErPajNjME]	Education	803 (3)	July 24, 2012 (374)	2.15
Pain management/nonpharm—Part 3 (painpallcare) [gV0v02gJIXI]	Education	116 (0)	November 9, 2010 (997)	0.116
Pain management by Dr PK Jain, Tata Memorial Hospital at BARC CME.30 March 2012 (Harry Ralte) [4G7VCNxzz3M]	Education	297 (0)	March 31, 2012 (489)	0.607
Pain management in HIV/AIDS (painpallcare) [eZd2YcPXbIc]	Science and Technology	343 (0)	February 10, 2012 (539)	0.636
Palliative care for prostate cancer—Dr Yvonne McMaster (ansellvideo) [ImqLFBajlac]	Education	477 (0)	August 24, 2010 (1074)	0.444
Physiotherapy.mpg (Saint Francis Hospice) [8BAcX-buYL0]	Nonprofits and Activism	916 (1)	December 22, 2009 (1319)	0.694
Prostate cancer: palliative therapy for advanced disease (Gerald Chodak, MD) [DyXA96up58c]	Education	857 (1)	November 19, 2008 (1717)	0.499
RE terminally ill and massage (massagenerd) [XZLsz4dGYvk]	People and Blogs	498 (3)	June 23, 2009 (1501)	0.332
RE: Positioning hospital and hospice massage clients (massagenerd) [w-zP6IO07mQ]	Education	1936 (2)	May 5, 2009 (1550)	1.25
Setting up a syringe driver in the community. Part 2 (Palldoc) [LIsGLKwaIdI]	Education	7885 (5)	June 8, 2009 (1516)	5.201
The connection: assessing and managing physical pain (ProHospiceSolutions) [nejD2IV5r5c]	Education	28 (0)	February 27, 2012 (522)	0.054
The neurobiology of cancer pain, palliation, and survival (painpallcare) [ncEI0Dbe9Hc]	Science and Technology	118 (2)	May 4, 2012 (455)	0.260
The palliative care patient and pain management (projectecho) [88ri3VNOd2E]	Science and Technology	313 (1)	November 1, 2011 (640)	0.489
What your doctor should ask you about pain (HealthDotCom) [qplSoJPYIHg]	Science and Technology	6803 (22)	June 19, 2008 (1870)	3.638
When a child is ill: the importance of asking questions (cvhcvcp) [RFTRDMB4iPM]	Education	57 (0)	December 28, 2011 (583)	Science and Technology; 0.098

<sup>a</sup>To access the video enter the following URL ([www.youtube.com/watch?v=](http://www.youtube.com/watch?v=)) and the id number.

<sup>b</sup>Number of days between video upload and August 1, 2013 retrieval.

to the video, the number of views for each video, and the corresponding number of “likes.” Finally, we computed a mean number of views per day to allow for comparison of the number of times a specific video was viewed based on the length of time it had been posted. Mean number of views per day ranged from 0.012 to 6.871. There were nine videos (21%) that averaged more than one view per day.

As shown in Table 2, most videos were listed under the Education category (56%), followed by Science and Technology (28%). Although all videos coded met the instructional definition, only one video was categorized as a “how-to” video. The 43 videos analyzed had 39,029 views (range 2–7885), with high variation ( $SD = 1718.206$ ), and 63% had been viewed 500 times or less. Only one video had been seen twice at the time of data collection, and only two videos were seen more than 5000

times. The mean number for viewers indicating “like” was 2.581 ( $SD = 4.9868$ ). Almost half of the videos (49%) were not “liked” by any viewer, with the other half receiving at least one “like” rating (range 1–22). Most viewers did not indicate a “dislike” rating (89%), and only one video was “disliked” three times. There was little audience response to the videos, with only 28 comments for the videos analyzed. Most videos had no comments (70%) and one video had seven viewer comments. Video authors (a term used by YouTube to identify creators of the videos) consisted of physicians, medical schools/programs, hospice agencies, and nonprofit organizations. Only three funding sources were identified in three videos (American Pain Foundation and Pennsylvania Department of Aging funded two videos).

