FOLIA 278

Annales Universitatis Paedagogicae Cracoviensis

Studia ad Didacticam Biologiae Pertinentia 8 (2018)
ISSN 2083-7276
DOI 10.24917/20837276.8.6

POPULARIZATION OF KNOWLEDGE – NEW EDUCATIONAL AND SOCIAL IMPLICATIONS

*Elodie Crespel*

# Empathic mediation of information: online forum for cancer patients

## Introduction

When fighting cancer, patients find medical responses formulated by health professionals and given by other patients, especially on the Internet. Patients are looking for information that will help them live better with the disease, treatments and their side effects. Some prefer an easy to understand analyses of their test results, others seek advice to keep their hair during chemotherapy, but most of them want to benefit from the experiences of other patients to prepare for what can happen to them, and thus reduce their fears. Patients go online to find an empathically mediated information, something that it is still hard to find within eHealth services.

eHealth consist of 3 key elements: 1) data obtained from the patient, 2) electronic transfer of data over a distance, and 3) patient-tailored feedback from a health care professional (Elbert, van Os-Medendorp et al. 2014). Communication in eHealth interventions is personalized and interactive in contrast to patient information websites on health and disease. Interaction among patients is not included, not even consider useful for patients. Therefore we research forums – one of the oldest forms of communication on the Internet. How digital communication supports, also known as on-line communities, can provide social bonds which can help patients and relatives as caregivers?

Our research seeks to understand how patients could obtain information and help through the use of online health communities. Knowledge mediation processes in online communities are laced with empathy and curation from individual experiences with the disease. First, we detail our methodology, deeply grounded in ethnographic approaches, then we present our results with the motivation to visit online forums, the power in helping others and the coping strategies gain with the patient to patient information.

## Methodology

Qualitative research aims to understand people's points of view, to discover how they make sense of their experiences (Kvale, Brinkmann 2008). The interview is the most common way to do this. A conversation between researchers and participants often build knowledge that is more relevant than simply observing a reality (Kvale, Brinkmann 2008). The original meaning of the word conversation means “to wander with” in Latin, so with the interview, the researcher spends time with the participant to glimpse their points of view.

Interviews were conducted via telephone or Skype for geographical reasons, so audio recording is self-evident. Many free software programs are available for recording and correcting audio quality. This way, all team members have the same audio files and can take notes and start the analysis without waiting for the transcripts. We chose to make an initial individual and then collective analysis in order to pool the interpretations of each researcher. To do this, several free software programs are available such as word processing (Miron, Dragon 2007) or Sonal “[which] thus transforms the chronology of transcription work, returning to the boundary between sound and written work. A transcribed interview takes the form of a series of both sound and text excerpts, which can either be reread or replayed, opening up new methodological perspectives” (Alber 2010).

In a qualitative study, the presentation of results will be descriptive. Further analysis remains to be carried out in order to derive a more refined conceptualization. We will essentially present the perceptions of the participants, because our process of knowledge construction is based on an empathic understanding of the representations of the subjects (or participants).

We circumscribe our research areas to online forums, because “in France, the sharing of experience between patients takes place notably in the forums and secondarily in the form of comments placed on blogs. Forums are provided either by commercial publishers or by patient associations” (Silber 2009). We have selected two forums. The first Doctissimo, being the most known and used as a general health forum and the second, the impatient ones, being a forum specialized on a type of cancer. We present in a synthetic way these two fields, inscribed in two different organizational logics: one, Doctissimo, is inscribed in a “lucrative” logic, the other, Les Impatientes, in a “non-lucrative” with a “deinstitutionalized” logic.

Doctissimo, created in 2000, has been the subject of several studies because of its popularity (Thoër 2012) on the development of online market content (Romeyer 2008), and on the search for information (Battaïa 2012). The site is ranked among the most visited in France, with 6.24 million unique visitors per month in 2008 (Romeyer 2008). Doctissimo is part of a business model focused on financing through advertising and operates on the basis of an articulation between a logic and economic actors (the Lagardère media group, private advertisers), and a logic and community actors (the multiple forums managed by a small team and an army of volunteers), all being supported by a software platform (Thoër 2012).

