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[Shani Orgad](#)

The cultural dimensions of online communication : a study of breast cancer patients' internet spaces

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A study of breast cancer patients' Internet spaces

Shani Orgad

ABSTRACT

Many have studied the deep interrelations between online spaces and offline contexts highlighting that Internet spaces are fundamentally embedded within specific social, cultural and material contexts. Drawing upon my study of breast cancer patients' CMC, this paper aims to contribute to our understanding of the role of cultural elements in shaping participation in, and design of, CMC environments. I use my study as an exploratory site for identifying cultural dimensions that should be taken account of in studying online spaces, and in designing, moderating and participating in those spaces. I show how both the breast cancer sites that I studied and their participants emphasise a sense of global similarity and commonality, while at the same time this CMC context is embedded within, and shaped by, specific cultural elements. I discuss how breast cancer patients' communication takes place within cultural settings that are fundamentally demarcated by North-American linguistic, national, temporal, spatial, religious, ideological and discursive borders. I conclude with a broader discussion of the importance of examining the cultural aspects of online contexts that we study, and by extension, the way that cultural elements shape the methodologies that researchers employ.

KEY WORDS

culture; cultural dimensions; global; CMC; North American; breast cancer

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INTRODUCTION: THE EMBEDDEDNESS OF ONLINE SPACES

The Internet has often been regarded as the manifestation of globalisation, particularly for its capacity to transcend national and cultural boundaries and its ability to make space and distance irrelevant (Khiabany, 2003: 141). At the same time, many have highlighted the deep interrelations between online spaces and offline contexts and the persistence of social and cultural borders in online spaces (Halavais, 2000). While Computer Mediated Communication (CMC) can facilitate what Giddens (1990) described as the stretching of relations across time and space, online spaces do not evolve in isolation from existing social and cultural processes and institutions. As scholars have increasingly acknowledged, 'cyberspace' is fundamentally embedded within specific social, cultural and material contexts (e.g. Khiabany, 2003; Mansell, 2004; Miller and Slater, 2000; Sassen, 2004). Studies of e-commerce, for example, highlight the national and organisational cultures within which both production and use of e-commerce are fundamentally embedded (Thanasankit, 2003). Studies of personal web pages, to give another example, show how embedded social identities pervade the supposedly 'placeless' nature of those web pages.

Recognising the embeddedness of online spaces and their interrelations with physical offline spaces requires an exploration of several aspects. One of them is the cultural dimension, by which I refer to examination of how cultural values, norms, and forces shape experiences of Internet use and design. This endeavour has been pursued in a considerable number of studies addressing the role of culture in various online contexts (e.g. CMC, personal home pages, online communities, e-commerce sites) from different scholarly perspectives (e.g. linguistics, political economy, geography, ethnography, among many others).

This paper aims to contribute to our understanding of the role of cultural elements in shaping participation in, and design of, CMC environments. I discuss specific cultural dimensions in a specific CMC context, namely the online communication of breast cancer patients. My discussion is based on a four-year study (Orgad, 2005a), which involved 41 interviews (online and offline) with breast cancer patients who used the Internet in this context, as well as textual analysis of related websites and online forums. I use my study as an exploratory site for identifying the cultural dimensions that are important in studying online spaces, as well as in designing, moderating and participating in those spaces.

I start by reviewing some of the studies that examined the embeddedness of online spaces within specific cultural contexts. This review is selective, rather than inclusive or exhaustive. It focuses on specific studies that constitute a useful background for my later exploration of the cultural dimensions of breast cancer patients' online interactions. I then present the case of breast cancer patients' online communication. Following a brief description of the study's methodology and its biases, which in significant ways inform the data and their interpretation, I present an analysis of the specific cultural dimensions that characterise breast cancer patients' online communication. I show how this online communicative space is fundamentally embedded in a specific cultural context, and is inextricably interwoven with existing offline linguistic, national, temporal, spatial, religious, ideological and discursive elements. Finally, drawing on my earlier analysis I conclude with a broader discussion of the importance of examining the cultural aspects of the online contexts that we study and, by extension, how cultural elements shape the methodologies we employ.

THE EMBEDDEDNESS OF ONLINE SPACES WITHIN CULTURAL CONTEXTS

Various debates illuminate the ways in which cultural elements – values, norms, communication expectations and preferences – influence and shape online spaces and CMC. Some studies investigate how large-scale structures in the new media landscape are embedded in specific cultural contexts. For example, the *digital divide* debate highlighted the ways in which access and use are embedded in larger disparities among the world's cultures and nations. Similarly, writers on *the political economy of the Internet* underscore that inequalities in the distribution, diffusion and construction of the World Wide Web (WWW) are implicated within broader structures of cultural dominance, particularly Western and American hegemony (Flew and McElhinney, 2002: 308). Scholars such as Herman and Sloop (2000), Matterlart (2002), McChesney (2000), and Schiller (1999) have shown how the accelerated conglomeration, commodification and commercialisation of this communicative space render it highly culturally specific, and particularly Western and American dominated. Works on *the geography of online space* also contribute to a recognition of online space as culturally embedded. For instance, analyses that map the geography of hyperlinks and examined the directionality of flows of online communication and information (e.g. Brunn and Dodge, 2001; Halavais, 2000), or accounts that examine the distribution of physical location of Internet hosts and hubs, (e.g. Gorman, 2002; Moss, 1998) demonstrate that the online space has certain geographical, cultural and national biases that often mirror biases in the offline world.

