

Does the Internet provide patients or clinicians with useful information regarding faecal incontinence? An observational study

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SUMMARY: Does the Internet provide patients or clinicians with useful information regarding faecal incontinence? An observational study.

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Background. *The Internet has become an important platform for information communication. This study aim to investigate the utility of social media and search engines to disseminate faecal incontinence information.*

Methods. *We looked into Social media platforms and search engines. There was not a direct patient recruitment and any available information from patients was already on public domain at the time of search. A quantitative analysis of types and volumes of information regarding faecal incontinence was made.*

Results. *Twelve valid pages were identified on Facebook: 5 (41%) pages were advertising commercial incontinence products, 4*

(33%) pages were dedicated to patients support groups and 3 (25%) pages provided healthcare information. Also we found 192 Facebook posts. On Twitter, 2890 tweets were found of which 51% tweets provided healthcare information; 675 (45%) were sent by healthcare professionals to patients, 530 tweets (35.3%) were between healthcare professionals, 201 tweets (13.4%) were from medical journals or scientific books and 103 tweets (7%) were from hospitals or clinics with information about events and meetings. The second commonest type of tweets was advertising commercial incontinence products 27%. Patients tweeted to exchange information and advice between themselves (20.5%). In contrast, search engines as Google/Yahoo/Bing had a higher proportion of healthcare information (over 70%).

Conclusion. *Internet appears to have potential to be a useful platform for patients to learn about faecal incontinence and share information; however, given one lack of focus of available data, patients may struggle to identify valid and useful information*

KEY WORDS: Internet Search Engine - Faecal Incontinence - Social Media - Internet health education - Pelvic floor diseases.

Introduction

Faecal incontinence (FI) is a distressing condition caused by involuntary loss of faeces through the anus. It is a stigmatizing disorder that affects the quality of life of patients significantly. Due to the nature of their symptoms, patients are often embarrassed and do not seek medical attention (1, 2).

Since the development of personal computers the Internet has developed and become an essential tool in our daily life. As the possibilities of communication using the Internet expanded, social media has evolved to offer different types of information ex-

change. Nowadays it is rare to see websites without links to social media icons and this form of digital media linkage is becoming a common means by which products and services are promoted. The most frequently used social media platforms, such as Facebook and Twitter, have millions of regular users around the world. According to Statista, one of the leading statistical companies, registered Facebook users worldwide increased from 100 million in 2008 to 1.49 billion in 2015, while registered Twitter users increased from 30 million to 304 million in the last five years (3, 4).

Information exchange in healthcare around the world is not exempt from digital media trends. In US alone, 90% of adults use Internet while approximately 12% of Internet users regularly research medical issues (5). This information may be useful for patient education and advocacy but also for the

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lifelong learning of medical professionals or research (6). Social media may also help patients and medical practitioners overcome barriers in the delivery of the health care by engaging and empowering patients (7). Although there is an abundance of information available, it is essential for both patients and professionals to identify contextually relevant information (8).

The primary aim of this study was to assess available information relating to faecal incontinence obtainable via social media and the most common internet search engines. The secondary aims were to compare the trends of existing information from social media platforms and an internet search engine.

Methods

Facebook, Twitter and Google/Yahoo/Bing were searched using keywords 'fecal incontinence' and 'faecal incontinence'. All Twitter tweets over a period of 24 months between November 2014 and October 2016 and also all the Facebook pages and posts over the same period were extracted. The first fifty entries in the three main different Internet search engines (ISE) were analyzed separately and together on two different days in July 2016 and June 2017.

All abstracted information from Facebook, Twitter and ISE were entered into an Excel file and di-

vided into five broad groups: advertisements for commercial incontinence products; patients support groups and communication between patients; complementary and alternative medicine; humorous; or, healthcare specific information. The last group was further divided into four sub-groups: generic hospital/clinic information; information from scientific journals/books; communication between healthcare professionals; or, information provided by healthcare professionals to patients.

