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**The Use of the Internet in the Lives
of Women with Breast Cancer:
Narrating and Storytelling
Online and Offline**

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by

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Abstract

This thesis explores the experience of breast cancer patients' online participation in relation to their illness. The research focuses on the work of narrating as the key process in patients' online communication. Empirically, it stems from the noticeable recent proliferation of breast cancer forums, particularly in online spaces. I argue that the production of a story and its telling online enables the patient to cope with a radically new situation in her life. The claim for the significance of breast cancer patients' online communication, particularly narrating, is located within the historical and cultural context of the illness.

In examining the process of narrating and storytelling, I draw on sociological and psychoanalytical theories of narrative and storytelling, and sociological debates on issues of health and illness, everyday life and the nature of agency, social exchange, and the tension between the public and the private. The study is based on a phenomenological study that included twenty nine online (e-mail) and twelve face-to-face interviews with breast cancer patients, and a textual analysis of related websites. It shows how the work of narrating is facilitated through the online space, highlighting it as a process that has significant consequences for their ability to cope with their illness.

The thesis concludes with a self-reflexive account of the employment of narrating as a conceptual, analytical and methodological tool for the study of breast cancer patients' processes of online communication. It argues for the need to acknowledge the constraints that shape the online space, calling into doubt its supposed openness, borderlessness, fluidity and lack of structure. In particular, the discussion highlights the persistence of the cultural dimension of the online communication, questioning the extent to which the nature of online communication is global, as is often argued. The concluding chapter uses the empirical case to engage with the broader concern with the relationship between media, communication and agency.

Key words: narrative; narrating; storytelling; Internet; online; offline; breast cancer; agency; interviews.

Disclaimer

[...] the task of transforming a living person into a character ties the hand of the writer. This happens because such a task, even when it is undertaken with the best intentions and deals with a respected and loved person, verges on the violation of privacy and is never painless for the subject.

Primo Levi, Moments of Reprieve (1979: 149)

I have made every possible effort to cause as little harm as possible to all the individuals whose online and offline stories I have incorporated into my account. Nevertheless, despite my best efforts, I might still have hurt somebody's feelings. If this is the case, I invite the reader to contact me at s.s.orgad@lse.ac.uk

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Acknowledgments

The Discovery

do not imagine that the exploration
ends, that she has yielded all her mystery
or that the map you hold
cancels further discovery

I tell you her uncovering takes years,
takes centuries, and when you find her naked
look again,
admit there is something else you cannot name,
a veil, a coating just above the flesh
which you cannot remove by your mere wish

when you see the land naked, look again
(burn your maps, this is not what I mean),
I mean the moment when it seems most plain
is the moment when you must begin again

Gwendolyn MacEwen (1996: 70).

The writing of this thesis has been a process of discovery, an exploration of the significance of breast cancer patients' use of the Internet. Many precious people have been with me in this process or have just been there for me when I needed support. The thesis could never have been written without the generous participation of the many women, and two men, whom I interviewed online and offline. My deepest gratitude goes to all those who were willing to tell their personal stories of using the Internet in the context of their own illness or that of their dearly loved. This thesis acknowledges not just those stories I have been able to quote, but also the many others that I came across online, and offline, and who were key to this process.

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Last but not least, during the writing of this thesis, my grandmother, Batya Goldberg, was always in my thoughts. She was diagnosed with breast cancer in 1960, at the age of forty-eight, in Kibbutz Kinneret, Israel. The experience of her illness was never discussed. At that time, breast cancer was shrouded in silence and cordoned off from public discourse, and so women like my grandmother who suffered breast cancer had no infrastructure to communicate the disease. It was definitely something that inspired me to enquire into the communicative space of the Internet and try to understand its centrality, today, forty-three years later, in the lives of women who suffer from breast cancer.

Now that I have completed the thesis, for a moment the exploration of the 'land' which I have studied for the last three years seems most obvious and plain. This is the moment, as Gwendolyn MacEwen writes, when I must begin again. It is thanks to all the people I have mentioned that I am able to embark on a new exploration.

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Introduction

All sorrows can be borne if you put them into a story or tell a story about them

(Isak Dinesen, cited in Arendt, 1958: 175).

The loss of interest in narrative is typical of societies in which people believe they have no power to shape their lives (Gare, 2002: 100).

Introduction to the research

This thesis explores the processes, practices, structures and forms involved in the online experience of women who suffer from breast cancer. More particularly, it focuses on one specific aspect that seems to be central and significant in breast cancer patients' online communication, namely *narrating and storytelling*. By the latter, I refer to the process of making a narrative and its telling. The research enquires into the ways in which breast cancer patients participate in online space to put their experience into a story.

The key argument is that the online experience furnishes breast cancer patients with, among other things, a means and a space to configure their experience into a story. The construction of a narrative and its telling, I suggest, constitute a way through which patients maintain and develop agency. That is, narrating as a process that enables patients to hold on to a sense of themselves as agents who have control, however little, over their lives. This process appears particularly pertinent in light of the recognition of cancer as a disturbance to everyday life. Patients' engagement in online spaces is understood as part of their attempt to regain the fundamentals that have been threatened following the disturbance of cancer (a theoretical assertion I develop in Chapter One). By exploring patients' engagement in narrating and storytelling in their online experience, my aim is to shed light on the significance of CMC for their capacity to cope with their illness. I want to enquire into the aspects and meanings of the process of narrating, as they emerge in patients' online experience.

However, while I claim for the significance of narrating and storytelling in patients' online experience, by no means do I claim for the supremacy of this activity, nor do I

argue for its exclusivity. On the contrary: there are myriad communicative processes and activities in which patients engage online. As shown by recent studies, and corroborated by patients' accounts in this research, the online space does not stand for one single thing in patients' lives. Rather, when going online, different patients do different things, at different stages of their illness, and for different purposes. They seek, appropriate and exchange information (e.g. McLellan, 1997; Eastin, 2001; Pew Internet & American Life, 2003), share experience and emotions (e.g. Sharf, 1997; Preece and Ghazati, 2001), ask questions, lurk (as I discuss in Chapter Six), and tell stories (e.g. Hardey, 2002; Eley, 2003). While I completely acknowledge the salience of these manifold activities and processes, and thereby the studies devoted to their exploration, it is the latter, i.e. narrating and storytelling, that I wish to focus on in this study. In Chapter One I provide the empirical and theoretical background for the decision to focus on narrating and storytelling as a key process in breast cancer patients' online experience. It should also be noted that focusing on narrating and storytelling does not imply that other activities (as mentioned above) cannot and do not take place at the same time. Nor does it suggest that narrating is quantitatively or qualitatively more significant than other processes. Thus, far from asserting narrating as an overarching way to understand patients' online communication, or a prescriptive model of what patients do online, this thesis endeavours to highlight narrating as one possible way to explain patients' online experience. This proposal is based on a qualitative study that included e-mail and face-to-face interviews with breast cancer patients, as well as a textual analysis of related online texts. The analysis of the data, as I discuss in Chapter One, suggested that narrating might be a helpful conceptual and methodological tool to critically account for patients' online experience.

Crucially, the focus of the thesis is *not* the *narrators*, that is, the online participants, but rather *the work of making a narrative* in which they are engaged. This is unlike studies on Internet use, whose concern is to characterise the *population* of Internet users (e.g. Nie and Erbring, 2000; Hoffman et. al, 2001; Anderson and Tracey, 2002). The latter kind of study is particularly evident in the research field of online health, where the aim is often to construct typologies of 'health seekers' or 'e-patients' and their online activities (e.g. Pew Internet & American Life, 2000; 2003). To put it simply, the unit of analysis of this study is the *process* of narrating rather than the *people* who engage in this process.

The discussion of narrating and its significance for patients' coping with illnesses (particularly chronic illnesses) is not new. In Chapter One I highlight the key ideas of this debate, mainly within the literature of medical anthropology and the sociology of health and illness. What is novel about this study, however, is that it explores the ways in which the link between narrating and illness is facilitated in the online space. The latter is seen as a techno-social space where patients engage in, among other communicative processes, the narrating of their experience. The key question the study addresses is: in what ways is the work of narrating facilitated through the online space and what consequences does it have for the patients involved? The research aim is to account for the specificity and the significance of online space in allowing patients' engagement in the construction and the telling of their story.

Following this introduction, in the remainder of the chapter I wish to pursue two major objectives. First, to contextualise the research empirically and theoretically. The empirical part introduces the reader to the landscape of patients' online communication of breast cancer. The theoretical discussion is a critical overview of current research on health online, particularly patients' online communication, and even more particularly the work done on patients' online communication in relation to breast cancer. It also discusses the studies that include narrative and storytelling in their exploration of CMC, highlighting their strengths and weaknesses. These are the key theoretical areas within which I locate my study. However, given their neglect or very limited way of addressing narrative and storytelling regarding CMC, the theoretical foundations for this thesis are to be found largely beyond the literature on CMC. These are discussed in depth in Chapter One, and employed throughout the thesis. Second, the chapter closes with a presentation of the structure of the thesis.

Contextualising the study: Why breast cancer? Why online?

Empirically, this research stems from the noticeable recent proliferation of breast cancer forums, particularly in online spaces (Sharf, 1997). On any of the major search engines, the key words 'breast cancer' retrieve hundreds of related websites (Appendix 1). Naturally, the majority of consistently active participants in those websites are women diagnosed with, or worried about, breast cancer.¹

Given the centrality of breast cancer in contemporary society (an issue which I explore in Chapter Two), the abundance of various kinds of online communication related to breast cancer, and especially patient-oriented resources, seems especially salient. In interactive spaces focused on chronic illness and cancer in particular, breast cancer forums are often the most active ones.²

Breast cancer-related websites commonly consist of *informative textual* features such as downloadable articles, medical research, statistics and glossaries of terms on aspects of a particular problem. There are also some *informative visual* features. For example, using Webcamera technology, websites broadcast surgical operations to help patients prepare themselves for surgery. Most websites also have *interactive* forums such as peer group e-mails, message boards, discussion lists, newsletters, online personal diaries and text chat rooms. These forums facilitate patient-patient communication and patient-health professionals communication. Many of the online forums are founded by breast cancer patients and survivors who run a website to communicate the experience of their disease. Other websites are owned by commercial and non-profit organisations and institutions.

Breast cancer patients engage in varied interactive activities including posting messages on message boards, sending e-mails to fellow sufferers, publishing their 'journey with breast cancer' (as they often call their personal online diaries), discussing aspects of the illness in text chats, sending prayers on 'praying message boards' to women who go through risky stages in their treatment, and reading and responding to breast cancer mailing lists (Appendix 2). The most notable participants in breast cancer related online forums are patients who are going through the illness or those who have gone through it in the past. Other participants include friends and family, caregivers (other than family), members of medical organisations, medical workers and other related experts.

The prominence of breast cancer in the discursive domain (both online and offline) is tied in with the material reality of the disease. The high prevalence of breast cancer is undoubtedly of concern: on average, one out of every eight women will suffer from breast cancer (and in some countries the statistic is even higher).³ Breast cancer is, thus, inevitably a central experience in contemporary society, if only because

everyone potentially knows someone who has or had the disease. The communication of a chronic illness so prominent in our everyday lives is highly consequential for the social reality of this illness.