Perhaps more relevant here are studies that investigate how cultural factors affect participants' interactions in specifically situated contexts of online exchanges. A key issue in this area is the role of *language* in underpinning the organisation of the online landscape and shaping online interactions. Studies in this vein highlight the increasing multiplicity of languages that people use online, and their social, cultural and political implications. For instance, the special issue of *JCMC* on 'The Multilingual Internet' (Danet and Herring, 2003) explores how cultural practices find expression in CMC in different languages and discusses the implications of this aspect. Another example is Warschauer's (2001) study of the use of the Internet to preserve and strengthen an indigenous Hawaiian language. He found that interacting in cyberspace in this indigenous language gave users the opportunity to explore and strengthen their sense of Hawaiian identity. At the same time, he showed how certain linguistic elements can constrain, and may even prevent, users' participation.

A related agenda concerns the Internet as a site for the construction, performance, and reinforcement of *national identity*. For instance, Miller and Slater's ethnographic study of the use of the Internet in Trinidad (2000) demonstrates the persistence and centrality of 'national borders' in the Internet use and online communication of Trinidadians. The authors discuss how participants in their study went to great lengths to make the Internet a place where they could construct, perform and enact their 'Trini-ness' (85), for instance, by describing chat rooms as 'liming', an allusion to 'de Rumshop Lime' (88-89), the local, down-market drinking place. Miller and Slater present these findings in part to challenge the view of the Internet as a global phenomenon which dis-embeds social relationships from their particular locale.

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Similarly, Cooks's (2003) analysis of the Panama'L listsev demonstrates how physical and geographical markers in the listsev are often recreated in the online dialogues of its members, and, more generally, how national forms are continually created and maintained online through discursive and non-discursive means.

A particularly productive group of studies that explored how participants' Internet use facilitates and reinforces a shared national identity focused on *diasporic online communities* (e.g. Mitra, 2001; Parham, 2004; Ranganathan, 2002; Tyner and Kuhlke, 2000). These studies highlight the potential of the Internet to instil a sense of nationhood among widely dispersed members and mobilise their collective efforts. Internet spaces offer unique opportunities for diasporic members to facilitate, maintain and intensify their sense of community by reproducing and maintaining cultural elements of the homeland, for instance. Studies have shown how discursive and representational means are employed online to frame diasporic members' experiences and the spaces in which they participate in relation to the culture of their homeland. For instance, online spaces are often constructed as a local (physical) space which is closely tied in with the homeland: the Trinidadian 'de Rumshop Lime' chat-rooms (Miller and Slater, 2000: 88-89), or the Haitian *Men Anpil* forum, which draws on a popular Kreyol saying to produce the sense of a collective network (Parham, 2004: 206) being two examples.

Language more generally, plays a central role in shaping and demarcating online diasporic sites. Even when the language used is that of the host country, expressions from the homeland's culture are often used by diasporic members to convey particular

meanings and speak to a communal spirit, for example, Filipino diasporic websites'

usage of the word *mabuhay* (Tyner and Kuhlke, 2000: 248).

What these examples show is that while online environments of diasporic

communities facilitate the fostering of relationships across time and space, they also

interact strongly with specific geographic spaces (either the homeland or the host

country) and their associated cultures. As some of these studies demonstrate, the

embeddedness of online spaces within offline spaces and cultures can be facilitating

and empowering for diasporic communities. At the same time, the interactions

between online environments and offline spaces and cultures can be complex and

limited, as Parham's (2004) study of participants' use of a Haiti diasporic online

forum underscores. While the forum's vision was to have discussion-list members in

various physical locations affiliate their local organisations to the online network to

enable online members to share ideas and resources stemming from their local

community work, the effort fell far short of the original vision, since the majority of

the online ties encompassed a very limited number of locations.

Studying situated online contexts that have an explicit national or ethnic component,

for instance Miller and Slater's (2000) ethnography of the Internet in Trinidad, or

studies of online diasporic spaces, leads the researcher, almost inevitably, to address

cultural issues as a necessary part of the analysis. However, this kind of reflexivity to

the cultural dimension of CMC (Wakeford, 2004: 133) should also extend to the study

of those contexts whose national or cultural aspects are less straightforwardly

apparent.

Some of the essays in the collection C*ulture, Technology, Communication: Towards an Intercultural Global Village* (Ess and Sudweeks, 2001) contribute to this critical endeavour, examining different manifestations of the role of cultural values and communication preferences in the implementation and use of CMC technologies. Several forthcoming edited collections would also seem to take up this challenge, including Adams and Smith's (forthcoming) *Electronic Tribes*, which claims to address, among other issues, aspects of cultural communication on the Internet, St. Amant's (forthcoming) *Linguistic and Cultural Online Communication Issues in the Global Age* which promises to explore the differences in language, cultural communication expectations, laws, and software standards that individuals encounter and need to consider when interacting online, and Herring, Stein and Virtanen's (forthcoming) *The Pragmatics of Computer-Mediated Communication*, which , among other themes, takes account of the culture-specific effects of CMC. More work in this direction would be welcome.

