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The Use of Social Networking Technology in the Promotion and Scaling Up of Complex Global Health Initiatives

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Abstract

Western medicine has a long tradition of humanitarian service in low resource countries and in crisis and disaster situations. However, advances in social network technology have dramatically changed the manner in which global health services are delivered. A new generation of healthcare professionals, modeled as social entrepreneurs, utilizing collaborative and nonprofit models is establishing relationships with healthcare professionals in host countries, to actively track early disease detection, scaling up of services and research. Oftentimes, technology allows healthcare professionals to contribute to these efforts remotely and without detracting from their routine clinical work as well as facilitating more flexible pathways for global health training in postgraduate education. This paper examines the limitations and opportunities for the utilization of social networking technology, including health care workers as social entrepreneurs, in early disease detection and in scaling up of services and research.

Key words: global healthcare entrepreneurs, global burden of disease, social network technology, low resource countries, scaling up, capacity building, social enterprise

Introduction

Despite growing momentum on the part of healthcare professionals from high resource countries to form collaborative humanitarian initiatives in low resource and post conflict situations, the majority of populations living in low resource and post conflict settings will not have access to a primary healthcare professional throughout their lifespan. The disparities in access to primary healthcare in low resource settings can be attributable to geographical,

financial, education and cultural issues, all of which contribute to the global burden of disease and subsequent poor quality of life, economic burden and social issues particularly amongst the poor. When healthcare is needed but delayed or not obtained health deteriorates, which in turn leads to loss of income, deterioration of health and subsequent increased healthcare costs both of which contribute to poverty for the whole family. Such scenarios are common in low resource countries and the relationship between poverty and access to health care is part of a larger cycle that is the global burden of disease, whereby poverty leads to ill health and ill health maintains poverty. In this paper we consider initiatives on the part of governmental, non-governmental organizations and commerce in improving access to healthcare in low resource settings using social networking technology (e.g. cell phones) as well as the key to successful cell phone usage to disseminate and engage healthcare, using targeted or universal approaches and pursuing a wide variety of strategies to finance their services.

However, the majority of this population will have access to a cellphone signal. Collaborative and non-profit organizations such as *Medic Mobile* ("*Medic Mobile, Right tools. Real impact.*," 2014) were created with the sole purpose of improving access to healthcare in low resource and disconnected communities using basic mobile communication tools. For example, *Medic Mobile* has built mobile applications for rural community health workers, caregivers and patients in Malawi using recycled cell phones. Social network technology has transformed global healthcare, especially in remote areas, by facilitating direct interaction with patients, remote training of healthcare workers and supporting research that addresses local health priorities.

To date, there are 481 mentions of *Twitter* on *PubMed*, the primary research database for healthcare sciences. These range from monitoring the use of Twitter amongst cancer patients in Japan (Tsuya A, 2014), or for identifying the motivation behind discussions on antibiotics (Dyar OJ, 2014), to digital drug safety surveillance (Freifeld et al., 2014). The key to the success of the collaboration between healthcare professionals and social networking technology is the potential to communicate and disseminate information on global health issues, a good example is immunization. India's Pulse Polio Program ("*India Polio Fact Sheet*," 2012) used social networking technology not only to provide information about the availability of a vaccine for polio, but also to communicate evidence that can save lives and address the dangers of taking an anti-vaccine stance. This year, three years after the program began, the World Health Organization, declared India a polio free country ("*Polio Eradication*," 2014). The eradication of polio in India is a testament to social media's capabilities when it comes to data sharing.

Healthcare Professionals as Social Entrepreneurs

Healthcare training programs around the world have recognized the potential and important role that its graduates might play in global health intervention in low resource settings.

