

Health Social Media and Patient-Centered Care: Buzz or Evidence?

Findings from the Section “Education and Consumer Health Informatics” of the 2015 Edition of the IMIA Yearbook

P. Staccini¹, L. Fernandez-Luque², Section Editors for the IMIA Yearbook Section on Education and Consumer Health Informatics

¹ INSERM UMR 912 SESSTIM, IRIS Dept, UFR Médecine, Université Nice-Sophia Antipolis, France

² Northern Research Institute, Tromsø, Norway

Summary

Objective: To summarize the 2014 state of the art in the areas related to consumer health informatics and social media.

Methods: We conducted a systematic review of articles published in 2014 in PubMed with a predefined set of queries. We identified 439 articles relevant for the review. The two section editors independently screened those papers taking into account their relevance to the topics covered by the section. In a second step, they jointly selected the 20 most representative papers as candidate best papers. Candidate best papers were then submitted for full review and scoring by external reviewers. Based on the scoring, section editors together with the IMIA Yearbook editorial board selected the four best papers published in 2014 in consumer health informatics.

Results: Helping patients acquire a healthier lifestyle is a crucial part of patient empowerment. In this line of work, new studies are exploring the efficacy of online health interventions for patient behavioral change. The special case of smoking cessation for consumers with low socio-economic status is particularly noticeable. Another study has explored how an online intervention can reduce the anxiety of women who experience an abnormal mammography. The team of PatientsLikeMe has studied how online support groups could play a role in the quality of life of organ transplant recipients. The patient perspective of online forums' users is also analyzed in the domain of anticoagulation therapy.

Conclusions: Online health interventions, many of them using social media, have confirmed their potential to impact consumer behavioral change. However, there are still many methodological issues that need to be addressed in order to prove cost-effectiveness.

Keywords

Social media, healthcare consumers, patients, health behaviour, internet, social network

Yearb Med Inform 2015;10:160-3

<http://dx.doi.org/10.15265/IY-2015-032>

Published online August 13, 2015

1 Introduction

Health literacy, defined as the ability to access, understand, and use health information, has been identified as an international public health goal. Facing the apparition of symptoms, the discover of a disease, or the experience of the side effects of a treatment, patients are trying to find support using online tools. The analysis presented in this synopsis is reviewing how social media can be used to support patient centered-care.

Patient-centered care has been a major topic of conferences, beyond the conferences such as Medicine 2.0, Health 2.0, which are focused on social media. We actually observe that patient-centered care-related issues are more and more present in the themes chosen by major conferences. For example, MIE (Medical Informatics Europe) 2014 had the theme “Improved healthcare through health informatics” and in MIE 2015, the main topic is “Digital healthcare empowering Europeans”. Similar trends can also be found in MEDINFO or in the AMIA Symposium where papers and panels related to social media are becoming common.

2 Methodology

We used PubMed to conduct our review. We built our query combining three sets of topics and one set of exclusion criteria. The first set of topics is related to “consumer health informatics” and “patient-centered care”. The second set concerns “communication technology”. The third one is focused on “social media”. The full query is reproduced below.

((“2014/01/01” [PPDAT] : “2014/12/31”[PPDAT]) NOT Bibliography[pt] NOT Comment[pt] NOT Editorial[pt] NOT Letter[pt] NOT News[pt] NOT Case Reports[pt] NOT Published Erratum[pt] NOT Historical Article[pt] NOT Legal Cases[pt] NOT legislation[pt] NOT literature review[All Fields])

AND (“people with”[All Fields] OR “patient centered care”[All Fields] OR “care coordination”[All Fields] OR “consumer health informatics”[All Fields] OR “health information”[All Fields] OR “consumer health information”[All Fields] OR “consumer product safety”[All Fields] OR “consumer satisfaction”[All Fields] OR “patient safety”[All Fields] OR “patient satisfaction”[All Fields] OR “personal health”[All Fields] OR “personalized medicine”[All Fields] OR “patient-reported outcomes”[All Fields])