I now present what I hope will be my contribution to this debate, namely an exploration of how specific cultural dimensions shape a particular health-related online context, the CMC environments of breast cancer patients. I see this case in terms of an exploratory site for identifying the cultural dimensions that should be taken account of in studying online spaces, as well as in designing, moderating and participating in those spaces. However, before embarking on the analysis of the specific cultural dimensions of this online context, I want to highlight several limits and biases of my methodology, as they influence the findings and my interpretation of the data in significant ways.

METHODOLOGY AND ITS BIASES

After lurking for several months in breast cancer-related online spaces, I posted

invitations on message boards, for women to share with me their experiences of using

the Internet in the context of their illness. I also e-mailed some women who had

provided their e-mail addresses in messages they had posted, or on personal

homepages. One of the websites I recruited a lot of participants from, was 'Shared

Experience' (www.sharedexperience.org). This website appears first on Yahoo!

search and second on Google search for the combination of the key words 'cancer

experience' (a combination which seems quite common among cancer patients

seeking exchange experiences). The 'Shared Experience' website is described by its

founder as 'a collection of first hand accounts by cancer patients and the people who

love and care for them' whose goal is to 'gather hundreds of thousands of stories and

make them freely available on the World Wide Web'

(www.sharedexperience.org/why.lasso).

I received 83 replies, from which I chose 29 accounts to use as data for analysis. The

next stage involved shifting the relationship with informants offline. Elsewhere I

discuss at length the rationale for, and implications of, the move from online to offline

relationships with informants (Orgad, 2005b). I contacted 15 of the 29 I had selected,

with most of whom I had maintained correspondence since their first response, asking

if they would agree to meet me for a face-to-face interview to follow up their written

stories in greater depth.

I conducted 11 face-to-face and one telephone interview. Ten of the face-to-face

interviews took place in the United States, and one in Israel, either in interviewees'

homes, or in public places such as diners. Except for a cancer website designer who was male, all the participants in the study were white women, mostly American, middle and upper-middle class, aged 32 to 76 (the majority between 40 and 60), most married with children. The analysis is based on the data generated from the online and offline interviews, as well as texts from websites and forums that I observed and collected over a period of four years. I use pseudonyms in the analysis for obvious reasons of confidentiality.

Of course, the data suffer from self-selection as well as other biases. For the purpose of this paper, and within the space available, I cannot discuss all of them here (see Orgad, 2005a). I do, however, wish to reflect on four specific biases that are particularly relevant, as they shape the findings that I present in this paper, and my interpretation of them in relation to the cultural issue, in significant ways.

First, I chose only top-level global domain websites (.com, .org. .net), both for the recruitment of participants for interviews and the analysis of forums and websites. I specifically avoided national domain websites[1] (e.g. .uk, .mx, .il), and top-level global domain websites with an explicit national affiliation, for example the American Cancer Society (www.cancer.org) and Cancer Survivors Network (www.acscsn.org), which is related to it. However, using the top-level global domain websites inherently confounded US websites, as most of them started up before the consolidation of national domain websites, and since the convention of using '.us' for US sites has never been adopted. Thus, the cohort of websites my analysis is based on are US-based, although they often present themselves as global rather than American.

Second, although access rates are increasing in many countries, Internet access and use are still a primarily Western, and to a degree Asian, experience. So inevitably the majority of the respondents to the messages I posted online were Western, and more particularly North American.

Third, I looked only at sites in the English language. I searched for websites, forums and discussion lists using English search terms (e.g. 'cancer experience') and the messages I posted on message boards were in English. Not surprisingly, therefore, it was mainly English-speaking women who replied to my online message, and subsequently participated in the study. What was surprising, however, was that respondents were mainly American. When I later tried to recruit women from the UK by posting messages on UK-based websites, in an attempt to overcome the initial overwhelming bias of US respondents, I received hardly any replies. Here neither access nor language seems to be an obstacle: the UK websites where I posted messages use English and are accessed by a considerable number of British users who are connected to the Internet. So why is it that a message posted on .com or .org sites generated lots of responses, whereas on similar .uk sites the same message generated so few? Later in the discussion I try to explain this methodological national bias.

Lastly, while I argue for specific cultural dimensions that characterise breast cancer Internet spaces and are predominantly North American, this study is limited in that it lacks a comparative perspective. A preliminary comparative analysis I conducted between US-based and UK-based cancer websites revealed fascinating differences as well as similarities, for instance in the approach to death in patients' postings. So a valid question would be whether sites in languages other than English, and with a

clear national orientation, would have demonstrated similar cultural biases to those

that I describe in relation to the English-speaking sites I studied.

EXPLORING THE CULTURAL DIMENSIONS OF BREAST CANCER

ONLINE SPACES

The proliferation of health-related communication online is often seen as a

manifestation of the 'electronic global village' facilitated by CMC. Popular discourse,

as well as much of the research on 'e-health', emphasises the idea that the Internet

enables people to communicate health issues world wide beyond physical, social, or

cultural borders. Hardey (2002), for example, describes patients' online

communication as forming a 'global Internet health advice network', and a 'global

community of care', 'within which people can rewrite their biography and transform

their social networks' (32). At the same time, cultural and national aspects play a

significant role in shaping health-related online contexts. Cultural values, norms,

beliefs, symbols and communicative patterns constitute significant 'borders', to

follow Halavais's (2000) metaphor, that demarcate and shape online spaces, and thus

need to be recognised and mapped.

