Social Media:
Building and Using Electronic Media to Improve Communications with Patients

Dori Schatell, MS
Using Social Media to Engage Consumers

Dori Schatell, MS
Medical Education Institute  9/2/2014
MEI Mission: Help people with chronic disease learn to manage and improve their health.
KIDNEY DISEASE IS A TSUNAMI IN PEOPLE’S LIVES
STRONG EMOTIONS ARE NORMAL
TERROR, ANGER, DEPRESSION...
WHAT WE FOCUS ON

Other countries don’t even bother to look at urea clearance
WHAT CONSUMERS FOCUS ON: THEIR LIVES
Internet & Social Media
EMAIL & LISTSERVS – Early “Social” Media; Still in Use
MESSAGE BOARDS – SEARCHABLE, ENDURING
Elaine
Yesterday at 11:17

I see a lot of mention here about middle molecules and such. I feel so undereducated about my dialysis! I trusted my medical professionals to tell me what I needed to know, and I'm finding I know the bare minimum. Could someone point me to a good article that explains things like middle molecules and how everything works. I am reading everything I can get my hands on to be better informed. Thanks everyone.

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Dori Schatell 😊
18 hrs · Like

Elaine I found Kidney School and have been going through that! It should be required for everyone newly diagnosed with CKD!!! I haven't ordered the book yet, but I plan to.
16 hrs · Like

Elaine thanks, again!
16 hrs · Like

Facebook Discussion Groups: Asynchronous, Temporary
Chronic Disease & Internet Use

- 51% of Americans have looked online re: health
- Chronically ill less likely to be online (62% vs. 81%)
- Issue: Lack of access, NOT lack of interest
- Key activities: Blogging & online health discussions

Pew Research Center: Chronic Disease & the Internet, March 24, 2010
Hearts In The Crossfire: Standard Hemodialysis Stuns Organs—But, There Is Hope!

This blog post was made by Dori Schatell, MS, Executive Director, Medical Education Institute on February 26th, 2015.
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<th>Social Media Use (Observed)</th>
<th>Reason?</th>
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What Can We Learn from Consumers?

✴ How they feel from day to day

Question of the Day: 4/29/2013?

How many bad days do you have in one week? Ex: nausea, weak, fatigue, etc.

Ken every time I have a treatment

Marie Always weak and fatigued. Nausea not so much anymore but it happens time to time

Lisa Normally no bad days. He felt bad this morning but the machine pulled off .7 over the target last night, so that is why!

Nancy Every Monday, Wednesday and Friday for treatment days. I ache so bad all over and run a low grade fever. Nausea on and off.
What Can We Learn from Consumers?

* What they worry about or fear

**Wally**
How many of you are, like myself, hesitant to travel because you don't want to leave your home dialysis center?

**Terry**
I'm flying to So-Cal in June, and will only go for the weekend so I can get back to my center Monday. I understand your concern.

**Ned**
Me me me

**William**
I've never been afraid to travel. Most centers accept travel patients, & even cruises accept dialysis patients. Don't hold back! Enjoy the ride!
What Can We Learn from Consumers?

What bothers them

Fran
Some days I feel like dialysis would be bearable if I didn't have a fluid restriction. This is truly what I struggle with the most especially on the weekends when I'm hot and all I really want to do is chug a giant glass of ice water.

Beth
So true! It's hard to keep it under, or right at 32 oz.

Kevin
Fluid limit is the hardest thing for me being on dialysis.

Kayla
I feel the same way.
What Can We Learn from Consumers?

What sort of support they have (or want)

Wilma I would like my family and friends to acknowledge the fact that I have been dealing with ESRD and dialysis for two years now. I would like someone to ask me how I'm doing, maybe come by and see me while I'm doing dialysis (it isn't contagious!!). It seems like out of sight, out of mind. I'm not asking for it all to be about me, me, me, but at least a little acknowledgement here and there would be nice.

Charles I think some sort of acknowledgement of what has happened. I've seen NO ONE (Family) in 11 months since I started tests for transplant and of course the start of dialysis???????
Suggestions for Social Media Observers

🌟 Follow P&P re: “Friending” posting
Suggestions for Social Media Observers

✴ Show R.E.S.P.E.C.T.
Suggestions for Social Media Observers

✴ Disengage

KEEP CALM AND DON'T TAKE IT PERSONALLY
Suggestions for Social Media Observers

Help with *questions*—beware of answers
Prime the pump – Ask questions to get things rolling
零容忍的政策，禁止垃圾邮件或欺凌行为

STARTING A SITE? LESSONS LEARNED
STARTING A SITE? SPOT SPAMMERS
STARTING A SITE? TRACK KEY INFO
✓ Offer info of interest to members
✓ Respond to requests
✓ “Like” posts
✓ Welcome new members
✓ Celebrate success
✓ Boost confidence

STARTING A SITE? GIVE MORE THAN YOU TAKE
Facebook Sites to Join

✴ https://www.facebook.com/groups/HomeDialysisCentral/

HDC

✴ https://www.facebook.com/groups/DialysisUncensored/

DDU
If your kidneys fail, dialysis can save your life.

But, dialysis is not just a medical treatment.

It can also affect every aspect of your lifestyle.

This tool will help you choose the right treatment for *you*, so you can feel your best *and* live the way you want to.
Take Aways

✴ People with kidney failure are in chaos
✴ THEIR priority is their lives—not their Kt/V
✴ Social media can help you understand consumers