

Réflexions sur la place et le rôle des médias sociaux en santé publique



Pascale Lehoux et Myriam Hivon
Chaire de recherche du Canada sur les innovations en santé
Département d'administration de la santé
IRSPUM, Université de Montréal

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J'haïs Facebook!

WORLD MAP OF SOCIAL NETWORKS December 2011



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sources: Google Trends for Websites/Alexa

(Source: <http://vincos.it/world-map-of-social-networks/>)

Contexte

- Usage croissant d'Internet même si des disparités d'accès demeurent
- Recherche sur usages d'Internet demeure parcellaire, mais s'est accrue rapidement
- Avènement du Web 2.0, simplification des outils de production multimédia et multiplication des appareils électroniques "mobiles"
 - Usage et confiance accrue des usagers envers médias sociaux
- Le champ de la santé publique, comme d'autres, sent le besoin, l'opportunité ou la pression de s'y intéresser...

Que sont les médias sociaux?

- "As the number, diversity, and inter-operability of new web-based and mobile platforms continue to proliferate, the characteristics and subcategories denoted by the term "social media" will need to be further disaggregated and refined."
- There is general agreement, however, that the new media environment is characterized by **interactivity, user generated content, and multidirectional communication flows**" (Schein et al. p.4).

De quelles façons ces outils sont-ils susceptibles de soutenir ou d'affecter le travail des experts en santé publique?

Objectifs de la présentation

- Adoptant le point de vue d'un chercheur "ordinaire," proposer quelques repères pour y voir plus clair et discuter avec vous du rôle des médias sociaux en santé publique
 - Où en est la littérature
 - Quelques constats et interrogations
 - Quelques références pour en savoir plus

Plan

- Que sait-on au sujet
 - Des interventions de santé publique exploitant l'Internet
 - Du potentiel et des usages des médias sociaux (Web 2.0)
- Implications pour pratique et recherche en santé publique
- Rejoindre qui, comment et pour faire quoi?
- De "vieux" défis dans de nouvelles bouteilles

Si le temps le permet...

The screenshot shows a news article titled "Pour réfléchir" with the subtitle "Le quotidien en milieu hospitalier et les risques associés aux technologies médicales". The article discusses a trip to Scotland where the author experienced a medical error involving a wrong knee. It highlights the importance of communication and patient safety. The sidebar includes categories like "Catégories", "Dossiers", and "Activités".

Entrevue filmée

The video player shows an interview with Richard Lapointe. The sidebar lists recent comments and activities related to toxicology and predictive medicine. The video duration is 12 min. 42 s.

Présentation voix hors champ

The video player shows a presentation by Claude Vieu. The sidebar features a 60th anniversary banner for the Department of Environmental Health and Safety.

Les fonctions de santé publique les plus interpellées...

Prévenir, promouvoir, protéger

1. Monitoring, evaluation & analysis of health status
2. Surveillance, research & control of risks/threats to public health
3. Health promotion
4. Social participation in health
5. Development of policies/institutional capacity for public health planning and management
6. Strengthening of public health regulation/enforcement capacity
7. Evaluation and promotion of equitable access to necessary health services
8. Human resources development and training in public health
9. Quality assurance in personal and population-based health services
10. Research in public health
11. Reduction of the impact of emergencies/disasters on health
(PAHO, www.lachealthsys.org)

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Ce qui se dégage de la littérature...

La recherche sur Internet
Et celle sur les médias sociaux

Interventions de santé publique tablant sur l'Internet

- Refers “to systematic treatment/prevention programs, usually addressing one or more determinants of health (frequent health behaviors), delivered largely via the Internet (although not necessarily exclusively Web-based), and interfacing with an end user.”
 - Ex., asthme, douleur chronique, diabète, consommation d'alcool/drogues, tabagisme, prévention ITS, poids, activité physique, prévention des chutes, santé mentale, Alzheimer
- “These interventions are typically highly structured, mostly self-guided, interactive, and visually rich, and they may provide tailored messaging based on end-user data” (Bennett & Glasgow, 2009, p.274).