Most instruction was framed as explanation that consists of talk with no onscreen action

*Table 2*  
**Characteristics of Instructional Cancer Pain Management Videos (n = 43)**

Characteristic	Values	Frequency	%
Category	Education	24	56
	How-To	1	2
	Nonprofits and Activism	5	12
	People and Blogs	1	2
	Science and Technology	12	28
Number of views	0–500	27	63
	501–1000	8	18
	1001–2000	4	9
	2001–5000	2	5
	5001–10,000	2	5
Times marked as “like”	0	21	49
	1	7	16
	2	4	9
	3	3	7
	4–10	5	12
	10+	3	7
Times marked as “dislike”	0	38	89
	1	4	9
	2	0	0
	3	1	2
Number of comments	0	30	70
	1	7	16
	2	2	5
	3	2	5
	4–10	2	5

(65%), followed by demonstration where the frame of instruction consists of action plus talk (35%). Frequency data revealed that 34 (79%) instructional videos were user-generated amateur videos, with only nine (21%) user-generated professional videos. None of the videos included the use of mainstream media (inclusion of a movie or television clip). [Table 3](#) summarizes the quality of sources within the videos. Approximately half of the videos did not provide qualifications of the speakers (49%) and most videos did not cite sources of information (70%) or provide balanced evidence (79%). Contact information was commonly absent (72%), whereas the identification of funding sources was almost always provided (93%). Few videos included advertising (28%).

An overview of the scope and design of instructional content that included the caregiver's role is depicted in [Table 4](#). Overall, examples were the most common literacy tool used (74%), followed by the use of illustrations (23%). Few videos provided instruction that included the use of tables (16%) and lists (12%). Eight videos (19%) did not include any literacy appropriate teaching tools and mainly depicted a person talking. Caregivers

*Table 3*  
**Quality of Sources in Cancer Pain Management Videos on YouTube**

Source Credibility Items	Yes, n (%)	No, n (%)
Did the video provide qualifications of speakers?	22 (51)	21 (49)
Did speakers cite sources of information?	13 (30)	30 (70)
If yes, was medical/scientific literature used?	13 (100)	
Did the speakers provide balanced evidence for specific treatment, commercial products, or services?	9 (21)	34 (79)
Did the speakers/video include contact information?	12 (28)	31 (72)
Did the video include advertising?	12 (28)	31 (72)
Did the speakers/video identify funding sources (verbally or in print)?	3 (7)	40 (93)

were rarely portrayed in videos (<1%), with most videos featuring clinicians (74%) and patients (21%), followed by other professionals (16%). Similarly, provider communication was predominantly clinician centered (77%), and only three videos were patient/family or family centered (7%). Teaching about pain assessment (35%) and addressing the need for caregiver education (23%) and the hesitancy to report pain (21%) were most prominent in video instruction. Least likely addressed was the caregiver's fear of pain medications (2%), caregiver concern about administering analgesics (2%), and acknowledging caregiver's prior negative health-care experiences (2%).

## Discussion

Although videos about cancer-related pain are available on YouTube, this systematic review project found that videos were less available on topics of pain management and assessment for cancer patients and caregivers. Most videos resulting from our search did not meet study inclusion criteria because they did not include specific steps or how-to explanations about pain management. Rather, videos consisted of recorded pain lectures for practicing clinicians and were, thus, categorized as “Education.” Similarly, a study on clinical education videos found wide availability of videos on YouTube for medical and nursing students; however, videos were less available on topics of pain management and assessment.<sup>29</sup>