AND (“ehealth”[All Fields] OR “e-health”[All Fields] OR “telehealth”[All Fields] OR “mhealth”[All Fields] OR “telemedicine”[All Fields] OR “electronic patient-physician communication”[All Fields] OR “personal health record”[All Fields] OR “electronic patient record”[All Fields] OR “online”[All Fields] OR “electronic”[All Fields] OR “information technology”[All Fields] OR “communication technology”[All Fields] OR “mobile”[All Fields] OR “on-line”[All Fields] OR “online systems”[All Fields] OR “patient portal”[All Fields] OR “decision support technique”[All Fields] OR “health

care access"[All Fields] OR "online health information seeking"[All Fields] OR "health information systems" [All Fields])

AND ("internet"[All Fields] OR "web"[All Fields] OR "website"[All Fields] OR "social media"[All Fields] OR "facebook"[All Fields] OR "twitter"[All Fields] OR "youtube"[All Fields] OR "social network site"[All Fields] OR "social web"[All Fields] OR "online social network"[All Fields] OR "social environment"[All Fields] OR "social process"[All Fields] OR "social competition"[All Fields] OR "social norm"[All Fields] OR "social feedback"[All Fields] OR "social influence"[All Fields] OR "social comparison"[All Fields] OR "social network"[All Fields] OR "discussion group"[All Fields] OR "support group"[All Fields] OR "social support"[All Fields] OR "community network"[All Fields])

The initial result of the query was a list of 439 articles. The first step was to class papers in two groups: those related to a clinical trial, and those reporting the descriptive analysis of social media data. Each article was reviewed to select a shortlist of 20 candidate best papers [1-20]. We used five selection criteria: level of relevance regarding the 2015 yearbook topic "patient-centered care coordination"; level of evidence of the results; design of the study: cohort analysis or intervention assessment; nature of the problem addressed: impact of public health intervention or patient's literacy. The 20 papers were then reviewed by external experts according to the Yearbook selection process grid. During a consensus meeting, editors finally selected the four best papers of "Education and Consumer Health Informatics" field published in 2014.

3 Results

Three major themes emerged from the selection of candidate best papers. The first theme is the use of online interventions to help patients avoiding risky-for-health behaviors, such as smoking [1] [17]. The project StopAd-

Table 1 Best paper selection of articles for the IMIA Yearbook of Medical Informatics 2015 in the section 'Education and Consumer Health Informatics'. The articles are listed in alphabetical order of the first author's surname.

Section
Education and Consumer Health Informatics
<ul style="list-style-type: none"> ▪ Brown J, Michie S, Geraghty AW, Yardley L, Gardner B, Shahab L, Stapleton JA, West R. Internet-based intervention for smoking cessation (StopAdvisor) in people with low and high socioeconomic status: a randomised controlled trial. <i>Lancet Respir Med</i> 2014 Dec;2(12):997-1006. ▪ Obadina ET, Dubenske LL, McDowell HE, Atwood AK, Mayer DK, Woods RW, Gustafson DH, Burnside ES. Online support: Impact on anxiety in women who experience an abnormal screening mammogram. <i>Breast</i> 2014 Dec;23(6):743-8. ▪ Vaughan Sarrazin MS, Cram P, Mazur A, Ward M, Reisinger HS. Patient perspectives of dabigatran: analysis of online discussion forums. <i>Patient</i> 2014;7(1):47-54. ▪ Wicks P, Sulham KA, Gnanasakthy A. Quality of life in organ transplant recipients participating in an online transplant community. <i>Patient</i> 2014;7(1):73-84.

visor, which is selected as best paper, is a good example of online intervention for smoking cessation [1]. A second major theme is the use of online interventions to improve patient compliance or management [1, 9, 11, 13, 14, 15, 18, 19]. Special examples are the studies from Obadina et al. [2] (also selected as best paper) related to anxiety self-management by patients with breast cancer, and from DuBenske et al. [18], which aims at supporting caregivers of cancer patients. There is clearly an increased interest for eHealth applications to cancer patients. The third theme is made of papers that seek a better understanding of how patients use online health communities. A good example, also selected as best paper, is looking for peer support within organ transplant patient communities [4].

In addition to those major themes, there is also a wide range of topics that highlight the broad scope of consumer health informatics and social media. Numerous studies analyze the modalities health consumers use to search for information and the characteristics of those health consumers [5, 7, 10, 12, 16, 20]. For example, studies have been looking for correlation between health status and online information seeking [5], or how online searching by patients affects the doctor-patient relationships [7]. Most of those studies are studying English websites and datasets, however some of them analyze less commonly studied languages such as Spanish [6] and Greek [7].