Health online

The proliferation of Internet use by breast cancer patients in relation to their illness is part of the broader phenomenon of the increasing use of the Internet for health related purposes. For instance, seventy-three million adult Americans, i.e. 62% of Internet users in the US, have turned to Internet sources to seek health information (Pew Internet & American Life, 2002a). According to a recent study, 24% of the Internet users who dealt with a major illness said that using the Internet was crucial to coping with it (Pew Internet & American Life, 2002b).⁴

A few years ago Burrows et. al. (2000) decried the scarcity of empirical studies about health and Internet. Today, health-related research on CMC seems to flourish across disciplinary boundaries. More and more researchers seem to acknowledge the potential role of the Internet in the context of health (e.g. Ferguson, 1996; Whitten, 2001; Rice and Katz, 2001). They explore the role the Internet plays in the communication among health professionals (physician-physician interaction) and patients (patient-patient communication), as well as its impact on the interaction between professionals and patients (e.g. Reents, 1999; Hardey, 1999). A review of the research agenda is provided at length elsewhere (e.g. Rice, in Rice and Katz, 2001), and is beyond the scope of this discussion. Within this agenda, this study relates to the work on patients' online communication.

In the following section I wish to present a brief critique of the core research agenda on patients' CMC, followed by an examination of studies that looked particularly at the use of the Internet by breast cancer patients. This critique provides the background for the later exploration of narrating in patients' online communication.

Patients' online communication

One of the major aspects that explains patients' motivation to go online and their online participation is information seeking. By allowing patients access to an increasing range of information about their illness and its treatment, the Internet

becomes a key actor in the transformation of the medical landscape (Bury, 2001: 268). Closely related to the broader agenda of sociology and psychology of health and illness, 'e-patients' (a term I am unsympathetic with, for reasons I will discuss later) are depicted as active, informed, health consumers. The notion of empowerment overrules the debate: drawing on the equation 'information (or knowledge) is power', studies reproduce similar findings about how the use of the Internet empowers patients (e.g. Pew Internet & American Life, 2002a; 2003; Ginossar, 2002; Millard and Fintak, 2002); how patients challenge physicians with the information they obtain online; how patients 'shop around' to ensure they get the best medical service and so on.

Another highly discussed issue regarding the use of the Internet for patient communication is online support groups (Rice, in Rice and Katz, 2001). This issue has been explored in numerous studies of different online contexts in which patients engage (e.g. *knee injuries*, Preece and Ghazati, 2001; *HIV*, Reeves, 2000; *Breast cancer*, Shaw. et. al., 2000; *Alzheimer*, King and Moreggi, 1998). In addition to the aspect of information seeking, those studies highlight the significance of emotional support and affirmation that patients can benefit from by participating in online support groups.

Given the prominence of Internet use for health related purposes, there is undoubtedly significance for establishing a body of research on the various contexts and ways in which patients make use of the Internet. Indeed, as the data analysis of this study will show, both information seeking and emotional/social support are central aspects of patients' online experience. The problem with most of the existing studies that focus on these aspects, however, is that they replicate similar findings in different patient-related online contexts. The claims they make are usually general, hackneyed and quite obvious, remaining at the level of arguing that 'patients use the Internet to share information, express their feelings and offer support'. The majority of the studies on patients' online communication that I came across emerge from abstract typologies of patients' activities. Often written from a psychological approach, but in some cases also sociological thinking, those studies are divorced from a broader cultural and social contextualisation (for instance, the cultural meanings of the specific health context examined). Patients' online experience is depicted as independent of the

social and cultural relations and practices in which it is embedded. As a result, accounts present overly functional categories to explain patients' experiences, for example, 'emotional support' 'esteem support' 'informational support' (Shaw. et. al., 2000), 'exchange of information', 'social support' and 'personal empowerment' (Sharf, 1997). While these categories seek to characterise patients' communication, too often they remain abstract generalisations that do not tell us what patients actually do online and what those activities mean for their lives. Unsurprisingly, in describing patients' experience, this kind of research often employs terms such as 'e-patients' (Pew Internet & American Life, 2003) or 'e-health' (Hardey, 2001; Whitten, 2001), as if patients' experience existed only in relation to their online participation. In short, what is beyond the realm of 'e-health' is left unexplored.

This limitation arises partly because the methodologies used to explore patients' communication are often quantitative and rather mechanistic (e.g. Pew Internet & American Life, 2002a; 2002b; 2003). They fail to enquire into patients' perception of their Internet use, online experience and their meanings for their lives. In other cases, where a more integrated approach is suggested and researchers do attend to patients' perceptions (e.g. Shaw. et. al., 2000), they tend to take patients' views mainly at face value. Consequently, the analysis they produce is mostly a thematic organisation of what patients said about their experience of Internet use. For instance, when discussing breast cancer patients' online communication, Shaw. et. al. (2000: 142) explain that the primary benefit of asynchronous communication is that women with conflicting schedules do not have to coordinate their schedules to chat at a specific time. This finding unquestionably derives from users' actual experience (based on interviews the researchers conducted), however the authors remain at this purely functional level of explanation. They do not attempt to elicit a more critical account of the social processes in which those patients engage, and the potential significance of the asynchronous nature of their communication for those processes.⁵

As a result of the limitations discussed above, a substantial part of existing literature on patients' use of the Internet remains somewhat isolated from the wider critical debate on CMC. Much of the research is done within rigid disciplinary boundaries and fails to assimilate a wider critical thinking about CMC. This kind of research is often conducted for (and often funded by) specific health organisations, which tends

to direct the enquiry towards a measurement of aspects such as the effectiveness of the communication, or the reliability and accuracy of the information provided. As a consequence, such research tends to enquire in a very limited way (if at all) into the *communicative* and *social* dimension of patients' online experience. Indicatively, features such as anonymity, lack of social context cues, and disembodiment are treated as variables in correlation with other variables such as 'social support' 'psychological support' and 'decision-making'. The following statement is typical of this positivistic approach: 'characteristics of the medium allowed users to manage their interactions with respect to expressiveness, stigma and obligations' (Rice, in Rice and Katz, 2001: 25, referring to a recent study by Walther and Boyd, in press).

A more critical engagement with the data is missing from much of the literature. For research to be significant and relevant we need to account for features such as 'anonymity' or 'disembodiment' as communicative potentials of the online space, rather than as technical properties. Categories such as 'social support' should not stand as independent of features such as 'anonymity'. They should be integrated into an understanding of patients' communication as a process, in which they draw (or not) on certain features of the medium, to accomplish their social projects. The questions that follow from such an approach are *how does patients' online participation connect (or not) to their offline experiences? And what is the relationship between patients' online social processes and broader offline cultural and social processes?* (based on Slater, 2002).

The online communication of breast cancer patients

To my knowledge, relatively few studies were done specifically on breast cancer patients' use of the Internet (Sharf, 1997; Shaw, 2000; Shaw. et. al., 2000; Liberman and Russo, 2002; Fogel, 2002) and they generally suffer from the limitations that characterise the literature on patients' online communication in general. The pioneer study on breast cancer patients' online communication, and probably the most useful one, is Sharf's study (1997) of the Breast Cancer List, an online mailing list for breast cancer patients and their caregivers. This is a highly descriptive study, however, given that it was among the first ones written on this context, it provides a good basis upon which we can examine breast cancer online communication in a more critical fashion. Sharf (1997) takes a functional (and rather simplistic) approach to patients'

participation in the Breast Cancer List. Based on her participant-observation in this forum she identifies three main functions of the list for its participants: exchange of information, psychological support and personal empowerment. Very little is said about the *specificity* of the online context for patients' experience. When Sharf addresses this aspect, she does it by comparing the online forum to face-to-face support groups. In so doing, Sharf commits the deterministic sin, by which she assumes a necessary difference, if not separation and opposition, between patients' online and offline experiences, and so she deduces from the different properties of online and offline communication, that patients' actual experience would be substantially different. Liberman and Russo's (2002) study has the same pitfall. In considering breast cancer online groups as a *variant* of face-to-face support groups, the authors attempt to isolate specific conditions of the online 'group culture'. The research of Shaw et. al. (2000), which is perhaps the major study of breast cancer patients' CMC to date, is yet another study that exhibits those inadequacies. Although it focuses on patients' experiences allegedly from 'an existential phenomenological approach', it actually overlooks the ways participants experience the Internet and the social meanings that are bedded in their experience. One of the key reasons for that lies in the actual design of their study. The study examines a system ('CHESS') that is installed in people's houses (after they receive formal training about how to use the system), and which is monitored by a facilitator. This creates a completely different setting from that of patients who use the Internet. The CHESS system appears like a *deus ex machina* introduced into patients' lives, and so does the experience of using it. The analysis depicts an experience that is separated from, rather than integrated with, patients' everyday lives. Indicatively, neither the latter study, nor those mentioned above, take into account the wider cultural and social context of breast cancer (e.g. public discourses of breast cancer) in which, arguably, patients' online experience is embedded.

In focusing on narrating in patients' online experience, this thesis attempts to draw on these existing studies, while, at the same time, to address their above mentioned critique. That is, this study seeks to treat patients' online communication as a complex social process, which is embedded in significant ways in certain social and cultural relations; to enquire into patients' views of their experience and analyse them in a

critical fashion; to highlight what patients actually do online, and to try to enlighten the question: why does it matter?

This is not to imply that the proposed account of narrating is the only viable way of meeting these objectives. Alternative frameworks, which I will try to acknowledge throughout the thesis, could be equally beneficial. What I do suggest, however, is that in the particular context of this study of breast cancer patients' CMC, narrating seems a relevant and helpful approach to examine the issue at stake, and to possibly overcome some of the shortcomings of the 'e-health' debate.

Narrating, storytelling and patients' CMC

The issue of narrating is relatively overlooked in research on patients' CMC and very few scholars have studied it so far (McLellan, 1997; Hardey, 2002; Eley, 2003; Orgad, 2004). Hardey (2002) is perhaps the most prominent researcher who addresses the issue of narrative storytelling in his examination of patients' online communication. Focusing on personal homepages of ill people, Hardey demonstrates how those online spaces constitute sites for patients' ongoing telling of their experience of illness. Drawing on key ideas in medical sociology about illness narratives, Hardey's analysis illuminates a significant aspect of patients' online communication, which is too often and too easily neglected.

Notwithstanding that, the problem with Hardey's account, as with accounts that were mentioned earlier, is that it regards the 'offline' experience as the baseline for the investigation of its online 'version'. For Hardey, patients' online narratives are simply a novel form of traditional written illness narratives. Along the lines of structuralist analyses of traditional illness narratives, he suggests his own typology of online illness narratives. Such a typology, however, appears unhelpful in enlightening our understanding of people's experience of Internet use in the context of their illness. McLellan (1997) too, in her study of the 'electronic narrative' of a child diagnosed with leukaemia is concerned with establishing the differences between 'conventional' health and illness narratives and online illness narratives. My experience of attending to breast cancer patients' voices has shown that patients' experience of online narrating should not necessarily be explained in relation to traditional forms of narrative construction. Rather, I would like to suggest, patients' online

communication, and in the context of this study narrating in particular, can be seen to be embedded in a wider culture of health and illness, of self-help and storytelling.

