EFFECTS OF ONLINE HEALTH INFORMATION SEEKING
ON PHYSICIAN/PATIENT’S ACTIONS

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Anno Accademico 2011/12
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I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Letizia Affinito
ABSTRACT

We conducted a national online survey about health care experiences associated with digital communication of prescription drugs. 46 percent of the sample (265 adults) found information about prescription drugs during their online search in the last 12 months.

40 percent of respondents agreed they didn't find exhaustive information about risks and benefits while 52 percent agreed it helped in following their physician's indications and advise.

Among the 84 percent of the sample who had a physician visit during which health information found online was discussed, 84 percent received a drug prescription with only 17 percent being the same drug found on internet, 74 percent was sent to a specialist and 80 percent received a diagnostic test prescription.

More than half also reported actions taken by their physician other than prescribing the drug brand found online.

20 percent respondents states that info found on the prescription drug in Internet reduced his/her trust in the physician while 41 percent states it helped in his/her communication with physician.

Despite concerns about online health communication’s negative consequences, we found no differences in health effects between patients who took “advocated”/“mentioned” drugs and those who took other prescription drugs.
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“There is now widespread agreement among both the general population and health professionals that a good deal of disease is self-inflicted, the product of our own imprudent behavior. The premise that individuals contribute significantly to their own ill health or premature death appears unassailable in view of the mounting evidence relating various personal habits and lifestyle choices, such as poor nutrition, smoking, alcohol and drug abuse, failure to wear seat belts, and unsafe sexual practices, to major causes of morbidity and mortality. While it is generally accepted that each of us is, to a certain extent, “dangerous to our own health,” there is far less agreement on what can or should be done about making people less foolish. In particular, there is the question of how far government should go in fashioning lifestyles to minimize the physical and mental harm we inflict upon ourselves and others in society through risky personal choices. Where does personal choice and collective responsibility begin? How we reconcile two of our most prized social values, personal freedom and good health?”

Howard M. Leichter, Free to be Foolish
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1. GENERAL INTRODUCTION

In this introduction we first outline the context to this thesis recalling main definitions of health communications and marketing. Second we describe the problem area and subsequent research focus. From there, we define our main objective as well as our research questions. We conclude this introduction with an overview of the organization of the thesis.

1.1 CONTEXT AND SCENE SETTING

Adding to Bill Gates’ quote, Charles Grant stated that “Communication is an essential component of health care”. Although this quote may demonstrate the thoughtful nature of health communication, it is also well understood that health communication is elusive and complex – in concept and definition, in creation/development and delivery as well as in measurement and management. This is further complicated when looking at health communication in relation to healthcare outcomes (as opposed to consumer goods communication) especially in business-to-consumer context (as opposed to a business-to-business environment).

To elucidate the wider context of this thesis, before moving on to defining health communication and describing its role in shaping and producing positive or negative healthcare outcomes, we start by highlighting the importance of ethical health communication.

“If you get health, then you have opportunity for literacy. Health first, then literacy. Once you have literacy, then you have a chance to bring in the new tools of communication. Let people reach out and have access to the latest advances”. 

Bill Gates
THE ETHICS OF HEALTH COMMUNICATION

Health communication is a two-way process and takes place among biomedical scientists, between scientists and medical practitioners, between health professionals and the mass media, and between the mass media and the public. Being a means of combating disease and improving or protecting health, it should be conducted in accordance with certain ethical principles, namely those of beneficence, non-maleficience, respect for personal autonomy, and justice.

Excessive health information may undermine the public's capacity to absorb essential advice and respond to it in a rational way. Journalists and communication professionals who communicate medical information should not compromise ethical principles for commercial purposes.

Good journalists and communication professionals recognize the limitations of facts taken out of context and are aware of their potential for misinformation and harm and out of the ethical shortcomings of communicating them. Concealing or misrepresenting a context may take the form of failing to identify a research sponsor, for instance in the event of studies on lung cancer sponsored by the tobacco industry.