Ce type d'interventions a fait l'objet de nombreuses recherches évaluatives

- “A veritable explosion in the number of randomized controlled trials (RCTs) testing Internet interventions has taken place, most emerging during the past half decade.”
- “The Internet as a platform has largely been deemed **efficacious**, and as the next generation of trials begins, greater attention will be needed to determine both the **effectiveness** and the **dissemination potential** of public health Internet interventions” (Bennett & Glasgow, 2009, p.274).

Synthèse d'essais randomisés (RE-AIM)

- Pénétration
 - Pas convaincante et fort gradient socio-économique, mais “grand” potentiel
- Efficacité
 - Oui, mais davantage p/r indicateurs primaires que secondaires; magnitude des effets mitigée; hétérogénéité composantes
- Adoption
 - Exige du “facteur humain”; complexité des messages “sur mesure”
- Implantation
 - Attrition élevée (40-50%); implication des employeurs/commanditaires
- Maintenance
 - Malgré coût marginal/individu rejoint faible, coûts initiaux + mise à l'échelle pourraient s'avérer élevés

Web 2.0: solution?

- Le Web 2.0, tout en étant une prolongation du Web "tout court", possède des caractéristiques propres
- Celles-ci pourraient bonifier
 - Recherche et surveillance
 - Conception/implantation des interventions
 - Augmenter pénétration/réduire l'attrition
 - Compréhension des perceptions et pratiques des populations

Plateformes du Web 2.0

Platform	Descriptions
Blog ("weblog")	A website that contains regularly updated entries displayed in reverse chronological order
Microblog	A form of blogging that allows users to send brief text updates or micromedia to be viewed by the public or a restricted group.
Social Networking Website	Online communities that share interests and/or activities
Wiki	A website that enables the easy creation and editing of interlinking Web pages
Social News and Bookmarking	Social bookmarking enables users to save and share links to Web pages organized by metadata (eg. "tags," or keywords). Social news sites often enable users to vote on links to news, bringing the most popular stories to the top.

(Source: Schein et al.)

Plateformes du Web 2.0

User Reviews	A website or site feature on which people can post opinions about people, businesses, products, or services
Photo/Video Sharing	A website that enables the publishing of a users' digital photos or video clips online, facilitating sharing with others
Virtual Worlds	A simulated environment in which users can interact with one another and with the environment
News Aggregators	A website that collects, collates, and organizes syndicated web content, creating a customized site where all desired content is centralized.
Widgets/Gadgets/Badges/Buttons	A small, portable stand-alone application that can be easily shared and embedded in another website.

Figure 1: Description of Social Media Platforms Adapted from (11).

(Source: Schein et al.)

Ce qui est spécifique aux médias sociaux

- "A "multi-way conversation," in which users participate as both creators and consumers of web content" (Schein et al., p.4)
- Ce qui est produit par les internautes
 - Passivement (nuages de mots-clés, mesures de popularité)
 - Activement (wiki, blogues, vidéos, fils RSS)

Ce qu'offrent les médias sociaux

- Pour ceux responsables de la surveillance, la recherche et l'intervention en santé publique
 - Corpus de données potentielles abondant et constamment renouvelé
 - Nouveaux moyens de recueillir des données originales (re: enquête numérique)
 - Nouveaux "partenaires" potentiels pour le recueil de données ou la surveillance
 - Outils "interactifs" de communication et d'intervention

"Infodemiology" et "infoveillance"

- Infodemiology:
 - "the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy"
 - "rooted in the idea that—at least for some areas and applications—there is a relationship between population health on one hand, and information and communication patterns in electronic media on the other"
- Infoveillance:
 - "Using infodemiology data for surveillance purposes" (Eysenbach, 2009)