Table 4  
Scope and Design of Instructional Content Addressing Caregiver's Role

Scope/Design	Definition	n (%)
Use of literacy tools <sup>a</sup>		
Use of examples	Speaker/narrator verbally said "for example" or visual example was provided	32 (74)
Use of lists	Used to highlight importance, help understand order of which things happen, make it easier to understand steps in a process	5 (12)
Use of tables	If-then tables to demonstrate sequence, consequence	7 (16)
Use of illustrations	Use of pictures, charts, graphs, map	10 (23)
Use of emphasis to highlight important concepts	Use of bold, italics, subtitles on slides or visual information	13 (30)
Not applicable	Video content did not include teaching tools.	8 (19)
Individuals appearing in video		
Patient	Real	3 (7)
	Simulated	6 (14)
Caregiver	Real	1 (2)
	Simulated	2 (5)
Clinician	Presence of individuals designated as physicians (MD and DO) and nurses (NP, RN, BSRN) either by verbal or print introduction or through attire (e.g., white jacket, scrubs) or setting (e.g., clinic)	32 (74)
Other professional	Presence of other professional either by verbal or print introduction or through attire or setting	7 (16)
Not applicable	No individuals in the video	6 (14)
Provider communication		
Patient centered	The video's message communicates directly with the patient.	6 (14)
Patient-family centered	The video's message communicates directly with the patient and his/her family.	1 (2)
Family centered	The video's message communicates directly with the patient's family member/friend.	2 (5)
Clinician centered	The video's message communicates directly with the provider.	33 (77)
Caregiver pain management myths addressed <sup>a</sup>		
Pain assessment	Not understanding how pain is assessed	15 (35)
Reluctance to administer medication	Concern that patient is sleeping too much, fear of medication addiction	7 (16)
Fear of pain medications	Fear of killing the patient	1 (2)
Noncompliance with pain medicine regimens	Deciding to withhold pain medications	3 (7)
Hesitance to report pain	Not reporting pain management decisions to staff	9 (21)
Negative past experiences	Prior bad hospice experience or negative health-care experience	1 (2)
Caregiver strain impacts pain management	Older caregiver issues, caregivers providing care to older and younger family members, fatigue	2 (5)
Need for caregiver education and patient care information	Caregiver does not know how or reports not being told	10 (23)
Concern about reporting pain	Fatalistic belief that pain is inevitable and cannot be adequately controlled	4 (9)
	Stoicism belief that individuals should be strong and tolerate discomfort without complaint	2 (5)
Concern about administering analgesics	Difficulty administering pain medications	1 (2)

<sup>a</sup>The total do not equal 100% as coders indicated all that applied.

Interestingly, there was low overall viewership of the videos and little audience response indicated by comments and "like" ratings. Although it is unclear and somewhat controversial on how to measure the popularity of videos in social media,<sup>30</sup> we chose to assess this by computing an average number of views per day. Whereas only 21%<sup>9</sup> of the videos had a mean view of at least once per day, more than half of those (five) were in the category of Education. The most viewed video and the category with the next most views of more than

once per day is the Nonprofit/Activism category. The only other video with a mean view of more than once per day was in the Science and Technology category.

Most pain videos on YouTube were user-generated amateur videos. YouTube introduces a platform whereby content and applications are, to a great extent, no longer created by professional groups at a high cost<sup>31</sup> but instead are continuously modified by all users in a collaborative fashion and at low cost.<sup>32</sup> YouTube supports the delivery of education that is

instantaneous, active rather than passive, facilitating a rapid low-cost sharing of experiences and opinions.<sup>33</sup> It provides an opportunity for domain experts and professionals in a given knowledge field to share insights with a specific community or the public at large, bypassing formal and costly structures of information dissemination that require lengthy and resource intense processes before the communication message reaches the intended audience. However, we must caution that the earlier study on clinical education concluded that clinical skills videos were not considered clinically robust.<sup>29</sup> Although findings from this study also indicate poor quality of source sharing and demonstration of evidence, source information in this video sample may have been available on a different platform, such as a Web site or curriculum module that housed the video, and thus, our findings only reflect a stand-alone account of video content. Future research is needed to examine the content of cancer pain management videos.