These datasets were further sub-divided by the number of tweets relating to common incontinence products, the number of tweets by individual hospitals or physicians and the number of followers and "likes" on each Facebook page.

Results

Facebook

There were 16 pages found on Facebook using the study key words: 4 were excluded because they were blank or contained information relating to urinary incontinence only. Of the remaining 12 pages, 5 (41%) pages were used by commercial companies or clinics advertising incontinence products: one page was set up by a company selling common reusable incontinence pants with 738 likes. The second page was used by an anal plug company with

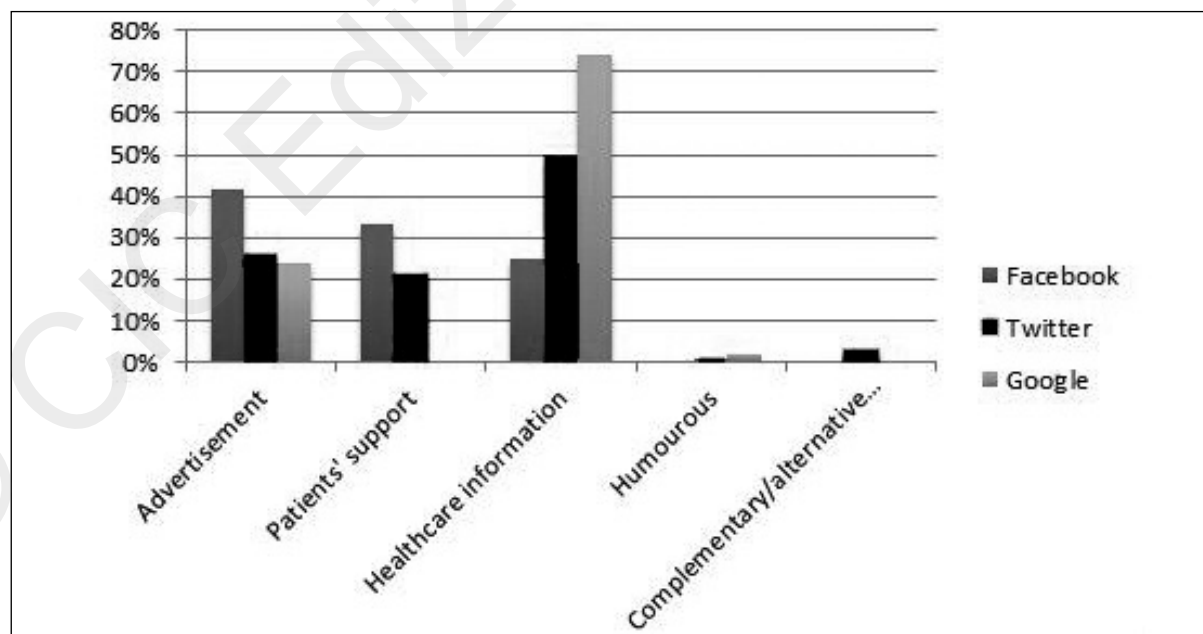


Figure 1 - Output from Facebook, Twitter and Google according to categories.

594 likes; the other three pages related to other incontinence products and all of these pages had less than 250 likes. Four pages (33%) provided incontinence related healthcare information: one was a Wikipedia page providing the scientific definition and treatment options for faecal incontinence which had 315 likes; the others two pages were set up by a hospital and a physician, respectively. These provided general information about FI and potential treatments, with both pages receiving less than 180 likes. The other 3 (25%) pages constituted patient support groups where people suffering from FI sought help, discussing available commercial products, hospitals, clinics and procedures. These pages had less than 100 likes each.

In the post section we found 192 entries over the last two years: 87 (45%) were advertising commercial incontinence products, 38 (20%) were post from patients support group. We also found 34 (18%) incontinence related healthcare posts related. For a better understanding the number of output in each category is shown in Table 1.