L'infodémiologie, une science en construction

- Permettrait d'analyser la "demande" d'information sur Internet et via les réseaux sociaux
 - Recherches/besoins d'information des internautes
 - Monitorer et mieux comprendre leurs comportements de recherche d'information
- Permettrait d'analyser "l'offre" d'information
 - Présence et importance de "disséminateurs"
 - Identifier des écarts à combler

Analyses potentielles "passives"

- Identifier les "mouvements" (housse/baisse) de désinformation
 - Ex. mouvement anti-vaccination
- Identifier les "mouvements" de demandes d'information
 - Ex. "epidemics of fear" ou début d'épidémies potentielles
- Monitorer l'efficacité avec laquelle les informations sont diffusées en cours de pandémie
- Monitorer l'implantation de politiques/interventions (voir rapidement comment les gens y réagissent)

Analyses potentielles "actives"

- À cause de sa nature interactive, l'Internet permet de recueillir des données directement auprès des utilisateurs
 - "when tracking search data for influenza specific keywords using the Google Ad method, it is possible to trigger an ad which leads to a quick online survey soliciting additional information from consumers" (Eysenbach, 2009)
 - Ex. GrippeMontréal
 - "Crowd sourcing": whoissick.org, sicklike.me
- Ou de diriger ces derniers vers des interventions (communicationnelles)

Améliorer la santé via communication sociale?

- Interactive Health Communication Applications (IHCAs) are computer-based, usually web-based, information packages for patients that combine health information with at least one of social support, decision support, or behaviour change support.
 - "appear to have largely positive effects on users, in that users tend to become more knowledgeable, feel better socially supported, and may have improved behavioural and clinical outcomes compared to non-users" (Murray et al., 2005; Cochrane Review).

Usages en situation de crise?



(Source: <http://mashable.com/2011/02/11/social-media-in-emergencies/>)

Implications et pistes de réflexions

Défis et obstacles

- “agencies’ capacity and responsiveness;
- the digital divide;
- the rapid evolution of social media platforms and usage patterns;
- and the lack of an evidence-base to guide best practices” (Schein et al., p.23)

De “vieux” défis dans de nouvelles bouteilles?

- Amplifier des messages
- Tenter de combattre la désinformation et le marketing
- Tentation d'une intervention “individuelle” (ex. sms personnalisés)
- Suivre en “temps réel” des symptômes/comportements permet d'ajuster les services en temps réel et de manière appropriée?

Rejoindre qui, comment et pour faire quoi?

- Qui est +/- joignable vs. qui devrait être rejoint
 - Facteurs à considérer
 - Ex. santé mentale (anonymat), langue/littératie, culture, isolement social et/ou géographique
 - Ex. mobilité, stabilité domicile, accès bibliothèque/centre communautaire, milieu de travail, etc.

Rejoindre comment?

- “the traditional once-a-day press conference featuring talking heads with a bunch of fancy titles has to be revamped and supplemented with Twitter posts, YouTube videos and the like.”
- The public needs to be engaged in conversations and debate about issues of public health, they don't need to be lectured to.”

-André Picard, The Globe and Mail, June 9, 2010

Quelle stratégie poursuivre?

Agency	Social Media Strategy
US CDC	Provide access to credible, science-based health information when, where, and how the public wants it. Use tools and platforms to: Reach new audiences; Reinforce and personalize messages; Build open information-exchange infrastructure
PHAC	“Monitor the conversation, participate in the conversation, initiate the conversation, share content, include social media in all marketing initiatives.” Create (Wikis, podcasts videos); Share (MSN, Google, Yahoo); Marketing (Flickr, YouTube, Facebook); Monitor and Participate (Google blog search, Technorati, Bloglines)
ONT MOHLTC	Listen; Refine; Leverage word of mouth advertising; Customize / provide relevant messages; Invite user-generated content

(Source: Schein et al.)

Et pour quels effets?