An obligation to benefit some people has to take account of any associated risk of harming others. The principle of beneficence implies providing net benefit, and health communicators should therefore make harm/benefit analyses. To do this they have to understand, weigh and specify the harm that is being risked and the likely benefits of an item of information. Assessments of harm and benefit may vary between members of the public, journalists, health communicators and doctors. Harm may result from a
misinformed decision as happened when the uptake of influenza vaccination declined in Italy following unbalanced and inaccurate reporting of the risks associated to the administration of the Novartis vaccine in October 2012. Journalists should try to anticipate the responses of their readerships and audiences, who should be informed about opposing views. Clearly, communicating information about harm and benefit in such a way as to respect the autonomy of individuals and their right to make up their own minds is ethically distinct from presenting it in a manner believed by a campaigning communicator to be beneficial. All persons involved in health communication have an ethical responsibility to do no harm to the public. Journalists’ loyalties should be to their readers rather than their sources. Where there is a risk of harm to the public, journalists and health communicators should take the public’s side. In some countries, such as France, medical Journalists have a written code of ethics. Elsewhere, for instance in the United States, ethical issues are decided on a case-by-case basis. In Italy, medical journalists don’t have a written code of ethics.

There is no written code of ethics for health communicators in no country, including Italy. Many countries have regulations requiring the pharmaceutical industry to communicate information about the safety of its products to consumers. In Italy DTCA is regulated by the **DL 24 aprile 2006, n. 219 - TITLE VIII**. Below we recall the articles more strictly related to the topic of our thesis.
Art. 113 “For the purposes of this Title, "advertising of medicinal products' shall include any information, activity or exhortation, designed to promote the prescription, supply, sale or consumption of medicinal products”

Art. 114: 1. It is forbidden any kind of advertising of a drug product for which no marketing authorization (AIC) has been issued in accordance with this Decree, Regulation (EC) n. 726/2004 or other binding Community provisions; 2. All parts of the advertising of a medicinal product must comply with the information listed in the summary of product characteristics; 3. Drug advertising: a) must encourage the rational use of the medicinal product, by presenting it objectively and without exaggerating its properties; b) not be misleading;

Art. 115 1. The medicinal products, their composition and their therapeutic target, are designed and manufactured for use without the intervention of a physician for diagnosis, prescription or monitoring during treatment and, if necessary, with the advice of the pharmacist can be advertised to the public; 2. It is forbidden to advertise to the general public medicinal products which can be supplied only by prescription or contain psychotropic or narcotic substances, in derogation from that prohibition the Ministry of Health may authorize vaccination campaigns promoted by pharmaceutical companies; 3. It is forbidden the distribution of medicinal products to the general public for promotional purposes; 4. Except as provided in the second part of paragraph 2 of this Article, it is forbidden advertising to the general public of medicinal products, whose dispensation burden, even if not entirely, is on the National Health Service, as well as' medicinal products referred to in subparagraphs a) , b) and c) of Article 3, paragraph 1, and Article 5;
5. In printed publications, radio and television broadcasts and messages for advertising, however, made public, it is forbidden to show images of a medicinal product or its name in a context that can facilitate the consumption of the product.

**Art.118:** 1. No advertising of medicinal products to the public can be carried out without the authorization of the Ministry of Health, with the exception of advertising in newspapers or periodical which, provided the provisions of Article 116 paragraph 1, only reproduce in its entirety and without modification the indications, contraindications, precautions for use, interactions, special warnings, adverse reactions described in the package insert, with the addition of a picture or a graphic representation of the outer packaging of the medicinal product; 2. The authorization is issued by the Ministry of Health, in consultation with the Committee of Experts referred to in Article 201 of the Consolidated Law Health, the Royal Decree of 27 July 1934, n. 1265, as amended.

In order to have a better understanding of the regulation we must distinguish between advertising and information.

**Information:** raise awareness, give information, provide data about people or things. It ’a personal right which is connected with the broader law of development of the human person (Article 3 of the Italian Constitution) and of expression.

**Advertisement:** adv activities to promote commercial purposes at the entire community of consumer knowledge and the favorable reception of certain products and services, in order to influence the behavior of individuals.
In addition to the DL 24 aprile 2006, n. 219 - TITLE VIII, drug advertising is regulated by the Code of Advertising Self-Regulation (art. 25) and by the Code of Professional Conduct Farmindustria - February 22, 2012 - Advertising in newspapers and magazines - 2.16 which states that “In the ambit of newspaper and magazine advertising, companies must comply with the rule of transparency and thereby accept, as an essential criterion, the net separation between information and advertising and hence guaranteeing the reader to be immediately able to recognize a promotional message, whatever its editorial or columnar layout.

