

Week 4

Helping Patients/Peers Connect with DHTs and Making Your Own Digital Health Technologies

QUOTE of the WEEK

As we embrace new forms of technology, including some outside the medical care framework, we must ask questions about how to preserve the therapeutic ingredients and yet meet the patient (or person?) where he/she is.

Concerns about reaching remote areas, bridging gaps in access to care, and decreasing isolation are clearly important, but the human factors that promote change and the changing socialcultural and healthcare landscapes are equally powerful.

Presentation Outline

 Helping Patients/Peers Get Positive Results from their Online Postings



Checking in with Patients/Peers

Presentation

- Building your own Online Support Group
- Lessons Learned from a Treatment Center with a Closed Online Forum for Patients/Peers
- Next Steps

In particular, the group was considered a "communal brain" and illustrates the potential for members to access a wealth of both factual and experiential information, advice and support.



Coulson & Shaw, 2013

Sense of Community

- Membership: Individuals have a feeling of belonging to, and identify with the community
- Integration and fulfilment of needs:
 - The goals of individuals match those of the membership as a whole
 - As members satisfy their own needs, they also meet the community's needs
- Influence: Members feel they matter within the community and that they can influence and be influenced by the community
- Attachment: Members share an emotional connection, and believe they share or will share common history, places, or experiences.

Others claim that just about everything that happens in face-to-face interactions also happens online—it just happens differently. Even leadership manifests differently online.



Important Concepts in OSGs

1st the community's willingness to respond to a member's message, because the responses provide the content through which participants gain benefit from others in the group

2nd is members' commitment to the community, which reflects their satisfaction with their experience

so....

our job is help ensure the community responds to our patient/peer and to increase the patient/peer's commitment to the OSG

Arguello et al., 2006

In online groups, **CONVERSATION** is the basic mechanism by which participants derive benefit.

Whether they are explicitly soliciting information or assistance, or implicitly seeking to direct the group's attention toward topics in which they are interested, individuals who attempt to start conversations are trying to increase the likelihood that the group will provide benefits they value. Engaging a community can be difficult. What you say, how you say it, who you are, and where you are all affect the likelihood of successfully interacting with an online community.

 While individual contributions and group collaborations are the most visible aspects of social media participation, every social system must have some way of establishing community norms and explicit policies if it is to survive.



Preece & Shneiderman, 2009

Previous research has found evidence of optimal matching in the types of support offered:

When asking for

Informational support for decisions
Emotional support in times of stress

help

Burke Parish, 2017

Definitions of Types of Support

- Informational support refers to information, knowledge, or advice to help the recipient "understand his or her world and to adjust to changes within it.
- Emotional support refers to messages fostering feelings of comfort and leading the recipient to believe that he or she is understood, respected, or loved. The commenter may convey that he/she feels empathy for the recipient, or may offer well wishes or prayers and encouragement.

Other Hints on Messages/Posting

- Direct solicitations, disclosure of recovery problems, and expression of emotions received the highest volume of supportive replies.
- Messages that did not reveal recovery problems, did not directly request support, and did not reveal negative emotions were more likely to go without any response from peers.
- Messages disclosing more mundane thoughts and experiences or that were neutral or positive might have indicated to peers that disclosers were successfully managing their recovery without help.

Other Hints on Messages/Posting

- Sharing both positive and negative emotions conveys ambivalence, which may require support providers' to solicit additional details or clarification.
- The value of making support recipients feel their emotions and concerns have been heard and empathetically understood.
- Consistent with the "triage" model, support often goes to individuals who explicitly express they are most in need, including individuals who disclose negative emotions or recovery problems, or directly ask for help.

Other Hints on Messages/Posting

- Support seekers may receive more feedback from their peers if they disclose their feelings and problems.
- When individuals disclose their emotions, emotional support provides needed validation and empathy, whereas advice may create distance between receivers and providers.

Other Hints – Newcomer Status

- The history of an individual within a community also plays a role in the success of individual group interactions.
- Theories of reciprocity suggest that posters with a history of contribution in online communities are more likely to receive responses, because others feel obliged to return the favor.
- Newcomers who attempt to start discussions will be less successful than members who have engaged in the community in the past.
- Similarly, models of group involvement suggest that individuals with a history of participation will be more committed than newcomers, and as such, are more likely to continue contributing to the community in the future.

Other Hints – Stay on Topic

- Each online community involves a limited set of topics that are related to its goal or purpose.
- These conversational topics help establish and maintain the unique identity of the community.
- Messages that relate to these topics are perceived as being relevant to the group, whereas messages that are 'off-topic' can be treated as undesirable noise that fails to contribute to the group and may even distract other members.
- Although community names and formal descriptions can indicate a group's topical focus, the discussions are what reveal the interests and knowledge of the community's members.
- Posts that are topically consistent with these discussions are more likely to receive a reply than off-topic posts, because they are likely to appeal to members' interests.