With regard to community animation, “on a forum such as Doctissimo, the self-regulation described is redoubled by the existence of five professional moderators, assisted by volunteer facilitators who have the possibility of deleting abusive messages, advertising, or giving contact details of doctors, and can report reprehensible behavior for punishment” (Akrich, Méadel 2009). Thus, the volunteer facilitators testify of an acute form of online empowerment that seems to participate for the patient of an asset to live well his disease and the side effects of the therapy.

However, as on most forums, the doctinautes (the members of the Doctissimo forums) only read the testimonies left by more active users (Romeyer 2012). But this does not mean that readers do not benefit from the testimony of contributors to move towards a better life and a form of resilience (patient education). However, it is difficult to assess the actual degree of empowerment for ordinary readers. In Doctissimo, interventions are complex, combining questions and answers (Clavier, Manes-Gallo et al. 2010).

In order to contact the moderators and doctinauts, we have created a profile. We initially preferred to send private messages to forum members according to several criteria. First, the date of the last messages sent. Some "sons" date back several years, it is difficult to know if the person is still active, even alive knowing that they are people with serious illnesses. Second, the type of cancer to study gender differences (breast cancer/prostate cancer) and also with other specialized forums such as the Impatients. Third, the degree of involvement of the doctinauts that is indicated under the pseudo of the person in terms of rank. Thus, a regular and a "golden doctinaut" do not have the same relationship with the forum.

The second forum, les Impatientes, was created in December 2001 by a computer engineer, Karine Sabatier after her mother's death from breast cancer. Her goal was to publish practical and concrete information, and to allow women to talk to each other about breast cancer. The forum has more than 10,000 enrollments in almost sixteen years of age lead a thematic forum for women affected by breast cancer. If the "files" section of the site has not been updated for several years (the moderators do not seem to be active on the site since 2014), new registrations are held every day and maintain the dynamism of the forum.

With a long immersion in the two forums, hours of in depth interviews, we extracted findings that resonated with other research and bring new light in how information is transmitted in health forums.

## Beyond the search for information

One of the many reasons for cancer patients to visit online forum is to reduce anxiety due to lack of information or social connection would contribute to psychological well-being[1] which, in turn, would contribute to patient life satisfaction. Integration into online communities is part of a form of patient well-being. This is why information research is a major theme in health and the Internet (Li et al. 2015), as patients reduce their concerns through information found on the Internet (Lee, Hawkins 2016). But the medical professional is concerned that patients find information of uncertain quality (Ebel, Stellamanns et al. 2015).

Online information can be used to gain more knowledge about the disease, treatments or how to cope with stress and emotional distress, especially it can affect how individuals perceive their loved ones' diagnosis (Lauckner 2015). However, not all patients and their families are prepared to decode the scientific and medical information available online. Most websites are too difficult for the general public

---

[1] Psychological well-being is considered an indicator of happiness and satisfaction (Keyes, Shmotkin, Ryff 2002).

to read (Storino, Castillo-Angeles et al. 2016). Patients go online not to seek medical information in the strict sense, but to share their experiences with the disease. In the light of the exchanges available on the online community provides a form of temperance or even a grid for reading symptoms that are not always interpretable. This is as much for patients who have already been informed of their pathology as for future patients trying to find answers to their concerns and who can extract alarmist testimonies that put them in an anxiety not conducive to well-being. The possibility of requesting information therefore becomes essential and functions as a collective filter that can avoid the sometimes anxiety-provoking dimension of online information.

Thus, Internet users seek information filtered by individual experience and not objective information. This experiential knowledge helps patients understand their disease and create new empirical knowledge (Akrich, Rabeharisoa 2012), but knowledge from the disease experience, especially that of other patients. Thus, an impatient woman (S) discovered the forum by chance, looking for "breast cancer" more than fifteen years ago. At first she had gone to the cancer league forum, then she kept looking and she came across the essentials, which she liked more because it is more personal. The league forum[2] offers medical answers via moderators. She found this interesting, but it did not meet her expectations. For her, as for many others, the impatient represent a community.