This diversity of controls perhaps gives good grounds for drawing up an international written code of ethics for the communication to the public of information pertaining to health.

With the advent of new media the number of people seeking health information online has tremendously increased but a lot needs to be done in the direction of developing national/international ethical standards.

In general, the most useful type of web site for patients with a specific disease is a commercial site that provides in-depth information on a wide array of regional specific health issues. It should be financially nonbiased, and it should meet high ethical standards developed for information transfer (Ullrich, Jr. et al 2002).

A standard of ethics for the dissemination of patient specific health information has not been universally accepted or imposed on the myriad of web portals available on the Internet. To address this issue, several organizations are trying to develop a standard code of ethics for the World Wide Web health care industry. Specifically, Hi-Ethics (Healthcare Internet Ethics), Health on the Net Foundation, and the Internet Healthcare
Coalition’s E Health Ethics Initiative have combined to develop an E-Health Code of Ethics.

These organizations have agreed that health web sites, at the minimum, should:

- provide health information that is secure and trustworthy.
- clearly identify online advertising and disclose sponsorships or other financial relations that significantly affect the site’s content or services.
- keep personal information private and secure and employ special precautions for any personal health information. empower consumers to distinguish online health services that follow their principles from those that do not.

At this writing, not all of these organizations screen or verify adherence to such a code of ethics. Currently, there simply are not sufficient resources or will among the industry to do this.

Some professional medical societies also are beginning to develop their own code of ethics, and to screen health information web sites as a service for their members.

As an example, the Journal of the American Medical Association (JAMA) has developed an extensive code of ethics, which is published on the web site of the American Medical Association (AMA).

In essence, patient medical education sites should at least provide pertinent information necessary for users to use in making an informed judgment about the accuracy of the information on the site and any potential source of bias.

For physicians to choose a web site most useful to their patients without needing regularly to scan more than the 25,000 available health web sites available, they may rely on web
review services that frequently audit web site quality and ethics. One service that does just this is provided by the National Institutes of Health (www.medlineplus.gov). This service provides free access to information collected from its own sources, other government organizations, professional societies, universities, and other high-quality sources. All of the sites have been rigorously screened, and recommendations are updated on a regular basis. This service ensures that the sites adhere to ethical standards and are of high quality.

Although MEDLINEplus is fairly new to the electronic arena, it (along with the rest of www.nih.gov) is already the second most popular health care Internet site. MEDLINEplus is an excellent resource for guiding physicians to health web sites that focus on issues pertinent to their needs. Similarly, The Department of Health and Human Services provides an Internet service (www.healthfinder.gov) that screens health care sites and links to those that meet its ethical and quality guidelines.

A high-quality search engine also can be a good starting point for finding reliable health web sites. Most search engines on the Internet use automated “spiders” and other technology to find and rank web sites, but unfortunately do not screen for quality, content, and ethical standards. Google (www.google.com) was recently deemed the best search engine by the Wall Street Journal.

The distinction between communication and marketing is poorly understood throughout the field of public health. They are often seen as interchangeable. Maibach et al. (2007) believe, however, that the concepts are distinct and that the distinctions are meaningful for
public health. Each method offers a different and complementary approach through which to advance public health objectives.

Healthy People 2010 – a publication that presents the current U.S. federal health objectives – defined health communication as "the art and technique of informing, influencing and motivating individual, institutional and public audiences about important health issues." This definition is laudable for its inclusion of the full range of audiences implied by an ecological framework. Borrowing from the strengths of each definition, we define health communication as "the production and exchange of information to inform, influence or motivate individual, institutional and public audiences about health issues."

The American Marketing Association defines marketing as "an organizational function and a set of processes for creating, communicating, and delivering value to customers and for managing customer relationships in ways that benefit the organization and its stakeholders." Inherent in this definition is the notion of the marketing exchange. Marketing and communication do overlap, both in concept and in how they are applied in public health. Marketing communication, or promotion, involves the use of communication to support the marketing process. The definitions above were provided with the specific intent of clarifying confusion in the literature where communication has often been mistaken for marketing, and vice versa.