Guidelines for Contributing in OSGs

- Receiving a response significantly increases commitment
- Helping users engage the community successfully will also serve to strengthen the community itself
- Newcomers who attempt to engage the group should receive responses
- Moderators should greet/welcome first-time posters
- Old-timers' prior posts may have increased familiarity, leading other members of the community to like them and be willing to respond to them
- Participating in the group in the past, old-timers may have learned how to form their messages so they are more likely to elicit responses from others, including testimonials, questions, and first-person pronouns. Review their responses, including self references ("I"), third-person pronouns, describing cognitive states and process, and expressing either positive or negative emotions all increased the likelihood that a message received a response.
- Read the prior OSGs discussions and stay on topic

Results suggest that assisting individuals with message construction, whether through examples, guidelines, or automated feedback, could help improve their experience within an online community.

- Write sample messages that patients/peers can use
- Review OSGs with patient/peers and identify messages that get the most responses
- Remind patients/peers to ask for information/support separately
 - Does anyone know a primary care doc or nurse practitioner that gets addiction?
 - I am really struggling today. I thought I would feel a lot better after 91 days of sobriety. Yesterday was great celebrating 90 days - today not so much. You all have helped me so much... suggestions you have today would be helpful.

A Post and Responses from SMART Recovery

♠ Forum ♦ Welcome To SMART (Intro) ♦ Success Stories ♦ 95 days sober - what finally worked for me

		Results 1 to 8 of 8	What to Expect at a SMART Meeting
Thread: 95 days sober - what finally worked for me			
Share this SMART Recovery Success Story! 🧗 💟 8*	Thread Tools -	Search Thread 🔻	What to Expect at a SMART
■ June 6, 2018, 2:21 PM		#1	
Wintercat •	Join Date: Posts:	Jun 2017 5	
95 days sober - what finally worked for me			P New Forum Posts
95 days sober - this is the longest I've been sober in a decade. The thing which clinched it for me was I decided to do a 30 day healthy eating challenge in March which included nutritious food, movement/exercise. When I started it, I honestly was not even thinking it would help me remove alcohol from my life, in fact I figured if I could go one week without alcohol that would be a big just started feeling great with everything I was doing. I hardly think about alcohol anymore. I started learning about nourishing my body, mind and spirit. I lost a total of 30 lbs so far and feel a change for me. I love waking up in the morning and loving myself for another day of sobriety. I do yoga almost daily now. I've heard people refer to it as "moving meditation" and I believe that afterwards and love how it challenges me. I'm thinking about getting my yoga instructor certification at some point. I'm a work-in-progress but feel I am conquering this! Instead of running for being pulled towards something inspiring, if that makes sense. I hope this post helps someone else or plants a seed. Wishing you all the best. Much love!	victory for me mazing. It's a I always feel	but then I ifestyle great	Hi Wintercat, Again Congrats on your success. I am glad that you find SMART Recovery site comfortable for you and you don't feel so alone. This Forum for success is really for people to explain 95 days sober - what finally June 13, 2018, 4:29 PM
	6 a	eply With Quote	Hi Turboharley - the 30 day health challenge I did was unrelated to Smart
Access SMART's Online Meetings, Forums, 24/7 Chat, Recovery Journals & Morel Register!	<u>– K</u>	epiy with Quote	Recovery or addiction, but it seems like there is something on this site according to what Woodswalker mentioned in their 95 days sober - what finally June 13, 2018, 12:11 PM
☐ June 6, 2018, 5:43 PM		#2	Thank you! Smart Recovery always made me feel like I was not alone and to stop
LINE 55 SMART MB Co-Liaison SMART Online Facilitator	Join Date: Location: Posts:	Dec 2010 Southwest Fl 23,569	 In the initial initial to be a start of the initial initiali initiali initial initial initia initial initial initial init
			Sure, turbo, join us. We started June 1st
			but you can still join. We'll probably start another in July. Just come over to the journals tab and you can keep track there. Good luck to you!
Hello Wintercat!!			95 days sober - what finally
Way to go!! Congrats on your success. 95 days is awesome. I loved your comment"It's a lifestyle change for me. I love waking up in the morning and loving myself for another day of sobrie	ty. "		June 12, 2018, 10:54 AM
Making a change is a choice!!			I would be interested in doing this 30 day challenge. Is there a certain one you did?
Thanks for sharing your success.			95 days sober - what finally June 9, 2018, 9:23 PM
LMR555			
"Discover the Power of Choice!"			
"The best time to plant a tree was 20 years and. The second best time is now " - Chinese Proverb			

