

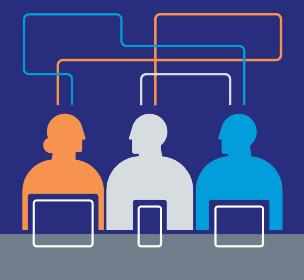
Social Media for Palliative Care: Education, Advocacy, & Collaboration

Rab Razzak, MD

Director, Outpatient Palliative Medicine

Johns Hopkins Medicine

August 17, 2017



CAPC National Seminar and Boot Camp 2017

Practical Tools for Making Change

November 9-11, 2017

Sheraton Grand Phoenix | Phoenix, Arizona

Pre-Seminar Boot Camp: Developing Palliative Care in Community Settings

November 8, 2017

2017 SEMINAR THEMES

- Program design for all care settings
- High-functioning teams
- Health equity in palliative care
- Quality measurement

HIGHLIGHTS

- Interactive sessions on cutting edge topics
- Networking events to connect and share ideas
- Office Hours with Seminar faculty for deep dive Q&A
- Poster session and reception

KEYNOTE LINEUP



Diane E. Meier, MD, FACP
Director, Center
to Advance
Palliative Care



Eric Widera, MD
Co-founder,
Geri-Pal



**Kimberly
Sherell
Johnson, MD**
National Health
Disparities
Expert



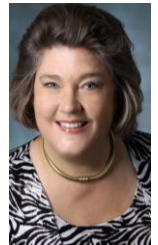
Ira Byock, MD
Founder,
Providence
Institute for
Human Caring



**Lauren Taylor,
MDiv, PhD(c)**
Co-author, *The
American Health
Care Paradox*



**Matthew
Gonzalez, MD**
Associate
Medical Director,
Providence
Institute for
Human Caring



**Lynn Hill
Spragens,
MBA**
Leading National
Palliative Care
Consultant

Social Media for Palliative Care: Education, Advocacy, & Collaboration

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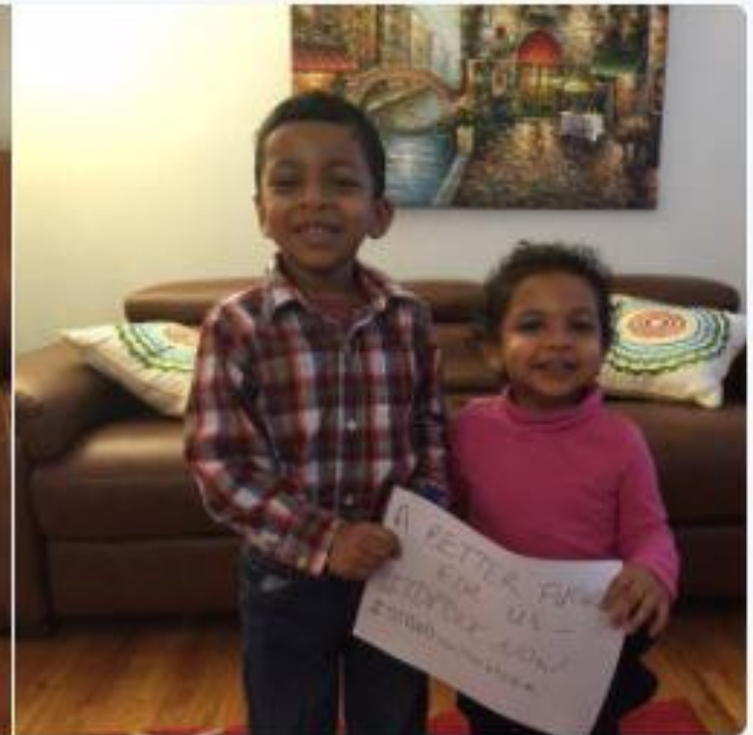
August 17, 2017

My SM Story



Rab Razzak @rabrazzak · 14 Dec 2014

@SenatorCardin @SenatorBarb, thank you for supporting Dr Murthy. We need him as our #TopDocNow. #StandWithVivek



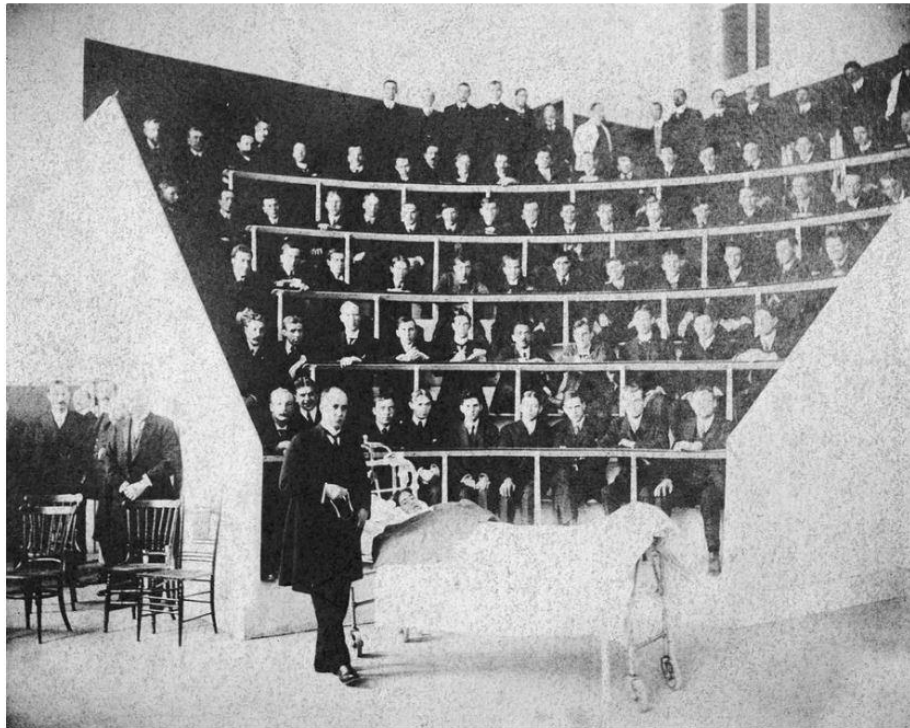
Pal Care Is Primed For Success

- Population we serve
- Promise to improve our healthcare system
- Meets triple aim- quality, cost and experience of care