Online communities of patients, rooted in empathy, allow them to solve each other's problems, share information, express emotions, support each other (Demiris 2006). Concretely, forum discussions are categorized into five main groups – everything related to 1) support, 2) medical, 3) emotions, 4) privacy, and 5) economics (Blank, Schmidt et al. 2010). These five groups are found in the criteria of well-being knowing that it is a complex set of environmental, professional, intellectual, emotional, financial, physical, spiritual, cultural and social elements. These criteria for well-being are grouped into three broad groups as defined by the World Health Organization (WHO) in 1945: "Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity". Online communities respond to these three characteristics of well-being: 1) physical with advice drawn from experiential knowledge of the disease and treatments, 2) mental through emotional support and the opportunity to express themselves, empowerment, and 3) social with a community of other patients to break isolation and find social support.

## Empowerment in Empathy

Empowerment can be found on three levels which are individual, organizational and community (Groen, Kuijpers et al. 2015). On the individual level, Groen, Kuijpers et al. (2015) identified five main attributes of patient empowerment: (1) being autonomous and respected, (2) having knowledge, (3) having psychosocial and behavioral skills, (4) perceiving support from the community, family, and friends,

---

[2] https://www.ligue-cancer.net/forum

and (5) perceiving oneself to be useful. The latter two were specific for the cancer setting.

Individual or psychological empowerment refers to an individual's ability to make decisions and exercise control over his or her personal life. Like feelings of efficiency or self-esteem, empowerment emphasizes the development of a positive representation of oneself (self-concept) or personal skills. The empowerment process is defined as "the ability of an individual to make decisions when faced with a specific situation or problem, alone or in interaction with resource persons, with the aim of adapting to that situation and exercising control over his or her own situation and personal life" (Brouard et al. 2014).

Empowerment is actively mobilized in public health discourses with the patient as an actor in his or her health. Patients cannot build their empowerment alone, they need health organizations and patient communities especially online. Not living near their oncology center, or too weak to travel, online communities are a viable alternative for patients, especially when they face their disease and the often harmful effects of treatments. At this point, e-health practices seem to us less understandable as manifestations of patients' desire for emancipation than as an expression of a program for shifting public health costs from states to citizens (Casilli 2011). Therefore, online forum is a free, always available source of comfort and knowledge for patients.

One impatient explained she does not always dare to say how she feels to her family; because she has the impression to complain constantly. She worried that her fears will be received as too great a burden. So, she unloads her troubles on the forum, where she can express herself, be understood, and help others. Indeed, feeling able to bring something to others offers an empowerment that may seem lost in the face of illness. Providing social or emotional support is just as rewarding for the person who receives it as it is for the person who offers it.

## Resilience in mediating knowledge

Discussion forums provide spaces for self-help and discussion, where everyone can express their fears, doubts and hopes (Akrich 2010). Emotion-focused adaptation is necessary to treat negative and uncontrollable events such as cancer (Turner, Grube et al. 2001). Several impatient mentioned reading blogs from other Forum members a way to reduce their anxiety when facing heavy cancer treatments. "Findings indicate that blogs function primarily as tools for emotion management and information-sharing rather than as tools for problem-solving or prevention and care" (Chung, Kim 2008). Despite the scary testimonies visible on the forum, the impatient S continues to read the new messages. She relates her own path in the disease by telling herself that she is not yet at that stage, and that she is lucky. She realized that she was afraid to leave behind those around her, her granddaughter, but at the same time she wants to see if her third daughter will have a baby. The forum helps people in accepting their mortality and helps them live with the burden of disease.

It is easier to cope with the disease with the hope of remission. This is the goal that the impatient E gave himself by testifying of his remission, and by answering systematically to the other testimonies of remission “it has been 8 years that I had not come on the site, but it is to say that I am always in remission”. Exchanging with people in the same situation helps to cope with life’s depression and anxiety during and after treatment. social support (tangible and affectionate support and positive social interaction, )may be fulfilled by the patient’s loved ones, whereas emotional and informational support involves others who can relate to and understand the patient’s experience (Kalbfleisch, Cyr et al. 2015). Our research corroborates the findings of and demonstrates the importance of online communities to patients.

