Blogging Illness: Recovering in Public

As a mode of open access public self-expression, blogs are one form of the unfolding massification of culture (Lovink). Though widely varied in content and style, they are characterised by a reverse chronological diary-like format, often produced by a single author, and often intimately expressive of that author’s thoughts and experiences.

The purpose of this paper is to explore the use of blogs as a space for the detailed and on-going expression of the day to day experiences of sufferers of serious illness. We might traditionally consider the experience of illness as absolutely private, but illness, along with the process of recovery, retains a social and cultural aspect (Kleinman et al). A growing body of literature has recognised that the Internet has become a significant space for the recovery work that accompanies the diagnosis of serious illness (Orgad; Pitts; Hardey). Empowerment and agency are often emphasised in this literature, particularly in terms of the increased access to information and support groups, but also in the dynamic performances of self enabled by different forms of online communication and Web production. I am particularly interested in the ongoing shifts in the accessibility of “private” personal experience enabled by blog culture.

Although there are thousands of others like them, three “illness blogs” have recently caught my attention for their candidness, completeness and complexity, expressing in vivid depth and detail individual lives transformed by serious illness. The late US journalist and television producer Leroy Sievers maintained a high profile blog, My Cancer, and weekly podcast on the National Public Radio website until his death from metastasised colon cancer in August 2008. Sievers used his public profile and the infrastructure of the NPR website to both detail his personal experience and bring together a community of people also affected by cancer or moved by his thoughts and experiences.

The blogger Brainhell came to my attention through blogsphere comments and tributes when he died in February 2008. Spanning more than four years, Brainhell’s witty and charming blog attracted a significant audience.
and numerous comments, particularly toward the end of his life as the signs of his deteriorating motor system as a result of Amyotrophic Lateral Sclerosis (ALS, or “Lou Gherig’s disease”) riddled his intimate posts.

Another blog of interest to me here, called Humanities Researcher, incorporates academic Stephanie Trigg’s period of illness and recovery from breast cancer within a pre-existing and ongoing blog about the intersection between professional and personal life. As I had crossed paths with Trigg while at Melbourne University, I was always interested in her blog. But her diagnosis with breast cancer and subsequent accounts of tests, the pain and debilitation of treatment and recovery within her blog also offer valuable insight into the role of online technologies in affecting experiences of illness and for the process of recovery.

The subject matter of illness blogs revolves around significant personal transformations as a result of serious illness or trauma: transformations of everyday life, of body and emotional states, relationships, physical appearance, and the loss or recovery of physical ability. It is not my intention in this brief analysis to overgeneralise on the basis of some relatively limited observations. However, many blogs written in response to illness stand out for what they reveal about the shifting location or locatability of self, experience and the events of ongoing illness and thus how we can conceptualise the inherent “privacy” of illness as personal experience. Self-expression here is encompassing of the possibilities through which illness can be experienced – not as representation of that experience, a performance of a disembodied self (though these notions have their merits) – but an expressive element of the substance of the illness as it is experienced over time, as it affects the bodies, thoughts, events and relationships of individuals moving toward a state of full recovery or untimely death.

**Locating Oneself Online**

Many authors currently examining the role of online spaces in the lives of sufferers of serious illness see online communication as providing a means for configuring experience as a meaningful and coherent story, and thus conferring, or we could say recovering, a sense of agency amidst a tumultuous and ongoing battle with serious illness (Orgad, Pitts). In her study of breast cancer discussion forums, message boards and websites, Orgad (4) notes their role in regaining “the fundamentals disturbed by cancer” (see also Bury). Well before the emergence of online spaces, the act or writing has been seen as “a crucial affirmation of living, a statement against fearfulness, invisibility and silence” (Orgad, 67; Lorde, 61). For many decades scientists have asserted that “brief structured writing sessions can significantly improve mental and physical health for some groups of people” (Singer and Singer 485). The Internet has provided an infrastructure for bringing personal experiences of illness into the public realm, enabling a new level of visibility.

Much of the work on illness and the Internet focuses on