

Using social media to educate women and healthcare providers on endometriosis: preliminary results

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ABSTRACT

Objective: This study aimed to evaluate the performance of our Facebook fan page and compare it to similar pages.

Methods: The authors reviewed page-specific metrics provided by Facebook, including number of fans, their age and sex, and country of origin; number of views, likes, and shares tied to our posts. A search for similar fan pages using keyword "endometriosis" found pages in Portuguese, English, and Spanish. They were analyzed for country of origin, authors, number of fans and posts, and were compared to our page.

Results: Our fan page went online on April 2016 and 127 posts have been published up to December 2017. Most of its 1746 fans (89% women; 11% men) were Brazilians (n=1677). Our audience comprised primarily women aged 25-34 (39%) and 35-44 (30%) years. The most viewed posts discussed thrombosis and oral contraceptives (n=11078); continuous use of oral contraceptives (n=6448); deep endometriosis (n=4425); intrauterine levonorgestrel system (n=4045); IVF and endometriosis (n=2885); and endometriosis and cancer (n=2431). Our search found 399 Facebook pages from 44 different countries. The United States (n=81), Brazil (n=49), and the United Kingdom (n=46) topped the list of countries hosting pages, while most of the fan pages were written in English. The majority of the pages were active and 20% claimed they were based on science. Physicians administered four of the 10 most popular pages. Page heterogeneity prevented comparisons between them.

Conclusion: Men and women have visited our Facebook fan page to obtain information on endometriosis. The pages found in our search were exceedingly heterogeneous and were not compared. Developing pages with sound information is an important step toward educating individuals about endometriosis and helping them make informed choices on available treatments.

Keywords: endometriosis, social media, patient education

INTRODUCTION

Endometriosis is a benign gynecological disorder characterized by the presence and growth of endometrium-like tissue in sites outside the uterine cavity, primarily on the pelvic peritoneum and ovaries (Giudice, 2010; Borghese *et al.*, 2018). It affects 5-10% of women of reproductive age and the main clinical features are chronic pelvic pain and infertility (Carneiro *et al.*, 2010; Borghese *et al.*, 2018).

Disease hallmarks vary, and there is a lack of pathognomonic symptoms and useful noninvasive clinical tests to diagnose individuals with symptomatic disease. In addition, clinical presentation also varies, with some women experiencing severe symptoms while others remain asymptomatic (Carneiro *et al.*, 2010; Borghese *et al.*, 2018). Consequently, delays of five to 11 years have been observed in the diagnosis of individuals with the condition (Ballard *et al.*, 2006). The need for invasive diagnostic tools, the complexity of clinical presentation, the multiple morphologies of endometriotic lesions, and the lack of well-designed studies with sufficient numbers of patients have hampered research and delayed the diagnosis and introduction of appropriate treatment for the disease (D'Hooghe *et al.*, 2003; Arruda *et al.*, 2003).

Although much has been published on disease awareness from the side of physicians, studies have indicated that women suffering from endometriosis undergo multiple medical evaluations and have their complaints dismissed or not taken seriously, which may contribute to diagnosis delay (Arruda *et al.*, 2003; Ballard *et al.*, 2006; Hudelist *et al.*, 2012). In addition, there is a paucity of published studies on the perceptions the general public has on endometriosis (Shah *et al.*, 2010). Unfortunately, the quality of information available is often unreliable and leads to unjustified fear and a sense of helplessness (Canis *et al.*, 2016). Studies have found that women are keen to learn more about endometriosis and its symptoms, and that they preferentially obtain information from schools or the Internet (Shadbolt *et al.*, 2013). Therefore, delays in diagnosing the condition might be mitigated if the general public were educated about the symptoms of endometriosis (Arruda *et al.*, 2003; Seear, 2009; Shah *et al.*, 2010; Hudelist *et al.*, 2012).

Online availability of health information has skyrocketed in recent years. People all over the world use the Internet as their primary source of health information, but unfortunately clear standards are not in place and information is often inaccurate (Hirsch *et al.*, 2017). Social media has been increasingly used to obtain health information and has certainly changed the way people seek and share information on healthcare, despite the apparent lack of information quality control. Little information is available on the uses, risks, and benefits of using social media to educate the general public, patients, and healthcare professionals (Moorhead *et al.*, 2013). This study aimed to assess the performance of a Facebook fan page developed by the Endometriosis Multidisciplinary Team of the Federal University of Minas Gerais to communicate reliable information on endometriosis and pelvic pain. An attempt was made at comparing our page to other pages in terms of number of fans, page activity, and post topics.

