

## Discussion

# Internet ethnography: A review of methodological considerations for studying online illness blogs



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## ABSTRACT

**Background:** In recent history, the Internet has emerged as a wealth of archived, ongoing, interactive, and socially mediated data. Conducting Internet ethnography is a fairly new methodological approach, however, it has been previously described as a valid form of inquiry. Illness blogs, in particular, have great implications for nurse researchers, as they are able to study the experience of illness in a naturalistic and longitudinal manner, often with greater detail than data relying solely on participant recall. Participants are able to produce online illness blogs as a way to share their own illness narratives and connect with others going through similar processes.

**Objectives:** The purpose of this paper is to discuss methodological considerations in studying online illness blogs through Internet ethnography.

**Methods:** This article provides an overview of Internet ethnography as an emerging qualitative method and an introduction to research using illness blogs. Through use of this method in an exemplar study of young women with cancer, key decision points are highlighted along with the study team's field experiences.

**Conclusion:** Issues pertaining to method applicability, active vs. passive involvement as a researcher, ethical considerations, what constitutes data, sampling approach, procedural and analytic decisions, and thoughts regarding reflexivity and voice of the research participants' are addressed. Strengths and limitations of the study of online illness blogs through Internet ethnography in nursing science are also discussed.

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## What is already known about the topic?

- Conducting Internet ethnography is a fairly new methodological approach, however, it has been previously described as a valid form of naturalistic inquiry.
- Illness data captured on the Internet data privileges the current experiences of patients and contain detailed accounts of disease processes and psychosocial ramifications.

## What this paper adds

- This paper explores methodological considerations of Internet ethnography in the context of nursing science using decision points from an exemplar study.
- This paper examines the need for fluidity, an iterative process, negotiation of study involvement as researcher, and early conceptualization of ethical considerations when using Internet ethnography.
- This paper describes the advantages in using this method to offer utility in studying experiences among populations that are traditionally difficult to study (e.g., end-of-life experiences, groups with stigma associated with their disease).

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## 1. Introduction

Over the past two decades, the Internet has become the most comprehensive electronic archive of written material and has significantly changed the way people communicate, access information, and live their lives. The daily influx of new information available online represents a wide range of current events, viewpoints, opinions, and virtual communities that allow ordinary citizens to have an active voice with an accessible medium in which to express it. Internet support groups, resources, social networking sites such as Twitter, Facebook, and Instagram, and illness blogs have recently emerged as popular media for patients, their caregivers and health care professionals (Thielst, 2007; Ziebland and Wyke, 2012). Online health resources play a supporting role in many people's lives as they pursue better health and navigate the healthcare system (McWilliam, 2009).

Illness blogs, or blogs that were initiated by users to document their experience with a specific disease, have many purposes and benefits. Blog writers documenting an illness are able to update family and friends through the course of treatment and recovery, become an advocate for and educate others going through the same experience, ask questions and get answers from their online community, and gain the emotional benefits of expressive writing (Pennebaker and Seagal, 1999; Thielst, 2007; Ziebland and Wyke, 2012). Illness blogs also grant a voice to patients through engagement in digital storytelling and socially mediated connection with others (Gubrium et al., 2013; Lagu et al., 2008; Ressler et al., 2012; Treadgold and Kuperberg, 2010). Additionally, because users may remain anonymous if they choose, there are vast implications for self-disclosure and subsequent support of potentially stigmatizing health topics (Rains, 2014; Saiki and Cloyes, 2014). It is estimated that 12% of adults with a chronic health condition maintain their own illness blog, and 28% read peers' illness blogs (Fox and Purcell, 2010).

While blogs are beneficial for the patients who write them (Stanton et al., 2013), they also offer a new modality for health care providers and researchers to understand lived experiences from digital storytelling and sharing of the illness narrative. The Internet as a social domain has extended the reach of human subjects research for social scientists and textual data found on these venues are a rich source for researchers interested in understanding the hermeneutics of patients' lived experiences (Bassett and O'Riordan, 2002; Eysenbach and Till, 2010).

Internet ethnography is a fairly new methodological approach, however, it has been previously described as a valid form of naturalistic inquiry (Markham and Baym, 2009; Miller and Slater, 2000). Previous work in this area has demonstrated that virtual technologies are best studied through a flexible and narrative approach that ethnography lends itself to (Markham and Baym, 2009). When compared to interview qualitative data, it has been noted that Internet data privileges the current experiences of patients and contain detailed accounts of disease processes and psychosocial ramifications (Keim-Malpass et al., 2013a,b). Unlike in-person interviews, researchers

do not have to rely on the participants recall (Seale et al., 2010). Because of the ease with which large amounts of archived materials can be accessed and analyzed, this source of data has considerable potential for direct observation of illness experiences (Seale et al., 2010).

This paper will discuss methodological considerations of Internet ethnography for use in nursing science by examining elements of an exemplar study involving Internet illness blogs of young women with cancer. Findings from this study have been previously reported (Keim-Malpass and Steeves, 2012; Keim-Malpass et al., 2013a,b) and methodological elements requiring decision were based on the study team's experience and documented in field notes throughout the process. To the authors' knowledge, this research was the first to use Internet illness blogs for hermeneutic interpretation immersed in an ethnographic context. In order to advance use of this unique and innovative methodology, key decision points are highlighted (Fig. 1), along with the study team's experiences in the field and strengths and limitations of the use of this method (Keim-Malpass and Steeves, 2012; Keim-Malpass et al., 2013a,b).

## 2. Methodological considerations

### 2.1. Introduction to Internet ethnography

As new forms of Internet ethnography begin to emerge, much of their epistemological underpinnings remain the same as traditional forms of ethnography. Ethnography

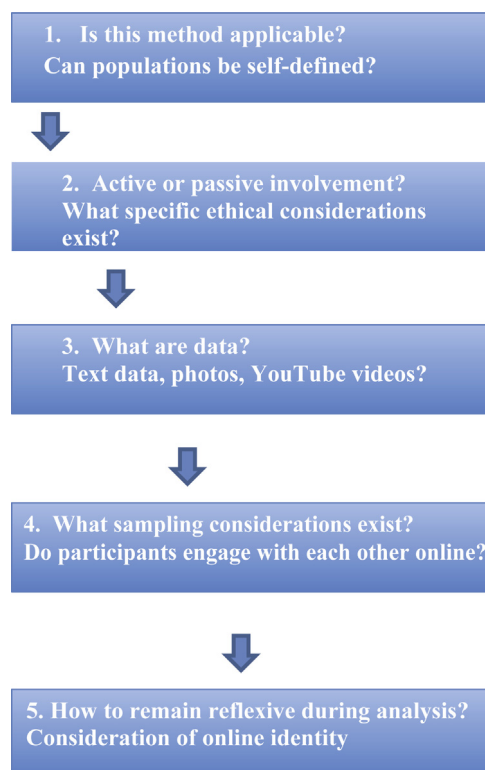


Fig. 1. Key decision points when using online ethnographic methods.

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