What role do social media play in advancing health literacy?

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Introduction

Advancing critical health literacy in Europe is entering a period of profound change and growth. While addressing health literacy has been a focus of public health professionals for many years, current health and economic challenges require a greater need for individuals to self-manage their health and health related behaviors and to access health services in a more efficient way. This new orientation on individual control is based on patients and health consumers needing to acquire health knowledge and engage in effective decision-making regarding their health behaviors. At the same time, this also places those without the necessary skills or resources at a disadvantage. Recent advances in web technologies, particularly social media, provide a unique opportunity to advance health literacy across Europe and the Globe.

The purpose of this discussion is to describe the role of social media in advancing health literacy, critical health literacy in particular, and examine the policy implications of this new mode of health communication. Health literacy consists of individual "Capacities, Skills, Knowledge, Motivation and Confidence to Access, Understand, Appraise and Apply health information to Form judgments and Take decisions, in everyday life in terms of healthcare, disease prevention and health promotion to improve quality of life during the life course." [1]. An important extension of the concept is 'critical literacy' which refers to "more advanced skills for critically analyzing information and using information to exert greater control over life events and situations." [2].

The discussion is organized in the following manner. I begin with a description of social media focusing on what is social media, coupled with a

brief sketch of the history followed with a review of the social media landscape. Next, I highlight features that suggest that social media can be an effective tool in health literacy. Moving from the potential of social media, I present several case studies of social media in health settings. The discussion ends with an overview of policy implications resulting from increased social media use for promoting health literacy and communicating health.

Social media operates quite differently than traditional media particularly in a health communication context. Social media possess several characteristics that set it apart from other technologies and traditional media but at its foundation, it is unique because of the reliance on user-generated content. Social media provides a level of participation that allows extensive oversight over information as well as responsiveness not found in traditional media sources. Significantly, it presents minimal barriers to people or organizations that seek to establish a social media presence. Social media includes the social features of Web 2.0 applications including participation, openness, conversation, community and connectedness.

Although social media is based on new information and communication technologies it really is nothing more than an extension of the traditional piazza or platz or town square. A piazza served a central role as a physical place for people to gather and communicate, usually in smaller groups that served individual communities during specific times (usually daylight) of the day. However, social media offers several important advantages compared to traditional interpersonal communication by minimizing the limitations of time and space. Social media enable people to organize according to common interests and engage in discussions, knowledge exchange and information sharing regardless of time or borders.

The emergence of the web and early web browsers like Mosaic laid the direct foundations of social media, in terms of opening up a new avenue of communication by facilitating the creation of non professional and personal web pages focused on a variety of interests and topics. For the first time, there was widespread access to a mass communication channel, but of

course setting up a web page required sufficient knowledge of at least HTML and an ever expanding cast of scripting languages, FTP, ISP protocols, and an infinite amount of patience. Social media dramatically advanced participation by offering a relatively uncomplicated, user friendly process to post/upload material.

There is a large diversity of social media including blogs (there are several types of these), RSS, wikis, podcasts, virtual worlds, games, social bookmarking, social networking, and message boards. Activities include posting information (in a very broad sense), sharing photos, videos, status updates, meeting people, linking and communicating with friends or people with similar interests, sharing ratings or bookmarks. Popular social media examples include Facebook, MySpace, LinkedIn, Twitter, Friendster, XING, Hyves, Wikipedia and many others.

Social Media is being used in a variety of health literacy promoting contexts. Patients talk with other patients, health professionals talk with each other, health organizations use them to communicate their services and mission with audiences, and health professionals are using them to facilitate skill and knowledge development among users and patients.

As we heard in the EHFG President's address on Wednesday and in many other presentations this week, we know that we must move towards creating the structures, systems, and policies that facilitate a health literate society where consumers can make informed and appropriate decisions about their health. The goal of independent informed decision-making requires more than posters and ads as the substance of health communication. Social media can advance health literacy because of 1) theory and research, 2) functional and technological attributes, and 3) widespread adoption.

