Ethnographic Discovery of Adverse Events in Patient Online Discussions:
Customer Relationship Management

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ABSTRACT

A healthcare provider can extend its customer relationship management program by sponsoring an online, patient discussion group. In those groups, patients may discuss adverse events that are inadequately addressed in the literature. The author, as a cancer patient, joined two online, patient discussion groups and identified four types of such adverse events. For each such adverse event, the patient findings, the medical literature, and the implications are noted. Extracts from the literature that were provided to the patients were welcomed by the patients. A literature review of one of the adverse events has been published in a medical journal. Factors are presented for healthcare providers to consider in deciding whether or not to sponsor an online, patient discussion group.

Keywords: computer-based communication systems; customer relationship management; ethnography; head-and-neck cancer; online patient communities; medical adverse events; quality of care issues

INTRODUCTION

Customer relationship management (CRM) systems are used in healthcare systems around the world (Alshawi, Missi, & Eldabi, 2003; Calhoun, Raisinghani, Tan, Untama, Weiershaus, & Levermann, 2005; Banaszak-Hol, & Hearld, 2006). A typical approach to CRM is to survey patient satisfaction and to address management steps to improve the results of the next survey (Zineldin, 2006). Data mining of Web information is an alternative way to learn what consumers think. In the financial sector, consumer views on particular investments have been assessed through the comments that those consumers make in online, discussion groups (Antweiler & Frank, 2004).

Many online patient groups are established by volunteers on free sites, such as groups.yahoo.com (Rada, 2006b). However, some healthcare entities maintain patient online discussion groups. For instance, the Joslin Diabetes Center runs an online, diabetes discussion group for the public, and experts from the Center provide feedback online. Kaiser Permanente Health Plan maintains numerous discussion groups moderated by Kaiser's professionals, but access is restricted to enrollees in the Kaiser Plan.

Healthcare professionals in online moderator roles address adverse events, among other things. An adverse event occurs when some intervention by a healthcare provider produces an unwanted reaction. For instance, radiation treatment for oral cancer can cause obstructive sleep apnea. The literature on adverse events addresses their causes, how to reduce them, and the impact they have on patients, staff, and healthcare organizations (Misson, 2001). Typically, healthcare professionals investigate adverse events through the medical record (Duff, Daniel, Kamendje, Le Beux, & Duvauferrier, 2005).

Listening to patients is a key to reducing adverse events (Cleary, 2003): "by relying on the observations and insights of patients such as Mr. Q., the physicians and staff will be able to close the gap between Mr. Q.'s experience and what they can achieve." The book *Partnering with Patients to Reduce Medical Errors* (Spath, 2004) emphasizes the role of patients in reducing adverse medical events.

Patients in online groups hold a unique and valuable position because of their sheer numbers and an intense focus on their shared illness. Patient groups may have contact with larger numbers of disease-specific patients than many physicians and have the luxury of spending many hours discussing similarities and differences. After hundreds of hours of conversation, patterns can begin to emerge. These patterns might lead to new insights about adverse events. Members of an online patient discussion group explored their treatment and made discoveries that were incorporated in a scholarly journal article (Ferguson, 2002).

This article explores the means by, and extent to, which participants in online patient-patient discussion groups provide useful information about medical adverse events. The hypothesis is that patient online group information can stimulate the discovery of important gaps in the medical literature. More generally, the argument is that these online groups can be an important resource for both patients and healthcare providers.

METHOD

The author is a medical doctor and a head-and-neck cancer (HNC) patient. As doctors become ill and see the world from the patient's side, they often have useful insights to share about the relationship between patients and healthcare providers (Rosenbaum, 1988). This author joined two HNC online patient discussion groups as a patient.

Since an online discussion group is self-documenting by nature, the opportunity exists for a participant in a group to review the discussion and to engage in a kind of retrospective ethnographic analysis. Studying online groups via ethnography is in many ways easier than studying face-to-face groups (Paccagnella, 1997). The term 'netnography' has been coined to apply to such ethnography (Kozinets, 2002): "As a method, netnography is faster, simpler, and less expensive than traditional ethnography and more naturalistic and unobtrusive than focus groups or interviews."

In the context of this research, an online group uses a software system that provides a searchable archive of previous messages. Members of the group create messages and post them to the system, and the system in turn distributes these messages to the group. The system may interface to a group member via an e-mail client or a Web site. The online groups noted in this article may include patients, a patient's family or friends, and others who want to help. This population will be typically represented with the umbrella term 'patients' with its meaning apparent in the context.