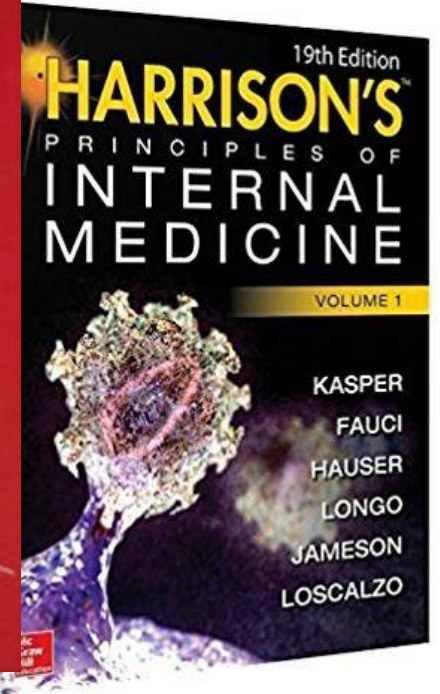
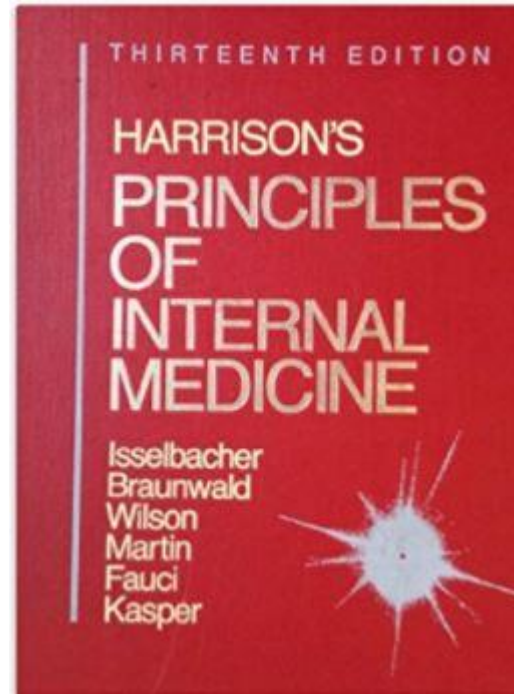
Challenges

- Relatively new field
- Confusion about what pal care is
- Number in workforce

Extra, Extra, Read All About It



William Osler Teaching Medicine is a photograph by National Library Of Medicine which was uploaded on July 11th, 2016.



The NEW ENGLAND
JOURNAL of MEDICINE

How we learn/teach now

- Lectures
- Journals
- Experiential
- Web-based
- Social media forums
- Books

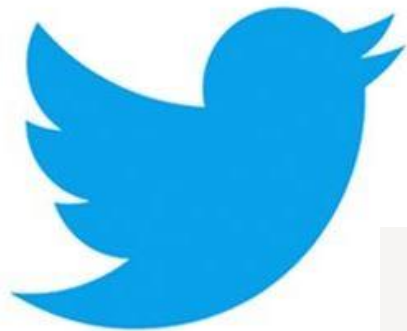
Social Media Forums

facebook



Instagram

Medium



LinkedIn



Podcasts

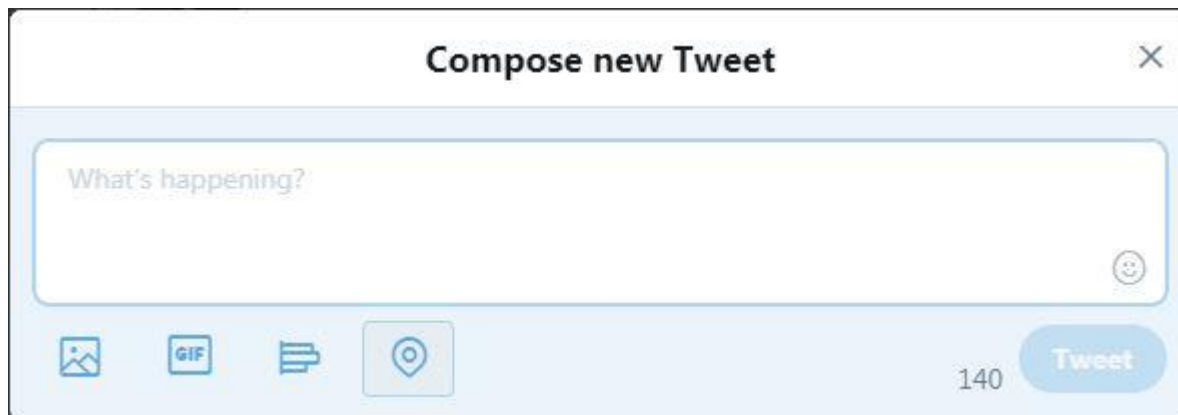


Twitter

- Rapid, scan-friendly content
- 140 characters or less
- Hyperlinks, photos (up to 4) or videos (up to 30 secs) can be attached
- Hyperlinks are attached as 23 characters
- Automatically detects geographical location