There are also methodological problems with works such as Hardey's (2002) and McLellan's (1997). Relying merely on online interaction with their informants and drawing on their online texts, resulted in a limited understanding of the ways in which patients' engagement in storytelling online is interwoven with their everyday offline lives. More generally, restriction to online interactions with participants is a methodological strategy used in many studies in the field of Internet studies (e.g. Donath, 1999; Baym, 2000) which often limits the interpretation of the context being researched (Hine, 2000; Bakardjieva and Smith, 2001).

Other studies, whether of patients' online communication or other CMC contexts, even if the notions of narratives and storytelling are mentioned, have been done in a very uncritical way. Denzin (1999), for instance, introduces the term 'cybernarratives' as if it was an agreed and clear term, which does not require any further exploration. In the same vein, in an e-mail message addressed to the members of the Association of Internet Researchers (Fox, 28 July 2003), Fox reports on a survey of 'e-patients' conducted by Pew Internet & American Life project, saying that the most enlightening aspect of the study was 'tons of wonderful/tragic/inspiring stories from all kinds of Internet users'. This enlightenment, however, remains out of the official report. Participants in this study were asked to fill in a semi-structured questionnaire, but, rather than follow this format, they chose to tell stories. This aspect remains un-addressed: rather than asking why storytelling 'took over' the question-and-answer format, and what this could potentially tell about the wider context of patients' online communication, the recent Pew report focuses on the old familiar and far too general issues: information seeking, social support, accuracy and validity of health information online, and the popular topics of health-related online searches.

This critique is the backdrop to this thesis. In exploring the online experience of women with breast cancer and particularly in focusing on their engagement in narrating and storytelling, the Internet is considered a medium and a space that is embedded in existing social relations and practices, and used in this context (Slater, 2002). Consequently, while I claim for the significance of narrating and storytelling in

the online experience of women who suffer from breast cancer, I do not claim for the supremacy of this activity, nor do I argue for its exclusivity.

Structure of thesis

Chapter One sets out the theoretical framework for exploring the claim for the significance of patients' online narrating. It starts by presenting the empirical justification for focusing on narrating and storytelling in examining breast cancer patients' CMC. On this basis, it then establishes a conceptual account of narrating and sets workable definitions for the key concepts to be examined throughout the thesis. In particular, the discussion dwells on three main aspects that characterise patients' online narrating: (1) emplotment and the construction of closure; (2) exchange and reciprocity; and (3) the negotiation of private and public. The analytical chapters that come later in the thesis (Chapters Five to Seven) are organised by those three dimensions of narrating, respectively.

Arguably, each of these dimensions can be seen as entailing processes and structures that do not constitute narrative or narrating. For instance, the issue of exchange that is suggested in Chapter Six as a dimension of narrating has been widely discussed in the literature as a central aspect of CMC regardless of narrating (e.g. Kollock, 1999). Thus, the reader should bear in mind that the proposal of those dimensions as facets of narrating is specific and purposive to this study. On the basis of the analysis of the data, the proposed dimensions seemed an appropriate and useful way to frame breast cancer patients' CMC in relation to the process of narrating. However the intention is not to supply prescriptive explanations; rather these are provisional formulations that can be open to contestation and alternative interpretations. In the concluding chapter, and more subtly throughout the empirical analysis, I try to reflect on some possible alternative readings to the one of narrating. Chapter One concludes with linking the discussion on narrating to the debate on the online/offline distinction, and a critique of the exclusion of the concepts of narrative and storytelling from the core agenda of CMC research.

In **Chapter Two** the claim for the significance of narrating in breast cancer patients' online communication is evaluated in relation to the cultural and social context of breast cancer. This chapter seeks to identify the underlying cultural ideas and

meanings of breast cancer, in order to understand how they frame and shape (as well as are shaped by) patients' online experience of communicating this illness. The discussion elucidates the historical context of breast cancer and its move from complete obscurity to the public arena. In this context, it shows how narratives and narrativity constitute one of the central elements of the social and cultural construction of breast cancer in contemporary society. This account constitutes a significant contextual backdrop for the later chapters' analysis of breast cancer patients' online experience.

Before moving on to the actual analysis, however, it seems necessary to introduce the empirical design of the study. This is the goal of **Chapter Three**. The discussion of the methodology and the methods employed in this research is both descriptive and critical. It describes the different steps of the empirical process, focusing on the move that was pursued from online interaction with the study's participants (e-mail correspondence) to offline interaction, namely face-to-face interviews. Beyond the methodological issues considered in the move to the offline context, I include some reflexive notes about the move from online to offline, stressing the conceptual turns made necessary by this shift. The appropriateness and salience of the methodology employed in this study, as well as its limitations, are qualified in the light of a critique of current methodological approaches to doing CMC research. In particular, I focus on the phenomenological approach that this study takes, stressing the significance of getting to grips with patients' perceptions and desires around their online experience. In addition, the discussion explicates the use of narrating as a methodological strategy and the consequent treatment of the data as narratives. The remainder of the chapter presents the key ethical considerations of the research, relating them to the ongoing debate on doing ethical Internet research.

Chapter Four examines online narrating in relation to two ways in which online communication has often been discussed: conversation and interactivity. These concepts, I suggest, have governed to a large extent the thinking about CMC. For the purpose of this study, however, I argue that narrating serves a more helpful and appropriate way of framing the online communicative processes of breast cancer patients. Thus, by locating online narrating in relation to other ways of understanding online communication, and of communication more broadly, this chapter seeks to (1)

clarify the boundaries of what this study construes as online narrating; (2) show how the latter might help us study breast cancer patients' CMC while overcoming some of the limitations of online conversation and interactivity; and (3) highlight the discussion of patients' online narrating as conceptually easing tensions between what has often been dichotomously perceived as 'dialogue' and 'dissemination'.

Although Chapter Four locates the discussion on patients' online narrating within a broader research agenda on processes of communication, both online and offline, it is not meant to advance narrating as an essentially privileged way of understanding these processes. On the contrary, its goal is to justify the relevance and usefulness of narrating for the specific context of this study, and to contextualise it in relation to other alternative concepts and explanations. By so doing, this chapter complements Chapter One to provide a theoretical context for examining the empirical data in the chapters that follow.

Chapters Five to Seven constitute the analytical part of the thesis. Their goal is to account for the specificity and the significance of the narrative processes and forms that emerge in patients' online communication of breast cancer. The analysis is based on two kinds of data: patients' accounts of their experience of online communication in relation to their illness, and breast cancer related online texts. **Chapter Five** focuses on the aspect of emplotment and the construction of closure. It explores the ways in which the online communication acts to furnish patients with frameworks of meanings for the construction of their narratives. The analysis examines how patients' engagement in narrating their stories online can be seen as a dialectical process that is coupled with the project of asserting themselves as survivors. **Chapter Six** aims to highlight the significance of the reciprocal relationships that emerge between patients online, for the facilitation of the production of their stories. I show how the specific uses patients make of online structures of exchange, enable them to engage in a process of storytelling, and how consequently this process endows them with powers to cope with their new situation in life.⁶ Another key dimension that emerges from patients' online experience in general and of narrating in particular is the negotiation of public and private. **Chapter Seven** develops this issue, demonstrating how patients' online narratives constitute a discursive site for the negotiation of the public

and the private in their lives, a tension that is bedded with the dual meaning of illness as both private and public.

The enquiry of chapters Five to Seven is part of a broader intellectual endeavour to explore the significance of the processes, relations and communicative forms that emerge from individuals' use of the Internet. The **concluding chapter** attempts to respond to this endeavour, by connecting key issues raised in the thesis to the broader thinking about CMC and the Internet. It uses the empirical case of patients' online narrating to engage with the broader concern with the relationship between the Internet, communication and agency: In what ways does individuals' use of the Internet enable them to realise their agency?

The concluding chapter reflects upon the key strengths and limitations of the study and opens up some wider issues that the study raises for future research. It consists of a self-reflexive account of the employment of narrating as a conceptual, analytical and methodological tool for the study of breast cancer patients' processes of online communication. In addition, it explores the potential contribution and limitations of the study, beyond the aspects of narrating. The discussion also examines the wider claim implied by this study about the therapeutic value of CMC, particularly for patients. Following from this is a consideration of a second issue, namely the application of the Habermassian model of public sphere to the study of CMC. Lastly, the concluding remarks call into doubt the view of the online space as open, borderless, fluid and unstructured, emphasising the need to acknowledge the constraints that shape it. In particular, the discussion highlights the persistence of the cultural dimension of the online communication, questioning the extent to which the nature of online communication is, as is often argued, global.

A final note on the format of this report. I use different fonts to reflect the different sources from which I quote. As can be seen in Table 0.1, when I quote an academic or any other published text which is not a direct part of the ethnographic material, I use the same font that I use in the report ('Times New Roman'), only in a smaller size. However, when I cite from face-to-face interviews to build my analysis, I change the appearance of the text to Arial font, with a single space. When I quote from online texts (whether the e-mail accounts participants sent me or texts I harvested from

public online forums), I use a Courier New font, with a single space. When I quote patients, whether from their e-mail accounts, face-to-face interviews or online postings, I do so without correction or grammar spelling. The data is presented in this unedited way to respect the feelings of informants.

Table 0.1 *Legend of citations*

| Font | Type of citation |
|---|--|
| Times New Roman font, double line space | citations from academic or other published texts |
| Arial font, single line space | citations from face-to-face interviews |
| Courier New font, single line space | citations harvested from public online forums |

¹ The online communication of breast cancer is predominantly female because the disease is overwhelmingly a women's illness. In addition, statistics consistently document that women constitute the main seekers of information on health online (Pew Internet & American Life, 2002a; 2003; Datamonitor, 3 September 2002; Houston and Allison, 2002). Therefore, ostensibly this study could be categorised under the heading 'women and Internet' or 'gender and Internet'. Fundamentally, however, this study is not about women. The 'unit of analysis' of this study is *not* women who suffer from breast cancer and use the Internet, but rather, the process of narrative construction in online space, to which I refer throughout the thesis as 'online narrating'. In my examination of breast cancer patients' use of the Internet, primarily on the basis of users' accounts, the gender of the users seemed to be only one factor, among many others (e.g. cultural identity), that frames the experience of use. The study attempts to map out the key dimensions of this experience, accounting for the gender aspect only when it is empirically relevant.

I do not ignore, however, the explicit connection between this study and the discussion on women's use of the Internet. So, while I stress that this connection is not the focus here, I think it is necessary to position this study in relation to the gender-based debate on Internet use. This is the concern of this extended footnote. The reason it is presented as a footnote rather than in the body of the actual analysis, is precisely because I regard it as a side-discussion, albeit pertinent and necessary.