The two HNC groups that the author joined explicitly welcomed any group members to use personally de-identified information in the online messages for research purposes. The author read the patient messages, identified messages of interest, studied relevant clinical, journal articles, and where appropriate shared extracts from the literature with the group. The author identified four cases where the information needs of the HNC patients led to the discovery of adverse events and gaps in the medical literature. For each case, the patient findings, the medical literature, and the implications are noted.

RESULTS

The four cases follow:

1. Patients in both groups frequently discussed ways to cope with their fatigue. Many patients reported signs and symptoms consistent with obstructive sleep apnea (OSA) in relation to this fatigue. The literature reveals incomplete information about OSA in HNC patients. Two articles provide interestingly different perspectives on OSA as a complication of the treatment of HNC. In one article, the incidence of OSA is 92% in patients treated for HNC (Friedman et al., 2001), while in the other article, 8% of treated HNC patients develop OSA (Rombaux et al., 2000). The literature at that time provided no mention of a radiated-only patient developing OSA, but one of the patients in the online group developed OSA after only radiation. Extracts of the literature were shared with the online group, and the patients expressed gratitude for that literature information. Furthermore, the observation of a gap in the literature became the basis of a published, medical, journal article (Rada, 2005a) and book chapter (Rada, 2007). In other words, the experience had two positive outcomes: increased patient satisfaction through knowledge gained and contributions to the medical literature.

2. Hyperbaric oxygen treatment (HOT) for osteoradionecrosis (ORN) of the mandible is routine in the United States. A patient in a discussion group presented his concerns about HOT for ORN and said: "Every dentist that I have seen in San Antonio has recommended HOT, but does anyone know if HOT is worth the $50,000 cost?" The patient went to Mexico and was told HOT for ORN was unnecessary. European studies have shown that HOT is not appropriate for ORN (Annane et al., 2004), but the American literature defends HOT (Mendenhall, 2004). Differences in the standard of care in one country versus another and the standard of care versus the ability to pay for the care create a kind of adverse event for the patient. Again, when extracts from the literature about HOT and ORN were shared with the

patients, they replied with messages including a 'thank you.'

3. Multiple participants (all older than 40) had initially gone to the doctor with a lump in the neck and been told that they had a branchial cleft cyst. As the cyst grew over months after the initial diagnosis, each patient sought further medical help and received the correct diagnosis of cancer. The medical literature reports that "80% of so-called branchial cleft cysts in the over 40s' age group are malignant (Andrews, Giddings, & Su, 2003)." The literature does not address the frequency of misdiagnosis, though this misdiagnosis is an important adverse event. After information from the literature was shared with the patients, some committed themselves to working with their communities to increase awareness of the danger signs of HNC.

4. Two patients reported shock (anaphylaxis) in response to a drug (amifostine) that was first being used during HNC radiotherapy. The literature at the time suggested that severe reactions to amifostine were rare in HNC patients: "Amifostine administration was well tolerated, with a low incidence of side effects" (Antonadou, Pepelassi, Synodinou, Puglisi, & Throuvalas, 2002). A year later the results of a clinical trial were published which confirmed what the patients feared (Rades et al., 2004): "Administration of amifostine during radiotherapy for HNC is associated with a high rate of serious adverse effects." When a new drug use appears, detecting uncommon adverse events may be supported by having patient groups monitoring and discussing their reactions to their treatments.

Some of the patients took this group information to their doctors and found that their doctors appreciated this information.

These four cases show, at least, three positive outcomes:

- Patients appreciated receiving extracts of the medical literature that pertained to their questions
- Secondary to their online participation, several patients became involved in community initiatives to detect HNC early
- Scholarly reviews of the medical literature have been published based on the gaps in the literature identified by the patients

When patients are confused about an adverse event, the possibility exists that healthcare professionals are also confused about these particular events and are unable to help. In a patient group, the patients may find opportunity to explore these troubling matters at length. From this study, patient groups can promote understanding about topics in which patients felt particularly unable to get adequate explanations from their healthcare professionals. The medical literature shows that these topics were little understood. For example, one journal article said the incidence of OSA secondary to HNC treatment was 92%, while another said the incidence was 8%, and very few other articles addressed this topic.

The majority of the discussion in the two HNC groups was not about the preceding, four adverse events. Much of the discussion was about emotional topics, such as a patient reporting the good news that the latest checkup with the oncologist revealed no progression of the disease and other patients congratulating the patient on

the good news. Patients often complained about the loss of saliva (xerostomia) secondary to the cancer treatment. However, this adverse effect is well documented in the literature, and the patient discussion did not shed new light on xerostomia nor suggest a gap in the literature.