Global health education has been integrated into existing domestic programs in order that healthcare professions have the specialist education, such as inter-cultural skills, health policy and development, health service planning, resource allocation and ethics, in order to make appropriate and effective contributions in low resource settings. Healthcare professionals possess many portable skills which equate with an entrepreneurial mindset. In keeping with core entrepreneurial skill sets healthcare professionals know how to build clinical judgment; are able to experiment and conduct research; make decisions with incomplete information and in times of uncertainty and have the courage to know when something will not work or should be ended. All of the above are likely to encourage local populations, governments and non-profits to invest in their idea.

Touch Surgery ("*Touch Surgery*," 2014), established by two United Kingdom based surgeons, developed a mobile surgical simulator, which enables users to practice surgical procedures on their cell phones from anywhere in the world, is a good example of physicians utilizing their entrepreneurial skills in the global health arena. Arguably on a larger scale, *Orange tele-communications* ("*Tele Health*," 2014) has developed several projects in collaboration with E-Health to provide secure and accessible storage of medical data in low resource settings where access to health-care is poor.

Early Disease Detection

The mobile phone has proved highly efficient in terms of its communicating and computing abilities in tracking outbreaks of communicable diseases in rural areas. Social network technology has the ability to provide instant data on potential epidemics to hasten the response time and ultimately save lives. The Real-Time Bio-surveillance Program (RTBP) was launched in India and Sri Lanka to test the potential of using cell phone in health data collection. In its pilot phase, RTBP sought to establish a mobile-based communications system, introduce a computer-based detection system and implement an e-Health based surveillance and notification system (WGC, 2010). The systems were evaluated over a one year period and data from its phase have informed the scale up phase.

Bengtsson, a physician at Karolinska Institute, Sweden in Collaboration with Children's Hospital Boston, tracks post disaster migration in low resource settings, in order that first responders know where to find large groups of affected people. Using cell phone data, Bengtsson and colleagues working in collaboration with Haiti's largest cellular carrier *Digicel*, showed that by mining anonymized cell phone data, it was possible to track population movements in Haiti during the January 2010 earthquake and the subsequent epidemic of cholera (Bengtsson, Lu, Thorson, Garfield, & von Schreeb, 2011). Bengtsson subsequently used cell phone records to track population movements after the cholera outbreak in Saint Marc and surrounding areas in Haiti ("*Environ Health Perspect*," 2014). The tracking further revealed that many members of the population were moving towards Port au Prince, the largest city in Haiti. This data was invaluable in planning healthcare intervention.

Scaling Up of Services

The term “scaling up” is now widely used in global health literature. It is primarily used to describe the process of expanding access, manpower, services, financial support and capacity in global health from pilot to meeting the needs of the local population. Scaling up generally involves a considerable increase in the volume of aid, accompanied by health initiatives and financial mechanisms. There have also been improvements in health outcomes and some examples of success large-scale programs. Healthcare entrepreneurs, often times at the forefront of such scaling up have utilized social network technology to obtain a better understanding of health interventions, strengthening the system quality issues and dealing with the challenges of sustaining scaled up services.

The scaling up of aid volumes for global health began in the late 1990's in response to the HIV/AIDS pandemic and in particular in response to the need to make anti-retroviral therapy widely available. The adoption of the Millennium Development Goals (MDG's) in 2000 and debt relief initiatives also helped to increase financial resources to fund global health entrepreneurship and social networking technology ("Millennium Development Goals," 2014). For example, Malawi government launched a human resources program via *LinkedIn* and twitter that increased recruitment of volunteers and nurse tutors (Palmer, 2006). Other examples include international donors financing the salaries of 2000 additional health workers in Kenya and the introduction of a range financial, housing, education and other incentives to encourage deployment of Zambian health workers to rural areas (Yu, Souteyrand, Banda, Kaufman, & Perriens, 2008). Pre-service training for health workers has been expanded in Ethiopia, Zambia, Mozambique and Uganda also using Social Network Technology (Group, 2009).