The gender-based debate on Internet use, often written from feminist perspectives, has chiefly converged around two central claims. **The first argument** is that Computer Mediated Communication enables the experiencing of a new sense of self, one that is significantly gender-free, fluid and decentred. This argument has often been part of a wider view of the Internet as the material manifestation of the philosophy of post-modernism (Wajcman, 2000). In this paradigm, the Internet has been regarded as a transformative space where gender categories become reconfigured (Consalvo and Paasonen, 2002: 2). Particularly influential in this context were Stone (1995) and Turkle (1996), who have come to stand for an approach to Internet studies where users are seen as having wider latitude than in traditional spaces to experiment with and explore multiple identities (Consalvo and Paasonen, 2002: 2). Such accounts highlighted how the deconstruction of identities is achieved through practices such as gender swapping, cross-dressing and making up personas. These studies highlighted two key features of Computer Mediated Communication as facilitating these practices: disembodiment and anonymity.

Indeed, *in the context of this study*, patients' capacity to maintain anonymity and disembodiment plays a crucial role in their experience of using the Internet in the context of their illness. However, this capacity seems to have a very different meaning from the post-modern idea of experiencing a gender-free deconstructed self. Patients' capacity of interacting online while remaining disembodied and anonymous seems to enhance their daily practices as real people. As I will show throughout the analysis, breaking away from their grounded identity is inextricably entwined with their everyday lives, which facilitates the ongoing reconstruction of their identity. In this sense, this study is better related to the more recent work on women and the Internet. The latter has shifted its view of the Internet 'from a place where identities were joyfully discarded, experimented with, or reconfigured' to a focus on the ways in which users' Internet practices are embedded into structures of everyday life (Consalvo and Paasonen, 2002: 4). Still, the concern of the current study is *not* with the ways in which

those practices are gendered, nor is it with 'the ways in which the category of women is being defined, marked, and understood in relation to the popular Internet' (Consalvo and Paasonen, 2002: 6).

The second claim in current debates on 'women and the Internet' is commonly identified with the 'cyberfeminist approach'. It stresses the networked organisation of the World Wide Web as inherently supporting feminist politics and styles of working. Internet culture, so the argument goes, erodes and subverts the culture of masculine dominance (Plant, 1995 in Consalvo and Paasonen, 2002: 3), by opening up new social and political possibilities which are not available and possible in other spaces and forms. The cyberfeminist approach was probably most inspired by Haraway's infamous manifesto of the 'cyborg' (1990), in which she claims for new politics enabled by new media, by reconfiguring the boundaries between bodies, technologies and gender. Particularly inspiring within this view was Plant's attempt to apply the metaphor of weaving to women's relationship with computers and cyberspace, so as to imply networking and connecting women to each other (Wakeford, in Terry and Calvert, 1997). Overall, researchers associated with the cyberfeminist approach have looked at the uses to which women can put the Internet to push their personal and political agendas in online space (e.g. Harcourt, 1999).

At the most basic level of this argument, the study of breast cancer patients' online communication is a good case in point. The networked organisation of the World Wide Web provides an ideal platform for the emergence of productive relationships that have a positive impact on the lives of women who suffer from breast cancer. A strong sense of coalition, collaboration, and networking emerges from the exploration of breast cancer online communication. At the same time, one should be wary of the danger of essentialising and romanticising women's activity of writing as a genuine act of generosity. Therefore, the reader of this thesis should bear both sides of the argument in mind. On the one hand, there is arguably a gender component to the ideas on the emergence of *communitas*, bonding and camaraderie between breast cancer patients. On the other hand, there is nothing *essential* about being a woman that gives rise to these online experiences. Online spaces of breast cancer patients are by no means inherently or fundamentally feminine. Rather, it is a confluence of different aspects, technical, social, cultural and personal that engenders this kind of online experience. What seems to structure and organise those different aspects, I suggest, is the act of narrating.

Furthermore, Cyberfeminists would tend to regard the figures on women as the main health information seekers online as a sign of liberation. I suggest, however, that it might signify a further extension and reinforcement of women's traditional role as caregivers, of both themselves and others. This line of argument goes hand in hand with recent feminist critiques that argue that in the context of breast cancer, the increasing stress on the self-responsibility and self-management of the patient – manifest in patients' proactive participation in online space – is not necessarily empowering and liberating. While women are urged to manage risk through techniques of self-surveillance, the actual governance of their health remains the responsibility of science and technology (Potts, 2000: 8). This claim would support feminist studies that portray the online space as a site for the hypergendering of identities, that is, how traditional gender-embodied identities are further endorsed, regulated and performed in online space.

To summarise, while the context of this study involves Internet users who are women, and who communicate online in relation to a feminine context, gender does not seem to emerge as the key factor that frames their experience of Internet use. Therefore, the specific practices of patients' online communication need to be situated in their connections to a range of areas and aspects in patients' lives, gender being one of them, although not necessarily the most significant.

In view of what I suggested here, I find it ironical that in the presentation of their recent collection of essays on women and everyday uses of the Internet, Consalvo and Paasonen (2002: 10) conclude that 'there is little if anything we can say about *women* and the Internet in general'. I wonder, why, then, researchers such as Consalvo and Paasonen still insist on producing those categorisations (their book is titled *Women and Everyday Uses of the Internet*). I think that there is much room for feminist and gender-based explorations of Internet use contexts, but only when the latter justify such a focus. The feminist agenda, in its complexity and richness, has much more to suggest, if indeed the online context that is being examined invites such an approach.

² For example, in 'Shared Experience' website about a quarter (536) of the whole collection of cancer patients' stories (2,260) are breast cancer stories (www.sharedexperience.org, data accessed on 7 October, 2003). In 'The Cancer Survivors Network' of the American Cancer society's discussion board, more than 60% of the messages (16,943) regarding cancer experience, are breast cancer-related (www.acscsn.org/Forum/Discussion/summary.html, data accessed on 7 October 2003).

³ For updated statistical figures on prevalence of breast cancer, see National Cancer Institute: http://cis.nci.nih.gov/fact/5_6.htm

⁴ The studies of Pew Internet & American Life refer to American users who seek health information online. Some studies claim that Americans are significantly more likely than Europeans to do so (Ketchum, 2003). I will address the cultural aspect of Internet use in the concluding chapter.

⁵ Throughout chapters Five to Seven, I discuss at length how the aspect of asynchronous communication is embedded in patients' experience and how it is constituted in the relationship between their offline and their online experiences.

⁶ Needless to say, the discussion in Chapter Six touches upon processes, practices and forms that stretch well beyond the context of narrating, and that could be thus explained in very different terms. Thus, 'exchange and reciprocity' should be understood as an analytical framework to examine the empirical context of patients' narrating in the online space. In no way does such an analytical framework deny the wider scope, and the different alternative frameworks, within which processes of exchange could be explored.

Chapter One

Narrating, Storytelling and Patients’ Online Experience

The aim of this chapter is to set out the theoretical framework to be employed in the thesis in exploring the claim for the significance of patients’ online narrating and storytelling. The proposed framework ranges over several key conceptual strands: the hermeneutic approach to narrative, drawing primarily on Ricoeur’s theory of narrative as an interpretative process and of the relationship between time and narrative, the concept of narrative agency (Brooks, 1994), and the conceptual connection between narrative and illness. The intention here is obviously not to settle any of these issues once and for all, but to indicate their general outline and their significance for the enquiry of this study.

The chapter starts with a brief explanation of the reason for focusing on narrating and storytelling in the context of this study. It then presents the conceptual framework of accounting for narrating and storytelling. The theoretical discussion first presents the definition of narrative with which this study intends to work. This definition furnishes a basis for a critical discussion of other approaches to narrative, particularly those associated with structuralist and formalist narratology. Following the discussion of the limitations of structuralist approaches to narrative, another approach is introduced, stressing narrative as a process. This leads to the key proposition that underlies the thesis: to shift from ‘narrative’ to ‘narrating’. Crucially, this proposition is suggested as a helpful way of elucidating the specific processes of communication studied in this research, rather than as an advancement of narrating as a framework for studying online communication in general. The following section explores in depth the concept of narrating. Drawing on Ricoeur’s thesis of narrative (1980; 1984), particularly his distinction between *lived* experience and *narrated* experience, narrating (and in the context of this study, patients’ online narrating) is suggested as a way of capturing ‘lived experience’. The discussion then highlights the link between narrating and agency. The conceptual link between narrating and agency is particularly associated with the hermeneutic approach to narrative. The latter is briefly discussed, stressing

that the notions of interpretation and appropriation are helpful in accounting for patients' engagement in narrating and storytelling online.

Next, another theoretical building block is presented: the psychoanalytical model of 'narrative agency'. The aim of this account is to theoretically substantiate the claim for the transformative and therapeutic power of the process of narrating. To pursue this goal, the analysis draws chiefly on Brooks' model (1994) of psychoanalysis as a site for storytelling, supported by the works of Spence (1982) and of Schafer (1980).

The discussion then moves on to exploring the particular implications of the concepts that were hitherto discussed, for the context of illness, particularly chronic illness. It connects the conceptual emphasis on the hermeneutic relationship between narrative and agency with current discussion of illness narratives within medical sociology and anthropology. In this context, the notions of 'biographical disruption', reconstruction and regeneration are discussed in particular.

The next section discusses this study's employment of narrating as a methodological strategy, highlighting its implications and limitations. In this context, I present the analytical framework that derives from the theoretical foundations and aims at substantiating the process of narrating and storytelling for the context of breast cancer patients' online experience. I then move on to examining three specific dimensions that, I suggest, constitute the process of patients' narrating and storytelling in the online context, namely: (1) emplotment and the construction of closure; (2) exchange and reciprocity; and (3) the negotiation of private and public.

Following the account of these three dimensions, I attempt to connect the ideas about patients' online narrating to a critical debate on the online/offline distinction. In the remainder of the chapter, in light of the recognition of narrating as a helpful way of thinking about breast cancer patients' online communication, a critique is levelled at the existing debate on the Internet for its exclusion of ideas on narrative and narrating.

Why narrating and storytelling? An empirical justification

As has already been said, breast cancer patients' online experience involves manifold communicative processes, practices, structures and forms. In particular, for many

participants, breast cancer online spaces offer a kind of a platform for the sharing and exchange of experiences with fellow sufferers (Sharf, 1997). Breast cancer patients exchange experiences with fellow-sufferers (and to a lesser degree with caregivers, family members, friends and health professionals) through using online textual applications such as message boards, e-mail, chats, and online personal diaries. The exchange of illness-related experiences on these spaces takes different forms. For instance, as reflected in the following extract, patients often engage in information exchange through a question-and-answer correspondence:

Great way to go online: what's the difference between CAF and CMF? You ask, and then you get back answers. You can get back answers, some women will tell you the all story of their life, but others will just get you an answer. (G, Interview 7).

Another form that breast cancer patients' online communication seems to take, which is alluded to in the above extract, is that of a storytelling.¹ Women seem to often express themselves on online spaces such as message boards or journals in narrated forms, to which they refer as 'stories' (my emphases):

My Story

In 1985, at the age of 36 when I was first diagnosed with breast cancer, the perception of this disease was quite different. There was no breast cancer awareness, there was not an understanding of the disease, no support systems and definitely not many options available. There were however many misconceptions. (a breast cancer personal online journal).