CATEGORIES AND PROCEDURES

Each of the preceding adverse events concerned more than one clinical specialty. The adverse events from the HNC groups might be categorized as follows:

- *A diffuse symptom*: OSA secondary to treatment for HNC may tend to be overlooked by otolaryngologists because the symptoms are diffuse and OSA is often addressed by sleep specialists rather than otolaryngologists.
- *Standard of care*: HOT, as part of the national standard of care for ORN, is not supported by clinical trials internationally, but the practicing otolaryngologist is not expected to dispute the national standard of care.
- *Primary care provider misdiagnosis*: A misinterpretation by the primary care provider might not be extensively documented or analyzed by the otolaryngologist.
- *Uncommon reaction to new drug*: When the drug amifostine was initiated for a new purpose, researchers needed further experience to uncover adverse events.

The foremost causes of adverse events as reported by the U.S. Institute of Medicine (Kohn, Corrigan, & Donaldson, 2000) are technical errors, diagnostic errors, failure to prevent injury, and medication errors. That

classification is, however, not necessarily the optimal one for understanding what can be gleaned from patient online groups.

If a provider has decided to support an online discussion group and to provide moderators, then it might guide moderators relative to the findings of this study. To find evidence of adverse events that are inadequately appreciated in the literature, a healthcare professional might:

1. *Join an online discussion group for patients with a particular chronic disease*.
2. *Identify a finding that is highlighted by a patient as a problem*. Findings may include symptoms, signs, laboratory or test results, observations, or specific events (such as hospitalization or receiving a bill). A finding is a problem when a patient says so.
3. *Review the medical literature to determine whether a medical intervention experienced by the patient might have a causal relation to the problematic finding*. Relevant PubMed 'Medical Subject Headings' are identified, a query is posed to PubMed, and full-text copies of journal articles are retrieved through membership in a medical library subscription program. Temporal relationship, strength of association, biological plausibility, and other relationships contribute to a judgment of causality (Darden & Rada, 1988).
4. *Determine whether the literature provides conflicting or unclear guidance*. Sometimes the published literature suggests conflicting algorithms for diagnosis or treatment, and more research is needed to harmonize the literature.
5. *Extract information from the literature and return that information to the group*. The extract should be clear to the

intended audience, embedded within a personal context, and made as a reply to recently posted message that has not already received a similar response.

If an extract from the literature is simply posted without context or explanation, then the impact, as measured by patient response, is less. Information systems can support this work by parsing patient messages and semi-automatically linking to relevant citations from PubMed (Rada, 2005b).

DISCUSSION

If one takes the preceding categorization of adverse events from online groups and tries to generalize further, one might note that the problems occur where the otolaryngologist's responsibility is blurred because someone else is also responsible. In general, adverse events may be least well understood where 1) the responsibility for the adverse event falls among several medical specialties and 2) the medical specialists inadequately communicate with one another. The four misunderstood topics discovered in this study were about patient conditions that require the coordinated attention of healthcare professionals from different disciplines, and this multi-disciplinary character of the topics may partly account for the relative lack of understanding about the topics.

The data from the online groups leads to qualitative results. For instance, the incidence of OSA in HNC patients is not expected to be the number of patients in the HNC groups that reported OSA because participants may have had OSA and not known it or did not mentioned it. In online groups, most participants are typically lurkers (Preece, Nonnecke, & Andrews, 2004). To obtain accurate incidence data, clinical trials might be needed.

The online patient information supported the identification of a problem which further research might solve.

If a healthcare provider wanted its employees to moderate online patient discussion groups with the intent of also helping identify adverse events, then a proposal to the provider's institutional review board might be in order. The patients joining the group would be provided a consent form that detailed the conditions, the patient alternatives, and other components of a proper consent form. Given that patients had to register to join the group, their successful registration would only occur after they noted online that they consented.

While patients might be asked to sign a consent form, they are not invited to the online groups to get a diagnosis or a treatment. Rather the groups support patient-patient interaction, and the patients are responsible for the content of the message that they share. If a knowledgeable person brings extracts from the literature to the discussion, those extracts cite the original source and are informational only. Responsibility for taking action based on the information rests with the patient.

The Johns Hopkins Department of Pathology hosts some online patient discussion groups. The Department has found that patients may express their gratitude for this service via financial donations to the Department. Thus, the costs associated with maintaining the discussion Web site may be offset by patient financial contributions. This observation links to the economics of religion. Interestingly, online patient groups have some socio-economic characteristics in common with the socio-economic characteristics of religious groups (Rada, 2006b), and the opportunity exists to exploit the literature on the economics of religion (Iannaccone, 1998) in understanding the

economics of online patient groups.