Therefore, the discussion of breast cancer online spaces will start by exploring the

aspects of breast cancer CMC environments that emphasise inclusiveness, global

commonality, and the sharing of experience and medical knowledge. I particularly

focus on the ways in which patients' CMC environments can facilitate cross-cultural

exchange of experience and information, transcending national and cultural borders.

However, I argue that we must at the same time acknowledge that these spaces are

significantly shaped by particular cultural values, principles and communicative

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patterns. So the next section explores the specific dimensions that mark these spaces as culturally embedded. More particularly, I show how breast cancer online spaces are fundamentally embedded in a specific cultural context, and are inextricably interwoven with existing offline linguistic, national, temporal, spatial, religious, ideological and discursive elements that are predominantly North American.

Breast cancer and patients' CMC: Beyond cultural borders

Due to its high prevalence in women all over the world breast cancer is undoubtedly a universal concern. During the nineteenth century and the first half of the twentieth century, the disease was largely excluded from public discourse. It remained a private experience that individual women suffered alone. More recently, especially since the late 1980s, breast cancer has moved, as Leopold puts it, 'from the closet to the commonplace' (1999: 215). 'Today breast cancer is the biggest disease on the cultural map' (Ehrenreich, 2001: 1a), and is increasingly communicated on a global scale. For instance, the pink ribbon, which represents the fight against breast cancer, has become an image whose meaning is shared by people across the globe. Multi-national corporations are central actors in the construction and perpetuation of the disease on a global scale. By supporting an ongoing global campaign to fight the disease, in which the pink ribbon is a central image, multi-national corporations such as Revlon, Ford, Tiffany, Estée Lauder, Ralph Lauren and others, contribute to global awareness of breast cancer. Indicatively, a recent medical report by a research biotechnological company carries the title 'The Global structure of Breast Cancer R&D' (BioSeeker, 2003). As far as actual treatment of the disease is concerned, this is still predominantly organised by national health systems. However, there is an increasing number of medical actors promoting programmes designed to eradicate the disease at

a global level (for example, Susan G. Komen's Breast Cancer Foundation's 2000

initiative 'Train the Trainer').

The way many of the websites devoted to patients' discussion of breast cancer

describe themselves enhances the message that these communicative spaces are all-

inclusive, scaling national, cultural or any other social boundaries. This is true for

websites with top-level global domain names (.com., org and .net), but interestingly

also for some websites with a national domain name (for instance .ca, .uk, .fr). This

construction of the website's mission and orientation as culturally inclusive usually

characterises different types of websites, run by global or national cancer

organisations, or founded by individuals who are involved in the illness in some way,

or constitute commercial sites of companies related to the fight against breast cancer

(pharmaceutical companies, for instance). Here are a few examples that put a gloss on

this observation. The Susan G. Komen Breast Cancer Foundation, a global leader in

the fight against breast cancer, is using its website to transcend the physical confines

of its conventional awareness raising event of 'Race for the Cure', in which women

run or walk for the fight against breast cancer:

> By leveraging the power of the Internet, the Komen Virtual Race for the
> Cure® brings people together from all over the world to make a difference in
> the fight against breast cancer. In exchange for a minimum $20 donation,
> anyone, anywhere can participate in the Komen Virtual Race for the Cure®,
> the first online fundraiser of its kind. (http://www.komen.org/intradoc-
> cgi/idc_cgi_isapi.dll?IdcService=SS_GET_PAGE&ssDocName=s_002296).

A similar portrayal of patients' online communication as culturally inclusive can be

seen in the way the Board Etiquette & Policy of the popular Canadian-based website

Breast Cancer Action Nova Scotia, (http://bcans.org/forum/help.htm#guide)

welcomes its participants to the patients' forum:

> Please keep in mind that people posting to the Breast Cancer Action Nova Scotia web site come **from all walks of life and from all over the globe and offer a variety of different viewpoints and opinions** (my emphasis).

Similarly, this is how *OncoChat*, an IRC environment for cancer patients describes

itself on its homepage:

> Welcome to our home on the Web! OncoChat is **a real-time global support community** for people whose lives have been touched by cancer… please note that **OncoChat is not a forum for religious discussion**. Choice of faith is often too sensitive an issue for people who are fighting to survive (http://www.oncochat.org, my emphases).

Patients themselves also often described their online communication of breast cancer

as extending the geographical and cultural boundaries of their lives. They particularly

stressed how in posting their message online they reached out to patients who are

remote from their locale, geographically and/or culturally. Yielding a large number of

replies, especially from respondents across the globe, was often seen by the poster as

a sign that her message had 'global' value, beyond her personal realm. For example:

> I got 19 responses so that was very good! [proud] […] People from Australia! Yah! That was good, very good! (interview 1).
>
> I posted that and then I heard from…a lot of other people e-mailed me after that. People from all over, I mean there was somebody from Canada, you know just from all over! From Oregon… (interview 6).