Collaborative Research

The use of social networking technology presents researchers with unprecedented opportunities to facilitate collaboration between scientists in high and low resource settings. The Cochrane Collaboration has published work reflecting on the potential of social media for disseminating the results of biomedical research and for providing up to date clinical information to healthcare providers (Sud, Ejaz, Fedorowicz, Mathew, & Sharma, 2011). While some groups are exploring the use of social media in peer reviewing research, based on their immediacy of interaction and potential to reduce costs (Gibson, 2014). There are also lessons to be learned from other knowledge generating, self-correcting communities, such as *Wikipedia* ("*Wikipedia*," 2014), regarding the mutually beneficial altruism and status that drives much social networking and the transparency and accuracy created through visible open review. However the positive innovative uses of social media while presenting opportunity are not without their limitations and drawbacks. They are open to abuse, as in the case of using *Twitter* to circumvent the traditional regulatory frameworks that aim to control direct consumer advertising by the pharmaceutical companies ("Use social media to strengthen health systems," 2014). However, unnecessary duplication of research is an issue in developed countries and competition for funds and publications risks breeding a culture of secrecy between scientists in order to protect their ideas.

However, in developing countries, where resources are scarcer and research results are more critical to saving human lives, there should be an even greater demand for a streamlined model of scientific cooperation and setting of research agendas.

Ethical Issues in Use of Social Networking in Medicine

Ethical issues are of prime concern when using social networking technology in health care. There are many ethical principles which are applicable to clinical care and social media. Some of the important principles are confidentiality, privacy protection, solicitation of testimonials and consent. Physicians must be careful about maintaining confidentiality of their patients while dealing with them with social media. Chances for breach of confidentiality are very high comparing to conventional face to face consultation. Informed consent is as important as it is in real time consultation. Physician must inform the patient about possible treatment options, risk, fees and prognosis. Ultimately, it should be the patient who will decide the course of treatment and not the physician. This kind of practice is well recognized in face to face to consultation, but can be easily missed in electronic communication. It becomes physician's moral duty to protect the privacy of the patients. In social media networking, it is possible to unknowingly leak patient information, and considering the dense nexus of networks in the current era, it doesn't need much efforts to identify a person. Therefore, physicians must be extra vigilant to protect the privacy of the patients. Moreover, practitioner should maintain record of the patients for legal purpose. Physician also should be careful while dealing with "friend or follow request" on networking sites. This may lead to development of alternative relationships, which may not prove healthy for the physician. Ethical issues pertaining to location and jurisdiction are also an important issue. Physician must be aware of the laws of other states and jurisdiction from which their online patients belong (<http://onlinetherapyinstitute.com/ethical-framework-for-the-use-of-social-media-by-mental-health-professionals/>).

In summary, the important ethical recommendations are as following: Physician should avoid using general networking systems like Facebook, Twitter etc. They also should encrypt the conversation with the patients. They should make their patient understand about the issues which should be handled online vs. in-person. Physicians should also avoid writing about their specific patients, and take their permission when necessary. They should always share credible information based upon research studies. They should always disclose any financial compensation received. Physicians must avoid anonymity, accurately state their credentials and mention whether they are representative of a body or not. They should in general avoid the "friend or follow requests" by the patients (<http://circ.ahajournals.org/content/127/13/1413.long>).

We give several illustrative examples of use of social media under 6 broad headings.

Case Study 1: Primary Care/Medical Care

Mayo clinic has been using social media technology quite well for the better health care delivery and information. They have made a special center called Mayo Clinic Center for Social Media