MATERIAL AND METHODS

Facebook was chosen for its status as the most used social media platform (<https://br.newsroom.fb.com/company-info/>). Our fan page was designed by the Endometriosis Multidisciplinary Team of the Federal University of Minas Gerais (UFMG) to educate visitors on matters related to endometriosis, including infertility. Topics were selected based on the most frequent questions and misconceptions presented by women during consultation. Sometimes topics were chosen based on news stories featuring issues related to endometriosis.

Since there is no defined standard of care or legal guideline on the use of social media in Medicine, we followed the American Congress of Obstetricians and Gynecologists (ACOG) Practice Committee Opinion on Professional Use of Digital and Social Media (ACOG, 2015) and the recommendations of the Brazilian Board of Medicine on safe online communication (CFM - Conselho Federal de Medicina, 2011). When developing content, we took into consideration the Social Media Guidelines and Best Practices published by the Centers for Disease Control and Prevention (CDC, 2012).

In summary, we aimed at keeping the content short and simple with weekly publications. All content was checked for scientific and medical accuracy. The page was closely monitored so that fan questions, comments, and feedback were promptly responded. Page-specific metrics provided by Facebook - number of fans, their age and sex, and country of origin; number of views, likes, and shares of each post - were regularly collected. As a rule, medical consultation was not provided online and visitors were encouraged to read the information provided and take their questions to a physician.

The team responsible for the page was made up of three professors from the Department of Obstetrics and Gynecology of the School of Medicine of the Federal University of Minas Gerais (UFMG) and four medical students supervised by Dr. Carneiro. The page did not accept ads or paid content.

We searched Facebook for fan pages using keyword "endometriosis" and found pages in Portuguese, English, and Spanish. Relevant pages were selected and the following data obtained: country of origin, authors (healthcare provider, medical doctor, or lay people), number of fans, number of posts, and posting frequency. We also tried to compare these pages against ours in terms of number of fans, page activity, and post topics. Additional metrics from the found pages such as fan age, sex, or country of origin were not available to us.

RESULTS

Our Facebook fan page went online on April 21, 2016, and 127 posts had been published up to December 2017. Most of its 1746 fans (89% women; 11% men) were Brazilians (n=1677) from the state of Minas Gerais, although individuals from other Brazilian states, the United States, and Europe have visited it. Our audience comprised primarily women aged 25-34 (39%) and 35-44 (30%) years, followed by younger females aged 18-24 years (9%). Men aged 25-35 years accounted for the majority of male fans (4%), followed by men aged 35-44 years (3%). Most visitors viewed our fan page on cell phones or tablets. The posts with more views discussed the following topics: thrombosis and oral contraceptives (n=11078); continuous use of hormonal contraceptives (n=6448); deep infiltrating endometriosis (n=4425); use of the intrauterine levonorgestrel system (n=4045); IVF and endometriosis (n=2885); endometriosis and cancer (n=2431); endometriosis and infertility (n=1299); and how to schedule an

appointment (n=1264). The numbers keep increasing day after day.

The search for other Facebook pages using keywords "endometriosis" and "endometriose" (Portuguese for endometriosis) found 399 pages from 44 different countries. The United States (n=81), Brazil (n=49), and the United Kingdom (n=46) topped the list of countries hosting pages. Most of the fan pages were written in English (n=272), Spanish (n=73), or Portuguese (n=51). In terms of activity, 311 (77.9%) fan pages were deemed active - at least one post in 2017 - and 20% claimed they were based on science (their owners included healthcare providers, mainly physicians). A Brazilian fan page from a clinic in São Paulo amassed the greatest number of fans (59,666). Physicians administered four of the 10 most popular pages.

The pages were extremely heterogeneous, and their differences in terms of objectives and content prevented further comparisons. Metrics from each fan page are available only to the administrators of each individual fan page, and therefore were not used for purposes of comparison.

DISCUSSION

Although our search yielded numerous fan pages on endometriosis, they were hardly comparable. Social media platforms may be a valuable tool to educate individuals about diseases and treatments. Persons with chronic conditions might be particularly engaged for the interest they usually show in learning more about their illness (Antheunis *et al.*, 2013; Griffiths *et al.*, 2015; Roberts *et al.*, 2017). Unfortunately, misinformation about health spreads easily across social media and physicians are often unable to meet all patient education needs (Brown *et al.*, 2014). Information exchanged via digital means of communication should be monitored for quality and reliability (Tonsaker *et al.*, 2014).