Autonomy	Competency	Relatedness / Social Connectedness
<ul style="list-style-type: none"> • Self-help management tools, e.g., quit smoking applications for Facebook, mobile phones • Personalized health information; development of patient-centered health records (Google Health, Microsoft Health Vault) • Health Portals such as Web MD, trusted sites for health information 	<ul style="list-style-type: none"> • Improve functional health literacy- through social network applications, interactive tutorials & medication reminders. • <i>Information Prescriptions</i> • Skills augmentation (similar to spell-checker, online applications can augment users skills to help them find and process health information); collective wisdom- users ranking, commenting and rating of health interventions 	<ul style="list-style-type: none"> • Patient and Health Intervention networks, such as online weight-loss social networks that provide individual and group incentives and monitoring • Health advocacy groups (e.g., Breast cancer awareness) • Shared Communities of Knowledge (e.g., Wiki Public Health)

(Source: Hesse, 2009 in Schein et al.)

Théories clarifiant la relation entre communication et comportements

- Avant de chercher à modifier des comportements, même via de nouveaux outils, encore faut-il comprendre ce que les gens pensent/font et pourquoi ils pensent/font ceci ou lieu de cela...
 - "Web-based social networking itself—a phenomenon facilitated by technological innovations—ultimately relies on theories that have been discussed by social scientists during the past half century" (Bennett & Glasgow, 2009, p.283)
- Lier des effets et des groupes (Murray et al., 2005)

Conclusion

- La recherche sur, et l'évaluation de l'usage des médias sociaux en santé publique vont continuer à croître
- Une difficulté réside en la capacité d'associer des contenus informationnels à des (changements de) pratiques spécifiques (études de réception/appropriation)
- Une autre provient de la diversité des applications/groupes cibles: les synthèses sont-elles "*context-sensitive*"?
- La démultiplication des stratégies/moyens communicationnels soulève des enjeux de ressources pour les experts de santé publique

Pour en savoir plus...

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- Change Foundation (2011). Using social media to improve healthcare quality (tool kit in 2 parts).
- 5 ways to use social media for better emergency response:
<http://qcn.com/Articles/2010/09/06/social-media-emergency-management.aspx?Page=2>
- Conférence L-R. Frigault, DSP-Montréal, Enquête GrippeMontréal:
<http://blogsgrms.com/internetsante/2012/03/12/surveillance-de-létat-de-santé-sur-internet/>

Quelques leçons tirées de notre expérience avec Hinnovic...

- Occuper un espace "intermédiaire" entre publications/conférences scientifiques et les médias
 - Éclairer les politiques/débat public...
 - Crédibilité universitaire
 - Peu de commentaires
- Usages diversifiés et inattendus, dont certains qui ne peuvent pas être "retracés"
- Trafic: qu'est-ce que ça signifie?
- Ressources humaines et \$ requises

Évaluer de telles interventions

RE-AIM element		Internet intervention example
Reach		Sixteen percent of diabetes patients invited to an Internet self-management intervention participated. Those declining were more likely to be Latino and male.
Effectiveness		Thirty percent of those randomized to an Internet smoking-cessation program quit compared with 12% in the control condition. The study showed no differences between conditions of weight change or quality of life.
Adoption		Forty percent of work sites approached to participate in an Internet health-information program evaluation took part. Work sites participating were larger, had more white-collar employees, and offered more wellness activities.
Implementation		The average number of log-ins in an Internet physical activity intervention was 5.2. Usage decreased over the eight-week intervention, and the number of overall log-ins and use of the social support forum were associated with greater improvement.
Maintenance (individual level)		At a 6-month follow-up, an Internet weight-loss program experienced 60% attrition. Those responding lost an average of 9 pounds. A mail follow-up of initial nonrespondents revealed an average weight loss of 8 pounds among this group.
Maintenance (setting level)		Of 24 schools participating in an online drug-abuse prevention program, 6 continued the program unchanged, 10 requested substantial changes or added their own components, and 8 discontinued the program.

(Source: Bennett & Glasgow, 2009)