Other studies corroborate this observation regarding the way in which participants

construct their online experience as cross-cultural and global. For instance, Miller and

Slater (2000: 91) indicate that the Internet was commonly perceived by Trinidadian

participants as 'a public place with a foreign audience, and it was therefore deemed

essential to maintain dignity, respectability and what was deemed a proper place in the world'. Darling-Wolf (2004: 520) reflects on a similar perception among participants in a completely different online context, of a Japanese celebrity fan community. 'Fans' interaction constantly reflected an acute awareness of the multiple cultural identities that were presented in the pages of the community's bulletin boards. Postings would often be addressed to "all you fans out there in the world" '.

So whether in a national CMC context such as the Trinidadian (Miller and Slater, 2000), or in a cross-cultural context like that of breast cancer patients', participants often tend to frame their online participation as an experience which transcends the national and cultural boundaries of their lives. In the case of breast cancer, as I have shown, patients' perceptions of their online experience often replicate the dominant construction and discourse that the websites themselves use. Patients commonly think of these spaces as social spaces that stress the commonality between participants, and their shared experience and knowledge, and which consequently give rise to feelings of camaraderie, companionship and strong bonding (Orgad, 2005a).

However, the notion of patients' online environments as inclusive and open to 'people from all walks of life and from all over the globe', as described by the forum of Breast Cancer Action Nova Scotia, is only one side of the coin. While patients' CMC spaces have real potential to facilitate cross-cultural exchange of experience and information and foster the commonality between their experiences beyond physical and cultural borders, these communicative environments at the same time are highly culturally structured. As I discuss in the next section, the online communication of breast cancer

patients, and the spaces I studied, are embedded within cultural settings that have a significant North American resonance.

The cultural dimensions of breast cancer patients' CMC

The linguistic dimension

Perhaps most obvious, yet nevertheless significant, is the overwhelming presence of English, especially American English, in breast cancer online environments. True, as acknowledged earlier, linguistically my study was circumscribed, insofar as it looked only at websites in the English language. Yet some of my interviewees whose mother tongue is not English visited those English-speaking websites, because, among other reasons, the information they found on websites in their own language was limited and insufficient. To be able to communicate and participate in the discussions that are held in English, as Darling-Wolf (2004: 524) observes, participants need to usually be above a certain level of education. Indeed, the non-native English-speaking patients whom I interviewed, whose postings I found online and who agreed to participate in my study, were middle-class and highly educated. Nevertheless, they admitted suffering from the barrier imposed by the use of English. So the linguistic dimension works as an exclusionary mechanism, not only in excluding non-English speakers, but also in excluding those below a certain level of education, among participants whose mother tongue is not English.

Yet there is another, perhaps more curious, exclusionary process taking place on English-language breast cancer websites. Given the universal prevalence of breast cancer, and the global agenda of related .com and .org websites, one would have expected to find on these sites a sizeable presence of English speaking participants

who were not necessarily North American, for example from India, Singapore, South Africa, the United Kingdom. Yet from my observations of these sites over four years, the majority of the participants is North American, with few English-speaking participants from other parts of the world. One explanation is that English-speaking participants not from the US will likely go to their national cancer-related websites. However, in the sections that follow I suggest other explanations that shed light on the North American bias of these breast cancer sites.

National health systems

Patients' conduct of their health is greatly determined by the national health system in which they are treated. Thus, the online communication of their health is necessarily connected to their national realities. For example, for a patient to be able to identify with a fellow-sufferer there has to be some degree of similarity between their medical options and treatments. Although there is, to some degree, a 'global structure' to the research and developments of breast cancer treatment, as a recent report (Bioseekers, 2003) purports, there are still significant differences and disparities between the kinds of treatment available in different countries, and even among patients in the same country. US participants, who are in the majority on most of the sites, have a generally common language regarding their medical treatment (although they differ, often hugely, in terms of the kind of insurance they have). However, when non-US participants participate in these forums, the differences in their national and cultural contexts are often glaring. The following account of a Greek participant in breast cancer patients' forums (hosted on top-level global domain name websites) is illustrative:

> In my country, doctors usually don't care about what a women [sic.], who is going to have a mastectomy, is thinking. So, they don't care about the

reconstruction. In Greece, no one told me about the reconstruction, in reverse
a doctor said, "now you have the cancer, you have to forget the breast" (online
interview 17).

True, the WWW enables participants to explore medical options and treatments
outside their locale and their national context. To pursue these options, however, they
must leave their physical place to get treatment abroad. The Greek respondent quoted
above was fortunate to have the financial means to afford reconstructive surgery in
the US. This, however, would clearly not be the case for many non-US participants.
For them, the national borders of their health experience – despite its multicultural
online dimension – remain ever more vivid.

It is also interesting to note that as a consequence of participants' exposure to the
experiences of patients treated in national health systems other than theirs, for
example the Greek woman cited above, assumptions about global similarity and
universal commonality can be significantly undermined. While in their interviews
participants emphasised the strong sense of similarity and commonality that emerges
among patients online, occasionally interviewees also voiced their appreciation of the
crucial differences between patients from different national contexts, as the following
excerpt from a UK interviewee captures so neatly:

> What shocked me most was just realising what it was like to live in a country
> that doesn't have a national health service, where women are actually
> discussing what treatment they can afford. They could recommend it to have
> radiotherapy, but can they afford to have it? That was the most shocking thing,
> really... (interview 11).

