

BMT Patients Connect: Social Media, Mobile & Online Communities


Darlene Haven
Sr. Manager, Medical Marketing
NMDP/Be The Match



Learning objectives

At the end of this session:

- Describe how patients are using Facebook and e-communities for emotional support
- Describe guidelines for engaging and monitoring social media with your patients
- Identify ways to use a post-transplant guideline mobile app with your patients




When a patient needs a connection and comfort

A young woman posts an honest and emotional video of how she is doing

I too lost my job, independence, some friends, but I gained so much from it.I tell people life post transplant is an emotional roller coaster...continue to post on Be The Match.

We're here for you! Keep your chin up...you will get through this.

You are so sweet! The only people that truly know how we feel are the ones that have been through this! So many people tell me that the fight will be worth it, but hearing it from two survivors means so much more to me!




When a patient wants to show gratitude

Share a memory of a nurse who made a difference in your life:

Shirley is amazing....we would not be here without her. **We refer to her as our angel.**

Liz, went above and beyond by coming to see us in the home after Dad was placed on hospice and even following up with my mother after my father passed. **We love you Liz.....**

...every single nurse I had throughout my treatment and recovery were without question the most amazing people. **I am forever grateful** to them for the tremendous care I received from these incredible human beings.



And when they want to celebrate

Kristina, survivor, summits Mt. Adams and posts this picture to share with the world she has triumphed

...and another new connection is made

Ok, I just had an allo transplant, home yesterday. I have been so worried that I wouldn't be able to do what I used to do, BUT seeing this picture helps me realize that I totally will get to a point where I can hike and climb again. Thank you for posting this.





Be The Match – Patients Connect




They aren't alone

- 80%** Of internet users (59% of adults) looked online for information on health topics
- 34%** Of internet users read someone else's commentary or experience about healthcare in an online news group, website or blog
- 15%** Of Social Network site users (7% of adults) have gotten health information there


Suzannah Fox. "The Social Life of Health Information." Pew Research Center, Washington, D.C. (2011). <http://www.pewresearch.org/2011/10/07/the-social-life-of-health-information-2011/>. Accessed February 12, 2014. By permission.




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Analyzing the need to express

- What are patients saying?
- High concentration of introspective words
- Cancer diagnosis disclosed twice as often as diabetes
- Unmet need for support by providers, family & friends?



Seeking Social Solace: How Patients Use Social Media to Disclose Medical Diagnoses Online. Accessed online 2/20/14. <http://russellherder.com/white-papers/>. ©2011 Russell Herder. By Permission, February, 2014.




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Using these insights in patient care

- Go where they are
 - Provide forums your patients seek
- Care for the mind as well as the body
 - Underscores the need for emotional support
 - It's what you say and how you say it
- Empower your supporters
 - Those diagnosed/treated want to lend support to others
- Understand the boundaries
 - They want a close relationship; not too close in social media

Seeking Social Solace: How Patients Use Social Media to Disclose Medical Diagnoses Online. Accessed online 2/20/14. <http://russellherder.com/white-papers/>. ©2011 Russell Herder. By Permission, February, 2014.



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Monitoring social media for a safe experience




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Monitoring social media at Be The Match

Participation guidelines posted

- We encourage you to participate
- Keep your posts relevant and respectful
- To protect privacy, we may remove posts
- Posts should not be considered medical advice.

Team in place to monitor and respond


- Seeking help from us
- Asking a medical question
- In emotional distress
- Privacy issues




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Our unique social media challenge


- Protect the rights and privacy of transplant recipients and bone marrow, blood cell or cord blood donors



Patients are told donor's age & gender



Donors are told patient's age, disease & gender



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Education & Guidelines

BE THE MATCH Keep it **CONFIDENTIAL**
GUIDELINES FOR SOCIAL MEDIA SHARING

You got the call!
You're a match for an 18-year-old girl with cancer symptoms.
Assessment: I can't wait to tell someone.

Don't WAT!
Patients trust you to keep their identity private.
Social media makes it easy to piece together "bits." Careless comments generate unwanted publicity and could be seen as a breach of the patient's privacy.

Today is 15
OK "I'm donating blood!"
Don't share the exact date of donation.

NOT OK "I'm donating blood!"
Don't share the exact date of donation.

OK "I'm donating blood!"
Don't share age, specific illness, or gender.