Twitter

There were 1,021 tweets between October 2014 and October 2015 (12 months) and other 1869 tweets between November 2015 and October 2016 for a total of 2890 tweets over two years with a difference between the two periods of 29%. More than

half of the tweets (1499, 51%) provided healthcare information; of these 675 (45%) were tweeted by healthcare professionals to patients, 530 tweets (35.3%) were between healthcare professionals, 201 tweets (13.4%) were from medical journals or scientific books, while 103 tweets (7%) were from hospitals or clinics which contained generic information about events and meetings. The next commonest type of tweet advertised commercial incontinence products (767 tweets, 27%), with three companies dominating (221, 206 and 140 tweets, respectively), while another 7 companies and commercial products were advertised with less than 20 tweets each with a few products appeared only once or twice. Patients used tweets to exchange information and advice between themselves (582 tweets, 20.5%). Twenty-eight (1%) tweets were made by promoters of alternative medicine including a combination of Aloe Vera, herbs and body exercises and only fourteen (0.5%) tweets were of a humorous or sexual nature. There were some hospitals/clinics and physician/doctors who tweeted more often than others: one hospital contributed 58 tweets (56% of all hospital-related tweets) and one colorectal physician tweeted 216 times (32% of all physician - physician and physician - patient tweets), which was double that of the next most prolific tweeting physician (16%). Two hospitals tweeted information 141 (26%) times relating to professional communica-

TABLE 1 - NUMBER OF OUTPUT ON FACEBOOK, TWITTER AND GOOGLE. IN THE FACEBOOK GROUP, FOUR PAGES WERE EXCLUDED BECAUSE THEY WERE BLANK PAGES. IN GOOGLE SEARCH RESULTS FROM TWO DIFFERENT TIME POINTS ARE SHOWN.

CATEGORY	Facebook		Twitter	Google	
	Pages	Posts		Jul 16	Jun 17
Advertising commercial incontinence products	5 (42%)	87 (45%)	767 (27%)	10	12
Patients support group/communication between patients	4 (33%)	38 (20%)	582 (20.5%)	0	0
Incontinence related healthcare information	3 (25%)	34 (18%)	1499 (51%)	39	37
• <i>Generic hospitals/clinics information</i>	0	5	103 (7%)	3	1
• <i>Scientific journals/books</i>	0	20	201 (13.4%)	8	10
• <i>Communications between healthcare professionals</i>	0	0	530 (35.3%)	2	0
• <i>Information provided by healthcare professionals to patients</i>	3	9	675 (45%)	26	28
Humorous	0	14 (7%)	14 (0.5%)	0	0
Complementary and alternative medicine	0	19 (10%)	28 (1%)	1	1

tions for physicians (meetings and conferences) and for patients (charity events, public events, new treatments available). Two professionals (307 combined) tweeted about international scientific meetings and conferences as well as disseminating new techniques or newly available treatments for faecal incontinence to patients.

ISE (Google/Yahoo/Bing)

In contrast, the analysis of Google undertaken during July 2016 demonstrated that this platform had a significant proportion of healthcare specific information (39 entries, 78%), with 10 (20%) commercial advertisements for incontinence products and 1 (2%) page relating to an alternative medicine therapy. A similar trend was also seen when Google was searched again on a different day in June 2017 with: healthcare specific information in 37 entries (76%), 12 commercial advertisements (23%) and 1 page relating to complementary medicine therapies (2%). Other common ISE such Yahoo and Bing showed very similar results which are briefed in Tables 1 and 2. Results are resumed in Figure 1.

Discussion

Internet has become increasingly popular as more patients go online and has revolutionized the way information are shared and accessed. Social media are an established platform for information exchange in recent years (9). Considering that social

media is potentially used by billions of users (3, 4), the availability of information via social media that relates to faecal incontinence is surprisingly sparse. Although faecal incontinence occurs across different age groups, it is more prevalent among older adults (10) who may be lagging behind in terms of Internet use compared to the younger generation who have grown up with Internet and are perhaps 'digital native' (11). According to the latest Pew Research Center survey which assessed Internet use (12), despite the steady increase in the number of users only 59% of people older than 65 currently use the Internet compared to 86% of all adults.