The temporal and spatial dimension

Another way in which patients' online spaces are inextricably interlinked with their

local, national and cultural spaces involves the temporal dimension of patients'

discussions. This aspect plays a significant role mainly in synchronous environments, such as chat rooms or 'prayer boards' where participants log on to discuss their experience, or to pray collectively online for the health of one of the group's members. There are also synchronous forums in which medical experts talk with patients. These activities are often set for 8 or 9 pm US east coast time, (see, for example chats on www.bcans.org or the Web Chat section in Susan Love's website: http://www.susanlovemd.org/community_chat_A_frames.html). For non-American participants, this timing is usually very inconvenient (e.g. the middle of the night), so they are excluded from those discussions.[2]

Similarly, non-American members are often excluded from discussions on offline activities such as breast cancer fund raising walks. These activities, which are frequent and quite popular, take place mostly in the US. It is unlikely that participants would cross the globe to attend them. Furthermore, as in the Haiti diasporic forum that Parham (2004) studied and which I mentioned earlier, the social relationships and outcomes that emerge from discussion and interaction on breast cancer forums are limited to specific offline locations, usually in the US. In short, because many breast cancer English-speaking sites are structured by US time and space, this limits their capacity to enable meaningful participation of non-US users in the discussions.

The religious dimension

One of the most notable cultural dimensions of patients' communication in online spaces is the prominence of references to a religious, and particularly a Christian, context. Prayers for one's health are almost always addressed to 'God', 'Father' or Jesus Christ. Empathy and camaraderie are often articulated by expressions such as

'God bless you', 'God bless all his children' and emoticons of angels (e.g. ^^Å^^

^^å^^). True, forums such as OncoChat (as cited earlier) monitor the discussions on

their spaces to avoid explicit discussion of religion and faith. Yet there is a significant

prominence of Christian discourse, symbols and references, with elements from other

religions rarely present. The following extract from a patient's posting is typical of

those found on English-speaking breast cancer forums:

> When I was diagnosed, I was terrified…I knew I couldn't do it alone, so I
> prayed a lot, and I asked my friends to pray for me, and I guess part of God's
> answer was to send people into my life who needed help and support during
> their own cancer experience…
> My fear of death seems to have gone by the wayside, and I'm finally able to
> understand that sometimes death IS the healing, and that one day that will be
> the case for me, as it is for everyone who leaves their physical body at the end
> of their little stay here on the planet. I came to understand at an emotional
> level the words from The Prophet,
> "Your fear of death is but the trembling of the shepherd when he stands before
> the king whose hand is to be laid upon him in honor.

Similarly, in response to the recruitment messages I posted on various patients'

forums, inviting women to participate in my study, many of the e-mail messages I

received included Christian references. For example:

> I'm a Christian and know that the prayers of others and the goodwill of God
> helped me get this far (online interview 30).

> I have a dear friend … who lives somewhere in the State of Wisconsin and is a
> little older than me (I'm 58). She [we] 'type' at each other frequently and I
> truly feel a bond between us. I am trusting God to put the 'right people' with
> the 'right people' to provide continued HOPE and WELL BEING (online
> interview 10).

Most of the breast cancer patients' forums I came across had a significant imprint of

Christian discourse. This does not mean that non-Christians or atheists cannot and do

not participate in these spaces. It does, however, imply that the Christian context is

likely to play a role in their communication, and as such is likely to frame their online

experience in meaningful ways. I found that the expression of camaraderie and

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bonding between women is often interlinked with references to Christian blessings and prayers. Even if patients do not appropriate this kind of religious discourse to communicate their feelings and support for others, they have, at least to some extent, to appreciate the significance of these discursive elements in their communication with fellow sufferers.[3]

The ideological and discursive dimension

The last aspect I want to discuss, in attempting to account for the cultural dimensions of breast cancer patients' online spaces, is what I would describe as the ideological and discursive border. Although much of what I have described thus far entails discursive and ideological aspects, in this section I want to focus on specific underlying values, which produce certain discursive practices that seem to shape this communicative space, and which have, as I will argue, a North American imprint.

As I noted in the discussion of the study's methodological biases it was mainly American women who replied to my online message, and consequently participated in the study; remarkably I received hardly any replies from women on UK websites. Beyond the entirely reasonable explanation that more American breast cancer patients are connected to the Internet than other patients in the world, I would suggest that the willingness to disclose one's personal experience has to do with the American culture of those respondents. The idea that 'If you talk about something you feel, then you will feel better', and the almost religious belief in the power of language to facilitate change is characteristic of US culture (Polanyi, 1985: 146). So the abundance of patients' often confessional disclosures on hundreds of breast cancer-related online forums is underpinned by the idea that it is possible to understand anything and

explain anything, through talking (Becker, 1994). This idea, as several critics have

argued (Becker, 1994; Polanyi, 1985), has a significant American imprint.

Some patients equate explicitly between active online participation, which involves

sharing experience and information, and the necessary positive and empowered

attitude necessary to be cured. The belief in the power of talking (online) as an

essential part of the cure is indicated by the following observation of a breast cancer

patient:

> The ones who stick around [online message boards] are the fighters…those
> that come on and are passive and feel it's just too hard to fight it, give up and
> give in to their disease and don't stick around (online interview 15).

