CELEBRITY EFFECT IN PUBLIC HEALTH AND BIOETHICS: AN "ITALIAN CASE" IN ENDOMETRIO-SIS PREVENTION COMMUNICATION

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ABSTRACT

Objective: To explore endometriosis-related digital seeking behaviour in Italy, after the showgirl Rossella Brescia announced to be affected by this gynecological disease.

Methods: We performed a retrospective search of web-activities related to endometriosis, carried out in Italy, in the last 5 years, using Google Trends with "endometriosis" as keyword and "search topic" as search strategy. We used the section Google News in order to check the impact of media coverage on web behaviour.

Results: Web-activities related to Rossella Brescia and endometriosis correlated in a statistically borderline significant way, even though peaks in endometriosis searches coincided with bursts in digital interest towards Rossella Brescia. Among the endometriosis-associated rising queries, "Rossella Brescia endometriosis" and "Rossella Brescia" were two of the most searched. Among Rossella Brescia-associated rising queries, "Rossella Brescia disease" yielded the first place (break out), whilst "Rossella Brescia endometriosis" the fourth place (breakout), "endometriosis" the fifth place (breakout) and "Rossella Brescia ill" the ninth place (breakout).

Conclusions: Practitioners should become aware of the importance of new media in communicating the disease with their patients and workers in the field of public health should strengthen their presence online, exploiting celebrity effect in order to disseminate rigorous but accessible information and raise public awareness against the disease, methods of diagnosis and prevention.

Keywords: celebrity effect in public health, communication ethics, Big Data, endometriosis, Google Trends.

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Introduction

Endometriosis is an oestrogen-dependent disorder caused by the aberrant presence of endometrial tissue outside the uterine cavity. It represents a puzzling disease characterized by pelvic pain, infertility, allergies, fatigue, and bowel problems. It is a non-lethal medical condition that disables only women and frustrates physicians who are frequently limited in their treatment success.

The painful symptoms of endometriosis were described as early as 1690, but endometriosis received its first mention in 1860 when Karl Freiherr von Rokitansky, an Austrian pathologist, wrote about the condition as "adenomyoma.", while the surgeon Thomas Cullen was the first to describe the clinical features of "adenomyomata" and provided the functional proof that the cells were of endometrial origin with a list of possible sites of adenomyotic lesions in the pelvic[1].

Sampson was the first to demonstrate specific endometrial activities, such as desquamation at the time of menstruation and decidualization in pregnancy[2]. Sampson's hypothesis, that rupture of an ovarian endometrioma caused superficial peritoneal endometriosis, was probably changed after the observation that the free, superficial peritoneal implants reacted like eutopic endometrium and derived from menstrual blood regurgitated into the pelvic cavity[3].

Recently endometriosis has been linked with endocrine, environmental, genetic, and immune factors[4].

In women with endometriosis progesterone resistance might impair decidualization and subsequent implantation in different ways, with an effect in genes, transcription factors, proteins and inflammatory mediators[5].

A recent study demonstrates, moreover, that the immune system is altered in infertile patients with endometriosis that could present antiendometrial antibodies in the serum and peritoneal fluid[6].

The public health impact of endometriosis is significant in terms of suffering, lost income, infertility, stress on families, and medical costs. Its estimated worldwide prevalence in reproductive-age women is about 10%[7], being higher in infertile women - in the range 25-40%[8].

For about 176 million women worldwide, whose lives are burdened daily by pain and/or subfertility, there is still no definitive treatment or prevention[9].

The economic burden of endometrosis is higly relevant, such as other chronic diseases, like diabetes. [Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis:costs and quality of life of women with endometriosis and treated in refferal centres Hum Repeod 2012; 27: 1292-9.]

In the era of e-health, patients tend to surf the Internet looking for health-related content[10]. Resources for endometriosis on the Internet include search engines, medical sources, advocacy sources, government sources, personal Web sites, public library databases, and social science sources[10,11].

Media (like TV and radio) and the new information communication technologies (ICTs, such as the Internet and, especially, the social networks) represent, indeed, an important source of information for gynaecological diseases, such as uterine fibroids[12].

It was calculated that in Google daily 4.5% health searches are about heath information. [Eysenbach G, Kohler Ch. What is the prevalence of health-related searches on the World Wide Web? Qualitative and quantitative analysis of search engine queries on the internet. AMIA Annu Symp Proc. 2003: 225-9.]

Social network websites, such as Facebook, otherwise, have an increasing active role in medical research as effective and cost-efficient recruitment method. [Whitaker C, Stevelink S, Fear N.The Use of Facebook in Recruiting Participants for Health Research Purposes: A Systematic Review.J Med Internet Res. 2017 Aug 28; 19(8): e290.]