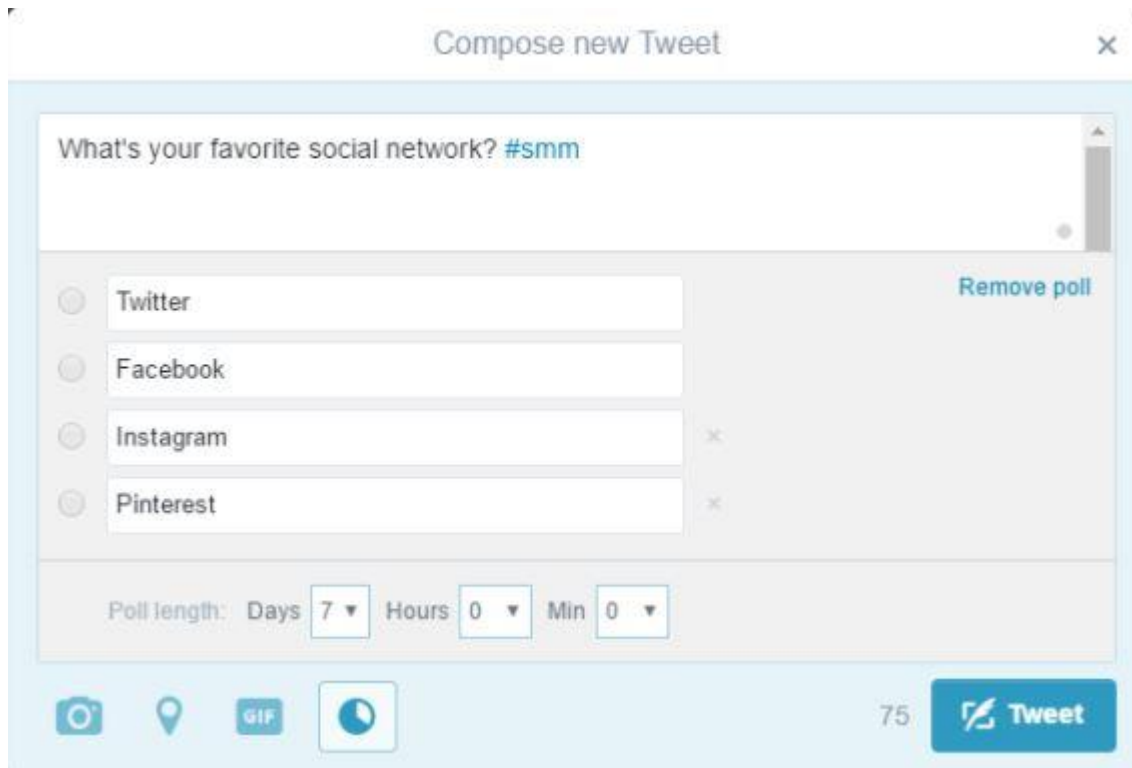
Twitter

- A tweet is a post on Twitter
- A retweet is a re-post of someone else's post



Twitter

➤ Polls



The screenshot shows the 'Compose new Tweet' window on a mobile device. The text of the tweet is 'What's your favorite social network? #smm'. Below the text, there are four poll options: 'Twitter', 'Facebook', 'Instagram', and 'Pinterest'. Each option has a radio button to its left. To the right of the options is a 'Remove poll' link. Below the options, the 'Poll length' is set to 7 days, 0 hours, and 0 minutes. At the bottom of the window, there are icons for adding photos, location, GIFs, and a video camera. A character count of '75' is shown next to the 'Tweet' button.

Twitter

- Hashtags (#) - allow topics to be categorized
 - #HPM
 - #PalliativeCare
 - #PalCare
 - Note, please avoid PC or PallCare

Twitter - Collaboration

 **Torrie Fields** @TorrieKFields · 2m
T3: In the last week I've talked to 6 caregivers, all saying they just wish they could get a manicure...clinic-salon partnerships? #hpm

1 2 5

 **renée berry** @rberry Following

Replying to @TorrieKFields


I LOVE this and it makes so much sense. I would be obsessed with a hospice organizing something like this!! #hpm

LIKES
4



9:59 PM - 31 May 2017

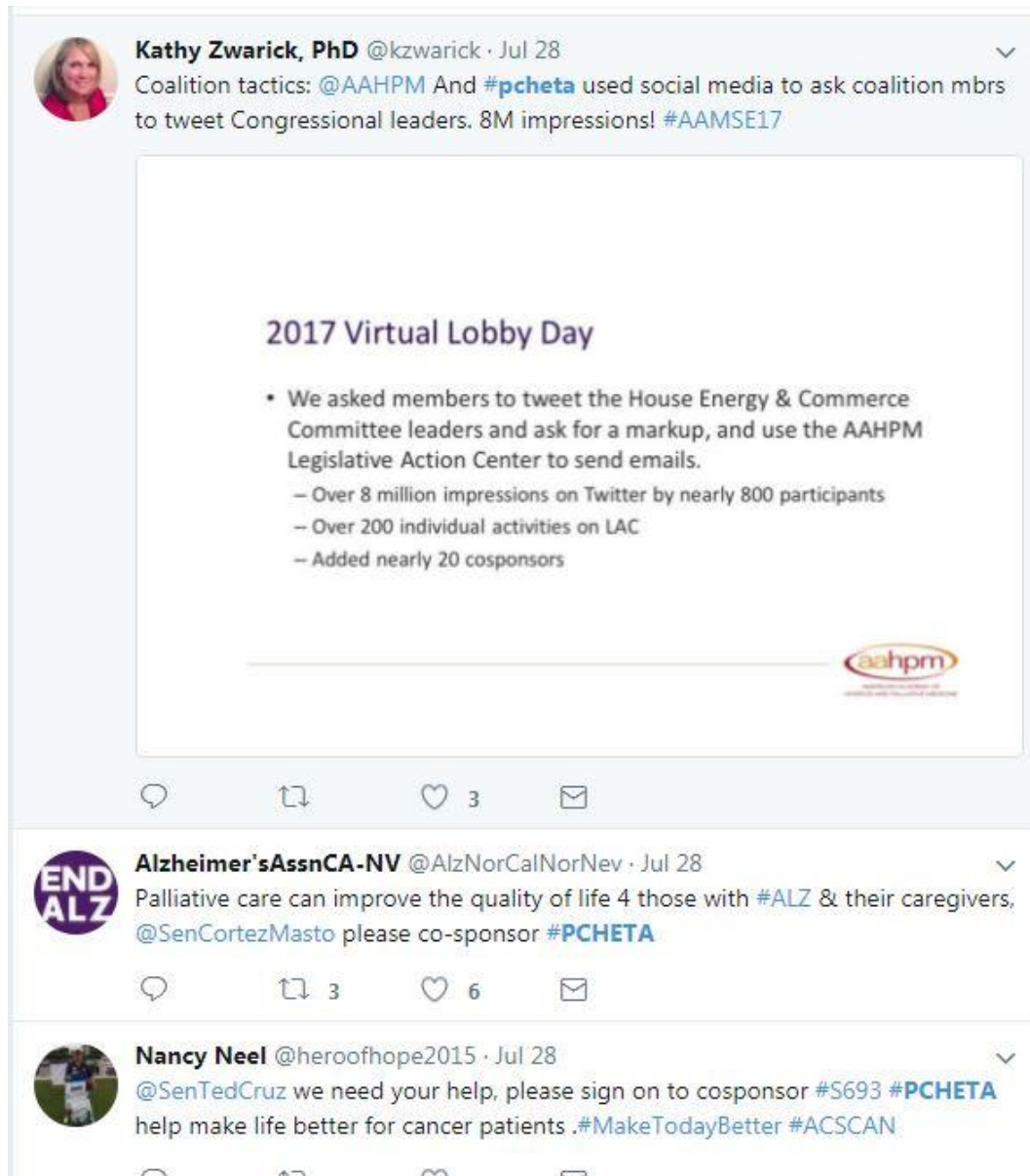
1 4



 **Torrie Fields** @TorrieKFields · 1m
Replying to @rberry
Let's do it!! #hpm

2

Twitter - Advocacy




The image shows a screenshot of three tweets from Twitter. The first tweet is from Kathy Zwarick, PhD (@kzwarick) dated July 28. It discusses coalition tactics used by @AAHPM and #pcheta to tweet Congressional leaders, mentioning 8M impressions and #AAMSE17. The tweet includes a graphic titled "2017 Virtual Lobby Day" with a bulleted list of activities and the AAHPM logo. The second tweet is from Alzheimer's Assn CA-NV (@AlzNorCalNorNev) dated July 28, promoting palliative care and asking for co-sponsorship of #PCHETA by @SenCortezMasto. The third tweet is from Nancy Neel (@heroofofhope2015) dated July 28, asking @SenTedCruz for help to sign on to cosponsor #S693 #PCHETA to help cancer patients, with the hashtag #MakeTodayBetter #ACSCAN.