Four papers were selected as best papers: two are focused on online health interventions and the other two reported the analysis of data extracted from discussion forums of online

communities [1-4]. The first two studies report on the evolution of online interventions for behavioral change. In the project StopAdvisor [1], the authors evaluated an online intervention for smoking cessation. The study included an online randomized controlled trial with more than 4,000 participants, and a follow up of 6 months, which is clearly a research design worth taking into consideration. Furthermore, the study focused on people with low socioeconomic status, which traditionally are not well represented in online health studies. They found that StopAdvisor was more effective than information-only websites within smokers of low socioeconomic status. This finding highlights the need of taking into account the socio-economical status when performing online health interventions. The second intervention trial aimed at determining whether an online support tool can impact anxiety in women experiencing an abnormal mammogram [2]. They enrolled 130 women for the study where an online intervention to reduce anxiety symptoms was evaluated. Women in the intervention group had lower level of anxiety.

The third and fourth papers are related to online communities and the use of discussion forums [3, 4]. Both have analyzed health data exchanged between patients across domains that constitute the core of patient-reported outcomes: symptoms, treatment effects, quality of life. One is related to a specific treatment with potential adverse effects (new-generation anticoagulant), the other one is related to patients with a specific health condition (patients with a single organ transplant). These studies are

clear examples of how data analytics of on-line health communities can help to better understand non-clinical aspects of patient health conditions.

4 Conclusions

All selected papers report the benefits and limitations of online tools providing information to patients either to change their behavior (smoking cessation), to better understand symptoms and subsequent diseases (abnormal mammograms), to declare medication side effects (anticoagulant treatment), or to support other patients overcome disease challenges (organ transplantation). There is a clear trend towards more studies to assess the effectiveness of online health interventions. However, it is still very uncommon that interventions aim at analyzing cost effectiveness issues.

References

- Brown J, Michie S, Geraghty AW, Yardley L, Gardner B, Shahab L, et al. Internet-based intervention for smoking cessation (StopAdvisor) in people with low and high socioeconomic status: a randomised controlled trial. *Lancet Respir Med* 2014 Dec;2(12):997-1006.
- Obadina ET, Dubenske LL, McDowell HE, Atwood AK, Mayer DK, Woods RW, et al. Online support: Impact on anxiety in women who experience an abnormal screening mammogram. *Breast* 2014 Dec;23(6):743-8.
- Vaughan Sarrazin MS, Cram P, Mazur A, Ward M, Reisinger HS. Patient perspectives of dabigatran: analysis of online discussion forums. *Patient* 2014;7(1):47-54.
- Wicks P, Sulham KA, Gnanasakthy A. Quality of life in organ transplant recipients participating in an online transplant community. *Patient* 2014;7(1):73-84.
- Tsai IH, Graves DE, Lai CH, Hwang LY, Pompeii LA. Association of internet use and depression among the spinal cord injury population. *Arch Phys Med Rehabil* 2014 Feb;95(2):236-43.
- Liu KY, Haukoos JS, Sasson C. Availability and quality of cardiopulmonary resuscitation information for Spanish-speaking population on the Internet. *Resuscitation* 2014 Jan;85(1):131-7.
- Rider T, Malik M, Chevassut T. Haematology patients and the Internet-the use of on-line health information and the impact on the patient-doctor relationship. *Patient Educ Couns* 2014 Nov;97(2):223-38.
- Tsimtsiou Z, Kirana PS, Hatzichristou D. Determinants of patients' attitudes toward patient-centered care: a cross-sectional study in Greece. *Patient Educ Couns* 2014 Dec;97(3):391-5.
- Thompson J, Coleman R, Colwell B, Freeman J4, Greenfield D, Holmes K, et al. Preparing breast cancer patients for survivorship (PREP) - a pilot study of a patient-centred supportive group visit intervention. *Eur J Oncol Nurs* 2014 Feb;18(1):10-6.
- White RW, Horvitz E. From health search to health-care: explorations of intention and utilization via query logs and user surveys. *J Am Med Inform Assoc* 2014 Jan-Feb;21(1):49-55.
- Shahrokni A, Mahmoudzadeh S, Lu BT. In whom do cancer survivors trust online and offline? *Asian Pac J Cancer Prev* 2014;15(15):6171-6.
- Gutierrez N, Kindratt TB, Pagels P, Foster B, Gimpel NE. Health literacy, health information seeking behaviors and internet use among patients attending a private and public clinic in the same geographic area. *J Community Health* 2014 Feb;39(1):83-9.
- Nagler RH, Puleo E, Sprunck-Harrild K, Viswanath K, Emmons KM. Health media use among childhood and young adult cancer survivors who smoke. *Support Care Cancer* 2014 Sep;22(9):2497-507.
- Gralla RJ, Hollen PJ, Msaouel P, Davis BV, Petersen J. An evidence-based determination of issues affecting quality of life and patient-reported outcomes in lung cancer: results of a survey of 660 patients. *J Thorac Oncol* 2014 Sep;9(9):1243-8.
- Gerber DE, Laccetti AL, Chen B, Yan J, Cai J, Gates S, et al. Predictors and intensity of online access to electronic medical records among patients with cancer. *J Oncol Pract* 2014 Sep;10(5):e307-12.
- Bhandari N, Shi Y, Jung K. Seeking health information online: does limited healthcare access matter? *J Am Med Inform Assoc* 2014 Nov-Dec;21(6):1113-7.
- Paek HJ, Kim S, Hove T, Huh JY. Reduced harm or another gateway to smoking? source, message, and information characteristics of E-cigarette videos on YouTube. *J Health Commun* 2014;19(5):545-60.
- Dubenske LL, Gustafson DH, Namkoong K, Hawkins RP, Atwood AK, Brown RL, et al. CHES improves cancer caregivers' burden and mood: results of an eHealth RCT. *Health Psychol* 2014 Oct;33(10):1261-72.
- Morse KD, Gralla RJ, Petersen JA, Rosen LM. Preferences for cancer support group topics and group satisfaction among patients and caregivers. *J Psychosoc Oncol* 2014;32(1):112-23.
- Jang H, An J-Y. Social Network Analysis of Elders' Health Literacy and their Use of Online Health Information. *Healthc Inform Res* Jul 2014; 20(3): 216-25.