*

I wish someone would listen to my **story**..... (a title of a message posted on breast cancer message board).

*

If there was no Internet, I might have chosen to tell the **story** of cancer and coping through lectures and talks with other patients (narrative 3).

*

I shared my **stories** on several sites and wondered which site that you read my **story** on? (Online narrative 13).

When we say that patients exchange stories or narratives in online spaces, at first sight, the notion of 'narrative' seems obvious. We are familiar with the concept of 'narrative' or 'story' on an intuitive basis, from the experience of our everyday life.

Indeed, the centrality of narratives to individuals' everyday lives is a theoretical supposition underlying this thesis.

However, beyond its commonsensical meaning, the concept of 'narrative' carries multi-faceted and complex intellectual baggage with it. Narratives have been studied (albeit sporadically) since Aristotle (Gare, 2002). Given the ample scope of the concept of narrative and its extensive and enduring study, a pertinent preliminary task is to define what is meant by 'narrative' in this study, specifically in relation to breast cancer patients' online experience.

A useful entry point to this task is an actual example of a text that was posted by a breast cancer patient on an online message board (the emphases are mine), and which seems to usefully demonstrate the characteristics of a narrative:

Diagnosis: When I was diagnosed last **November**, it was already **too late**. I found a lump in my left breast **last summer**. I had benign lumps in my breast for years. Normally they went away **after some days**. So I thought **this time**, and forgot them. In **September** I noticed the lump again. It even was a bit bigger. I went to my doctor who told me not to care. In **October** the lump was nearly twice as big as the lump I first found in **July**. My doctor still said I do not have to care, the lump is benign and will disappear from alone. In **November** I moved to a different town, so I had no time to think about the lump. **Late** in **December**, I found the lump was much bigger now. But as **Christmas** was coming, there was **no time**, too, and I wanted no illness. Things got worse in **January**. I awake **one morning** with my breast red and swollen. I was shocked when I saw little ulceration down the breast. My new doctor was shocked when he saw me. He told me after some test that I have terminal inflammatory breast cancer and only **a few months left**. It was a shock for me, too, finding out that there is a large cancer killing me. It had already spread to my lung, liver, intestines and bladder.

Treatment: I get palliative care. Morphium for pain.

Quality of Life: Is getting worse. The tumor is growing very **fast**. My doctor never saw such a **fast** growing. The skin ulceration of my breast is getting larger. Half of the skin is ulcerated, and the tumor inside my breast nearly fills it. I am getting skin metastasis in my axillary and around my belly button.

General Comments: I am angry that I did not see a doctor **last Summer** and forced him to look closer.

What is so prominent in this text is the way in which the narrator reorganises the course of her illness as a chain of events, ordered clearly on a timeline. The temporal ordering allows the narrator to make sense of her experience: to organise people, events, and information that she encountered into a coherent framework of meaning. Events that were 'objectively' disconnected from the experience, such as Christmas or moving to a different town, are incorporated into a coherent story. The above text could be therefore described as a narrative:

[A] constellation[s] of *relationships* (connected parts) embedded in *time and space*, constituted by *causal emplotment*' (Somers, 1994: 616, italics in original).

Implied in this definition of narrative, as could be well observed in the text cited above, is that we can 'discern the meaning of any single event only in temporal and spatial relationship to other events' (Somers, 1994: 616). In other words, narrative renders understanding only by connecting parts to a constructed configuration. When the narrator writes 'I awake one morning' the meaning of *one morning* can be fully grasped only in relation to the events that preceded it.

Emplotment is the procedure that configures the different events into a whole by 'grasping them together' and directing them toward a conclusion or ending, thereby giving significance to independent instances (Polkinghorne, 1991; Somers, 1994, based on Ricoeur, 1984). Through emplotment, the author is able to construct a significant configuration of relationships between the different instances: she organises her story along all the alarming moments she had ignored, relating each one to a specific month in the year. Her online narrative constitutes a framework that configures different events, actions and experiences into a plot, through which she tries to make sense of her illness. Hardey (2002) describes a similar process in his examination of patients' personal homepages, for instance, in the online story of Teresa, a patient diagnosed with Hodgkin's Disease:

Like the other accounts provided on the home pages Teresa's narrative is given a coherence and order by the way that events are linked together retrospectively within a broadly sequential framework (36).

From narrative to narrating

In employing this definition of narrative to explore patients' online communication, and particularly by putting the emphasis on the process of emplotment, this study seeks to move beyond structuralist perspectives of narratives (most associated with the work of Lévi-Strauss, 1968 and Barthes, 1977) and the formalist narratology, which is primarily indebted to Vladimir Propp (1968). Structural approaches conceived of narrative as a formula: a recombination of various relatively changeless syntactical elements (Rickards, in Brooks, 1994: 3). In stressing the *form* as taking

precedence over the content (Lévi-Strauss, 1968: 204), structuralists and formalists underscored the universal, ubiquitous, and eternal nature of narratives. At the same time, however, they failed to *explain* their ubiquity, that is, to reveal their significance (Gare, 2002: 93). Their exclusive concern with narrative as a *form* overlooked the *process* in which narrative is being configured and the meaning of this process for individuals' everyday social lives.

Media studies have predominantly followed the structuralist and formalist path in their exploration of the relation between media and narrative. The chief focus has been exploring narrative qualities of different media texts. For example, news (Bird and Dardenne, 1988), television documentary programmes (Silverstone, 1983; Silverstone, 1984; Silverstone, 1988),² and advertising (Berger, 1997; Kozloff, 1992, employing Propp's formalist functions of Russian folktales to analyse advertisements). The importance of such structuralist analyses of media narratives was in highlighting the *mythical* character of the media in general and television in particular (Silverstone, 1988; Bird and Dardenne, 1988). They used the analysis of media as narrative to shed light on the wider values, symbols and meanings that exist in contemporary culture. As Kozloff (1992: 69) expressed it:

[...] narratives are not only the dominant type of text on television, but narrative structure is, to a large extent, the portal or grid through which even nonnarrative television must pass.

Notwithstanding the significance of structuralist analyses of media narratives, they suffer from the limitation of the wider structuralist approach to narrative. A question that remains unanswered in current narrative analyses of media texts is why those stories, being told by and through the media, matter: How have those stories come into being? Where do they come from (in terms of their history, organisation, the influence of specific individuals)? What psychological and social consequences do they have for their audience, as much as for their producers? (Kozloff, 1992).³

These shortcomings of the structuralist approach to narrative and its merits, are manifest in studies of online illness narratives. In a similar line to the brief analysis of a patient's online text presented before, McLellan (1997) and Walstrom (1999) demonstrate in great detail how texts that patients post online contain the *structural*

elements of narrative. They highlight the ways in which narrative elements (e.g. author's positioning as a protagonist, see Walstrom, 1999), are employed by participants in their online representation. This line of analysis is limited, however, in its capacity to reveal the specificity and significance of those mediated narratives and their consequences for both their tellers and listeners. For one, as Hardey (2002) notes, many of the narrative elements that appear in patients' online texts, have been already described in earlier research on illness narratives.

Therefore, for the purpose of examining breast cancer patients' processes of online communication, this thesis seeks to move beyond a structural perspective and an analysis of narratives as structures. It suggests that, in examining breast cancer patients' online communication, it is useful to shift the focus from *narratives* to *narrating*. That is to say: the subject of this study is not patients' online texts as narrative *forms*, but rather patients' work of *making* those texts online, and its significance for their lives. In this formulation the emphasis is not on the final product, but, rather, on the struggle to produce it, that is, to produce a framework that would organise disconnected elements into a whole and direct them toward closure.

So narrating is more than simply self-disclosure or sense-making and less than a fixed delimited text. It is the middle ground between the two. Thus, the exploration of narrating falls neither in the domain of literary analysis that is concerned with the textual properties of narrative, nor in the psychiatric domain whose focus is the process of confession. Narrating is about an attempt to communicate one's experience to others, including strangers, by ordering it in time and gearing it to a closure.

To put it differently, examining patients' online communication as a process of narrating, reframes the concept of narrativity from *representational* to *ontological* (Somers, 1994: 613). The concern with ontological narrativity highlights the centrality of narratives in social life, and more particularly in processes of self-formation and the construction of identity. These ideas derive, of course, primarily from Ricoeur's theory of narrative. The latter is highly central to the theoretical foundations of this thesis. In a complementary manner, in its emphasis on narrative as a process (rather than just a discursive form), the theoretical framework draws on Brooks' (1994)

psychoanalytical account of the processual notion of narrative (which is itself inspired by Ricoeur).

Narrating is, of course, one of various communicative processes in which patients engage when they go online. Some of these activities involve the production of specific kinds of text, for example, as shown earlier, question-and-answer. Other processes, such as information seeking, do not necessarily elicit the production of a text that is posted online. Narrating might materialise into production of a narrative – a delimited textual form that orders experience in time and directs it toward closure. It might, at the same time, not involve the actual creation of a final product (narrative), but still occupy a meaningful process, in that it allows patients to attempt to make sense of their experience in a certain way.

At the heart of the enquiry into patients' narrating are the questions: What is the significance of the production of a story and its telling in relation to patients' online experience? In what ways does this process affect patients' way of being? How does the story a patient seeks to produce and tell online enable her to act?

Theoretical framework: narrating as a conceptual tool

The following section constitutes the theoretical foundation for addressing the above questions. It aims to clarify and qualify the theoretical assertions that will later inform the analysis of the data on breast cancer patients' online communication. The theoretical framework of this thesis is predicated upon the tradition of hermeneutics that views narratives as a continuing interpretation and reinterpretation of experience, rather than as a record of what happened. In particular, Ricoeur's seminal thesis of the relationship between time and narrative is of key importance.

For Ricoeur (1980; 1984), narrative is the fundamental structure of the experience of time. It is the only temporal form that succeeds in capturing the sense of *lived* time. Unlike, for example, clock or calendar time forms, narrative bears a mimetic relationship to experience as *lived*. The mimesis in narrative is threefold, that is, it consists of three moments: prefiguration, configuration and refiguration (Gare, 2002: 94). First, there is a pre-understanding of the world as action. At this stage there is a symbolic system that furnishes a descriptive context for particular actions (Ricoeur,

1984: 58). The second moment of mimesis involves the representation of action according to specific rules of emplotment: the making of a structure that configures the pre-understanding. This 'configurational arrangement transforms the succession of events into one meaningful whole' and 'imposes the "sense of ending" on the indefinite succession of incidents' (ibid.: 67). This moment of emplotment 'opens the kingdom of the *as if*' (ibid.: 64). The third moment is the appropriation and actualisation of the structure (the plot). It is the moment where the world of the text (the structure) and the world of the hearer or the reader (action) intersect (ibid.: 71). In short, through the configuration of experience into a narrative, people

are provided with room to maneuver, to think about the way they construe the way they live, which allows them to refigure their lives by appropriating new structures (Gare, 2002: 94). .