One metric by which to gauge the relevance of communication and marketing to public health practice is the extent to which they are capable of creating – or contributing to – beneficial changes in each of the five fields of influence. Figure 1 illustrates our contention
that communication and marketing each have potential to contribute to beneficial changes in all five fields of influence, and Figure 2 identifies the specific uses, or roles, of communication and marketing as they have been explored in public health to date.

Figure 1 - Communication and marketing potential to contribute to beneficial changes

Figure 2. Specific uses, or roles, of communication and marketing in public health
The type and availability of communication vehicles that can be used to convey public health information to individuals has grown dramatically over time. Some of these communication vehicles – e.g., brochures, small group counselling sessions, interactive DVDs, email and text messages – are well-suited to providing information to individuals on a one-to-one, or a one-to-few, basis. These communication vehicles can be effectively tailored to respond to individual attributes of the person receiving the information. Other communication vehicles – e.g., TV, radio, newspapers, movies, websites – are well-suited to providing information on a one-to-many, or mass, basis. It is worth noting, however, that when we use communication vehicles on a "one-to-many" basis, we are typically attempting to influence individual-level attributes of people (e.g., self-efficacy) \textit{en masse}, rather than attempting to influence attributes of the population per se (e.g., collective efficacy). The latter use of communication, as explained below, is a relatively unexplored opportunity in public health.
Until just a few years ago advertising of prescription drugs was aimed almost exclusively at physicians and other health professionals. Although physician drug detailing (in-person visits by drug company representatives) has been criticized for exerting undue influence on prescribing habits, physicians’ training and experience equip them, at least in theory, to process and evaluate advertisers’ claims and make informed prescribing decisions for their patients.

The near-exclusive focus on physicians changed in the late 1990s, when the pharmaceutical industry increased its use of direct-to-consumer advertising (allowed in USA and Scandinavia) while in Europe, DTC adv was introduced using a “disease awareness” model: disease information/education as a catalyst to both engage consumers and create a dialogue/relationship between company (corporate brand) as the owner of the product brand and the consumer as end user or carer.

Disease awareness approach is recognized as follows:

- Communication process, non an event
- Information/education instead of adv/promotion
- Built around a disease or medical condition, not a specific treatment or a product brand

With the advent of Internet and the increase of online health information seeking, European and Italian customers, mostly from medium-high social/educational level target, are increasingly exposed to DTC adv.
The great popularity of Social Media sites has definitely added a new dimension to the discipline of marketing and health communication. Social Media has taken its place on the list along with traditional media such as TV, Print, Radio, Outdoor, WOM and more recently Digital. And out of all the marketing options Social Media offers, Advocacy is being heralded as the “holy grail”.

Prior to the arrival of the internet, an individual may have recommended a brand to a handful of friends, they can now recommend (or advocate) the same brand to hundreds of friends and followers, or millions via forums, blogs and customer reviews. This is why social media is such a useful marketing and communication tool: a brand message can be disseminated in a very cost efficient way.

Advocacy can be defined in many ways: to recommend, to provide references, to be an ambassador for a brand. Plainly put Advocacy is people talking nicely about an organisation and recommending what the organisation has to offer to other people.

There are numerous studies which tell us that I trust real people (this is true both of friends and of any other consumer we read online) more than we trust the “big corporations” talking to us via advertising. With the growing popularity of Social Media sites, the answer to this dilemma has become obvious: Advocacy.

Individuals broadcasting a brand message to their peers has proven to be an extremely effective marketing strategy- there are real examples of brands such as Merck which has launched a Facebook campaign to maximize the effect of communication for its vaccine brand Gardasil. More than 50.000 fans have joined the Gardasil Group in USA (http://news.yahoo.com/women-steps-prevent-cervical-cancer-210417326.html). This successful online campaign uses surveys, stories, cards, banners and more to promote
and provide information about the brand (USA) and papilloma virus (Italy/Europe) (http://scienzaesalute.blogosfere.it/2011/06/papilloma-virus-sintomi-e-precauzioni.html).

