Chapter 5.18
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.

INTRODUCTION

Customer relationship management (CRM) systems are used in healthcare systems around the world (Alshawi, Missi, & Eldabi, 2003; Calhoun, Raisinghani, Tan, Untama, Weiershaus, & Leervenn, 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.
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.