NOT OK "I'm donating to an 18-year-old girl with cancer!"
Don't share age, specific illness, or gender.

Thank you
for your commitment and discretion.

NATIONAL NURSING BOARD **BE THE MATCH**

Social Media Guidelines for Nurses

NATIONAL NURSING BOARD **BE THE MATCH**

Case study: Jamie

Jamie is a hospice nurse for 12 years. Maria, one of her current patients with cancer, posted on a hospital-sponsored page to keep friends up-to-date. Jamie followed the postings, including one where Maria described her depression and struggles with pain control. Jamie was empathetic, and posted a reply, "I know you've been struggling lately and hopefully the [new meds] will help."

White Paper: A Nurse's Guide to the Use of Social Media. ©2011 The National Council of State Boards of Nursing (NCSBN). By Permission, February, 2014. https://www.ncsbn.org/Social_media_guidelines.pdf

Audience Response

What Jamie did was:

1. Fine, because she was posting on a hospital-sponsored site
2. Fine, because she confirmed what Maria had posted
3. Not acceptable, because her post was available to friends and family, who then saw more information than Maria had shared
4. Both 1 and 2

Case study: Nicole

- Nicole has been a transplant nurse for 15 years. After a very difficult day, she posted on her private Facebook page: "Hardest day of my life. Today we lost a precious little girl to neuroblastoma. My heart is broken and I'm angry."
- In a different frame of mind the next day, Nicole decided to delete the post. Nobody had yet commented on the post.

Adapted from White Paper: A Nurse's Guide to the Use of Social Media. ©2011 The National Council of State Boards of Nursing (NCSBN). By Permission, February, 2014. https://www.ncsbn.org/Social_media_guidelines.pdf

Audience Response

Was Nicole's post OK?

1. Yes
2. No

Where Nicole went wrong

- Although no patient information was technically disclosed the Board of Nursing could rule:
 - If you knew the nurse, the patient or the patient's family, it would be possible to identify who was being discussed.
 - She just disclosed private patient information
- Facebook is never private
- Deleting a post doesn't guarantee it's gone

Social Media Guidelines for Nurses

- National Council of State Boards of Nursing (NCSBN) and American Nurses Association (ANA) have collaborated on guidelines
 - NCSBN Guidelines for using social media responsibly
 - ANA principles of using social media
 - Resources:
 - Social Media White Paper on Guidelines
 - www.ncsbn.org/Social_media_guidelines.pdf
 - Articles, training presentations, brochures to download
 - www.ncsbn.org/2930.htm

Could you unintentionally disclose?

- Common *mistaken beliefs* of social media:
 - Is private and accessible only to intended recipient
 - Content deleted is no longer accessible
 - Is harmless if patient private info is accessed only by intended recipient
 - Is acceptable to discuss a patient, if not identified by name
 - Confusion between patient's right to disclose and need for healthcare providers to disclose

White Paper: A Nurse's Guide to the Use of Social Media. ©2011 The National Council of State Boards of Nursing (NCSBN). By Permission, February, 2014. https://www.ncsbn.org/Social_media_guidelines.pdf

How often does this occur?

2010 NCSBN survey of BONs (Boards of Nursing)

- 72% of respondents reported complaints of patient privacy violations on social media
- Of those, 79% took disciplinary actions
 - Censure of licensure, letter of concern, license conditions or suspension

White Paper: A Nurse's Guide to the Use of Social Media. ©2011 The National Council of State Boards of Nursing (NCSBN). By Permission, February, 2014. https://www.ncsbn.org/Social_media_guidelines.pdf

But on the other hand...
Harness the power of social media to inspire
1,208,782 views...and counting!!



Ever heard of Seattle Mama Doc?