The aim of the current investigation is to explore endometriosis-related digital seeking behaviour in Italy in a 5-years period, using Google Trends (GT), an online tracking system of Internet hit-search volumes that merged with its sister project Google Insights for Search (Google Inc.), after the showgirl Rossella Brescia announced to be affected by this disease.

Materials and methods

GT has been extensively used in the field of biomedicine, as shown in the recent systematic review by Nuti and collaborators[13]. In particular, it has been exploited for tracking infectious diseases, both for monitoring and surveillance purposes[14] and for investigating the public interest for outbreaks, like Ebola and Zika epidemics, especially in terms of reaction to media coverage[15]. It has been used also in the field of public health, for investigating the digital behaviour related to vaccination practices and organized screening programs[16], neuropsychiatry[17-19],   otolaryngology[20,21], rheumatology, and dermatology[22,23], among others. In the current study, we performed a retrospective search of web-activities related to endometriosis, carried out in Italy, in the last 5 years, using GT (freely accessible at https://www.google.com/trends) with "endometriosis" as keyword and "search topic" as search strategy. In particular, our analysis began in 2012, when Rossella Brescia came forward about her fertility problems related to a diagnosis of endometriosis.

We used the section Google News in order to check the impact of media coverage on web behaviour. We also searched for "Rossella Brescia" for comparison purposes, using the same strategy.

Searches can be performed using "search term" or "search topic" option. The first strategy enables to search exactly what entered by the user, whilst in the second search approach, GT enables to search all websites not only including that given keyword but related to the entered term. We focused our analysis on the "Related Searches" section, which shows queries (and not keywords) that are related to the entered terms (which are instead true keywords). In particular, GT distinguishes between top and rising queries. Top queries are the most popular or "evergreen" queries within the used search parameters, and, as such, tend to stay relatively consistent across time periods. On the contrary, rising queries tend to increase in term of relative interest. This rise in interest is expressed in percentage; with the term "breakout", GT indicates an increase above 5,000%.

Results

Web-activities related to Rossella Brescia and endometriosis are shown in Figure 1. Correlation resulted 0.12 (borderline significant), even though peaks in endometriosis searches coincided with bursts in digital interest towards Rossella Brescia.
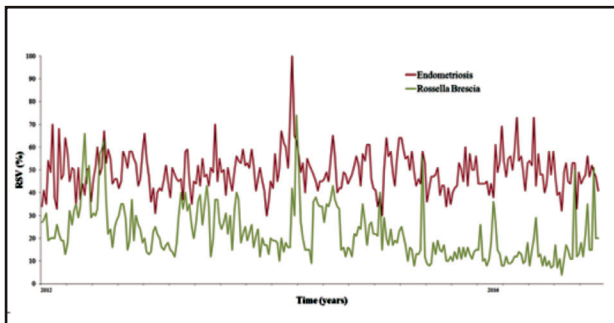
Figure 1: endometriosis- and Rossella Brescia-related web-activities performed in the last 5 years in Italy. *Abbreviations: RSV (Relative Search Volume).*

Among the endometriosis-associated rising queries, "Rossella Brescia endometriosis" and "Rossella Brescia" were two of the most searched, as shown in Table 1. The other related queries regarded endometriosis symptoms, pharmacological treatment and diagnosis.

Among Rossella Brescia-associated rising queries, "Rossella Brescia disease" yielded the first place (break out), whilst "Rossella Brescia endometriosis" the fourth place (breakout), "endometriosis" the fifth place (breakout) and "Rossella Brescia ill" the ninth place (breakout).

ENDOMETRIOSIS-RELATED RISING QUERIES	INCREASE (%)
Rossella Brescia endometriosis	Breakout
Rossella Brescia	Breakout
Endometriosis IV stage	Breakout
Sibilla® pill	Breakout
Crohn's disease	Breakout
Visanne® (Dienogest)	+2,550%
Visanne® (Dienogest) endometriosis	+2.400%
Endometriosis disability	+550%
Pelvilen®	+500%
Endo-mondo	+350%
Ovarian endometrioma	+300%
Pap-test	+250%
Dienogest	+250%
Endometrioma (endometrial cyst or endometrioid cyst)	+110%
Uterus	+70%
Ovaries	+50%

Table 1: Table 1: endometriosis-related rising queries and their respective increase in percentage, as captured by Google Trends.

Discussion

Rossella Brescia is an Italian showgirl, dancer and radio speaker, born in Apulia in 1971. In 2012, she revealed to suffer from endometriosis and to have undergone different operation for cyst removal. She has openly disclosed to different magazines her story and her desire to have a child, despite her disease.