Implicit in this observation is a fundamental recognition of the inextricable relation between narrative and agency. The following section explores the concept of agency and discusses its relation to narrating.

The concept of agency

The ability to make sense of experience and construct a plausible story that one can incorporate into one's life is a requisite for one's agency, that is, one's capacity to act. Written from a phenomenological perspective and taking the 'fine grain' of everyday life seriously as an integral basis of enquiry (Gardiner, 2000: 3), this study adheres to the central scope that thinkers like de Certeau and Lefebvre accord to agency. Agency emerges from the capacity of individuals, in this case, breast cancer patients, to project and think utopically outside, beyond the constraints of their conditions, and so to 'elude what determines thought and imagination' (Langbauer, 1992: 51, in Gardiner, 2000: 17). As Lefebvre asserts: 'we are all utopians, as soon as we wish for something different' (in Gardiner, 2000: 18).

The notion of agency, as construed here, stresses the *potential* for individuals to transform their existing social conditions (Gardiner, 2000). Such a focus has particular significance when a disruption of daily routines such as cancer is concerned. As actors who can no longer rely on commonsensical notions, following the disruption of what previously constituted the taken-for-granted in their lives, they are highly receptive to

alternative modes of being. It is then that the utopian moment, which is emblematic of a longing for a different and better way of living, arises. As Bakhtin had it, in such contexts, ‘the buds and shoots of new potentialities’ are heightened dramatically (in Gardiner, 2000: 20).

At the same time, notwithstanding the centrality of ideas on transformative capacity, activity, creativity, and potentiality in explaining patients’ online engagement, in adopting the concept of ‘agency’ this study seeks to avoid an overemphasis of the resistant and utopian qualities of users’ everyday practices. The notion of agency regards the processes in which patients are involved – in this case particularly in relation to their use of the Internet – as essentially dialectical. Such a view draws closely on Giddens’ (1984) influential theorisation of human agency. It implies, on the one hand, that the construction of a narrative is a way by which a patient can realise her transformative potential. That is, her capacity to circumvent the disturbance being imposed on her life by the cancer, and to monitor her actions. On the other hand, the utopian dimension is contained insofar as

Agency refers not to the intentions people have in doing things, but to their capability of doing those things in the first place (Giddens, 1984: 9).

That is, patients’ capacity to reflexively monitor their action (through, among other means, the use of the Internet) should be evaluated in terms of their actual capability to act, and the constraints in which they operate. Such a view maintains recognition of the significant role that different structures continuously play in one’s capacity to achieve desired goals. This dialectic will run as a thread throughout my exploration of online narrating as a site for the realisation of patients’ agency.

The hermeneutic link between agency and narrating

The link between agency and narrating implies that, in order to realise our transformative capacity, we need to engage in the creation of narratives. ‘It is essentially through narratives that individuals become more than the conditions of their existence’ (Gare, 2002: 97). In short, narrative production constitutes a *source* for agency. At the same time, however, it is also its *product*. As Bruner (1987: 12-13) puts it:

[...] the mimesis between life so-called and narrative is a two way affair: [...] Narrative imitates life, life imitates narrative.

de Certeau (1984: 78) elaborates this point in his contention that a theory of narration is indissociable from a theory of practices, as its condition as well as its production. Regarding the art of telling as exercising an art of thinking, for de Certeau the story 'does not limit itself to telling about a moment. It *makes* it.' (ibid.: 81). So the particular story one tells produces particular kinds of behaviour and vice versa: the story being produced constructs one's behaviour in a particular framework that makes sense.

Narrating, self-formation and interpretation

The hermeneutic relation between narrating and agency suggests that, in interpreting symbolic forms, individuals incorporate them into their own understanding of themselves and others, using them as vehicles for reflection and self-reflection, as a basis for thinking about themselves and others (Thompson, 1995). Narration is a central process by which this self-reflection is exercised and performed. Individuals understand themselves and construct their self-identity by working and reworking their interpretation of their own biography in the form of a narrative and a story (Giddens, 1991).

So the symbolic project of the self is a project increasingly nourished by available mediated symbolic materials, 'materials which the individual weaves into a coherent account of who he or she is, a narrative of self identity' (Thompson, 1995: 210). Thompson refers to this process of incorporating symbolic forms (and media products in particular) into one's self-narrative as '*appropriation*'.⁴ This process, he argues,

may provide a narrative framework within which individuals recount their thoughts, feelings and experiences, interweaving aspects of their own lives with the retelling of media messages and with their responses to the messages retold (ibid.: 43).

Having said that, appropriation is not necessarily always geared towards the production of self-narrative. While in the context of this study appropriation is taken to be a process tied in with the act of narrating, appropriation refers to an extended process of understanding and self-understanding. It describes the assimilation of a

message and its incorporation into one's life context (Thompson, 1995: 42). It might indeed elicit the production of a narrative, that is, a framework to accommodate a new message, and take hold of its meaningful content by making it one's own (ibid.). It might, at the same time, describe a more general process, which has to do with interpretation, sense-making and individuals' self-elaboration, but which does not necessarily have to do with the production of the specific delimited discursive form of narrative.

This more general process of interpretation and sense-making has been widely studied by audience research in relation to the reception of media products (e.g. Hobson, 1982; Ang, 1985; Radway, 1987; Livingstone, 1998). Recently 'e-health' studies have also been addressing the issue of appropriation and interpretation by patients who encountered medical information online (Pew Internet & American Life, 2000; 2003; Hardey, 2001; Eastin, 2001). One of my interviewees specifically related to this aspect:

It takes time to know whether or not breast cancer patients have been helped or misdirected by information that they have picked up on the Internet. The most important issue, of course, is **interpretation**.
(Online narrative 9, my emphasis).

Audience research in general and, in particular, Internet studies that examined patients' engagement in interpretation and appropriation of health information, furnish a useful framework for thinking about breast cancer patients' online communication as an interpretative process. Building upon this framework, this study centres on the process of producing a story and its telling online as a possibly helpful way to understand how patients make sense of their illness. Narrating is seen as a fundamentally interpretative process. It differs from any other sense-making and self-understanding activity in that it is geared toward the production of a narrative. This does not mean that narrating must result in the final product of narrative, but it definitely has to involve some kind of attempt, if not struggle, to produce it, that is, to create a framework that would 'grasp together' and integrate into a complete story out of multiple and scattered events, directing them toward a closure (Ricoeur, 1984).

True, the boundaries between 'narrating' as construed in this thesis and a more general notion of 'interpretation' or 'sense-making' are hard to demarcate. Arguably,

if there is not a clear, bounded 'product' that constitutes the outcome of that process, anything could be claimed to be part of narrating and so this process becomes extremely broad and ill-defined. I am aware of this conceptual pitfall which has been a central thorny issue in the debate on narrating. I try to reflect on this difficulty and account for its implications throughout the analysis and in the concluding chapter. At the same time, I do hope to enlighten the potential explanatory power of narrating as a conceptual tool for the examination of breast cancer patients' online experience. In so doing, this study aims to add two key elements to the existing research on media reception. First, users' engagement in interpretative processes is framed as narrating and storytelling, rather than described in general terms of appropriation and sense-making. Second, this study explores users' engagement in interpretative processes in the context of the Internet. While the bulk of studies on the 'making sense' of mediated texts has focused on television, few studies have focused on the communicative context of the Internet.

Narrative agency: The therapeutic in the 'talking cure'

A related debate that I wish to incorporate into this discussion, to endorse the emphasis on the link between narrating and agency, is provided by psychoanalytical thinking about the therapeutic power of narrating. Since Freud's inauguration of psychoanalysis the reconstruction of a coherent self-narrative has been held as a therapeutic goal (Polkinghorne, 1991: 150). A recent interest in the processual and hermeneutic nature of psychotherapeutic practices (Mattingly and Garro, 2000: 7) has brought forward the argument about the significance of narrative construction for the process of therapeutic change. Notable in this context is Brooks' notion of 'the agency of narrating', which he develops in his account *Psychoanalysis and Storytelling* (Brooks, 1994).

Closely drawing on Freud's notion of transference, Brooks' model emphasises narrating as a means of establishing truth. He argues that the work of narrative construction (herewith: narrating) is a process that aims at finding an explanation that will resume in the future towards a desired end. Narrating is geared towards finding a workable 'truth'. Spence termed it 'narrative truth':

Narrative truth is what we have in mind when we say that such and such is a good story, that a given explanation carries conviction, that *one* solution to a mystery must be true. Once a given construction has acquired narrative truth, it becomes just as real as any kind of truth; this new reality becomes a significant part of the psychoanalytic cure.

(Spence, 1982: 31, my emphasis).

Hence a well-constructed and coherent narrative possesses a kind of narrative truth that is 'real and immediate and carries an important significance for the process of therapeutic change' (Spence, 1982: 21). In other words, the work of narrative construction is seen as the fundamental process in seeking and achieving a cure. Narrating enables and strengthens the capacity of the narrator (in the psychoanalytical context, the analysand) to contextualise things that are beyond his/her control.

Fundamentally, in assuming psychoanalysis as the scene of storytelling, theorists (Brooks, 1994; Schafer, 1980; Spence, 1982) accentuate the source of therapy in the *process* of making narrative, rather than in the actual narrative that is being produced. Ogden (2000: 66) summarises this idea in his discussion of the process of mourning following emotional losses:

What one "makes" in the process of mourning [...] is far less important than the experience of making it.

The idea of the therapeutic power of narrating resembles Lévi-Strauss' thesis (1968: 197) about the curative value of myths:

The cure would consist, therefore, in making explicit a situation originally existing on the emotional level and in rendering acceptable to the mind pains which the body refuses to tolerate.

Unlike Brooks, however, for Lévi-Strauss the source of the cure is a *social* myth which the patient receives from outside, and which does not correspond to his/her former personal state. By contrast, for Brooks, the patient constructs an individual myth with *inner* elements drawn from his/her past (Lévi-Strauss, 1968: 199). Lévi-Strauss' notion of narrative as curative is therefore essentially structuralist, while Brooks' view of narrative truth (and thus its therapeutic power) is essentially

situational. Narrative truth, *a la* Brooks, is not eternal, nor does it necessarily follow changeless syntactical elements (Rickards, in Brooks, 1994: 3). Rather, narrative truth is 'self-conscious, interminable textual edition of the past, a story always under revision' (Schweizer, in Brooks, 1994: 15).

Narrating and illness

The concern with the relationship between narrating and self-formation is particularly evident in the literature on the relationship between narrative, narrating and illness.⁵ This literature furnishes a central theoretical and analytical context for this study. Within medical anthropology and the sociology of health and illness, narrative and narrating are commonly seen as a means of conveying the biographical disruption caused by illness, especially chronic illness (Bury, 1982; Kleinman, 1988; Frank, 1995; Mattingly and Garro, 2000).⁶ Well known in this context are the accounts of Lorde (1980) *The Cancer Journals*, Kleinman's (1988) *The Illness Narratives* and Frank's (1995) *The Wounded Storyteller*. These accounts highlight illness as 'a call for stories' (Frank, 1995: 53): a situation of crisis that invigorates a creative engagement in an interpretative activity of constructing a story.