When the differences in social media coverage were probed, there was an interesting trend. Despite nearly 1.5 billion users on Facebook, the number of Facebook pages relating to faecal incontinence was very few. We noted a larger number of posts in Facebook but are still few if compared to other platform such Twitter. Therefore there were greater numbers of tweets containing a wide variety of information, which may reflect the more spontaneous and short nature of tweets. Twitter may be appealing to some users as they can remain anonymous and be passive recipients of information. Some users follow well-known specialists and hospitals for the latest information that they would otherwise have no 'non-digital' means to access. The short nature of tweets may also suit busy physicians, clinics, and hospitals allowing them to provide healthcare information, given these can be posted easily while on the move or in-between clinical sessions and other duties. Face-

TABLE 2 - NUMBER OF OUTPUT ON THE THREE MAIN INTERNET SEARCH ENGINES: GOOGLE, YAHOO AND BING. THERE WERE NO DIFFERENCES BETWEEN THESE GROUPS.

CATEGORY	Google	Yahoo	Bing
Advertising commercial incontinence products	12	14	13
Patients support group/communication between patients	0	1	1
Incontinence related healthcare information	37	35	36
• <i>Generic hospitals/clinics information</i>	1	2	2
• <i>Scientific journals/books</i>	10	8	8
• <i>Communications between healthcare professionals</i>	0	0	0
• <i>Information provided by healthcare professionals to patients</i>	28	25	26
Humorous	0	0	0
Complementary and alternative medicine	1	0	0

book tends to offer more interaction with one's work colleagues, school friends and alumni, real life friends and close people, thus it could be awkward to publicly express 'like' for incontinence groups and products. In contrast, our ISE searches yielded more scholarly information. This is probably due to the fact that these platforms use over 200 factors to rank pages and fine tunes their search protocol over 500 times a year to filter information (13) and using keywords such as 'faecal incontinence' have enabled the search to focus on scientific information. As expected we did not see any differences between the vary ISE.

The abundance of available information makes it difficult to filter and identify appropriate information one is looking for on Internet. On occasions, incorrect or non-usable medical information could be found on social media. A previous study of social media in urinary incontinence found that 47% of the information on Facebook was not usable and 60% of incontinence-related healthcare information on Twitter was not from health care professionals (14). The current study, there were a few dominant hospitals and physicians providing most of the information on faecal incontinence available via social media, which may represent skewed and regional specific information on management of faecal incontinence. As with other information on the Internet, judgment is paramount to pick and choose information wisely. Clearly, healthcare professionals can contribute to the available pool of information and improve the quality and content available via social media (15-19).

Some of the limitations of this study include the use of the specific key words such as 'fecal incontinence' and 'faecal incontinence'. We considered use of other terms such as 'bowel accident', 'stool leakage' or 'leak from back passage'. However, this inflated the number of tweets massively and it was impossible to filter other types of leak such as domestic pipe leak, toilet overflow, and tweets of sexual, explicit or humorous nature, from information relating to faecal incontinence. A limitation of this study was that the search was conducted during a defined period which may reflect the trend at the time of this study only.

Conclusions

Internet seems to play an important role in patients who suffers from faecal incontinence. Social

media appears to provide a platform for patients who want to learn about their condition and share health related or commercial product information with each other. Although Facebook is a widely used social media, we have identified that Twitter is used more actively by both healthcare professionals and patients to exchange information. For healthcare professionals seeking information on faecal incontinence, Internet search engines offered more focused entries on healthcare information. Given the abundance of information, patients may struggle to differentiate valid and useful groups/websites/tweets. Further work is needed to improve the quality of information available via social media and to make it more interactive to help patients, support groups and to more effectively share valid and useful information.

Declaration of conflicting interests

The Authors declare that there are not conflict of interest regarding the publication of this paper.

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Ethical details

This research did not involve humans and ethical approval was not necessary.

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