Chapter X

Ethics and Engagement in Communication Scholarship: Analyzing Public, Online Support Groups as Researcher/ Participant-Experiencer

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ABSTRACT

This chapter asserts an engaged research approach that aims to meet the ethical challenges of public, online support group studies. First, the intrinsic ethical orientation of the theoretical framework undergirding this approach is detailed. Second, how this approach may guide qualitative-interpretive analyses of public, online support groups is explored. This section features two excerpts from a larger study conducted of one such group. Third, three additional features of engaged research that bolsters its capacity to address the ethical concerns of public, online support group studies are presented. The chapter with a call and rationale for future engaged research of such sites, stressing the benefits to research and support group communities alike.

INTRODUCTION

Innovative uses of the Internet are transforming social structures worldwide. For example, healthcare systems have been challenged and improved as medical advice has flourished online (Ferguson, 1997; Kassirer, 1995). The Internet has also come to serve an important therapeutic role in housing support groups for those struggling with various physical and psychological afflictions (Barak, 1999; Ferguson, 1996; Grohol, 1999). The recent proliferation of these groups is likely due to their many advantages. Some of these advantages include relatively inexpensive, 24-hour access to discussions (and their archives) with others coping with rare or stigmatized conditions; increased self-disclosure, intimacy, a sense of autonomy and a recognition of oneself as an expert over time; decreased dependency on caretakers; communication apprehension (e.g., pressure for immediate response); access to social status markers (e.g., gender, race, socioeconomic status and age); and mobility barriers to group participation (Finn, 1996; Miller & Gergen, 1998; Murphy & Mitchell, 1998; Winzelberg, 1997). The continued growth of these online forums suggest that group participants view their disadvantages—such as, possible isolation, misinformation and promotion of problematic behavior (Finn, 1996; Fox, 1998; Grohol, 1999)—as tolerable.

A prime attraction of online support groups is their ability to provide participants access to practical information and emotional support for coping with various afflictions (Colon, 1996; Sharf, 1997; Walstrom, 1999, 2000b; Winter & Huff, 1996).[1] Such groups are also seen as safe environments for openly sharing problems and for finding relief from social stigma. However, perceptions of the safety of online support groups have diminished, as researchers unfamiliar with group culture have begun joining and studying group interactions (Eysenbach & Till, 2001). With this trend, controversy has ensued over the need for ethical guidelines for online support group research. Attempts to address this need are challenging, for appropriate guidelines are seen differently across global cultures and academic disciplines (Waern, 2001; Jankowski & van Selm, 2001). Creating ethical guidelines for online support group studies is seen as imperative, given the highly emotional and sensitive issues that participants discuss. That is, the group participants in these high-risk research contexts are regarded as requiring special protections from harm (Chen, Hall, & Johns, in press; Wearn, 2001). Thus, global and cross-disciplinary efforts are being made to establish ethical guidelines for such types of research (Ess & Association of Internet Researchers, 2002; Frankel & Siang, 1999).

Here I propose and aim to demonstrate an ethical approach to communication study of online support groups that are publicly accessible (e.g., USENET groups). This engaged research approach features two interlaced interpretive positions. The first position, *participant-experiencer*, entails the role of active contributor to the group being studied. This role specifically refers to a researcher who has personal experience with the central problem being discussed by group participants. The second interpretive position, *analyst*, involves the role of a skilled examiner of support group interactional processes and practices. Each position contributes distinct, valuable perspectives to an engaged research process. A participant-experiencer stance supplies historical and emotional understanding of the discussions, drawing both on one's background as a cultural member (or "native") of the local support group and of the larger social community that group represents.[2] An analyst viewpoint brings empirical insight to the systematic patterns occurring within support group exchanges, drawing on theoretical and methodological tools.

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