(MCCSM) for the application of the social media network to improve health care information. Mayo clinic is active at various social media platforms like twitter, facebook and YouTube. It has approximately 836,000 followers on twitter where it posts updates on various health care topics. It has also started Social Media Residency which is an intensive one day course which focuses on strategic use of social media in healthcare. They have produced a book with title 'Bringing the Social Media Revolution to Health Care' which represents strategic reasons to integrate social media into health care communications. MCCSM also produces educational webinars for its social network members which depict how various forms of social media can impact health care. Mayo provides Social Media Health Care Network accounts. Member of this Social Media Healthcare Network can have access to various teaching tools like Learning Modules and Webinars. Moreover, on their website (mayoclinic.org), they provide basic information about most of the diseases for general population. People learn about risk factors, symptoms and possible treatment options for the particular disease. On their facebook profile, they update recent health articles from various sources, answers the health related questions and posts interesting and inspirational medical and surgical cases. Apart from disease and its management, it also delivers information regarding healthy lifestyle and preventive measures. According to the list (HCSML- Health Care Social Media List) prepared by Ed Bennet, an advisory board member for MCCSM, there are currently 1563 health care organizations all over the US who are actively using one or another type of social networking sites (<http://network.socialmedia.mayoclinic.org/hcsml-grid/>). This suggests that social network is becoming an essential part of health care organizations. However, utility of such network is limited. Sometimes, it becomes a social forum where people get personal with one another because of contradicting views and the conversation transcends the purpose for what it was intended. Moreover, one can use such networks to malign the image of the organization and spread misconceptions.

Case Study 2: Health Worker Stability and Security

Physicians are increasingly using social network for their practice. A research study was conducted by Care Continuum Alliance and QuantiaMD in 2011 to determine how clinicians are using social media and the views of clinicians for different aspects of social media in health care (<http://www.quantiamd.com/q-qcp/DoctorsPatientSocialMedia.pdf>). Approximately 4000 clinicians participated in the survey. According to the survey, more than 65% of the participants used social network platform for professional purposes. Education was the prime purpose of such networking. They also utilized the social networks for expert advice on patients conditions, discuss professional challenges or simply to stay connected. It was evident in the survey that participating physicians were more interested in online "physician - physician interaction" than "physician -patient interaction". For the diagnosis and treatment, over 40 percent of the clinicians believed that there was no alternative of actually seeing and examining the patient. Security of the online transmitted information is also the concern for physicians. It is likely that more physicians will be open for social media networking when these security concerns are satisfied. According to the report, there are many online patients as well as physicians communities. Physicians believe that these communities have positive effect on the patients and

40% of the participating physicians already recommended patient communities to their patients. Half of the physicians were ready to join these communities as a professional guide. However, such communities have drawbacks also. For example, some physicians believe that such communities are source of misinformation and platform for blaming and complaining for doctors and other health allied bodies. Many of such communities become social chat rooms. Significant number of clinicians found it possible to interact with their patients online for easy access and better quality care. However, they felt that concern regarding privacy, liability and compensation must be addressed first.

Case Study 3: Preventive Medicine/Vaccination

Social networking technology, such as facebook and twitter, can significantly contribute to health care initiatives. They can be utilized as an effective tool for research data collection. One of such use has been demonstrated by a study in Minnesota conducted by a research team led by Dr. Erik J. Nelson (Nelson, 2014). They advertised about an online survey for Human Papilloma Vaccination on facebook to a targeted locality. Males and females from 18-30 years within the 25 miles radius of Minneapolis participated in the survey, 2079 individuals responded to the advertisement; of which, 1003 completed the survey. The study found that 13% of the male and 65.6% female respondents had at least one shot of HPV. While the data for the whole state depicted different numbers: 53.8 % for women and 20.8% for male; and numbers for national data were: 34.5 % for females and 2.3 % for males. The researcher found this method cost effective and feasible. Also, this study suggests the necessity for local estimates as vaccination rates varies considerably from state and national statistics. This way, measures can be directed to particular region with less vaccination rate.