A range of health communication and behavior theories such as the Integrative Model of Behavior Prediction, Social Cognitive Theory, Health Belief Model, and Theory of Planned Behavior incorporate constructs that hypothesize the effects of knowledge, social norms and values, attitudes and opinions, behavioral control and self-efficacy about health behaviors. The functionality of social media contributes to the establishment and

reinforcement of social norms/subjective values and the development of increased knowledge and skills. There has been increasing awareness of the connection between improved social networks and health behaviors.

Social media is characterized by a high degree of functional diversity meaning that it can be used for multiple health issues and problems, operating on different types of devices and operating systems. Hence one can access and participate in social media on a desktop or smart phone. It is possible to tailor communication messages according to theory-based constructs and even the literacy levels of recipients. One can stimulate discussion, allowing people to engage in discourse in order to obtain knowledge, share emotions, or be expressive. There is every reason to anticipate that web accessible computing devices will grow smaller in size and larger in processing power and this will facilitate real time data collection and distribution of information. Given the widespread use of mobile phones, even in regions of Africa, social media is now available to vast numbers of people worldwide and will continue to grow.

A brief overview of utilization patterns reflects a widespread acceptance of this new media. Most Europeans are using the Internet but rates vary among countries. According to Eurostat 2009 data, 65% of EU households have Internet access at home, ranging from 30% in Bulgaria to 90% in the Netherlands. 60% of the EU population (aged16 to 74) use the Internet at least once a week; 48% use it every day [3]. Social media use in some European countries equals or exceeds rates found in the U.S. According to Neilson data reported in The Economist, British and Italians spend more time on social media than Americans, although Germans and French spent nearly 1/3 less time. However, Germans spend more time on YouTube than any other country, spending over 5 hours a week viewing online videos [4]. One of the dramatic transformations now taking place is the adoption of social media by population groups previously thought of as lagging. In particular, approximately 42% of older people in the United States have used social networking applications [5].

Next, I would like to briefly describe a few examples of how social media is used for health communication focusing on a few notable examples.

The World Health Organization's 1000 cities, 1000 lives campaign uses social media to communicate about health inequalities in cities [6]. The ultimate goal is to encourage representatives of local and national governments to develop policies to protect and promote health, across multiple sectors, including the environment, health, transport, education and urban planning. Specifically, 1000 cities aims to open streets to health in public spaces, ideally by closing off portions of streets to motor vehicles and 1000 lives aims to collect 1000 stories of urban health champions who have taken action and had a significant impact on health in their cities (http://1000cities.who.int/).

The U.S. Centers for Disease Control and Prevention (CDC) use social media "to provide users with access to credible, science-based health information when, where, and how [they] want it. A variety of social media tools are used to reinforce and personalize messages, reach new audiences, and build a communication infrastructure based on open information exchange" [7]. A mix of social networks, like MySpace, blogs, and mobile phones, are used for communication about H1N1 (swine flu), food contamination, colorectal cancer, HIV testing, breast cancer, and other important health topics (http://www.cdc.gov/socialmedia/).

The FAN project (Family, Activity and Nutrition), funded by the local Public Health Department (Canton Ticino) and Health Promotion Switzerland, is providing parents and their young children (ages 6-12) in Switzerland with weekly communication using an interactive Web 2.0 powered social media platform (using Wordpress) that allows users to share experiences, tips, and ideas, view skill teaching videos, and receive tailored e-mails and SMS reinforcements to improve their diet and physical activity behaviors. [8] The use of the social media aspects of the program website are being tracked and through these data and the pre and post survey data, we will be able to understand differences in outcomes associated with how users exploit the social aspects of the website (http://www.fanticino.ch/).

"PatientsLikeMe" is a social networking platform freely available for patients across the globe [9]. It serves as a platform for patients to talk with one another about living with a disease, get information about treatment options, clinical trials, lifestyle issues, reducing barriers and concerns, and effectively communicating with their health care providers. Patients can share questions, symptoms, current medication regimens, and their health history and status and seek advice and tips from other "patients like them". PatientsLikeMe goes even further in extending the concept of user generated data by collecting and publishing data related to treatments and managing an illness and disease such as ALS, MS, Parkinson's and AIDS. . (http://www.patientslikeme.com/)

The recent adoption of social media by prominent health organizations helps to understand some of the challenges and potential successes that lay ahead. Social media increases the capacity to engage in more extensive health communication and there is extensive public support for communication with people about important health issues. For example, in the case of addressing childhood obesity, Eurobarometer data showed that a plurality of respondents from a majority of EU countries identified increased communication with parents followed by additional education in schools and their top two policy choices for addressing childhood obesity [10]. The spread of social media affords many opportunities for enhancing and supporting critical literacy, but further growth in use will undoubtedly benefit from a policy environment that recognizes potential of social media, fosters increased understanding of how it influences health literacy and promotes collaboration among health providers, researchers and patients. Decision makers at different levels will have a varied number of factors to consider that have not been typical during the past. International cooperation will be essential.