Correspondence to:

Pr Pascal Staccini
 IINSERM UMR 912 SESSTIM, IRIS Dept, UFR Médecine,
 Université Nice-Sophia Antipolis
 28 avenue de Valombrose
 06107 Nice cedex 2, France
 E-mail: pascal.staccini@unice.fr

Appendix: Content Summaries of Selected Best Papers for the IMIA Yearbook 2015, Section Education and Consumer Health Informatics

Brown J, Michie S, Geraghty AW, Yardley L, Gardner B, Shahab L, Stapleton JA, West R
 Internet-based intervention for smoking cessation (StopAdvisor) in people with low and high socioeconomic status: a randomised controlled trial

Lancet Respir Med 2014 Dec;2(12):997-1006

The aim of this study was to assess a new interactive internet-based intervention for smoking cessation (StopAdvisor), designed with a particular attention towards the socioeconomic status of smokers. This online randomized controlled trial was conducted in the UK between Dec 6, 2011, and Oct 11, 2013. Inclusion criteria included being older than 18 years, smoking every day, and seriously willing to make a quit attempt. The intervention consisted in using a stop-smoking website that sends email reminders, being followed up at 7 months, and being contacted by emails and phone calls. 4,613 participants participated to the study and were randomized either in the StopAdvisor group (n=2,321), or the control group (n=2,292) using the information-only website. 1,300 (28%) participants were lost for follow-up. In the subsample of participants with low socioeconomic status, the benefit of StopAdvisor was evident for both primary and secondary measures compared with the information-only website, whereas in those with high socioeconomic status, no evidence of a difference was shown. Authors' findings showed that the interactive internet-based smoking cessation intervention StopAdvisor is more effective than an information-only website for smokers with a low socioeconomic status.