Kathy Zwarick, PhD @kzwarick · Jul 28
Coalition tactics: @AAHPM And #pcheta used social media to ask coalition mbrs to tweet Congressional leaders. 8M impressions! #AAMSE17

2017 Virtual Lobby Day

- We asked members to tweet the House Energy & Commerce Committee leaders and ask for a markup, and use the AAHPM Legislative Action Center to send emails.
 - Over 8 million impressions on Twitter by nearly 800 participants
 - Over 200 individual activities on LAC
 - Added nearly 20 cosponsors



Alzheimer's Assn CA-NV @AlzNorCalNorNev · Jul 28
Palliative care can improve the quality of life 4 those with #ALZ & their caregivers, @SenCortezMasto please co-sponsor #PCHETA

Nancy Neel @heroofofhope2015 · Jul 28
@SenTedCruz we need your help, please sign on to cosponsor #S693 #PCHETA help make life better for cancer patients. #MakeTodayBetter #ACSCAN

Twitter - Education

 **Rab Razzak** @rabrazzak · Apr 11 ▼

#PalCareTip of the week: In challenging #conversations when people want a #miracle, use #AMEN protocol. #hpm ascopubs.org/doi/abs/10.120...

  2  

 **Rab Razzak** @rabrazzak · 3 Aug 2016 ▼

Replying to @LoriRuder

@drosielle @tsmit136 #AMEN protocol jop.ascopubs.org/content/early/...

#Affirm

#Meet them where they r

#Education

#NoMatterWhat

#HPM

 3  1  4 

Twitter - Education

↻ Dr. Amy Davis Retweeted



Eduardo Bruera, MD @edubru · Aug 3

Dexamethasone 4mg bid better than placebo for cancer fatigue at day 8 and 15
[1.usa.gov/1cVWLRm](https://www.clinicaltrials.gov/ct2/show/study/NCT01870153) #hpm



1



18

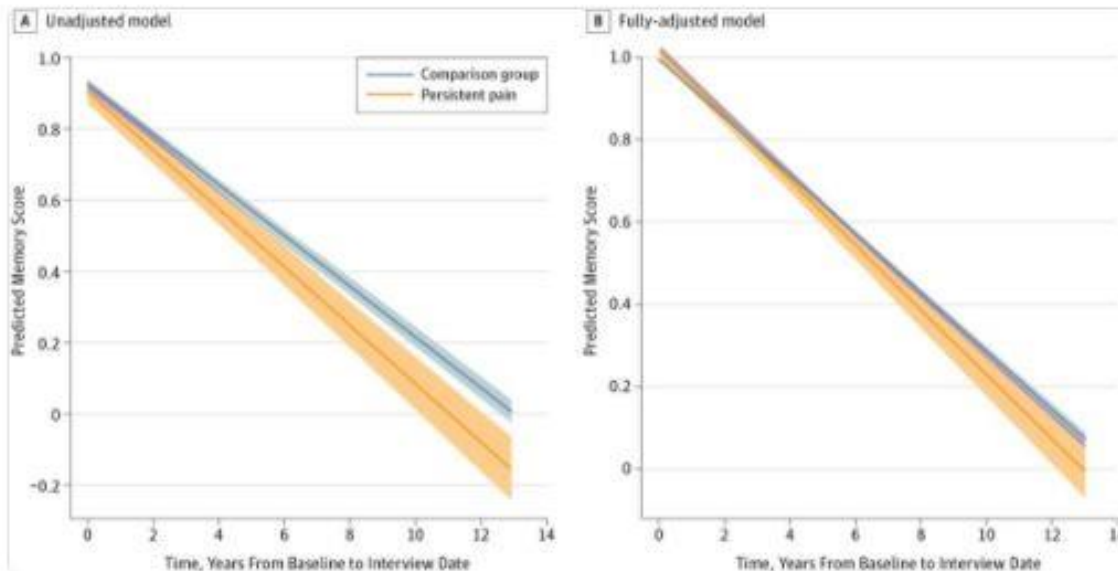


24



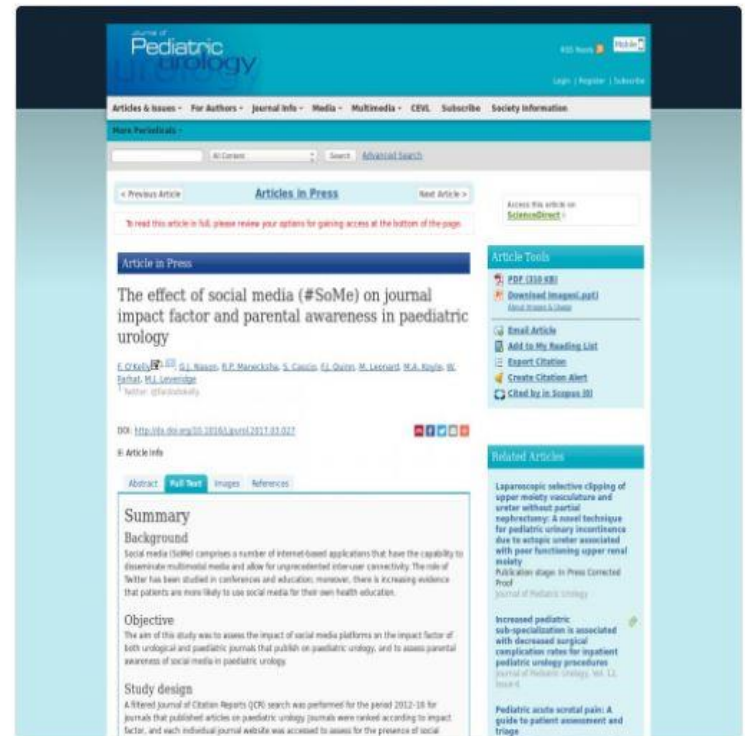
Christian Sinclair @ctsinclair · Aug 8

Long-term persistent pain associated with long-term cognitive decline #hpm
[jamanetwork.com/journals/jamai...](https://jamanetwork.com/journals/jama)



Journals and Impact Factor

- High journal impact factor = highly influential
- Number of times article is cited
- NEJM- 54.42



Twitter – The Best

- Great analytics
- Can interact with anyone
- News spreads fast
- Promotion and marketing

Twitter- Sample Page



Tweets
4,365

Following
1,156

Followers
1,197

Likes
4,004

Lists
1

Moments
0

Edit profile

Rab Razzak
@rabrazzak

Palliative care doc. Asst Prof
@HopkinsMedicine & @JHUNursing,
health care advocate & amateur
comedian. Views are my own. RT ≠
endorsement.

