Chapter 5.18
Ethnographic Discovery of Adverse Events in Patient Online Discussions:
Customer Relationship Management

Roy Rada
University of Maryland, Baltimore County, USA

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.

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.

7 more pages are available in the full version of this document, which may be purchased using the "Add to Cart" button on the publisher's webpage:
www.igi-global.com/chapter/ethnographic-discovery-adverse-events-patient/36790

Related Content

Using Strategic Planning to Improve Performance Management and Its Impact on Organizational Success: A Study of Private Sector in Iran
Ahmad Ali Mohassesiand Rozita Shahbaz Keshvari (2015). *International Journal of Strategic Information Technology and Applications (pp. 44-63).*
www.irma-international.org/article/using-strategic-planning-to-improve-performance-management-and-its-impact-on-organizational-success/148712

A Systematic Approach to Evaluating Open Source Software
Norita Ahmadand Phillip A. Laplante (2011). *International Journal of Strategic Information Technology and Applications (pp. 48-67).*
www.irma-international.org/article/systematic-approach-evaluating-open-source/52071

Examining the Approach Used for Information Technology Investment Decisions by Practitioners Responsible for IT Planning in Namibia
Karna Naidoo (2009). *Strategic Information Technology and Portfolio Management (pp. 402-407).*
www.irma-international.org/chapter/examining-approach-used-information-technology/29757

A Methodology for Developing an Integrated Supply Chain Management System
Yi-chen Lanand Bhuvan Unhelkar (2009). *Selected Readings on Strategic Information Systems (pp. 66-75).*
www.irma-international.org/chapter/methodology-developing-integrated-supply-chain/28688

The Planned and Materialized Implementation of an Information System
P. Reijonenand J. Heikkila (2006). *Cases on Strategic Information Systems (pp. 116-130).*
www.irma-international.org/chapter/planned-materialized-implementation-information-system/6434