Obadina ET, Dubenske LL, McDowell HE, Atwood AK, Mayer DK, Woods RW, Gustafson DH, Burnside ES

Online support: Impact on anxiety in women who experience an abnormal screening mammogram

Breast 2014 Dec;23(6):743-8

The purpose of this pilot study was to evaluate the impact of an Early Comprehensive Health Enhancement Support System (CHESS) on women with an abnormal screening mammogram by assessing anxiety, breast cancer worry, and patient satisfaction with the radiologist. This trial randomized 130 of these women to either online support (the intervention group) or to a list of five commonly used Internet sites (the comparison group). There was a significant difference in the modification of the State Anxiety scores between the comparison group and the Early CHESS group at biopsy ($p=0.02$), but not at the time of diagnostic work-up ($p=0.24$). There was no significant difference in the change of scores for the Breast Cancer Worry subscale between the comparison group and the Early CHESS group, either at diagnostic work-up ($p=0.60$) or at the time of biopsy ($p=0.72$). The results of this study show that Early CHESS decreased anxiety in women who experienced an abnormal screening mammogram at the time of biopsy, but not at diagnostic work-up. Early CHESS was designed to empower women to seek more information regarding abnormal mammograms and to get their questions answered, but the results of this study indicate that earlier in the work-up process, when there is no identifiable care team, providing a resource like Early CHESS is not enough to help reducing anxiety.

Vaughan Sarrazin MS, Cram P, Mazur A, Ward M, Reisinger HS

Patient perspectives of dabigatran: analysis of online discussion forums

Patient 2014;7(1):47-54

This study examines the perceptions and experiences of a new anticoagulation treatment consumers (dabigatran) through the thematic content analysis of comments posted by patients and their caregivers on virtual discussion forums and Internet support groups related to anticoagulation and atrial fibrillation. Authors identified 468 unique posts regarding dabigatran that were posted between January 2011 and September 2012 on 10 websites. Five broad thematic categories emerged from the posted comments: general concerns about safety and efficacy, questions about indications and contraindications, questions about the proper use and storage, questions about diet and drug restrictions, and experiences with perceived side effects. A primary concern was the lack of antidote to reverse the effects of dabigatran if bleeding occurs. Several questions pertaining to the use of dabigatran concurrently with other medications or medical conditions were noted, and patients expressed confusion about instructions for using dabigatran before and after medical procedures. Many patients provided several criticisms about the medication packaging, and found it inconvenient or difficult to open. Finally, some perceived side effects were reported, among which some had not been observed during clinical trials. The authors concluded that online communities may provide real life information about topics of concern for patients and researchers such as medication side effects, proper use, safety, but also topics that may not be a priority for researchers although they demonstrate to be important for patients (e.g. medication convenience or packaging).

Wicks P, Sulham KA, Gnanasakthy A
Quality of life in organ transplant recipients participating in an online transplant community

Patient 2014;7(1):73-84

In 2010, PatientsLikeMe collaborated with Novartis Pharmaceuticals to develop and launch an online community to gather organ-transplanted patients. In this paper, authors described key characteristics of the community, assessed patients' quality of life as compared to other patients using PatientsLikeMe, and considered the benefits and limitations of such a tool. Patients with a single-organ transplant, limited to heart, lung, liver, kidney or pancreas, who created their account between 1st March 2010 and 31st December 2010 were eligible to be included in the study. A total of 3,057 patient accounts were created in the PatientsLikeMe Organ Transplant community during the chosen period, among which 1,924 patients were included in the analysis: 1,097 (57%) kidney, 345 (18%) liver, 288 (15%) heart, 179 (9%) lung, 15 (1%) pancreas. Examining the five primary symptoms common to all organ types, significant differences were observed. Pancreas- and liver-transplanted patients were most likely to report depressed mood, anxious mood, and fatigue as moderate or severe. 1,215 quality-of-life (PLMQOL) assessments were completed. Comparison showed poorer physical scores for lung-transplanted patients. Comparison with new entrants in other PatientsLikeMe communities during the same time found average values of quality-of-life scores were similar to those of HIV patients, and both groups generally scoring far better than patients with epilepsy, fibromyalgia and ME, mood disorders, Parkinson's disease, multiple sclerosis or ALS. In conclusion, authors highlighted that immediate access to patients who received an organ transplant provides a different type of data to public health statistics or claims data-with an emphasis on the lived experience of disease. They found that encouraging patients to support one another to overcome their disease challenges could ultimately improve health outcomes.