

EXPANSION OF THE ROLE OF WEB-BASED SOCIAL NETWORKS RELATED TO SYNTHETIC MESH/TAPE COMPLICATIONS.

Hypothesis / aims of study

Following a prior review of the literature on blogs and forums for patients affected by synthetic mesh and/or tape (SMT) complications (1) and additional FDA notifications (2,3), the list of popular forums and information on these web-based networks was updated. We determined the new developments in this dynamic SMT complications field assisting distressed women with their care and legal needs.

Study design, materials and methods

A review of available blogs and forums on SMT complications was conducted using the terms “mesh complications”, “mesh blogs”, and “polypropylene mesh removal” in Internet search engines for the United States and several other countries. Forums from a prior report were analyzed for updates, and new forums with their founders were identified using same search methodology through Internet Explorer. The number of posts and new fields from 07/2011 – 10/2013 was recorded. To avoid reading bias, 200 postings from each year (July 2011-Dec 2011, Jan 2012-Dec 2012, Jan 2013-Sept 2013) were examined for each site using a random number generator which generated a number from 1 to 10. The number of posts and new fields from 07/2011 – 10/2013 was recorded, and then divided into categories based on broad content (personal stories, supportive replies to complaints, patients recommending physicians, legal stories, newspaper/article stories with reactions, positive other).

Results

Although 4 social networks became inactive, 4 expanded and at least 5 new major ones surfaced (in italics in Table 1). While personal stories and support remained a prominent topic of discussion, other categories increased (Figures 1 and 2), such as the number of posts discussing physician referrals (PRP) and reactions to news stories (N) (Table 1). Additionally, the number of posts designated to personal stories of original surgery complications (PS) decreased. Finally, discussion about the topic expanded internationally.

Interpretation of results

Although the popularity of social networks and web forums did not decrease with the corresponding decline in implantation of SMT devices, the content on these sites did reflect a change. The number of personal stories regarding complications from original implantation of the device declined (based on calculations from the two most populated sites). On one of these sites, Topix.com, the decline in personal stories corresponded with an increase in posts concerning news stories/reactions to news stories (Graph 1). On the other site, Hystersisters.com, the number of personal physician recommendations for device removal increased markedly (Graph 2). These findings could reflect a growing awareness among the patient community about removal resources, rather than patients' needing an outlet to vent frustrations or share their complications. Differences between the administration (editors, board of trustees, funding) of the old and new web-based forums were also noted. Limitations to this study include a limited participant pool. Several of the web-based forums required registration and/or fee to be able to access the forums, thus, we were not able to collect data from these sites. In addition, the quantitative analysis of the data could have been skewed by strings of irrelevant posts on several of the forums.

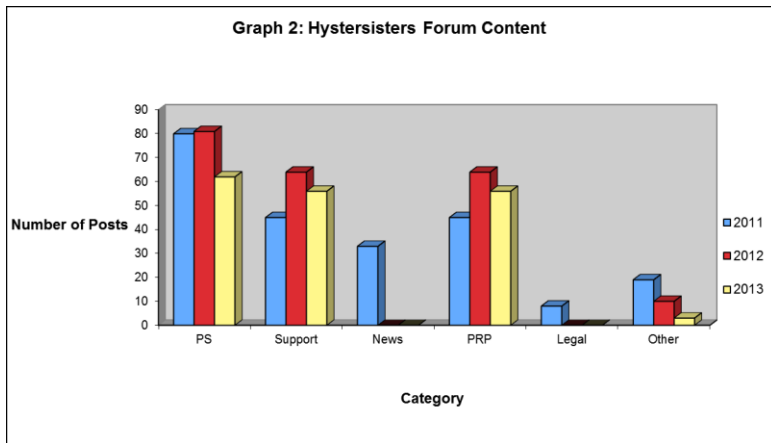
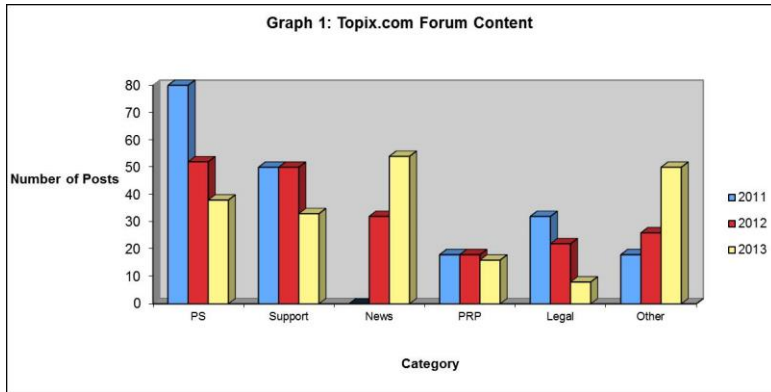
Concluding message

Web-based social networks for women suffering from SMT have expanded and the contents have broadened with new domains being introduced. Patient networking remains a dynamic force in the current debate on the future of these procedures.

Country	Website	Forum Name	Number of Posts since 07/ 2011	PRP % increase	N % increase	PS % decrease
US	www.topix.com	"Lawsuit filed Gynecare TVT bladder suspension tape"	2,619	0%	27%	21%
	www.hystersisters.com	"Mesh Erosion Support"	934	0%	27%	0% (includes PS stories from device removal)
	www.tvtno.org	Website Blog & Facebook group	Accessed by fee			
UK	www.tvt-messed-up-mesh.org.uk		Accessed by fee			
	Tvtinfo.wordpress.com					
<i>Scotland</i>	www.tvt-messed-up-mesh.org.uk/scotland-mesh-news					
Canada	www.healthcentral.com	"TVT Removal"	150 238			

		"Victim of Mesh Erosion"				
<i>New Zealand</i>	Individual blogs & reactions to news stories					
<i>Australia</i>	Individual blogs & reactions to news stories					

Abbreviations: PRP: Personal Referral of Physician; N: Reports and reactions to News stories; PS: Personal Stories



References

1. BJU 108:1539, 2011
2. FDA website 2011
3. FDA March 27, 2013 notification

Disclosures

Funding: none **Clinical Trial:** No **Subjects:** NONE