

How social media is helping patients cope with illness

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Kindness can be multiplied a thousand times

This is what Ramon Rodulfo learned when he started a blog chronicling his journey as a person living with HIV (PLHIV). It began as a simple online diary for Rodulfo, a fitness expert, but other PLHIVs discovered it and started sharing their own experiences. Reader questions prompted him to post a list of HIV testing sites and AIDS treatment hubs in the country. Subsequent support programs and partnerships with both government and private organizations eventually led Rodulfo to create The Project Red Ribbon Care Management Foundation.

“Social media is where we advertise,” said Rodulfo during the Healthcare Social Media Summit (HCSM) held last February 21, 2015 in Cebu City. “The problem with HIV and AIDS in the Philippines is that it has no face. But in the blog, in the stories that other people share in the blog, their questions, their struggles, their journey in the HIV testing, their personal experiences in the treatment hub – all of those humanize the disease.”

The foundation runs multiple programs for PLHIVs, most of which are coursed through social media for information dissemination and/or actual implementation. These include:

- Education and awareness campaigns
- HIV testing and treatment assistance



Mr Ramon Rodulfo during his talk at the Healthcare Social Media Summit.

- Phone hotlines
- Professional and peer counseling (face-to-face/online)
- Online support groups
- Health and fitness programs
- Skills development training
- Monitoring

According to Rodulfo, his website now reaches over 5,000 readers daily; the foundation's Facebook (FB) page currently has 1,560 likes. For others planning to run similar social media programs, Rodulfo offered the following tips:

- Maintain the platform – keep it credible, accessible and frequently updated.
- Safeguard patient rights – protect their identity, privacy and confidentiality; employ moderators to prevent cyberbullying.
- Regulate – observe guidelines; monitor content; encourage users to self-regulate.

- Sustain – interact with readers; provide useful information; create human interest stories; focus on potentially “viral” content.
- Make it personal.

From doctors to patients to social media advocates

Two HCSM organizers, Drs Gia Sison and Narciso Tapia, never imagined they would find themselves on the other side of the doctor’s desk. Their struggles with breast cancer and polycystic kidney disease (PKD), respectively, and the succor they found online was what inspired them to become social media advocates.

“I live on borrowed time,” said Sison, an occupational medicine specialist and former WHO consultant. “I don’t have a foundation, but through Facebook stories, and through Twitter, I started to reach out.”

Sison, who already had a blog prior to her breast cancer diagnosis, continued writing and became active on Twitter, where she currently has over 8,000 followers. Her online community has now become a second support group of sorts; when she tweeted she was going for her

yearly scan, she found herself inundated with messages of encouragement.

Tapia, an assistant professor at the Cebu Institute of Medicine and overall research coordinator of Vicente Sotto Memorial Medical Center, said the internet helped pull him out of the despair he felt when he found out he had PKD. He discovered the blog of a young girl who had the same condition and it helped him realize, “Life goes on.”

Today, Tapia writes his own blogs that tackle life with PKD. He created an FB page that helped him raise funds for his medical expenses when he was diagnosed with end-stage renal failure. He also founded the Smiling Kidneys Club, a support group for hemodialysis patients in Cebu.

These are just some of the ways that today’s patients are turning to social media to help them cope with their conditions. While acknowledging that there is still a significant digital divide in the Philippines, the HCSM organizers expressed hope that more patients will be able to benefit from the confluence of social media and healthcare. 