📍 Baltimore, Maryland

📅 Joined June 2009

🖼️ 279 Photos and videos



Tweets
Tweets & replies
Media

↳ You Retweeted



Peter Pronovost @PeterPronovost · 18h

Beyond patient education and med rec, we should seek more robust
#patientengagement strategies for medication safety ow.ly/emry30eoaw1

Ladder of Patient and Family Engagement

		Description and Examples of Engagement Strategies
Degrees of Engaging	5	<p style="text-align: center;">Integrate</p> <p>Integrates patients and families as full team members in care; supports patient-driven goals in and out of the healthcare setting. Patient and family involvement on care team transforms healthcare.</p>
	4	<p style="text-align: center;">Partner</p> <p>Partners with patients to become collaborators and consultants in their care. Patients are involved in decision making. Patient input impacts care. <i>e.g. Patients manage medication lists, collaborate with clinicians through portals; further on use of patient-generated data in electronic health records (adverse event reporting, patient reported outcomes); use transition coaches</i></p>
	3	<p style="text-align: center;">Empower</p> <p>Empowers patients with skills and tools to communicate and engage with their care team. <i>e.g. Patients provide feedback to clinicians through portals; programs build communication skills to discuss needs with pharmacist</i></p>
Informing	2	<p style="text-align: center;">Inform about Engagement</p> <p>Encourages patients to engage and communicate with their health care team. Patients are informed about their health care and encouraged to ask questions. <i>e.g. Patients are given handouts, booklets, computer programs about communicating with clinicians and error prevention.</i></p>
	1	<p style="text-align: center;">Inform about Healthcare</p> <p>Provides patients with information about medications. Patients are informed of health care but not about ways to become more involved. <i>e.g. Patients are given handouts, booklets, computer programs about medications</i></p>

🗨️
↻ 36
❤️ 47
✉️



Rab Razzak @rabrazzak · 2h

Replying to @RebeccaAslakson

Congrats! So proud of you! Well deserved. #HPM Rockstar!

Your Tweet activity

Your Tweets earned **1,983 impressions** over the last week



View your top Tweets

Who to follow · Refresh · View all



Anna Dauer @DauerHPM

Follow


✕



J Kalweit Schmeling @Dr...

Follow

✕



Rebecca Gagne @Rebecca...


Follow

✕

🔍 Find people you know

Trends for you · Change

20



Twitter - Analytics

Analytics Home Tweets Audiences Events More ▾

Rab Razzak ▾  Sign up for Twitter Ads



Account home

Rab Razzak @rabrazzak

Page updated daily

28 day summary with change over previous period



Aug 2017 - 15 days so far...

TWEET HIGHLIGHTS

Top Tweet earned 1,100 impressions

Expert Call: What's next for the #ACA with @ASlavitt @haroldpollack via @Drsforamerica #ProtectOurCare docs.google.com/forms/d/1g82kC...

↻ 2 ❤️ 2

View Tweet activity

View all Tweet activity

Top Follower followed by 25.5K people



Minda Wilson

@_mindawilson FOLLOWS YOU

Corporate Attorney & Affordable Healthcare Advocate | @bizjournals "2017 Woman of Influence" | Author of

Top mention earned 17 engagements

 April @mrs_ama12 · Aug 10

@DrSriram @kidoctr @namd4kids @Dr_ScottK @dmarie208 @SeattleMamaDoc @DrJaimeFriedman @yayayarndiva @freckledpedidoc @rabrazzak @CongressmanRaja Why are vaccines treated differently than any other medication 😊

View Tweet

Top media Tweet earned 479 impressions

Welcome @DraCruzOliver to @HopkinsMedicine @Hopkins_GIM #PalliativeCare Our newest faculty member! #hpm pic.twitter.com/V8Od0aaTrW

ADVERTISE ON TWITTER

Get your Tweets in front of more people

Promoted Tweets and content open up your reach on Twitter to more people.

Get started

AUG 2017 SUMMARY

Tweets	4	Tweet impressions	3,317
Profile visits	286	Mentions	3
New followers	11		

Twitter - Analytics

Seven Myths about Palliative Care

1	Myth	I don't want my patient to lose hope so I don't want my patient to see palliative care (PC).
	Truth	Patients who receive palliative care maintain hope and hope increases. There are no studies that show patients have less hope. Hope is the same or greater. Hope is reframed. Source: <i>J Palliat Med</i> . 2015 Dec;29(12):2109-25.
2	Myth	My pediatric patient is too young for PC.
	Truth	PC can be provided for any patient with serious illness at any age and at any stage and can be provided with curative therapies. Source: www.ccapc.org
3	Myth	I don't want my patient to become depressed or anxious.
	Truth	Patients have less depression and are less anxious when palliative care is involved. Source: Temel et al. <i>NEJM</i> 2010; 363: 822-34. Higginson et al. <i>Lancet</i> 2014; 383: 917.
4	Myth	Palliative care is end of life care.
	Truth	End of life is a small part of PC. Palliative care deals with an array of patients with various symptoms, which we aim to better control and help figure out the patient's preferences for care. Source: www.ccapc.org
5	Myth	I don't want all care to stop for my patient, so they cannot receive hospice care.
	Truth	Patients on hospice get coordinated care by a group of doctors, nurses, social workers, chaplain, etc. and the focus is comfort. Many medications are continued while on hospice and meds can be added for comfort. Source: www.ccapc.org
6	Myth	My patient will die sooner if on palliative care.
	Truth	Patients who receive concurrent palliative care live longer. Source: Temel et al. <i>NEJM</i> 2010; 363: 822-34. Higginson et al. <i>Lancet</i> 2014; 383: 917. <i>J Clin Oncol</i> . 2015 May 15;33(18):2535-42.
7	Myth	I think I do a good job of controlling symptoms.
	Truth	You may be doing a good job. Palliative care has been shown to improve QOL, symptoms and distress. Source: <i>J Pain Symptom Manage</i> . 2015 Dec;50(6):258-67.

 **JOHNS HOPKINS**
MEDICINE

3 134 120 ||| v

Impact is Measurable

Tweet activity



Rab Razzak @rabrazzak
7 Myth about #PalliativeCare #BetterCare #hpm @HopkinsMedicine @JHUNursing @HopkinsMedNews
pic.twitter.com/kHrhipbAw



Reach a bigger audience
Get more engagements by promoting this Tweet!