## Conclusion

Our research has shown that patient engagement in health forums meets richer and deeper needs than simply seeking information. Through discussions and meetings on the forums observed, patients meet their needs to talk with other people with cancer (preferably the same) and thus break their isolation and give meaning to what happens to them. While remaining anonymous and at home, forum members help and support each other in difficult times.

Online forum in health seems to participate in the well-being of the patient, by allowing them to become actor of their informational care and by opening the way to autonomous forms of education in health on line (Nambisan 2011). Patients learn to gain resilience and fight loneliness. Health professionals and institutions can no longer simply advise to avoid the Internet, they must now find info-communication devices to integrate community uses of the Internet in health care pathways. Most importantly, online forum cannot provide information without mutual support (Potts 2005).

## Funding

We would like to thank the Burgundy-Franche-Comté region and the European Regional Development Fund for their assistance, which has enabled us to study this subject, a real social challenge. Moreover, this work has benefited from State aid managed by the National Research Agency under the program “Investments for the future” bearing the reference ANR-11-LABX-0021-01 - Labex LipSTIC.

## References

Akrich M., 2010), *From Comunities of Practice to Epistemic Communities: Health Mobilizations on the Internet*, Sociological Research Online, 15(2), 10.

Akrich M., Méadel C., 2009, *Les échanges entre patients sur l’Internet*, La Presse Médicale, 38(10):, 1484–1490.

Akrich M., Rabeharisoa V., 2012, *L’expertise profane dans les associations de patients, un outil de démocratie sanitaire*, Santé publique, 24(1), 69–74.

Alber A., 2010, *Voir le son: réflexions sur le traitement des entretiens enregistrés dans le logiciel Sonal*, Socio-logos. Revue de l’association française de sociologie, 5.

Battaïa C., 2012, L’analyse de l’émotion dans les forums de santé. Conférence JEP-TALN--RECITAL.

Blank T.O., Schmidt S.D., Vangsness S.A., Monteiro A.K., Santagata P.V., 2010, *Differences among breast and prostate cancer online support groups*, Computers in Human Behavior, 26(6), 1400–1404.

Casilli A., 2011, *Usages numériques en santé: conflictualité épistémique et sociale dans les communautés de patients en ligne*, Internet: des promesses pour la santé, 181–191.

Chung D.S., Kim S., 2008, *Blogging activity among cancer patients and their companions: Uses, gratifications, and predictors of outcomes*, Journal of the American Society for Information Science and Technology, 59(2), 297–306.

Clavier V., Manes-Gallo M.C., Mounier E., Paganelli C., Romeyer H., Staii A., 2010, Dynamiques interactionnelles et rapport à l'information dans les forums de discussion médicale. Web social: mutation de la communication. F. Millerand, S. Proulx and J. Rueff. Québec, QC**,** 297–314.

Demiris G., 2006, *The diffusion of virtual communities in health care: Concepts and challenges*, Patient Education and Counseling, **62**(2), 178–188.

Ebel M.D., Stellamanns J., Keinki C., Rudolph I., Huebner J., 2015, *Cancer Patients and the Internet: a Survey Among German Cancer Patients*, Journal of cancer education.

Elbert N.J., van Os-Medendorp H., van Renselaar W., Ekeland A.G., Hakkaart-van Roijen L., Raat H., Nijsten T.E., Pasmans S.G., 2014, *Effectiveness and cost-effectiveness of ehealth interventions in somatic diseases: a systematic review of systematic reviews and meta-analyses*, Journal of medical Internet research, 16(4).

Groen W.G., Kuijpers W., Oldenburg H.S., Wouters M.W., Aaronson N.K., van Harten W.H., 2015, *Empowerment of Cancer Survivors Through Information Technology: An Integrative Review*, Journal of Medical Internet Research, 17(11), e270.