At the macro policy level, social media can assume a role in altering the fundamental approach to health care and management by cultivating individual capacity to make appropriate decisions, remain up to date on health knowledge, and cope with individual or family health changes. A necessary policy area will focus on ensuring access for groups, in terms of

socioeconomic status, literacy, and disability that are vulnerable to health disparities. It will be particularly important to make available computing devices, such as mobile phones, and access to Internet services as social media health applications increasingly use mobile phone services and the cost of using mobile phones may be prohibitive for some. We also must determine how social media will be used for emergency and crisis communication.

Given the explosion of health information available, there will certainly be a need to clarify responsibilities and consequences of providing health information and advice. Privacy and confidentiality issues are a focus of policy makers already. This type of policy will test the balance between the need to permit individual health data and information to be available for evaluation and research purposes and the equally important need to uphold the rights of individuals who use or participate in social media health programs. Technological advances will advance issues related to linkages and interoperability between electronic patient records and applications like PatientsLikeMe.

Organizational policies will have relevance for nearly all organizations and to some extent individuals who use social media. Early steps should include the establishment of a comprehensive strategy on how to use social media to advance organizational goals and objectives and how to monitor social media. Depending on the type of organization or issue, it may be more productive to monitor discussions and contribute to influential social media sources rather than creating a social media presence. Additionally, it will be important to develop social media guidelines and procedures. Organizational policies will have an administrative focus on employee conduct while using social media and how they represent the organization on social media during non-employment related online activities. It is important to address legal issues such as copyright, disclosure and privacy. The unique combination of skills required for social media will motivate small but important changes in staffing and management practices related to the need for personnel skilled in

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social media and health communication. Of course, sufficient time for social media activities will need to be allocated.

Research and funding policies should aim to encourage research and creativity, especially in terms of using communication as something more substantial than symbolic gestures consisting of posters and occasional advertisements. Increasing research, education and capacity with a particular focus on linkages between theory and practice and the development of best practices is needed. A productive approach would include promoting collaboration among researchers, health care providers and health organizations in planning social media strategies for promoting critical health literacy. Fostering transparency in research especially in terms allowing access to data for subsequent studies, and the development of a comprehensive archive of specific communication/message materials is also needed. This will additionally help to reduce research and development costs since researchers will be able to draw from existing content.

Social media is changing the health literacy and health communication landscape by providing accessible and uncomplicated methods to share and exchange knowledge, ideas, and experiences, and establish linkages among users. The current social media environment provides signs of future health literacy promoting communication that will significantly depart from traditional and largely symbolic poster, broadcast media, and advertising approaches to distributing and sharing health information. But it should be remembered that a defining characteristic of social media is that it is user-generated material.

Invariably there are a variety of challenges that will hinder the growth of social media and it is unwise to overstate the capacity of technological advances to magnify the effects of health communication in the face of complex multifaceted factors that influence health behaviors. As greater numbers of people take up social media, it may be that they will exhibit lower literacy levels that influence their consumption and comprehension of social media content. Assumptions about social media based only on early adopters' patterns are not necessarily going to hold over the long term. It is important to avoid the temptation of confusing simple knowledge about social media with

knowledge and understanding, or social media literacy, that leads to appropriate and effective use of social media. There is little from the development of social media that suggests there is an ultimate end game; patience, planning and persistence will be the hallmarks of enduring successful social media health communication programs. Decision makers and policy makers should recognize that social media is a very dynamic collection of technologies that can be at times unpredictable but offer the basis on which to pursue improved health outcomes for all population groups and contributes to effective sustainable health care systems.

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