A healthcare entity that wants to sponsor an online discussion group has many options. For instance, the entity might or might not assign a healthcare professional as a moderator to the group. Providing a moderator is costly. Healthcare professionals have many demands on their time and often do not see participation in an online patient discussion group as a cost-effective use of their time. For the typical healthcare provider in the United States, efforts invested in an online discussion group cannot be billed to a health insurance company on behalf of the patients in the group. On the other hand, some healthcare entities have found that the goodwill generated by sponsoring an online discussion site stimulates financial donations from patients. A financial cost-benefit analysis that considered a wide range of factors, such as staff cost and patient loyalty, would be appropriate before an entity decided how much, if anything, to invest in online patient discussion groups.

CONCLUSION

Customer (or patient) relationship management is important to healthcare providers, as is minimizing adverse events secondary to healthcare decisions. One source of information that has been largely overlooked by the healthcare industry comes from online patient discussion groups. Online patient groups may provide an opportunity for healthcare providers to both build customer relationships and explore adverse events.

The author participated as a patient, though he is also a doctor, in two head-and-neck-cancer online patient groups. Patients discussed various types of adverse events, but four types were particularly intriguing for the gaps between what the patients needed to know and what the literature offered. These adverse events have been categorized as involving a diffuse symptom, a standard of care, a primary-care doctor's misdiagnosis, and uncommon reaction to a drug. The cases are multi-disciplinary in nature. The gaps in the literature create an opportunity for someone to produce a synthesis of the literature that highlights the gap and to publish that synthesis in a scholarly medical journal.

As measured by their responses, patients appreciated receiving information from the literature about their adverse events. A systematic approach to identifying such adverse events and providing relevant literature to patients is sketched based on the experiences of the author. Software can support the retrieving of relevant literature, but posing the response in the context of the patient's concerns requires human judgment.

One could continue this work in several directions. Patients in online groups typically focus on sharing empathy and information (Ebner, Leimeister, & Krcmar, 2004). Under what conditions do members of a group want primarily empathy or primarily information? What kinds of information are most useful? Some preliminary experimental results on identifying patient groups that prefer information over empathy have been established (Rada, 2006a).

Patients will have questions and comments about the quality of and cost of care from various providers. This kind of information may be comparable to what healthcare entities want from patient satisfaction surveys. To what extent and how can that kind of information be systematically mined from patient online discussion groups?

People seeking health-related information on the Web are one of the most common

users of online discussion groups. Healthcare entities might benefit by paying further attention to the content of these discussion groups. This article has presented insights about dealing with adverse events in these groups and, more generally, framed some of the issues that a healthcare provider should consider.

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REFERENCES

Alshawi, S., Missi, F., & Eldabi, T. (2003). Healthcare information management: The integration of patients' data. *Logistics Information Management, 16*(3-4), 286-295.

Andrews, P., Giddings, C., & Su, A. (2003). Management of lateral cystic swellings of the neck, in the over 40s' age group. *J Laryngol Otol, 117*(4), 318-320.

Annane, D., Depondt, J., Aubert, P., Villart, M., Gehanno, P., Gajdos, P., & Chevret, S. (2004). Hyperbaric oxygen therapy for radionecrosis of the jaw: A randomized, placebo-controlled, double-blind trial from the ORN96 study group. *Journal of Clinical Oncology, 22*(24), 4893-4900.

Antonadou, D., Pepelassi, M., Synodinou, M., Puglisi, M., & Throuvalas, N. (2002). Prophylactic use of amifostine to prevent radiochemotherapy-induced mucositis and xerostomia in head-and-neck cancer. *International Journal of Radiation Oncology*Biology*Physics, 52*(3), 739-747.

Antweiler, W., & Frank, M. (2004). Is all that talk just noise? The information content of Internet stock message boards. *Journal of Finance, 59*(3), 1259-1295.

Calhoun, J., Banaszak-Hol, J., & Hearld, L. (2006). Current marketing practices in the nursing home sector. *Journal of Healthcare Management, 51*(3), 185-200.

Cleary, P. (2003). A hospitalization from hell: A patient's perspective on quality. *Annals of Internal Medicine, 138*(1), 33-39.

Darden, L., & Rada, R. (1988). Hypothesis formation via interrelations. In: A. Prieditis (Ed.), *Analogica* (pp. 109-128). London: Pitman.