Of note in this study is the lack of attention to the role of the caregiver in cancer pain management instruction. To address the caregiving role, caregivers need demonstration videos that include easy-to-teach lists and tables. They need to be featured in the videos, and information needs to be credible and easy to find. Videos can be tailored by illness, relationship between patient and caregiver, and care setting. YouTube videos can be a tremendous resource for caregivers who are searching for additional information and support<sup>1,34</sup>; however, this platform has not yet been fully recognized by providers as a way to disseminate such information to the caregiving audience.

Nurses have higher recognition of the need for Internet guidance than medical specialists and may play a more active role in referring to and discussing content of educational videos.<sup>21</sup>

Recent psycho-oncology Internet intervention recommendations have included skill building as a featured component, and video-sharing Web sites such as YouTube may be a viable option for providing evidence-based, empirically tested intervention material that may affect caregiver competence and psychological care.<sup>35</sup> Oncology nurses have the opportunity to recognize the support of their educational efforts through the use of

reinforcing YouTube video demonstrations for their teaching related to pain.

### *Limitations*

Although this study sheds light on the availability of instructional cancer pain management videos as a caregiver resource, several limitations should be noted. First, we were not able to capture the entire number of videos available through YouTube as the maximum results for any search is restricted to 500 videos by YouTube. Second, whereas the study represents a preliminary first step in understanding YouTube as a possible platform for providing information to caregivers, the findings are limited. It is not known if the search terms chosen are representative of the search behavior of caregivers; the search terms used in this study may have biased the findings toward identification of videos targeting a more clinical audience. Further, search terms may not have generated the full breadth of instructional videos available. Admittedly, the research team did not explore the most appropriate search terms to be used, warranting even further investigation.

Interviews and surveys with caregivers are needed to further investigate their personal use of YouTube and their attitude and perception of YouTube as a credible source of information. If caregivers do, indeed, report ease of use and satisfaction with YouTube, then researchers could better develop and test educational resources delivered through video-sharing Web sites. Further research should address the use of personalization services available through technological platforms, such as Google, and other video-sharing Web sites, such as VIMEO. Finally, this study focused on pain management education for caregivers as they play a pivotal role in home-based cancer care. However, additional caregiving topics could easily be addressed through the YouTube platform, and we encourage others to explore the medium in the delivery of their own caregiving intervention work.

### *Implications*

Despite these limitations, this work has important implications to clinicians creating educational pain videos. Future research will need to address the appropriate length of instructional videos, who should be featured, and how to ensure that literacy tools are used

so that pain management instruction is understandable for informal caregivers. Of particular concern in the development of instructional videos is audio and video track synchronization, wherein the steps in a process are verbalized and then demonstrated.<sup>23</sup> Good quality instructional videos include a narrator's neutral tone with clear language, narrator presentation as a peer, and simple steps without tiny details.<sup>11</sup> Videos need to ensure that they represent multiple perspectives, appropriate visuals, and ensure objectivity.<sup>36</sup>

Although standardized education does improve caregiver well-being, caregiver intervention research has found only small to medium effects<sup>37</sup> and caregivers still experience difficulty with caregiver tasks.<sup>38</sup> Additionally, few caregiver interventions have been translated into standard care practice.<sup>14</sup> The costs associated with intervention start-up impede the translation of caregiver interventions into standard practice.<sup>37</sup> Oncology providers would be well served to use the low cost YouTube platform to reinforce their face-to-face teaching with patients and caregivers not only on the challenging topic of pain but also other side effects and treatments. Video reinforcement of traditional teaching would allow caregivers repetition and 24-hour access to information that they received during a high stress rushed visit in a clinic or office environment. Targeted communication with the specified design characteristics should be developed and tested for efficacy. This study provides important background information on how health technology, such as a video-sharing Web site YouTube, is currently being underused to provide information specifically for informal caregivers.<sup>14</sup>

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