Disruption and the need for reconstruction

The point of departure for understanding the significance and centrality of the process of narrating for patients' coping is the notion of disruption. Illness, chronic illness in particular, constitutes a disruption or a disturbance of the continuity of people's everyday life (Bury, 1982). Bury framed this aspect as 'biographical disruption' to highlight the way in which acute illness alters the relationship between the patient's body, her self and her surrounding environment.

As a consequence of this disruption, patients engage in what Frank (1995: 54) called 'a repair work on the wreck': a continuous endeavour to manage this disturbance by regaining their ontological security and the continuity of their self-identity, fundamentals that have been seriously threatened. In this context, narrative construction plays a central role in patients' coping (Bury, 1982; 1991; Williams, 1984; Becker, 1994; Hydén, 1997: 51). The notion of narrative reconstruction describes the conceptual strategies people employ to create a sense of coherence, stability, control and order in the aftermath of the 'biographically disruptive' event of

illness (Lawton, 2003: 27). Narrating is seen as enabling the narrator to regain order and re-establish continuity in life after a disruption. It provides an arena for 'coming to terms' with a problematic experience and making sense of what is happening. Through stories, patients convey how the lived experience of chronic pain affects the way they thought about themselves, their lives and their futures (Mattingly and Garro, 2000: 28).

Along similar lines as the psychoanalytical thesis of narrating as therapeutic, depicting illness in the form of narrative is seen by medical sociologists and anthropologists as a way of contextualising illness events, experiences and symptoms, by weaving them together within a biographical context. Narrating the chronic illness within the framework of one's life story enables the narrator to give meanings to events that have disrupted and altered the course of one's life (Bury, 1991; Hydén, 1997: 51; Williams, 1984). More specifically, narrating involves what Giddens (1991) called 'reflexive monitoring':

“ [The] perpetual readjustment of past and present to create and sustain a coherent self-story” and thus to re-create memory and assume responsibility (Crossley, 1999: 1687, citing Frank, 1995: 65).

In framing illness storytelling this way, Frank (1985) highlights the process of narrating as an exercise by which ill people refuse their bodies' surrender to illness and medicine, reclaiming their control over their bodies and their capacity to act. This is not to deny discursive forms other than narrative, and communicative processes other than narrating which can be equally significant for patients' coping (e.g. information seeking). However, in the context of this study, which focuses on the discursive domain, and on the basis of the empirical data on breast cancer patients' online communication, narrating emerges as a particularly central and interesting way of patients' attempt to manage the disruption. Hence it seems worthy of exploration.

What all this boils down to is recognition of narrative as a significant site for the realisation of a patient's agency. Narrating her experience is a way for a patient who has suffered a severe crisis in life to come through it, emerging as a new or regenerated human being (Hydén, 1997). The construction of narrative (as well as

other processes) is a way of becoming capable of thinking beyond the constraints of her conditions, realising her transformative capacity.

Narrating as a methodological strategy

Conceiving narrating as a site for the constitution of personal agency implies that, methodologically, the 'evidence' for agency is to be found in the act of storytelling itself. In other words, to study people's narrating and the ways this process is implicated in their agency, the researcher needs to access sites of storytelling, where people try to construct a story out of their experience, and tell it to others. Narrating is an ongoing process which takes place in numerous sites, from the least observable site – that is, people's minds – to public spaces where storytelling can be observed, for instance patients' face-to-face support groups. One of Geertz's highly influential assertions has been that the accounts people (informants) give of themselves to strangers (researcher), is a way to yield insight into their selves. In this vein, this study explores patients' engagement in a process of narrating by examining the accounts they give to strangers: the e-mail and face-to-face accounts patients gave me as a researcher, and the accounts they give to each other online. Both situations – the act of constructing an account and telling it to the researcher (a stranger), and engaging in storytelling online – are considered as part of the wider ongoing process in which patients construct their self-narrative. In this sense, this study employs 'narrating' as a methodological strategy. It employs a methodology that invites the informants (breast cancer patients) to create an account in front of a stranger (the researcher); whether by e-mail, and/or face-to-face interviews. These accounts constitute reports about their online experience and at the same time they are themselves sites of storytelling, where patients' construct their self-narrative. At the same time, the analysis relies also on an observation of online spaces where patients' tell their stories and exchange them with fellow-sufferers. By observing these textual spaces (message boards, mailing lists, personal homepages, e-mail), the researcher gains another kind of access to patients' storytelling. In Chapter Three, I elaborate on the considerations involved in the design of this methodology and its potential limits. At this point, my aim is to highlight the sense in which narrating constitutes not only the core conceptual tool upon which the research is predicated, but also its key methodological strategy.

Critics of the processual/situational approach to narrative would argue that we cannot simply assume that there is an inextricable link between narrating and agency. That is, we cannot assert the centrality of narrative in constituting agency without evidence beyond the realm of narrating. Methodologically speaking, this approach would argue, we need access to data that stretches beyond informants' own accounts, and beyond the moments of storytelling. We need to obtain ethnographic material that does not rely merely on people's own reports and that yields insights into the ways in which the process of narrating translates into people's lives. In the case of this study, such an approach would ask: how does patients' engagement in narrating in the online experience feed into their actual coping with their illness? To be able to address this question along the lines of this approach would mean the need for ethnographic material of patients' lives; to see how the story they tell, or try to construct online, is interlinked with their 'offline' realities. How does patients' narrating online connect, or not, to their interactions with family, friends, their medical encounters, and their social life?

I fully recognise the merit of this approach, and its implied criticism of the approach taken by this study. In Chapter Three I will explain in detail why despite the merits in this ethnographic approach, it did not seem appropriate for this study, what rationale stands behind the research design and what at the same time its limits are.

Analytical framework:

Narrating and storytelling in the online experience of breast cancer patients

The account presented thus far, of the hermeneutic, mimetic relationship between narrating and agency and its particular implications for the context of illness, provides the 'umbrella' framework for explaining patients' online experience. In light of this framework, I suggest regarding the online environment as a significant space where patients seek to capture the sense of 'lived time' through the production and the telling of their personal narrative (among other activities and processes). Breast cancer is a life-threatening disease, in which one's everyday *lived* experience has been fundamentally disturbed. Patients are thus involved in a continuous attempt (whether consciously or not) to control the uncontrollable; to capture the *lived* experience that has been threatened by the intrusion of cancer into their lives. Under these circumstances, narrating appears to be a central process that can facilitate patients'

‘super-project’ of capturing their *lived* experience. In other words, it is a way to encompass the ‘real time’ of experience, and so ‘capture’ life and gain a sense of control, particularly in a situation where life is threatened.

This claim is illustrated in an extreme fashion in the online narrative cited earlier. Time is what the narrator lacks the most; she has only a few months left to live. Constructing a narrative that would make sense of her experience seems to be the only possible way by which she can capture time. Her narrative is a stubborn attempt to master time, to take control of what is beyond her control and to relive her *lived* experience. Indeed, what seems so revealing in this story is that, despite the fact that the end of the story is predetermined, there is a strong sense of ‘being-in the-world’ (to use Ricoeur’s term):⁷ there is a sense of being relentlessly and progressively driven towards an end. The narrator refuses to let her story be that of a ‘roller coaster’ over which she has no control. Rather, she struggles to establish herself as an active actor who made a choice. There is a clear sense of responsibility for the situation and of being in control all the way to the end. Through narrating her experience, she comes to realise how constrained her situation is, but at the same time, by configuring her experience in the structured form of a narrative, she creates an opportunity of order and control, however limited this opportunity may be.

The broader argument underpinning this thesis is that in allowing a site for the production and telling of narrative, the online experience enables patients to realise their agency. In the data analysis (Chapters Five to Seven) I will demonstrate how online narrating is implicated in an ongoing dialectical process in which the patient/narrator negotiates desires with reality and potentiality with constraints; how narrating allows patients to think beyond the constraints of their existence, while at the same time helping them realise their actual capacity to act. The account will focus on the specificity and the significance of the online communicative context in facilitating this dialectical experience.

In light of the theoretical discussion provided in this chapter, the analysis of breast cancer patients’ CMC will focus on patients’ struggle to make sense of their experience by seeking the construction of a framework of meaning, that configures their experience into a story, directing it toward some kind of ending. Thus, the focus

of the analysis is not on the final product, i.e. the textual forms women post online, but rather the processes, activities and structures that are involved in their attempt to produce a narrative. To further clarify: a patient might never have posted a text that qualifies as a 'narrative' in its conventional sense (a delimited textual form), yet still be engaged in a process of narrating.

This kind of analysis is arguably prone to criticism; it allows narrating to become extremely broad and ill defined, unanchored to a clear fixed textual form that stands for 'narrative'. It implies that narrating can embrace different utterances or discourse that contain narrative elements, yet do not constitute a 'narrative' which can be encompassed by any conventional definition. To put it crudely, anything can become narrative, and everything patients do online can be seen as related to a process of narrating and storytelling. While I am fully aware of these limitations in employing this notion of 'narrating', and I will indeed try to consider their implications throughout the analysis and in the conclusions, at the same time I hope to show the potential explanatory power of this approach, in the context of breast cancer patients' CMC. Notwithstanding the caveats of framing patients' online experience in terms of narrating and storytelling, this framework, I suggest, might enlighten our understanding of the processes, practices, structures and forms involved in those patients' online experience.

I now wish to narrow down the scope of the discussion, moving on to examining specific dimensions that constitute the process of patients' narrating and storytelling in the online context. My aim is to substantiate the process of online 'narrating' and 'storytelling' as presented in the broad theoretical discussion, asking what kinds of things this process stands for. The dimensions identified provide analytical tools by which I later, (specifically, in Chapters Five to Seven), evaluate the significance of this process as manifested in users' accounts, as well as in actual online communicative forms that can be technically observed (e.g. messages posted on online message boards).

The dimensions represent three key aspects that characterise patients' online narrating: emplotment and the construction of closure, exchange and reciprocity, and the negotiation of private and public. As already mentioned earlier, these are not

distinctive aspects of narrating and CMC. Nor do these dimensions constitute clearly demarcated analytical categories. Rather, the operationalisation of the concept of 'narrating' into these three specific dimensions is purposive for the context of this study. These are dimensions that emerged from the analysis as central and thus appeared helpful in framing patients' engagement in the narration of their experience. The intention is, by no means, to offer prescriptive categories for understanding patients' online experience.

Thus, the following presentation recounts (only) the theoretical notions that are useful in later enlightening the empirical data. The analysis presented in Chapters Five to Seven develops in depth each of the three aspects: the aspect of emplotment and the construction of closure is discussed in Chapter Five, the issue of exchange and reciprocity is explored in Chapter Six, and Chapter Seven focuses the negotiation of private and public through narrating. The discussion of each aspect highlights the ways in which the online context frames (and is framed by) the process of narrating, and thereby patients' experience of illness. I now wish to briefly introduce the three key dimensions of patients' online narrating.