Get started

Impressions	17,807
Total engagements	1,162
Media engagements	645
Detail expands	142
Retweets	134
Likes	120
Link clicks	61
Profile clicks	50
Hashtag clicks	6
Replies	3
Follows	1

Facebook - Groups

Treating Cancer: Hope v. Hype

Public Group

Discussion

Members

Events

Photos


Search this group

Shortcuts

- Treating Cancer: Hope ...
- UPW New York 2017 20+
- Stand with Murthy - Viv...
- Slow Medicine 20+
- Life & Wealth Mastery F...
- March for Science 20+
- Physicians Against ... 20+
- Date With Destiny Fl... 7

Liz Szabo shared a link.
August 7 at 3:14pm


Ira Byock lists several examples of unnecessary treatment that increase pain, suffering (and cost). One example is providing multiple doses of palliative radiation for painful bone mets, even though one dose is just as effective. Why do doctors overtreat and overtest?



Why do we pay for bad health care?
With end-of-life care, second opinions or prior authorization for high-risk procedures could help prevent useless and perhaps harmful interventions.
STATNEWS.COM

Like Comment Share

5



Photoshop and Lightroom
207,003 members

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Facebook Professional Page

Center to Advance Palliative Care (CAPC)

Center to Advance Palliative Care (CAPC)
August 14 at 2:53pm · 🌐

Palliative care champions should be aware of the pressing issues facing our health-care system today, and be prepared to discuss how we can help decision-makers achieve their goals by improving care for those with serious illness.

The National Academy of Medicine (NAM) has long been committed to improving the care of serious illness. Revisit this blog post by Marian Grant regarding the NAM Vital Directions Initiative. <http://bit.ly/2toQr4W>

"To be effective palliative care champions, clinicians and other stakeholders must understand how palliative care fits into the priorities of policymakers and influential organizations."

By Marian Grant, DNP, ACNP-BC, ACHPN, FPCN, RN, Health Policy Consultant

Palliative Care Can Contribute to the National Academy of Medicine's Vital Directions Policy Initiative

PALLIATIVEINPRACTICE.ORG

Like Comment Share

8

2 shares

Write a comment...

Center to Advance Palliative Care (CAPC)
August 11 at 2:40pm · 🌐

Use #CAPCSeminar17 to share your thoughts, insights and feedback from this year's CAPC National Seminar 2017 on social media. Join us this November in Phoenix at National Seminar 2017. Register today.

Send Message

Nonprofit Organization in New York, New York
5.0 ★★★★★

Community See All

Invite your friends to like this Page

6,433 people like this

6,243 people follow this

Megan Sipe-Mooney and 25 other friends like this or have visited

About See All

+1 212-201-2670

Send Message

www.capc.org

Nonprofit Organization · Medical & Health

Pages liked by this Page

AGS The American Geriatrics Society Like

NHDD National Healthcare Decision Support Like

GerIPal GeriPal Like

English (US) · Español · Português (Brasil) · Français (France) · Deutsch

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Facebook © 2017

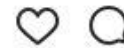
Instagram



aahpm
Phoenix Convention...

Following

aahpm Paul Bennet, Shoshana Berger, and BJ Miller discuss redesigning the end of life #hpm17



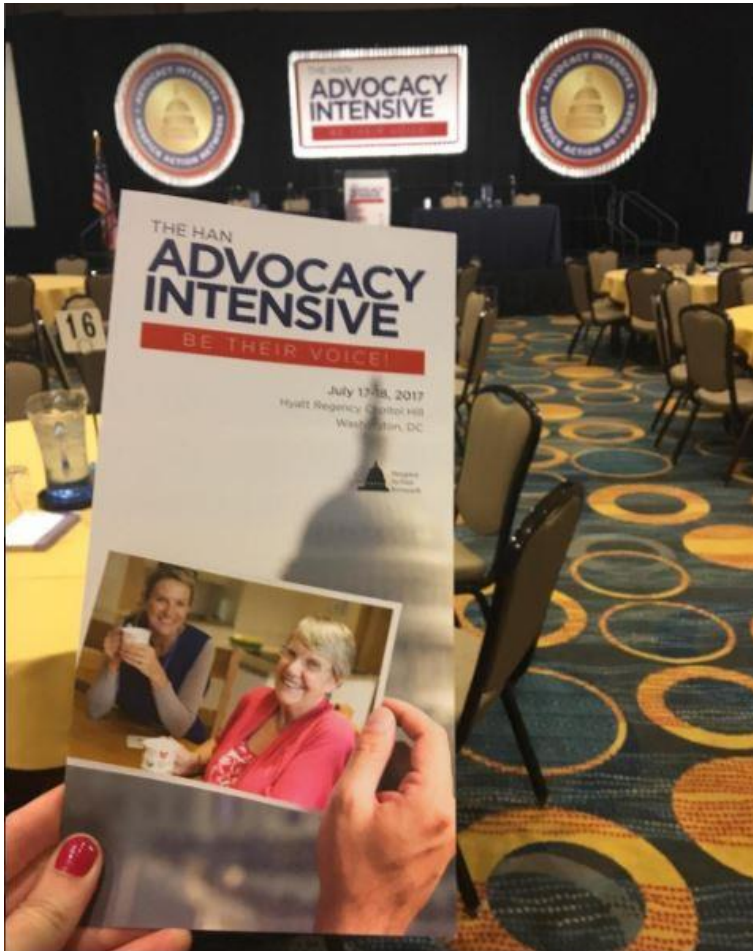
29 likes

FEBRUARY 24

Add a comment...



Instagram - Advocacy



nhpco
Capitol Hill

Following

nhpco Over 230 hospice advocates are in Washington, D.C., for the Hospice Action Network Advocacy Intensive to tell their stories on Capitol Hill. We thank them for their commitment to our community and to their patients and families. #grassrootsadvocacy #hpm #hospice #palliativecare #endoflifecare #dc #capitolhill

lovefromatx Thank you for your hard work!!!
Yes!!



44 likes

JULY 17

Add a comment...



YouTube

Featured Videos

The Center to Advance Palliative Care (CAPC) is the nation's leading resource for palliative care development and growth. As a national, member-based organization, we provide hospitals, health...



Palliative Care Nurse Leadership: Have the Passion
CAPC Palliative
35 views • 6 months ago



Community-Based Palliative Care Needs Assessment: Step One
CAPC Palliative
27 views • 6 months ago



Communicating with Frontline Clinicians
CAPC Palliative
33 views • 6 months ago



Goals of Care: Explaining Encounter Codes Part 1
CAPC Palliative
82 views • 6 months ago



Scaling Communication Skills Training Part 1
CAPC Palliative
56 views • 6 months ago

Popular uploads



The Human Connection of Palliative Care: Ten Steps for...
76,982 views • 4 years ago



Improving Palliative Care Across the System
3,573 views • 2 years ago



Palliative Care -- The "Aha" Moment
3,102 views • 9 years ago



What is Palliative Care
2,837 views • 9 years ago



Working with Referring Physicians: "Walk in their shoes"
2,563 views • 2 years ago

Managing Growth

Palliative care experts offer advice on how to deal with programmatic growing pains.