Reader to Leader Process



Reader to Contributor

- Help peers/patients move from being on the sidelines:
 - reading content
 - watching others
 - to gradually making small contributions that become larger and more frequent as their confidence grows and they feel empowered and appreciated
- Suggest modest first steps- liking a comment, adding a positive emoji like a thumbs up, etc.
- Uploading a picture
- Correcting information without interacting



Preece & Shneiderman, 2009

Contributor to Collaborator

- Discuss one's efforts contribute to the common good of the group
 - Suggest taking on a role supporter, information provider, and caregiver
 - Some group members answer questions and never post a question
- Suggest looking for a contributor whose posts they connect with or like
- Post messages that engage the contributor- 'What Susan said struck a cord with me as I had a similar experience in early recovery. Although she said it much better than I could have. Thanks Susan.'
- Build trust by speaking authentically, make kind remarks that encourage contributions by the group
- High quality contributions can generate requests for assistance or invitations to collaborate within the community- write a blog or do a podcast or facilitate a discussion

Collaborator to Leader

- Leaders
 - Contribute the Most Content
 - Are passionate and show both positive and negative emotions
 - Are Not afraid to reveal their identity
 - Take on responsibility for the OSG
 - Mediate disputes among contributors and deal with troubled group members
 - Lock paging or block access
 - Prevent abuses
 - Mentor newcomers

In the community, *PatientsLikeMe*, members receive profile stars to indicate the amount of health information they've shared. The stars show other members who has shared how much. Once a member receives the maximum three stars, they can apply for mentor.



Learn more



Sign in

Join now

Young, 2013



Checking In With Patients/Peers

- Ask patient/peers to:
 - Identify which DHTs they are using- Abstinence vs. Health focused
 - Describe frequency of use and attendance patterns
 - Identify which OSGs or SNS they feel the most comfortable with and/or accepted by? Why?
 - Share with you some correspondence (threads, messages, etc.) they have received
 - Describe any problems they have experienced
 - Show you new sites or groups and if ask if they have or will share their experience with other peers
 - Identify any advice or messages that they question its veracity or causes confusion
 SPEND TIME CHECKING IN

Building an Online Community

- To build a thriving online community, organizations must ensure:
 - they have organizational commitment
 - the financial and human resources to not only start an online community, but also to support its growth and to evolve with the community throughout its life cycle.
- Before deciding whether to start an online community, resourcestrapped health organizations should perform an environmental scan and consider whether their proposed community differs from those that exist or whether it makes more sense to seek collaborative opportunities with an established community
- Investment in community management is imperative to an online community's success

Young, 2013

Life Cycle of an Online Community

Inception

- Slow, direct, growth
- Limited levels of
- engagement
- No sense of community
 0 50% activity initiated
- by community

stablishment

- Referral/direct growth
- Medium levels of
- · Limited sense of
- community
- 50 90% activity initiated by the community

Maturity

- Referral growth/Promo
 growth
 - High levels of engagement
 - Strong sense of
 - 90 99% activity by the
 - 90 99% activity by th community

Mitosis

- Community splits/grows into more focused groups
- · Repeats from inception for
- each unique group

Online Community-Inception Phase

- During the inception phase, the community manager
 - develops relationships with potential members
 - invites them to join and participate and encourages them to remain active
 - helps establish tone and style
 - recruits and nurtures an active core group to be community ambassadors
- Core members, including volunteers, play a vital role in the success of a community. They provide activity, but they also
 - establish the tone of the conversation
 - welcome newcomers
 - connect people in the community
 - give lurkers (people who read but do not post) the confidence to join the conversation
 - invite people to the community
- Core members also help make improvements to the community, such as identifying possible barriers to participation and usability problems.
- In the inception stage, all new members are potential core members.

Online Community-Establishment Phase

- Members generate more than 50% of the activity and ends when they generate most (90%) of the growth and activity and when the sense of community starts to develop
- Community manager focuses on:
 - adding, nurturing, and supporting core members
 - increasing activity with an eye to deepening the sense of community
 - continuing with the growth strategy and broadening outreach
 - expanding community tools

Online Community- Maturity Stage

- Begins when more than 90% of activity and growth are generated by members
- Many successful communities oscillate between the establishment and maturity phases as members retire from the community and community management strategies circle back to inception and establishment phase tactics to spawn new activity with new members.
- Size of the community reaches its critical mass, activity continues, and a sense of community is well established.
- While mature communities are often considered self-sustaining, the need for community management strategy and activity remains
- The community manager's attention turns to
 - training core members to assume roles to maintain activity stimulating referrals
 - promoting the community to new members intensifying the sense of community
 - assessing and optimizing processes
 - developing collective value

When a community grows to a point where the majority of members feel it is too large and too active, they will start to think they can no longer influence the community and they disengage. If the community manager does not do enough to mitigate this situation, the community will quickly die.



Evaluation of Online Community Activity

Table 2

Examples of growth and activity data that community managers could collect.