Advocacy is better than advertising because of the trustworthiness of the advocate or “ambassador”. It becomes more efficient when the ambassadors are high influencers, opinion leaders, people with gravitas, but it is not limited to these kinds of people. An organisation will be pleased to have anyone talking positively about them, be they high influencers or not. Advocacy can drive sales, it can defend current customer relationships and above all it can build brand equity.

The role of health advocacy is to influence governments and national/international agencies in beneficial and health-promoting ways, and to raise the profile of health-promoting organizations, ensuring that their voices are heard and taken note of (IUHPE, 1999). Both Health promotion and public health are currently involved in a form of self-advocacy, obliged to re-invent themselves as “investments” in times of tough global competition for finite resources (Labonte, 1999; WHO, 1999). Ironically, the lack of concrete and universally accepted definitions for the term “health” and “health promotion” that so irritates critics is probably the factor which provides sufficient flexibility and scope for such reinvention. Advocacy for health therefore fulfils two functions: it is both a form of practice and a useful strategic tool for a discipline which has to be self-promoting as well as health-promoting in order to survive in the demanding contemporary environment of national and international health work (Carlisle, 2000).

In May 2012, Facebook logged its 900 millionth user. It is estimated that 80 percent of the world’s online population use social networks on a regular basis. In the United States, the
share of total online time spent on social networking platforms more than doubled from January 2008 to January 2011, from 7 percent to 15 percent.

The latest challenge for health communication in the 21st century is web 2.0. Although modest at first, spending on web 2.0 in health communications is increasing following the increasing trend in consumers use of internet to seek health information.

A survey conducted in 2010 by Doctor's Guide Publishing has, in fact, shown that 30 percent of the top 50 pharmaceutical companies have not activated any kind of social media presence, while only 11 and 20 of the top 50 pharmaceutical companies have at their disposal an authorized channel respectively, YouTube and Twitter. Their limited use was also evidenced by the lack of investment made by the pharmaceutical companies, with only 4 percent (more than $ 4 billion) spent in the promotion on the Internet, which was a small part dedicated to social networks and social media.

The reason for this limited presence was and, probably, is largely dictated by the absence of guidance from the Food and Drug Administration to regulate the use of these information channels and that relate to the content of the discussions on drugs in social networks. The guidelines governing the information directly to the public via the traditional media (print, radio and television) necessitates that it is clear which risks to which undergoing patients taking a particular drug and the side effects it causes. In social networks and social media content, however, are supplied directly by the citizens through their contributions and comments.

It is therefore impossible to test the rules that apply to traditional media.

Based on the CENSIS data (October 2012), 32 percent of the respondents said they use the internet to search health information. More specifically, 90 percent look for information
on specific diseases, 59 percent look for information on physicians and healthcare providers, while 14 percent participate in forums, communities, other ways of exchanging information and experiences among peers.

It is interesting to notice an increase registered in the number of aged people using internet from 56.4 percent in 2006 to 73.6 percent in 2012 mostly if we compare the data with the mean value (respectively 64.3 percent in 2006 and 73.2 percent in 2012).

Based on a recent survey from GfK EURISKO, 46% of internauts sought health information in Internet in the last 3 months. They used Internet:

- To confront and share information/opinions/experiences with peers (17%):
  - Friends/relatives (26%)
  - Physician (23%)
  - Patients affected by the same disease (16%)
  - Pharmacist (8%)

- To seek health information (42) on:
  - Diseases/health discomfort (36%)
  - Drug/treatment products and solutions (23%)
  - Healthcare providers (21%)

The use of blogs and forums to discuss their health problem with peers registered a significant increase from 2% in 2011 to 17% in 2012.

Based on a survey from GfK EURISKO (October 2011; Italian population 14 years old up, n= 4,000), 51 percent of the Italian population connected to the Internet in the last 3 months, 35 percent searched for health information. 13 percent users (around 2.3 million
people) was over 54 years old (last 3 months); 18 percent used the Internet to search for health/medical information.

They used the Internet to get:

- Health information (35%)
- Disease information (25%)
- Treatment/drugs information (13%)
- Health providers/Physicians (10%)
- Discuss with other people through blogs/forums (2%)

They use information to:

- Discuss with physician (54%)
- Discuss with pharmacist (31%)
- Decide which drug to purchase (17%)