

Maintaining the Social Flow of Evidence-Informed Palliative Care: Use and Misuse of YouTube

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ABSTRACT

This review article is aimed to explore the use of the social media website YouTube (www.youtube.com) as an evidence resource in palliative care, for patients and caregivers, students and professionals, and providers and policy-makers in developing countries' settings. The reviewed evidence reiterated the role of this social media website in palliative care practice, education and research in the area of cancer. Efficacy studies on impact of such media on palliative care delivery in developing countries are still lacking.

Key words: Social media, Palliative care networking, Public health education

INTRODUCTION

The rising popularity of internet-based technologies, such as applications for social networking, media sharing or blogging, has drastically changed the way in which healthcare professionals interact with educators, peers, and the outside world.^[1] Twitter, Facebook, and YouTube are three most popular social networking sites, which professional associations and bodies utilize to develop interpersonal communication.^[2]

These websites combine media production and distribution with social networking features, making them an ideal place to create, connect, collaborate, and circulate among public. By encouraging the general public to become media creators and social networkers, new media platforms like YouTube offer a participatory culture in which people can develop, interact, and learn.^[3]

YouTube is an increasingly important medium for consumer health information with content

provided by healthcare professionals, government and nongovernment organizations, industry, and consumers themselves.^[4] The objective of this article was to highlight the role of YouTube in palliative care in terms of practice, education, research, and administration.

YOUTUBE AND PALLIATIVE CARE PRACTICE

Jackson *et al.*^[5] said that YouTube could help a clinical practice retain its existing patients and attract new patients to the practice through public education and online marketing. YouTube had enabled new and efficient exchange of personal stories by cancer survivors, including the sharing of personal cancer experience with their caregivers, thereby informing the development of narrative-based communication, particularly in maintaining authenticity and emotional engagement.^[6]

Wittenberg-Lyles *et al.*^[7] in their systematic review identified 43 videos that provided video-based instruction.

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They were primarily talk-based without any onscreen action, mostly user-generated amateur video, and had poor quality sources of information. Videos were also clinician-centered and the majority of videos addressed the need for caregiver pain assessment and caregiver education, with a few addressing specific caregiver pain management barriers.

Diagnostic or therapeutic procedure-related videos

Mammography

Basch *et al.*^[8] reviewed 173 videos on mammography in YouTube and found that greater public comments were present for consumer-created videos than professional-created ones, the latter portraying more general information. Two-thirds were on preparation for testing and only one-third were on procedure-related pain, anxiety, and fear. Half of the videos were on test results and one-fourth were on medical/family history.

Bowel preparation and colonoscopy

Basch *et al.*^[9] analyzed 280 videos on bowel preparation and found that: Professional-created videos had more views (focusing on purgative type and completing the preparation) and consumer-created ones had more comments (emphasizing palatability, disgust, and hunger during the procedure) which would have direct impact on attitudes toward colon cancer screening.

Rhabdomyosarcoma

Clerici *et al.*^[10] studied 149 videos on pediatric neoplastic diseases (rhabdomyosarcoma and soft tissue sarcoma) and found that only 25 videos were useful. 82.5% of the videos were provided by patients and families, with most of them commemorating the death of their child. Thus, social media helped as a strategy for coping with the child's death by providing an opportunity for describing caregivers' impressions and experiences.

Prostate cancer

Steinberg *et al.*^[11] analyzed 14 prostate-specific antigen (PSA) testing videos, 5 radiotherapy videos, and 32 surgery videos on YouTube and found that surgery videos had more viewers, and were of long duration. The information content was found to be fair or poor for 73% of all videos, with bias in nearly 69% of videos.

Human papillomavirus vaccination

Briones *et al.*^[12] examined 172 videos for source, tone, and viewer responses and found that most of them were news clips or consumer-generated content. The majority of them were disapproving of vaccination and were liked by viewers. The analysis showed that there were accusations of conspiracy and infringement of civil liberties.

Ache and Wallace^[13] analyzed 146 videos and found that three-fourths of them portrayed HPV vaccination in a positive manner, and one-third of the clips generated at least one posted comment.

Breast reconstruction

Tan *et al.*^[14] analyzed the quality and quantity of 100 videos and found three distinct factors-patient, oncological, and reconstruction factors, with most of the videos providing patient education as a useful resource [Table 1].