Case Study 4- Engineering and Environment

Approximately, 8000 tons of Solid waste is generated per day in Delhi - National Capital Region (NCR) of India. The working condition of waste handlers and traders in India is far from safe. They unknowingly deal with toxins generated from plastics and electronic waste. *Chintan* is an NGO based in New Delhi, India. Chintan has formulated a network with local organizations like “New Delhi Municipal Council”, “Ghaziabad Nagar Nigam”, “Safai Sena” and “Resident Welfare Association” to set up a solid-waste handling system (<http://www.chintan-india.org/index.htm>). This system has replaced the conventional waste handling and created greener and safe methods and protocols for cost-effective waste disposal. Chintan is also going

to develop an “online marketplace” and “an integrated mobile application” which connects waste recyclers and waste generators directly (<https://impactchallenge.withgoogle.com/india2013#/chintan>). This method will improve the working environment and general living of waste recyclers. Moreover, this endeavor is supposed to create a big impact on the control of pollution in this region of India.

Case study 5: Water and Sanitation

Sanitation is one of the major issues in developing countries. Waterborne diseases like hepatitis A, typhoid, and infectious diarrhea resulting from poor sanitation facilities are prevalent in these countries. Overall health of the community and nation can be enhanced by improving sanitation facilities in these countries. Based in Pune, India, *Shelter Associates* is an NGO working for the better sanitation in the urban slums of Pune and few other cities in this region of India. The NGO is an integrated network of architects, community workers, analysts and social workers. It has partnered with *Baandhni*, which is a group of poor men and women from several cities in Western India (<http://shelter-associates.org/>). Shelter Associates has created a Geographic Information System (GIS). The broad purpose of the GIS system was to generate spatial data about the underserved areas that will help city planning. This system conducts digital mapping of the urban slum areas with poor sanitation facilities and assigns it with socio-economic data of the respective area. This data includes employment, education and family size. It also includes information of infrastructure and facilities such as toilets, water etc. Thus, the map will demonstrate the service gap and potential areas for improvement in facilities. *Shelter Associates* will make this map available for partners, government and civil societies (<https://impactchallenge.withgoogle.com/india2013#/shelterassociates>). This way they are facilitating the authorities in their work over sanitation and other essential living facilities.

Case study 6--Globalization/economics

Globalization has been the key for development since the era of cultural-revolution. In the modern era, the term globalization is not limited to establishing a franchise or business center in the other part of the world. Information Technology (IT) and Social Network (SN) has expanded and redefined the meaning of globalization. The latest example of it is the “Ice Bucket Challenge” for Amyotrophic Lateral Sclerosis (ALS) awareness campaign. This challenge has gone viral on social media platforms like Facebook and Twitter (http://www.nytimes.com/2014/08/18/business/ice-bucket-challenge-has-raised-millions-for-als-association.html?_r=0). Without such well spread social networks, the campaign might not have succeeded up to this level in the terms of global penetration. Tele-radiology is a healthcare

product of information technology and networking, which is gradually being popular all over the world. Use of radiological imaging is constantly increasing, while the growth of the number of radiologist has not paced with it. Moreover, specialized radiological services are generally localized in a few higher centers. With the advent of tele-radiology, these limitations have been overcome. With the help of broadband internet, high speed telephone lines and the latest cloud services, a radiologist sitting in one country can evaluate the scans from the other countries (<http://www.dianassociates.com/contact.html>). Thus, information technology and networking has transcribed the world into a compact and connected domain.

Conclusion

Social network Technology has changed the landscape of global healthcare delivery across low resource settings by giving people who live in isolated rural areas the ability to connect with healthcare systems in other cities or countries. A phone call can compress the time it would have taken a healthcare professionals to assess risk and make decisions in patients. Social Network Technology has enabled healthcare professionals to meet many of the global health challenges in resource limited areas. Social Network technology has changed the way in which healthcare professionals view global health in terms of the ability to impact upon populations, collect data in real time, develop intervention strategies that were previously inconceivable. However, the challenges go beyond simply determining the manner in which to reach the greater amount of people using Social Network Technology. More research is needed as to how human capacity and resources can keep pace with technology that Social Network Technology is ethical to use and is integrated into the training curriculum of healthcare professionals.