In the current report, we documented how Rossella Brescia's announcement of suffering from endometriosis resulted in a burst of endometriosis-related web-activities.

Rossella Brescia's disclosure of her own disease represents, indeed, an important example of the so-called "celebrity health narratives", which blur the boundaries between private and public, reframe and reshape our perception of health and disease, break or at least reduce stigma and may drive healthy and preventive behaviors[24].

In the past, other celebrities, such as Jillian Michaels, Emma Bunton and Whoopy Goldberg came out about their health status and their experience of struggling to conceive naturally because of endometrosis. They have been proof of the opportunity to conduct a successful public life despite the invalidant sintoms of this disease, and helped to increase public attention to this disease, the best methods of diagnosis and treatment, as

well as the more appropriate prevention strategies.

The most famous example maybe is the disclosure of Angelina Jolie. Desai and Jena[25] found that daily BRCA test rates increased immediately after her disclosure, from 0.71 tests/100,000 women to 1.13 tests/100,000 women. However, overall mastectomy rates remained unchanged, while 60-day mastectomy rates among women who had a BRCA test fell from 10% to 7%. Authors speculated that Angelina Jolie's disclosure reached a broad audience, but failed to reach that specific sub-population target being at higher risk of developing breast cancer.

However, whilst the impact of a celebrity's disease has been highly investigated in the field of oncology, less is known about celebrity effect in the specialty of gynecology and reproductive medicine. Shadbolt and colleagues[26] recruited 131 women aged 16-25 years old in a survey investigating what young women know about endometriosis, what they would like to know and how they would like to receive information. The authors found that the Internet was the second source of information and that, in order to promote early detection of endometriosis, health promotion activities should exploit channels like ICTs.

Hirsch and coworkers[27] systematically assessed the content of endometriosis-related websites. After initially identifying 750 items, they analyzed in depth 54 online sites. They found that authorship was not stated in over a third of sites. Further, approximately half of the websites did not report information sources or scholarly references. Only few sites were of high quality, with most sites being scarcely readable. Only one disseminated accurate, rigorous information.

Celebrities disclosures quickly reach a broad audience, and highly impact on population's information need and awareness, even though with some gaps and distortions. Professionals in the health-care sector should act as a "tipping point"[28] for delivering accurate information, eventually correcting inaccurate information disseminated by media, thus improving and increasing knowledge related to a given disease.

According to a recent systematic review conducted about googling endometriosis and information available in the internet, reported that in 2017 only 16/750 Word Wide Web pages containing information concerning endometriosis were credible and accurate. The providers of online health information should adhere to codes of conducts in order to limit the diffusion of web pages that lack expert supervision. [Hirsch M, Aggarwal S, Barker C, Davis CJ, Duffy JMN. Googling endometriosis: a systematic review of information available on the Internet.Am J Obstet Gynecol. 2017 May; 216(5): 451-458.e1.]

However, our study is plagued by some limitations that should be properly acknowledged: the shortcomings concern the lack of transparency of the GT-based algorithm, that returns relative, normalized values instead of raw, absolute figures, thus hindering further handling and processing of the data. Further, the number of web-activities refers only to Google, which is only one of the extant search engines, even though the most used worldwide. Moreover, GT captures only a segment of the population, that is to say the individuals that actively use ICTs (the so-called "digital divide"). Another limitation is given by the fact that we did not investigate any "real-world" outcome of Rossella Brescia's disclosure of her disease: in other words, we did not assess whether the number of referrals to gynecological centers/facilities increased after the disclosure. For these reasons, this study should be considered as a pilot investigation, warranting further research in the field.

Conclusions

ICTs play a major role in the nowadays society: Rossella Brescia's disclosure of suffering from endometriosis resulted into a peak of web activities about this issue. Practitioners should become aware of the importance of new media in communicating the disease with their patients and workers in the field of public health should strengthen their presence online, exploiting celebrity effect in order to disseminate rigorous but accessible information and raise awareness about the most appropriate measures of treatment, prevention and early detection. Moreover, if the vip is testimonial to disease awareness campaigns, the effect obtained becomes effective and it is enhanced and transmitted by different media: internet, tv, radio, newspapers, etc… [29].

This approach will be particularly successful in diseases like endometriosis, for which optimal care of patients predicts a multidisciplinary and personalized approach in order to consider the various treatment options, such as laparoscopic surgery, that in some cases was demonstrated to improve pregnancy rate[33,31].

The use of celebrities' image is a successful tool to involve a wider part of the population and it permits to obtain also relevant sums in fund-raising for medical research on different diseases.

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