The majority of our fans (39%) were young Brazilian women aged 25-34 years. A Brazilian study showed that patient age was inversely related with the time it takes for females to be diagnosed with endometriosis (Arruda *et al.*, 2003). Therefore, educating women in this age group might shorten the time until diagnosis, improve their quality of life, and decrease healthcare costs (Arruda *et al.*, 2003; Hudelist *et al.*, 2012; Seear, 2009). The interest sparked around the condition in social media represents a golden opportunity to educate women on endometriosis, since they prefer to acquire information on the subject from schools and the Internet (Shadbolt *et al.*, 2013). Unfortunately, we were unable to find studies on the use of social media to educate the public on endometriosis.

Although the majority of our fans were women (89%), men also showed interest in the published posts. Shah *et al.* (2010) showed that men and women have limited knowledge of the signs and symptoms of endometriosis, which in turn may contribute to delays in diagnosis. Educating physicians may also decrease delays in diagnosis (Arruda *et al.*, 2003). Hirsch *et al.* (2017) published a recent evaluation of information available online on endometriosis. The authors did not find Internet pages that contained high quality, accurate, credible health information about endometriosis. Unfortunately, this may result in patient misinformation, an issue physicians must be aware of.

Despite the recognized role of social media in providing information, healthcare providers and public healthcare institutions are still reluctant to use social media platforms (Antheunis *et al.*, 2013; Moorhead *et al.*, 2013). Physicians have not fully adhered to online communication or social media in daily practice (Brown *et al.*, 2014). However, studies showed that people rely on information available online and many times use the web as a primary source of information (Antheunis *et al.*, 2013; Griffiths

et al., 2015). Patients apparently search the Internet not as a substitute for advice from a physician, but as an attempt to gain more knowledge of their condition and of what their physicians told them. This may allow patients to play a more active role in therapy and improve communications with their physicians (Al Ghamdi & Moussa, 2012; Griffiths *et al.*, 2015; Roberts *et al.*, 2017).

Various explanations have been advanced for diagnostic delays, with implications touching physicians and female patients. Women treated for irregular periods might have difficulty distinguishing normal cycles from abnormal cycles, and might therefore take longer to seek help for endometriosis. It has been suggested that diagnostic delays might be reduced if women were informed of what to expect in normal and abnormal menstrual cycles (Seear, 2009).

Strategies to tackle this issue include the development of programs and training courses to improve the diagnostic skills of present and future gynecologists and family physicians. In addition, education initiatives targeting the general population may help to build awareness of endometriosis as an important cause of menstrual pain and subfertility, thereby urging affected women to seek evaluation and treatment. Social media may play a vital role in this setting.

Social media may also enhance patients' access to healthcare information and other educational resources (Moorhead *et al.*, 2013; Roberts *et al.*, 2017). Eighty percent of Internet users search specifically for health-related information, and many search for physicians, healthcare providers, and treatment options (Warden, 2017). In 2016, Facebook reported that approximately one billion people had the Facebook app on their smartphones, and that a significant portion of them used the app to search for health-related information.

The posts with more views discussed topics often seen with controversy and fear by the public. The use of oral contraceptives and the alleged associated risk of thrombosis, the risk of cancer in women with endometriosis, along with the potential risk of infertility in women with endometriosis ranked atop the list of post views. This may reflect the debate surrounding these topics and the need for reliable sources of information to deal with questions left unanswered after consultation with a physician. Social media is a golden opportunity to educate the public, dissipate myths, and provide patients with sound information to influence their decisions (Moorhead *et al.*, 2013; Roberts *et al.*, 2017). Unfortunately, misinformation about health spreads easily across social media and influences patient decisions.

In conclusion, we have developed a Facebook fan page for men and women of reproductive age seeking information on endometriosis. Preliminary findings indicated that our page on endometriosis has attracted the attention of males and females. Although many fan pages on endometriosis are available, they are quite heterogeneous and the quality of published information cannot be easily assessed. Developing pages with sound information is an important step toward educating men and women about endometriosis and helping them make informed choices on fertility and available treatments. Physicians and healthcare professionals should seize the opportunity and use social media to promote patient healthcare and education.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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