References

- Bengtsson, L., Lu, X., Thorson, A., Garfield, R., & von Schreeb, J. (2011). Improved response to disasters and outbreaks by tracking population movements with mobile phone network data: a post-earthquake geospatial study in Haiti. [Research Support, Non-U.S. Gov't]. *PLoS Med*, 8(8), e1001083. doi: 10.1371/journal.pmed.1001083
- Dyar OJ, C.-S. E., Holmes AH. (2014). What makes people talk about antibiotics on social media? A retrospective analysis on twitter use. *J Antimicrob Chemother*.

Environ Health Perspect. (2014) Retrieved 06/05/2014, 2014, from <http://ehp.niehs.nih.gov/120-a30/>

Freifeld, C. C., Brownstein, J. S., Menone, C. M., Bao, W., Filice, R., Kass-Hout, T., & Dasgupta, N. (2014). Digital drug safety surveillance: monitoring pharmaceutical products in twitter. [Research Support, U.S. Gov't, P.H.S.]. *Drug Saf*, 37(5), 343-350. doi: 10.1007/s40264-014-0155-x

Gibson, M. (2014). The Growing Role of “Post-Publication Peer Review” and Social Media Retrieved 06/05/2014, 2014, from <http://www.gbsi.org/blog/2014/01/growing-role-post-publication-peer-review-social>

Group, W. H. O. M. P. S. C. (2009). An assessment of interactions between global health initiatives and country health systems. *The Lancet*, 373(9681), 2137-2169.

India Polio Fact Sheet. (2012) Retrieved 06/5/2014, 2014, from <http://www.polioeradication.org/Portals/0/Document/InfectedCountries/India/PolioIndiaFactSheet.pdf>

Medic Mobile, Right tools. Real impact. (2014) Retrieved 06/5/2014, 2014, from <http://medicmobile.org/>

Millennium Development Goals. (2014) Retrieved 06/05/2014, 2014, from <http://www.un.org/millenniumgoals/>

Nelson, E.J., Hughes, J., Oakes, J.M., Pankow, J.S., Kulasingam, S.L. (2014). Estimation of Geographic Variation in Human Papillomavirus Vaccine Uptake in Men and Women: An Online Survey Using Facebook Recruitment. (*J Med Internet Res* 2014;16(9):e198) doi:10.2196/jmir.3506

Palmer, D. (2006). Tracking Malawi's human resource crisis. *Reprod Health Matters*, 14(27), 27-39.

Polio Eradication. (2014) Retrieved 06/05/2014, 2014, from http://www.unicef.org/india/health_3729.htm

Sud, V., Ejaz, K., Fedorowicz, Z., Mathew, M. E., & Sharma, A. (2011). Cochrane: spreading the message of research to students and juniors. [Editorial]. *Cochrane Database Syst Rev*(8), ED000026. doi: 10.1002/14651858.ED000026

Tele Health. (2014) Retrieved 06/05/2014, 2014, from <http://healthcare.orange.com/eng/discover-e-health/all-folders/telehealth>

Touch Surgery. (2014) Retrieved 06/05/2014, 2014, from <http://www.touchsurgery.com/>

Tsuya A, S. Y., Tanaka A, Narimatsu H. (2014). Do Cancer patients tweet? Examining the twitter use of cancer patients in Japan. *J Med Internet Res*, 16(5), e137.

Use social media to strengthen health systems. (2014) Retrieved 06/05/2014, 2014, from <http://www.scidev.net/global/health/opinion/use-social-media-to-strengthen-health-systems.html>

WGC, S. (2010). Real-Time Biosurveillance Pilot Programme in Sri Lanka: Lessons Learned. *Sri Lanka Journal of Bio-Medical Informatics*, 1(3).

Wikipedia. (2014) Retrieved 06/05/2014, 2014, from <http://www.wikipedia.org/>

Yu, D., Souteyrand, Y., Banda, M. A., Kaufman, J., & Perriens, J. H. (2008). Investment in HIV/AIDS programs: does it help strengthen health systems in developing countries? *Global Health*, 4, 8. doi: 10.1186/1744-8603-4-8