Duff, F., Daniel, S., Kamendje, B., Le Beux, P., & Duvauferrier, R. (2005). Monitoring incident report in the healthcare process to improve quality in hospitals. *International Journal of Medical Informatics, 74*(2-4), 111-117.

Ebner, W., Leimeister, J., & Krcmar, H. (2004). Trust in virtual healthcare communities: Design and implementation of trust-enabling functionalities. In: R. Sprague (Ed.) *37th Annual Hawaii International Conference on System Sciences* (pp. 182-192). Hawaii: IEEE.

Ferguson, T. (2002). *Key concepts in online health: E-patients as medical researchers*. Retrieved August 2005, from http://www.fergusonreport.com/articles/fr00903.htm.

Friedman, M., Landsberg, R., Pryor, S., Syed, Z., Ibrahim, H., & Caldarelli, D. (2001). The occurrence of sleep-disordered breathing among patients with head and neck cancer. *Laryngoscope, 111,* 1917-1919.

Iannaccone, L. (1998). Introduction to the economics of religion. *Journal of Economic Literature, 36,* 1465-1496.

Kohn, L., Corrigan, J., & Donaldson, M. (Eds.). (2000). *To err is human: Building a safer health system*. Washington, D.C.: National Academy Press.

Kozinets, R. (2002). The field behind the screen: Using netnography for marketing research in online communications. *Journal of Marketing Research, 39*(1), 61-72.

Mendenhall, W. (2004). Mandibular osteoradionecrosis. *Joural of Clinical Oncology, 22*(24), 4867-4868.

Misson, J. (2001). A review of clinical risk management. *J. Qual. Clin. Practice, 21,* 131-134.

Paccagnella, L. (1997). Getting the seats of your pants dirty: Strategies for ethnographic research on virtual communities. *Journal of Computer Mediated Communication, 3*(1), online at http://ascusc.org/jcmc/vol3/issue1/paccagnella.html.

Preece, J., Nonnecke, B., & Andrews, D. (2004). The top five reasons for lurking: Improving community experiences for everyone. *Computers in Human Behavior, 20*(2), 201-223.

Rada, R. (2005a). Obstructive sleep apnea and head and neck neoplasms. *Otolaryngology-Head and Neck Surgery, 132*(5), 794-799.

Rada, R. (2005b). Software for patient-patient discussions. In: H. Mili (Ed.), *Montreal Conference on E-Technologies 2005 (MCeTech2005)* (pp. 205-209). Montreal, Canada.

Rada, R. (2006a). Citations in online patient groups. In: P. Isaias, M. McPherson, & F. Bannister (Eds.), *e-Society 2006: IADIS International Conference* (pp. 106-109). Dublin, Ireland: International Association for Development of the Information Society (IADIS) Press.

Rada, R. (2006b). Membership and online groups. In: P. Isaias, M. McPherson, & F. Bannister (Eds.) *e-Society 2006: IADIS International Conference* (pp. 290-293). Dublin, Ireland: International Association for Development of the Information Society (IADIS) Press.

Rada, R. (2007). Sleep and quality of life in head and neck neoplasm. In: J. Verster, S. Pandi-Perumal, & D. Streiner (Eds.), *Sleep and quality of life in head and neck neoplasm* (pp. in press). Totowa, New Jersey: Humana Press.

Rades, D., Fehlauer, F., Bajrovic, A., Mahlmann, B., Richter, E., & Alberti, W. (2004). Serious adverse effects of amifostine during radiotherapy in head and neck cancer patients. *Radiotherapy and Oncology, 70,* 261-264.

Raisinghani, M., Tan, E.-L., Untama, J., Weiershaus, H., & Levermann, T. (2005). CRM systems in German hospitals: Illustrations of issues & trends. *Journal of Cases in Information Technology, 7*(4), 1-26.

Rombaux, P., Hamoir, M., Plouin-Gaudon, I., Liistro, G., Aubert, G., & Rodenstein, D. (2000). Obstructive sleep apnea syndrome after reconstructive laryngectomy for glottic carcinoma. *Eur Arch Otorhinolaryngol, 257*(9), 502-506.

Rosenbaum, E. (1988). *A taste of my own medicine, when the doctor is the patient*. New York, NY: Random House.

Spath, P. (2004). Preface. In: P. Spath (Ed.), *Partnering with patients to reduce medical errors* (pp. xix-xxiii). Chicago, IL: American Hospital Association Press.

Zineldin, M. (2006). The quality of healthcare and patient satisfaction: An exploratory investigation of the 5Qs model at some Egyptian and Jordanian medical clinics. *Int J Health Care Qual Assur Inc Leadersh Health Serv, 19*(1), 60-92.

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