Great example of connecting with parents/patients with credibility and engagement

- Blog: <http://seattlemamadoc.seattlechildrens.org/>
- Twitter: [@SeattleMamaDoc](https://twitter.com/SeattleMamaDoc)
- Facebook: <https://www.facebook.com/SeattleMamaDoc>

Audience Response

Which of the following describes you:

1. I am not sure if my hospital has a social media policy
2. My hospital has a policy, but I am unsure of all of the rules
3. My hospital has a policy, and I am fully trained on all of the rules

Find out more

- Not all social media interaction is off-limits
- Find your hospital's social media policy
- If they don't have one, access samples
 - <http://socialmediagovernance.com/policies.php>
 - <http://sharing.mayoclinic.org/guidelines/for-mayo-clinic-employees/>
- Practical guidance: The use of social media in oncology practice.
 - Dizon, DS, Graham D, Thompson, MA. J Oncol Pract. 2012, Sep;8(5)

Mobile App for Post-Transplant Guidelines

Importance of the Guidelines

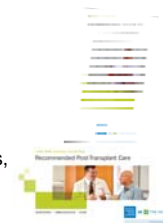
- Based on published research, Majhail, NS et. al. *Recommended screening and preventive practices for long-term survivors after hematopoietic cell transplantation, 2012.*
- Improving outcomes are increasing the number of survivors. These patients are at risk for developing complications months to years after transplantation. Ongoing monitoring is needed to prevent late complications or reduce their severity.
- The guidelines:
 - Provide most up-to date recommendations
 - Improve clinicians' ability to provide quality patient care before and after transplant
 - Improve patients' ability to advocate for themselves

From published guidelines to resources




Clinical Toolkit Contents

- Three-part long-term survival guidelines:
 1. Long-term screening recommendations
 2. Vaccinations
 3. GVHD screening recommendations, including photo atlas
- Referral guidelines
 - Timing for 18 diseases
 - Outcomes data



Patient Toolkit

- Patient-friendly version of the long-term screening recommendations
- 6, 12, 24+ month guides
- Each includes tests, evaluations and glossary
- Checklist to prepare for checkup
- Space for notes
- Includes Mobile App information



BeTheMatch.org/careguide

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Patients' reported use of guidelines

- > 95% → Understand that post-transplant care is important to their health
- 91% → Know the recommended tests 6-months post-transplant.
- 92% → Should talk with primary doctor about seeing specialists.
- 23% → Shared the guides with their provider.
 - 85% Believe my doctor knows the tests to give me
 - 46% Forgot to bring a copy of guide to appointment

National Marrow Donor Program, 2013. Unpublished Data

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Mobile App For Patients and Clinicians



- Referral timing guidelines with outcomes data
- Post-transplant care guidelines + GVHD screening/photo atlas
 - Patient and physician versions
 - Choose risk factors (age group, gender, GVHD, steroid exposure, TBI) and get individualized post-transplant recommendations
- E-mail results
- Links to references/outcomes data
- iPad®, iPhone®, Android®


BeTheMatchClinical.org/guidelines

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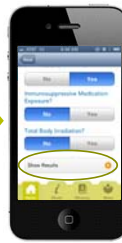
Mobile App

Choose time, risk factors (age group, gender, GVHD, steroid exposure, TBI)

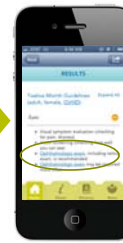
Personalize




Show results



See tests



Glossary



E-mail results to patient; to print

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Online Campaign to raise awareness of need for post-transplant care

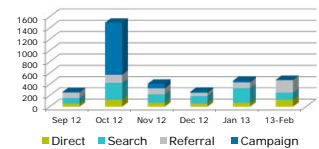


Plus Google Ads to Patients

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What we learned

- Patients are looking for post-transplant support
- Patients can be engaged through online ads and Google ads
- Mobile app downloads and web traffic increased
- 12,700+ downloads



Month	Direct	Search	Referral	Campaign
Sep 12	100	100	100	100
Oct 12	100	100	100	1400
Nov 12	100	100	100	100
Dec 12	100	100	100	100
Jan 13	100	100	100	100
13-Feb	100	100	100	100

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Ideas for using the mobile app

- Provide hard copy to patient; share app option
- Ask patient to download so they have with them
- Show/share app during appt:
 - GVHD pictures for what to watch for
 - Tests they can expect in next visit
 - Instructions to share with referring physician
 - Use personalization features; email to patient



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Summary

- Your patients want and need social connection
- If you can, tailor how you relate to these needs
- Share Be The Match Patients Connect Facebook
- Find out your hospital's social media policy
- Patients are using online technology, like mobile apps, to manage their healthcare
- Share post-transplant guidelines app to help them stay connected after transplant



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A Powerful Thank You

My husband had his transplant 26 days ago from an unrelated matched donor from the national registry. Our 8 year old son wrote this letter to the donor.