The interviewee equates patients' active online participation with their active

approach to their illness, and vice versa: those who choose the 'passive' route and

give up their online participation are equally surrendering to the illness. This view of

the 'fighter' who communicates and 'sticks around' online, is closely related to an

ideological premise which is embedded in an American belief system. It is the

ideology of autonomy and self-determination; the idea that the individual is the

central figure on the world stage(Polanyi, 1985).

Frank (1995: 63) further develops the discussion of the cultural context of this

ideology:

> North Americans share a cultural reluctance to say that their lives have gone
> badly in some significant respect and to mourn the loss of what was desired
> but will never happen.

Indeed, a reluctance to admit failure and loss seems to be continuously endorsed and

perpetuated in the CMC of breast cancer patients. True, my data are biased insofar as

I interviewed only those who survived the illness and who naturally emphasise their triumph over cancer. Yet I think that this is an inherent bias of many of the websites: the voices of non-survivors, of despair, hopelessness and death are excluded or at least marginalised and contained in the postings. For example, at the time of writing this paper, out of 553 breast cancer related messages posted on the 'Shared Experience' forum, less than 6% of the messages included the words 'death' or 'die' (and its conjunctions), of which a third of the messages (less than 2% out of the total messages) mentioned death in a negative context. Among the other two thirds of the messages that mentioned death and dying, most described it in a positive way, for instance 'breast cancer doesn't necessarily mean a death sentence'. Along similar lines, the titles of the messages that women post, often of painful and difficult experiences, are mostly cheerful and triumphal: 'a sense of humour helps', 'don't fear having a breast biopsy', 'I made it through biopsy without a hitch!', 'against all odds', 'bald and proud', 'living for love', to mention just a few. The actual content of the messages follows similar lines. Elsewhere (Orgad, 2005a), I also discuss how participants who post messages where they express shock, despair and fear, often following the reception of the news of their diagnosis with cancer, are 'directed' by online 'veterans' who have won the battle against cancer, to adopt a positive attitude, and how gradually, those voices of despair and fear are transformed into ones of hope and cheerfulness. In short, the online colloquy of breast cancer patients is chiefly about enablement and hope, as Sharf (1997) and Pitts (2004) bear out; participants make the online discussion about living with the illness, rather than dying from it.

While not dismissing the importance and value of the positive and cheerful attitude governing breast cancer websites, my intention is to highlight that this mental and

psychological attitude is not culturally naked. While the motifs of self-responsibility,

triumphalism and cheerfulness are emblematic of the wider culture of breast cancer

(Ehrenreich, 2001; Leopold, 1999), and are also present in non-American websites,

there is still a significant US cultural context in the discourse on breast cancer. It is

interesting to note that the only interviewee who was critical of this kind of cheerful

discourse was one of my non-American interviewees:

> ...there is an awful sentimentality about it [breast cancer]… for instance, **it struck me that most of the time what women seem to want to discuss was reconstructive surgery, and particularly on the American sites that seemed to be the norm.** There seemed to be no debate about it …particularly on the American sites there was this thing about: does your doctor say soy is good or bad? That kind of things went on. […] **I just thought: you're not allowed to say these kinds of things in this forum! This is not what it's for! I was tempted to do but I didn't do it because I thought it would be so difficult to find a way of framing any of those things and actually make any kind of difference!** (interview 11, my emphases).

This reflection underscores that to be able to participate in those breast cancer spaces,

one has to share a certain emotional repertoire and a vocabulary of meanings, which

is, as the interviewee observes, particularly American. Culture, as Swidler (1995: 27,

cited in Yang, 2003: 486) argues 'influences action "not by providing the ends people

seek, but by giving them the vocabulary of meanings, the expressive symbols, and the

emotional repertoire with which they can seek anything at all'". One reason why the

breast cancer sites that I studied draw mainly North American participants (and

sometimes, as the quote above illustrates, may exclude non-American ones) is that

they are underpinned by a common North American cultural repertoire. Whether the

participants are Americans or not, they must work within this setting, which

inevitably has a particular cultural 'baggage'.

CONCLUDING REMARKS: STUDYING THE CULTURAL DIMENSIONS OF ONLINE CONTEXTS

A key implication of this discussion is that we need to address the complexity of what we mean by 'global' in talking about the Internet and CMC. In this study, that patients' CMC is global means it has the potential to facilitate communication and information exchange between patients across the globe and offer an inclusive space for participants from all cultural backgrounds. At the same time, it also means that there are barriers that prevent this potential from being fully realised. Websites and their services are often constructed as though they transcend physical, geographical, national and cultural borders, and for many patients the online space indeed represents a place beyond the contexts of their locale, that transcends the social and cultural barriers they encounter in their daily contexts. However, while space and time are stretched (to follow Giddens' metaphor) they certainly do not disappear as constitutive factors. On the contrary, time and space, and thereby cultures and national contexts, continue to play a central role in the shaping of the Internet and CMC.

Literacy, exclusion and inclusion

This study suggests that online participants must not only be competent in the use of CMC in the technical sense, but must also have social and cultural competency, that is, knowledge of the discursive frameworks and the 'hidden rules' of the communicative contexts in which they engage (to paraphrase one of my non-American interviewees). The most computer literate of all my interviewees was one of the (few) non-American (but English speaking) breast cancer patients. However,

she felt she was not sufficiently *culturally* competent to participate actively in any of the online discussions. While technical literacy has usually been used as an explanatory factor of processes of inclusion and exclusion in Internet access and use (e.g. Warschauer, 2003), the concept of new media literacy is more complex, involving not only technical knowledge and skill, but also cultural competence. This study merely scratches the surface of this potentially rich discussion of the need to expand the concept of new media literacy.