Kalbfleisch M., Cyr A., Gregorio N., Nyhof-Young J., 2015, *Investigating coping strategies and social support among canadian melanoma patients: A survey approach*, Canadian Oncology Nursing Journal/Revue canadienne de soins infirmiers en oncologie, 25(1), 60–65.

Keyes C.L., Shmotkin D., Ryff C.D., 2002, *Optimizing well-being: The empirical encounter of two traditions*, Journal of personality and social psychology, 82(6), 1007.

Kvale S., Brinkmann S., 2008, InterViews: Learning the Craft of Qualitative Research Interviewing, London, Sage Publications.

Lauckner C., 2015, *The emotions and action tendencies associated with viewing online cancer information among patients' loved ones*, Journal of Health Psychology, 1–13.

Lee S.Y., Hawkins R.P., 2016, *Worry as an Uncertainty-Associated Emotion: Exploring the Role of Worry in Health Information Seeking*, Health Commun, 31(8), 926–933.

Li F., Li M., Guan P., Ma S., Cui L., 2015, *Mapping publication trends and identifying hot spots of research on Internet health information seeking behavior: a quantitative and co-word biclustering analysis*, Journal of Medical Internet Research, 17(3), e81.

Miron J.M., Dragon J.F., 2007, *La recherche qualitative assistée par ordinateur pour les budgets minceurs, est-ce possible*, Recherches qualitatives, 27(2), 152–175.

Nambisan P., 2011, *Information seeking and social support in online health communities: impact on patients' perceived empathy*, Journal of the American Medical Informatics Association, 18(3), 298–304.

Potts H.W., 2005, *Online support groups: an overlooked resource for patients*, He@lth Information on the Internet, 44(1), 6–8.

Romeyer H., 2008, *TIC et santé: entre information médicale et information de santé*, tic&-société, 2(1).

Romeyer H., 2012, *La santé en ligne. Des enjeux au-delà de l'information*, Communication. Information médias théories pratiques, 30(1).

Silber D., 2009, *Médecine 2.0 : les enjeux de la médecine participative*, La Presse Médicale, 38(10), 1456–1462.

Storino A., Castillo-Angeles M., Watkins A.A., et al., 2016, *Assessing the accuracy and readability of online health information for patients with pancreatic cancer*, Journal of the American Medical Association, Surgery, 151(9), 831–837.

Thoër C., 2012, Les espaces d'échange en ligne consacrés à la santé: de nouvelles médiations de l'information santé. Internet et santé, usages, acteurs et appropriations, collection santé et société. C. Thoër and J. J. Lévy. Québéc, QC, PUQ, 57–92.

Turner J.W., Grube J.A., Meyers J., 2001, *Developing an optimal match within online communities: an exploration of CMC support communities and traditional support*, Journal of Communication 51(2), 231–251.

## Empathic mediation of information: online forum for cancer patients

### Abstract

In this paper, we describe our research about cancer patients' use of the Internet, especially online forums. Many studies in health communication have focused on the benefits of online communities for cancer patients, but few have looked into how the group contribute to the individual and vice versa. This paper offers a detailed review of the current issues with e-health and a discussion of theories and concepts helpful in understanding the phenomenon of online communities. It follows with the methodological approaches considered in order to study such a delicate subject. Finally, we shall discuss the gap between official discourse and the reality face by cancer patients. Health organizations have an economic incentive to promote patient empowerment. Medical professional and health care facilities could benefit by including online forum in their treatment protocols, but it is not the case. Patients are warned not to go online, which they do because too many questions are left unanswered, feeling overwhelm by the treatments and how to deal with side effects. This paper shows that patients gain much more than information, they gain an empathetic group of other cancer patients. And the search for information is more efficient with empathy and social and emotional support.

**Key words:** on-line communications, forums, cancer patients, knowledge mediation processes

**Elodie Crespel**
ATER au département communication de l'IUT Besançon-Vesoul
Membre du CIMEOS
University Institutes of Technology, IUT Besançon-Vesoul
email: elodie.crespel@univ-fcomte.fr