Tips for Managing Growth: Find a Balance
CAPC Palliative
141 views • 2 years ago



Tips for Managing Growth: Team Wellness
CAPC Palliative
230 views • 2 years ago



Tips for Managing Growth: Educate Others in Palliative Car...
CAPC Palliative
401 views • 2 years ago



Tips for Managing Growth: Self Care
CAPC Palliative
176 views • 2 years ago



Tips for Managing Growth: Put the Patient First
CAPC Palliative
224 views • 2 years ago

Leveraging Data



YouTube

The screenshot shows a YouTube search results page for the query "ted talks palliative care". The left sidebar contains navigation options: Home, My channel, Trending, Subscriptions, Get YouTube Red, and Get YouTube TV. Below these are sections for LIBRARY (History, Watch later, Favorites, Liked videos) and SUBSCRIPTIONS (One Islam Produ..., Rob O'Reilly, Cutie Marxist, Influencive). A "Browse channels" button and "YouTube Movies" link are also visible.

The main content area displays six video results:

- What really matters at the end of life | BJ Miller**
TED
1 year ago • 2,770,758 views
At the end of our lives, what do we most wish for? For many, it's simply comfort, respect, love. BJ Miller is a palliative care ...
19:08
- Palliative Care, a Different Voice in Healthcare: Timothy Ihrig at TEDxDesMoines**
TEDx Talks
3 years ago • 44,476 views
Healthcare expenditure is the biggest threat to America's economy, due to an aging population and a system in which physicians ...
13:30
- Telemedicine - making palliative care better | Trina Diner | TEDxThunderBay**
TEDx Talks
1 year ago • 803 views
Trina Diner knows more people die in hospital than die at home, and that is not always preferred. Her engaging talk addresses ...
11:35
- BJ Miller: Death as Part of Life**
Arts & Ideas at the JCCSF
1 year ago • 10,679 views
Despite best intentions, today's fractured healthcare systems largely compound our collective fear of the end of life as a time of ...
1:20:35
- I See Dead People: Dreams and Visions of the Dying | Dr. Christopher Kerr | TEDxBuffalo**
TEDx Talks
1 year ago • 307,660 views
Dr. Christopher Kerr speaks at a 2015 TEDx event Buffalo, New York. Dr. Christopher W. Kerr is the Chief Medical Officer at The ...
17:26
- How to Talk End-of-Life Care with a Dying Patient - Atul Gawande**
FORA.tv
6 years ago • 37,722 views
Complete Premium video at: http://fora.tv/conference/new_yorker_festival_2010 Practicing surgeon Atu...
ATUL GAWANDE
The New Yorker Contributor, Surgeon
3:02

Podcasts

The screenshot shows a SoundCloud player for the GeriPal PodCasts. The main player area features the GeriPal Podcast logo on the left, a red play button icon, and the title "Vicki Jackson and David Ryan: Living with Cancer". A waveform visualization is shown below the title, with a progress bar indicating 0:10 of a 32:14 duration. To the right of the waveform are icons for SoundCloud, a heart, and a share button. Below the main player is a list of other podcast episodes with their respective play counts.

Podcast Title	Play Count
GeriPal PodCasts - Vicki Jackson and David Ryan: Living with Cancer	214
GeriPal PodCasts - The Battle For Veterans' Healthcare: An Interview with Suzanne Gordon	465
GeriPal PodCasts - Optimizing Aging Collaborative: An Interview with Anna Chodos	445
GeriPal PodCasts - Life After the Diagnosis: A Podcast with Steve Pantilat	611
GeriPal PodCasts - Making Friends with the Enemies of the People: an Interview with NY Times Reporter P...	499
GeriPal PodCasts - How to Recommend to Stop Cancer Screening: An Interview with Nancy Shoenborn	480
GeriPal PodCasts - Vanessa Grubbs on Hundreds of Interlaced Fingers	491

Blogs



Home About Contribute Disclaimer Privacy Enter search keyword
All Contributors Post Type Symptoms Setting

Should Clinicians Be More (or Less) Politically Active?



by Christian Sinclair Politics and healthcare are occupying much of the news cycle this summer with all of the discussions around the possible repeal of the Affordable Care Act (AKA Obamacare). On one hand it can be viewed as must-see reality TV with all of the drama and back and forth arguments with passionate opposition. Late-night TV hosts help turn the drama into satire and give everyone a good laugh and some entertainment. Yet it is important to see that this will greatly impact the care of the patients we see every day. To be...

Tweet

Wednesday, July 26, 2017 by Christian Sinclair

Choice: The Hidden Curriculum in Palliative Care



By Paul Carr Thank you to Dr. Naheed Dosani and the excellent team at William Osler Health Centre for inspiring this post. What three words describe the essence of palliative care for you? When I asked my friends, family, and colleagues, the most common answers are: pain management, personal and spiritual support, and end of life planning....

Tweet

Monday, July 17, 2017 by Pallimed Editor

Palliative Care & CHF: PAL-HF trial



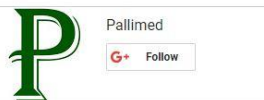
The main results of PAL-HF - a randomized, controlled trial of specialty palliative care team involvement in advanced heart failure patients - have just been published in...

Tweet

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24 friends like this



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PEOPLE RECENT POPULAR

Recent Comments

4TimesAYear
"haloperidol and risperidone (H/R from now on) worsened delirium in 'palliative care patients,' and were associated with higher mortality, compared to placebo." Good heavens, I

Palliative in Practice

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The Palliative Pulse, July 2017 LATEST ISSUE

PART 2: Ways to Overcome Implicit Bias in Palliative Care

In Part 2 of our interview with Dr. Kim Curseen, we discuss ways to overcome various types of biases, and the methods she employs in order to reduce the harmful consequences of unconscious bias for patients and families. [read more](#)

Spotlight on Pediatric Palliative Care: National Landscape of Hospital-Based Programs, 2015-16

In this post, Maggie Rogers, MPH, and Rebecca Kirch, JD, provide key findings on 52 hospital-based pediatric palliative care programs that participated in the National Palliative Care Registry™ in 2015/2016. [read more](#)

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Social Media for Education

ORIGINAL STUDY

A Call for New Communication Channels for Gynecological Oncology Trainees: A Survey on Social Media Use and Educational Needs by the European Network of Young Gynecological Oncologists

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David Lindquist, MD, PhD,§§ Stephan Polterauer, MD, PhD,|||| Vladislav Sukhin, MD, PhD,¶¶##
and Polat Dursun, MD, PhD,¶¶##*

Objective: The aim of the study was to assess patterns in the use of social media (SM) platforms and to identify the training needs among European gynecologic oncology trainees.