YOUTUBE AND PALLIATIVE CARE EDUCATION

An increasing amount of health education resources for patients and professionals are distributed via online social media channels and thousands of health education videos are disseminated via YouTube.^[15] YouTube is increasingly being used as a global online platform for disseminating health information and providing public

Table 1: Comparison of YouTube videos on diagnosis/therapeutic procedures

Authors	Subject/topic	Number of videos in YouTube	Identified factors	Objective of resource
Basch <i>et al.</i> (2014)	Mammography	173	Consumer-versus professional-created videos	Testing, procedure-related pain, anxiety and fear, test results, medical/family history
Basch <i>et al.</i> (2014)	Bowel preparation and colonoscopy	280	Consumer-versus professional-created videos	Purgative type, completing the procedure, procedure-related palatability, disgust, and hunger
Clerici <i>et al.</i> (2012)	Rhabdomyosarcoma	149	Usefulness, source of uploader, theme	Coping with child's death in pediatric neoplastic diseases
Steinberg <i>et al.</i> (2010)	Prostate cancer	14	Surgery-related, radiotherapy-related	Information content accuracy was poor, with lot of bias
Briones <i>et al.</i> (2012)	Human papillomavirus vaccination	172	Source, tone and viewer responses	Disapproval of vaccination, accusations of conspiracy and infringement of civil liberties
Ache and Wallace (2008)	Human papillomavirus vaccination	146	Manner of portrayal, viewer responses	Positive propagation
Tan <i>et al.</i> (2014)	Breast reconstruction	100	Patient, oncological and reconstruction factors	Patient education

health education.^[16] Few authors recommended integration of YouTube into medical,^[1] nursing,^[17] and dental curricula,^[18] even though many videos were targeted toward clinical skills education.^[19]

YOUTUBE AND PALLIATIVE CARE RESEARCH

Konijn *et al.*^[20] opined that “YouTube provided (a) An environment to present manipulated media materials in controlled experimental designs; (b) an environment to study effects of peer feedback on various media contents; (c) a format to design a media-based questionnaire, such as their Media, Morals, and Youth Questionnaire.” Hence, YouTube could be an effective medium in scientific communication to collect data for research, and with many limitations to conduct direct-contact studies, online studies thus provide a viable alternative.^[21]

DISCUSSION

Use of YouTube

Topps *et al.*^[22] opined on the use of YouTube, “YouTube was found to provide many advantages over self-publication, particularly in terms of technical simplification, increased audience, discoverability, and analytics.”

Mazanderani *et al.*^[23] opined, “social media technologies provide patients with novel opportunities for advocating for particular treatments; generating alternative forms of “evidence” built on a hybrid of personal experience and medical knowledge. Healthcare practitioners need to engage with new digital forms of content, including online social media. Instead of disregarding sources not considered “evidence-based”, practitioners should enhance their understanding of what “experiential-evidence” is deemed significant to patients, particularly in contested areas of healthcare.”

Misuse of YouTube

Hayanga and Kaiser^[24] opined about the misuse of YouTube, “the application of a formal appraisal to a freeware website that is unregulated, uncensored, and designed more for entertainment than the dissemination of evidence-based medical advice may lend false gravitas to an unstructured, unvalidated online rating system as well as medical credence to a conduit of popular culture.”

Referring to YouTube for information on palliative care has demonstrated its own risks and benefits, although the

latter overweighs the former if content providers, care providers, and organizations take responsibility and foster a new era of evidence-informed palliative care by uploading patient-based videos based upon real-life situations.

Madathil *et al.*^[16] in their systematic review found that YouTube contained misleading information, predominantly anecdotal, which contradicts the established reference standards and a higher probability of a lay user finding such content. YouTube was also used as a medium for promoting unscientific therapies and drugs that were yet to be approved by the appropriate regulatory agencies and hence has the potential to change the beliefs of patients concerning controversial topics like vaccinations.

Information retrieval was misled by inappropriate hits due to lack of search tags and accepted taxonomies for listing of videos.^[15] YouTube videos must be carefully analyzed in order to avoid misleading, inaccurate, obsolete, and incorrect health content, which could be improvised using domain-based ranking.^[25]

In the era of technology-driven scientific dissemination in evidence-informed palliative care, the consumers in resource-rich countries utilize social media sites to inform themselves on decision-making choices whereas in resource-poor settings, it is the provider who holds responsibility for the accuracy of videos uploaded in YouTube so that effective public transformation could be facilitated to improve services to the needy. Future studies could explore these differences in order to develop policies to implement evidence-informed palliative care through information technology and social networking.

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Conflicts of interest

There are no conflicts of interest.

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