More generally, studying the cultural dimensions of the online contexts we study also urges an expansion of the research agenda in relation to processes of exclusion and inclusion in CMC. This agenda should consider how the cultural specificity that frames CMC contexts works to exclude and include not only certain participants, but crucially also certain meanings. That is, the important questions are not just who is online and who is not, but also which meanings are available online and which are excluded, and why. Among those who are online, who are the active participants and who are not? Who remains a lurker, and why? How much does the cultural context explain these dynamics of exclusion and inclusion? In the context of my study, for instance, there is a significant (though quite latent) sense of 'us' and 'them' that emerges in participants' discussions and works to include some and exclude others. This exclusionary process has less to do with the technical competency or even the language proficiency of participants, than with their cultural backgrounds. One of my North American interviewees said: 'If your paper can just relieve my **Brit** friends of the expense of being on-line **with us**, the world would be nearly perfect' (online interview 31, my emphases). While this comment conveys a powerful sense of companionship and sisterhood with fellow-sufferers across the Atlantic, it implies that

the interviewee, who is American, regards the online space as a primarily American place, where fellow-sufferers from other countries may join, but not the other way around.

The methodology's cultural dimensions

Beyond a recognition of the cultural dimensions of the contexts we study, we must also acknowledge that our methodologies have social and cultural borders. It would be naïve to think that Internet research is research which transcends national and cultural borders. In my study the methodology employed was significantly informed by the specificity of participants' cultural location. Their location facilitated their online recruitment and their collaboration in being interviewed both online and face-to-face. The respondents' openness and the ease with which they very quickly disclosed their intimate experiences, are largely due to their North American cultural context. Thus the question remains: Would I have had the same degree of success in employing this methodology in a different culture? The answer is probably not, at least not in the UK, if the comment of one of my British interviewees is anything to go by: 'You would have never found *me* online", she told me.

So, as much as participants' online experience is fundamentally embedded in their cultural and social context, so are the studies done on them. For example, the contexts of Internet use examined by *Pew Internet & American Life*, the methodology and the approaches adopted, are fundamentally North American. This kind of significant research, which determines research agendas and shapes the way CMC is understood, should be more reflective of the cultural framework in which it is embedded.

One way to develop this reflexivity, as I tried to demonstrate in my analysis, is to attempt to unravel the often-latent cultural underpinnings of the discourse, communicative patterns, structures and relations that we examine. Such reflexivity necessarily involves taking a critical distance from both the discourse and meanings that govern the online spaces that we study, as well as from the accounts of our informants. This does not imply a questioning or undermining of the validity and authenticity of our informants or the texts that we examine. It means going beyond the face value meanings, to ask: What role does culture play in shaping these discourses, meanings, communicative patterns and interactions?

Another helpful way to account for the potential cultural dimensions of CMC is to adopt a comparative approach. As Wakeford (2004: 133) points out, 'if studies of the internet took on board the comparative Trinidadian experience [of Miller and Slater's study], many of the ways in which we talk about social relationships and new media might be far more adventurous. Or at the very least, we might become more reflexive about their cultural specificity'. Although more researchers are conducting comparative cross-cultural studies of CMC and new media contexts (e.g. Livingstone and Lemish, 2001; Ran-Priel and Shapira, 2004; Vishwanath, 2004) the number of published studies is still small. As Livingstone (2003: 478) argues 'In a time of globalization, one might even argue that the choice *not* to conduct a piece of research cross-nationally [and cross-culturally] requires as much justification as the choice to conduct cross-national [and cross-cultural] research.' This observation seems ever more true in the context of studying the Internet, which has a manifest cross-cultural nature on the one hand, but which is significantly embedded in and demarcated by cultural aspects, on the other.

At the same time, we should be wary of the danger of essentialising cultures and communicative patterns. There is a very thin line between identifying the role that culture plays in shaping certain aspects of an online communicative context, and depicting this communicative context as essentially North American, Asian, or Latin American. Furthermore, while in this paper I have emphasised the cultural differences between certain CMC contexts and others, we must also acknowledge the similarities between different CMC contexts.

Recognition of the cultural specificity of the CMC environments that we study does not disqualify our studies from contributing to the wider conceptualisation of CMC. On the contrary, being more reflective about the cultural specificity of the online contexts that we study is crucial to a better understanding of 'What dominant principles, values, and perceptions of power are being embedded in our technologically-mediated interactions' (Mansell, 2004: 103). The aspect of power, as Mansell observes, has been too often neglected in micro-sociological studies of Internet use and practice, and addressing the cultural question is one way to bring it to the fore.

ENDNOTES

[1] The distinction between global domain names and national domain names is based on Mueller (1998).

[2] One of the exceptions I came across is www.breastcancer.org which offers a twenty-four hours a day, seven days a week chat room for members and friends of its community.

[3] Ran-Priel and Shapira's (2004) cross-cultural study of memorial websites corroborates the observation about the prominence of religious discourse and symbols on American websites.

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