Methods: In 2014, a web-based survey was sent to 633 trainees from the European Network of Young Gynaecological Oncologists (ENYGO) database. The 14-item questionnaire (partially using a 1- to 5-point Likert scale) assessed respondents' use of SM and preference for workshop content and organization. Descriptive analysis was used to describe the mean scores reported for different items, and the internal reliability of the questionnaire was assessed by Cronbach α .

Results: In total, 170 ENYGO members (27%) responded to the survey. Of those, 91% said that they use SM platforms, mostly for private purposes. Twenty-three percent used SM professionally and 43% indicated that they would consider SM to be a clinical discussion forum. The respondents said that they would like updates on conferences and professional activities to be shared on SM platforms. Complication management, surgical anatomy, and state of the art in gynecologic oncology were identified as preferred workshops topics. The most frequently indicated hands-on workshops were laparoscopic techniques and surgical anatomy. Consultants attached a higher level of importance to palliative care education and communication training than trainees. The mean duration of the workshop preferred was 2 days.

Conclusions: This report highlights the significance of ENYGO trainees' attachment to SM platforms. Most respondents expect ENYGO to use these online channels for promoting educational activities and other updates. Using SM for clinical discussion will require

Social Media for Research



OPEN ACCESS

Palliative care research centre's move into social media: constructing a framework for ethical research, a consensus paper

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ABSTRACT

Background Social media (SM) have altered the way we live and, for many, the way we die. The information available on even the rarest conditions is vast. Free from restrictions of mobility, time and distance, SM provides a space for people to share experiences of illness, death and dying, and potentially benefit from the emotional and practical support of others in similar positions. The communications that take place in these spaces also create large amounts of 'data' which, for any research centre, cannot be ignored.

However, for a palliative care research centre the use of this 'data' comes with specific ethical dilemmas.

Methods This paper details the process that we, as a research, went through in constructing a set of ethical guidelines by which to work. This involved conducting two consensus days; one with researchers from within the centre, and one with the inclusion of external researchers with a specific interest in SM.

Results The primary themes that emerged from the consensus meetings includes; SM as a public or private space; the status of open and closed groups; the use of historical data; recruiting participants and obtaining informed consent and problems of anonymity associated with dissemination.

Conclusions These are the themes that this paper will focus on prior to setting out the guidelines that we subsequently constructed.

INTRODUCTION

The online world is alive with the topics of illness, dying and death^{1 2} and for a palliative care research centre this wealth of communication has implications for research practices. In a recent paper 'Using social media in supportive and palliative care research',³ its authors present

a detailed overview of how social media (SM) have evolved as a tool for research within the field of palliative care, but stops short of making any recommendations with regard to ethical and moral stances. It concludes with a call for ethical guidelines to be constructed for the use of SM. This paper details the processes that we followed when initiating the construction of our own set of ethical guidelines.

BACKGROUND

SM can be defined as any 'web-based applications that allow people to create and exchange content'.³ In this sense, SM can be understood to include blogs, microblogs, internet forums and social networking sites.³ The benefits of SM as a research tool are potentially vast and very tempting; they enable the opportunity to cross spatial and time barriers that exist in traditional research, they afford direct access to potential research participants, and provide a means of accessing vast amounts of data, quickly and efficiently. As an academic unit attached to a clinical trials unit, our research centre is committed to mixed methods research, and it has become clear that SM are an area of research rich with potential, but one which is also laden with ethical and practical challenges. Whereas guidance on the use of SM has been issued for healthcare professionals,⁴⁻⁶ which takes a view of SM as 'new circumstances in which established principles apply',⁵ no clear guidance currently exists for researchers interested in using SM.

Recent papers exploring the use of SM in supportive and palliative care have

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Social Media for Discourse

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Using social media to create discussion

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<https://doi.org/10.12968/ijpn.2015.21.11.525>

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Analysis of Twitter Data

[BMJ Support Palliat Care](#), 2015 Jun;5(2):207-12. doi: 10.1136/bmjspcare-2014-000701. Epub 2014 Sep 2.

Social media and palliative medicine: a retrospective 2-year analysis of global Twitter data to evaluate the use of technology to communicate about issues at the end of life.

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⊕ Author information

Abstract

BACKGROUND: Social media describes technological applications which are used to exchange information in a virtual environment. The use of social media is increasing, in professional and social contexts, on a variety of platforms such as Twitter; however, the scope and breadth of its use to discuss end-of-life care has not previously been reported.

AIMS: To determine the frequency, sentiment and trend of Twitter 'tweets' containing palliative care-related identifiers (hashtags) and/or phrases sent by users over a 2-year period.

METHODS: A 2-year retrospective analysis of Twitter posts (tweets), between the 1 August 2011 to 31 July 2013, using a social media analytics tool: TopsyPro. Thirteen search terms were identified and analysed for tweet volume, frequency, sentiment and acceleration.

RESULTS: A total of 683.5K tweets containing a combination of 13 palliative care terms were analysed. The tweet volume for all terms increased by 62.3% between 2011-2012 (262.5K) and 2012-2013 (421K). The most popular terms include 'end-of-life' (210K), #hpm (114K) and 'palliative care' (93.8K). Sentiment was high with 89% of tweets rated more positive than all other tweets sent on Twitter during this period. The term 'Liverpool Care Pathway' experienced the highest percentage increase in tweets (55% increase) reaching a peak in July 2013.

CONCLUSIONS: A lot of discussion about palliative care is taking place on Twitter, and the majority of this is positive. Social media presents a novel opportunity for engagement and ongoing dialogue with public and professional groups.

How-To Guide

- Purpose
- Audience
- Content
- Channel

Content

- Photo or sign
- Name/handle
- Brief bio- title, interests
- Link to your page
- Examples of your work, articles
- Brief comment on the link
- Schedule tweets

Grow

- Follow
- Tag
- Hashtag
- Engage
- Generosity

Caution

- Time
- Company
- Notifications
- Being overwhelmed

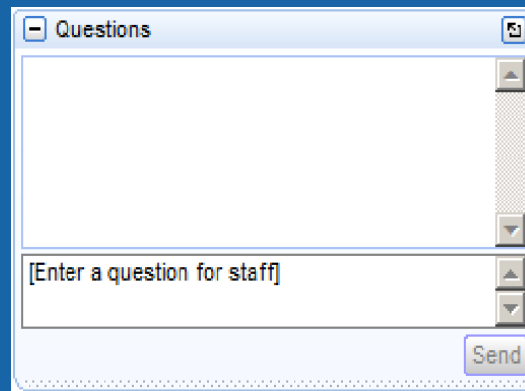
Thanks

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Questions and Comments?

Please type your question into the questions pane on your webinar control panel.



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