Measurement (monthly)	Key questions	
Number of first-time visitors ^a to community	Are people finding the community? What outreach tactics can be used, or technolog optimizations made, to increase the number of visits?	
Number of new members (registrants ^b)	What is the conversion rate from visitor to member? Is there a usability barrier to registration? Is the platform optimized to motivate visitors to become members? Are outreach tactics attracting the kind of people suited to the community?	
Number (or percentage) of active members ^C who made a contribution (post)	What is the conversion rate from registrant to active member? What motivates people to participate (high conversion rate)? Why are people motivated to register, but not to participate (low conversion rate)?	
Number of new active members	What influences are successfully motivating new members to participate and then to become active members?	
Number of returning active members	Are an increasing number of regular members remaining active? Why or why not?	
Total number of active members	Have new members become active members? Why or why not?	
Total new posts	Is activity consistently increasing? Where is activity greatest (eg, discussion forums, blogs, groups, polls)?	
Average number of contributions per active member	Is this number increasing or decreasing? Should more effort be dedicated to activity of existing members rather than growth? What activities are contributing to increased activity or not?	

^aVisitor = someone who has visited the community but has neither registered nor contributed.

^bMember (registrant) = someone who has registered with the community but has not yet made a contribution. ^cActive member = someone who has made a contribution within a determined period of time (eg, past month).

Online Support Group Moderators

- Our findings describe a range of altruistic motives which appear to underpin the decision to become a moderator and to support the group and its members
- Helper-therapy principle
- It was common for group moderators to
 - personally value the opportunity to both offer support to others as well as receive it
 - 'give back' to the group
 - have an increased sense of self-efficacy and self-esteem through the process of helping others
 - help individuals in order to limit the extent to which they may be ruminating about their own problems.
 - help sustain a healthy and productive online community
- more 'experienced' or veteran members may feel especially motivated by the need to connect to and maintain the community, as opposed to new members who may derive benefit by sharing their own experiences
 Coulson & Shaw, 2013

Online Support Group Moderators

- Moderators described needing to nurture their group to ensure it offered a safe space for members
- Clear rules for the group were considered essential:
 - engagement
 - trust
 - organization skills
 - compassion
 - kindness
- Online support groups can be empowering for both the group member and moderator alike.

9 TIPS for Professionals Using Social Media

- Consider social media a dialogue not a monologue
- Understand that the impact of social media is not in who follows you but who follows who follows you
- Share useful information
- Accept that the line between professional and private is eroding
- Be an early tester of technology but not an early adopter
- Get noticed by standing out
- Follow people you know who are already experienced in social media
- Work collectively
- Use common sense online just as you do offline

Table 2. Recommendations for Physicians Who Have Blogs or Practice Websites

Context	Recommendations for Ethical and Professional Conduct	
Writing about patients	Avoid writing about specific patients when possible or obtain patient permission and state explicitly	
	Protect identity of patients through deidentification or fictionalize encounters and state explicitly	
	Use respectful tone	
Health-related content	Share credible health information and resources	
	Counter inaccuracies in the media	
	Place results of recent studies in context	
	Use patient education videos	
Endorsements and advertisements	Disclose any in-kind or financial compensation received	
	Beware of making false or misleading medical claims	
Identification	Avoid anonymity	
	Accurately state credentials	
	State whether you are or are not representing your employer or institution	

Writing a blog using patient/peer case examples

Posted by Matthew McLean | Sep 15, 2017 | Planning & Methods for Podcasting | 12 •



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In this article we're going to walk you through every stage of launching your show, from planning to publishing. By the end, you'll know exactly how to make a podcast, and hopefully be motivated to do it as soon as possible!

HOW TO START A PODCAST IN 8 CHAPTERS

- 1. Plan your podcast, from listener, to problem, to unique solution.
- 2. Name your podcast and don't take long to do it!
- 3. Plan initial episodes to get a feel for your topic and its longevity.
- 4. Choose a format which balances quality and sustainability.
- 5. Choose your equipment and use it to record a show.
- 6. Produce your show in a sustainable way.
- 7. Publish your podcast to iTunes and elsewhere.
- 8. Think about next steps, promotion to monetisation.

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Upc	oming Events
Jun	Saturday Night Open AA Meeting
16	View this event
Jun	Progress Not Perfection NA Meetin
20	View this event
Jun	Saturday Night Open AA Meeting
23	<u>View this event</u>



Progress Not Perfection NA Meeting

ion NA Meeting

https://heartview.org/





- 1. Review DHTS
- 2. Create lists of DHTs
- 3. Consult with peers/patients on what DHTs they use
- 4. Think about how to implement DHTS in your services
 - Survey all patients/peers on their use of technology
- 5. Try it out with a few patients/peers



Interested in Technical Assistance???