Emplotment and the construction of closure

When a person contracts a chronic illness such as breast cancer, how the situation will develop is largely unknown. There is no temporal horizon by which the illness can be evaluated (Hydén, 1997). While a patient's main endeavour might be regaining certainty and control, the reality of the illness does not allow final closure as there is always the risk of recurrence. Since an absolute cure from breast cancer is never guaranteed, one can never completely end the story of one's cancer.

Thus, the work of narrating, especially the imposition of closure, is fundamentally problematised in the context of chronic illness. On the one hand, the construction of a narrative plays a pivotal role in providing the patient with a sense of control, especially through the turning of the past (which is beyond the patient's control) into present narrative (McLellan, 1997). It constitutes an attempt to impose closure on what cannot be completely closed. At the same time, a central problem in illness narratives is that they often lack an ending. Illness narratives, as Good argues (1994, paraphrased in Hydén, 1997), are forever in search of meaning. They are constantly

changing and being renegotiated, depending on changing perspectives and other changes in illness process. The tension between lived experience and narrated experience is ever more complicated.

In Chapter Five I will try to shed light on the ways in which this tension is manifest in patients' online experience. Certain online forms, I argue, encourage the production of patients' stories, enabling them in implicit (and sometimes explicit) ways to emplot their experience. The process of online narrating directs the personal experiences patients communicate towards the construction of closure. In this sense, the online discursive domain, particularly in its narrated form, serves to close the experience. At the same time, the dynamic unfixed nature of online communication allows users to change and revise their texts. In this sense, online narrating facilitates the ongoing production of an experience that has no final closure.

In exploring this dimension (Chapter Five), the discussion will focus on the ways in which online narrating enables this dialectical process. The analysis of breast cancer patients' online communication will look at the particular elements that enable the process of constructing a narrative, geared towards a closure, yet allowing, as Good (1994, in Hydén, 1997) put it, a forever search of meaning. While these elements are not necessarily unique to the process of narrating online, my goal in Chapter five is to highlight the specific implications they have for the online communication of breast cancer. The analysis enquires into the ways in which specific online properties are embedded in patients' dialectical process of survival: of closing, and leaving open, forgetting and remembering at the same time.

Exchange and reciprocity: The dialogic nature of narrating

The dialogic model of exchange, as I discuss in Chapter Four, has framed to a large extent the study of CMC. Indeed, in the context of patients' online communication, exchange structures and processes play a central role. One of the most debated features in this respect is patients' exchange of medical information (Sharf, 1997; Rice and Katz, 2001). Similarly, I suggest, patients' engagement in the construction of their narratives, is tied in with processes and structures of exchange. In the online spaces of breast cancer, narrating is often based on a reciprocal interaction between tellers and listeners. The online space constitutes a dialogic socio-technical structure,

which facilitates a dialogic process of patients' narrating in significant ways. This argument will be explored in detail in Chapter Six.

The analysis of the role of exchange in patients' online experience, particularly in relation to narrating, will be informed by several theoretical assertions that emphasise the interrelation between exchange and storytelling. As such, they seem a useful proposal with which to frame the discussion of breast cancer online communication. I now wish to briefly summarise these arguments.

According to Brooks (1994) and Spence (1982), in order to become a workable truth that enables the teller to cope with his/her condition, the narrative truth must be confirmed. The confirmation requires a perspective external to one's own. That is to say, the confirmation of one's narrative must come from an external listener [an understanding which resonates with Bakhtin's notion of the dialogic word. For Bakhtin (1984), the word is always implicitly in a situation of exchange]. This implies that narrative has to be established on a structure of exchange. The teller has to have an implicit knowledge that there is the *Other* who confirms the truth of her story.

Based on Freud's notion of transference, Brooks (1994) develops the idea of the transferential condition of narratives. By the latter he refers to the dialogic relation that emerges between the teller and the listener, and the dynamic interaction of the production and interpretation of narrative, as a vital condition for the cure to occur (ibid.: 50). In psychoanalytic terms, in order for a construction of a story to succeed, it must be based on a 'jointly authored work of way of working' (Schafer, 1980: 32).

A related sociological perspective of this idea is the conception of social life as joint action. As Blumer (1969: 70) has it:

[...] everywhere we look in a human society we see people engaging in forms of joint action.

One such form is narrative; no story can be ever told in a social vacuum. Narratives

[...] emerge in joint actions, become objects for interpretation in joint actions, and can be refashioned through joint actions (Plummer, 1990: 136).

The above discussion is a theoretical foundation for the analysis that will be presented in Chapter Six, and that will engage with the questions: Why is the reciprocal dimension so central to the process of narrating on breast cancer online spaces? In what ways is patients' online experience of narrating embedded in, and facilitated by, online structures of exchange?

Negotiating the public and the private

Another important theoretical thread that informs the analysis concerns the relations between narrating, the public and the private. More specifically, the exploration of patients' narrating in online spaces draws upon literature on the publishing of a personal story in a public space. The act of publishing a personal story in a public space expropriates it from the domain of the private and locates it within a wider framework. In publishing one's personal story in a space where others have previously published their similar stories, a story is displaced, beyond the private sphere and the subjective experience of its narrator, in a communal and fundamentally public domain.

Indeed, one of the key aspects of illness narratives that are described in the literature is the transformation of illness from an individual into a collective phenomenon. Narrative is seen as an attempt at collectivising the illness. Through narrative, the illness is removed from the private sphere and becomes a part of an all-encompassing, political and social context. In short, through narrative, the illness experience becomes a collective experience (Hydén, 1997). Rosenblum (2000) discusses writing in contexts of suffering⁸ as having a cathartic function insofar as the suffering of the individual (the narrator) can become something that is shared. Frank (1995), too, stresses the implicit tension in illness narratives of gaining a public voice in order to relate a private experience. While there is an increasing force of the privatisation of illness, relegating it to one's private sphere, there is, on the other hand, the collective force of a 'general unifying view' which homogenises patients' experience (Frank, 1995: 64, citing Lorde, 1980).

This is the theoretical foundation for the discussion in Chapter Seven regarding the ways in which patients' engagement in narrating their experience online might enable them to negotiate the private and the public in their lives. The analysis reflects on the

meanings of private and public that emerge around the act of narrative construction in online space. To understand the connection between narrating and the negotiation of public/private and its specificity in patients' online experience, it is desirable to engage with the wider meanings of the public/private dichotomy in social life, and in contemporary culture. The underlying assumption is that the significance of patients' online experience is embedded in those wider meanings. While, at this stage, the discussion of the wider context of the private/public tension remains undeveloped, it constitutes a central axis of the discussion of Chapter Seven. The key theoretical basis for this discussion will be Warner's (2002) instructive account *Publics and Counterpublics*.

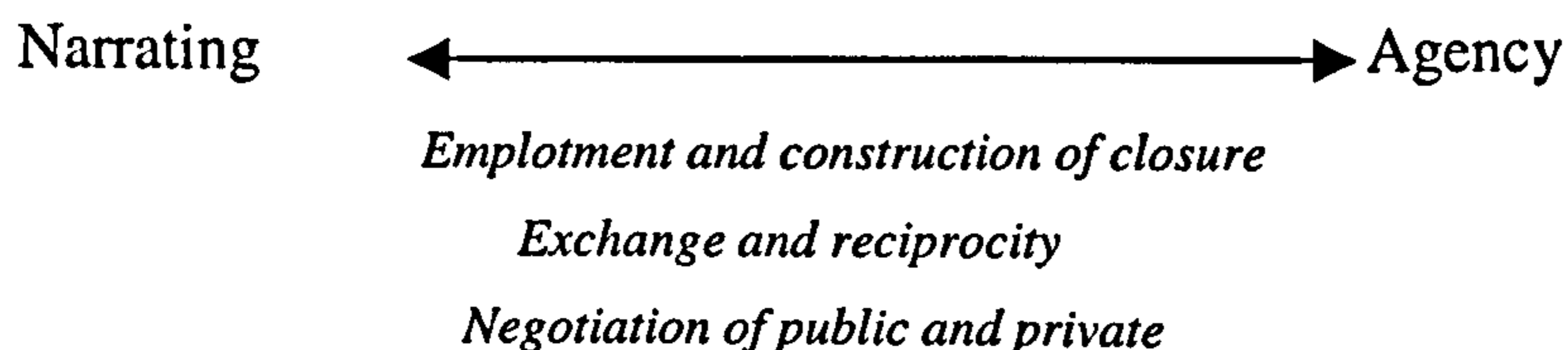
Online narrating and storytelling: Turning a 'full stop' into a 'comma'

Do not place a period where God has placed a comma! I have tried to live my life that way. This (breast cancer) is just my comma in life.
(A message posted on a breast cancer message board).

The discussion thus far has been only a brief excursion into the proposed dimensions of patients' engagement in online narrating. It provides an introduction to the core exploration of this thesis: to show how the different ways in which narratives are constructed and told on the online space comprise a communicative situation that frames patients' experience of illness in profound ways. The analysis will explore each dimension in relation to the process in which the narrator/storyteller constructs a story out of the symbolic materials available to her. Having said that, one should bear in mind that the presentation of the three dimensions of patients' online narrating is suggestive rather than exhaustive. While the three dimensions are discussed in relation to the process of narrating, this is not to deny that they can relate other relevant processes and structures to patients' online experience, such as, for example, information seeking or lurking. The analysis of the data along the three dimensions seeks to demonstrate how narrating constitutes a means for patients in their refusal to succumb to their illness and their attempt to regain the normality and mundanity of their everyday lives. The experience of the construction and the telling of a story is illuminated as a way in which a patient becomes capable of turning the disruption imposed by the cancer into a mere 'comma', and consequently is endowed with powers that enable her to cope with her new station in life.

The following diagram (Figure 1.1) summarises the proposals made thus far, about the relationship between the process of online narrating and the realisation of agency:

Figure 1.1 *The relationship between narrating and agency*



Drawing upon the theoretical framework that has been presented in this chapter, I suggest that agency and narrating work in a dialectical relation. The dimensions listed in *italics* are the key processes that embody this dialectical relation. It is through the act of narrating that those processes are pursued and, as a consequence, a patient realises her capacity to act. In this sense, narrating constitutes a main *source* for agency (working in the direction from the left-hand side of the diagram to its right-hand-side). At the same time, it is only when one is capable of acting, thinking beyond the constraints of one's conditions, that one can pursue these projects (the italicised dimensions) and engage in narrating. Thus, narrating is, at the same time, the *product* of agency (going from the right-hand-side of the diagram to its left-hand-side). This framework of narrating and agency is provisional rather than in any way definitive or global. It does not mean that every patient engages in narrating, and that they do it to the same extent. As I show in the analysis, there are patients whose online experience does not involve storytelling. This is not to say they do not realise their agency, whether in other sites of storytelling or through different social activities altogether. In the concluding chapter I will revisit narrating as a conceptual framework and consider its limitations.

Patients' online narrating and the online/offline distinction

The emphasis on the interlink between narrating and agency in patients' online experience opens up a possibility for thinking about the ways in which their online and offline worlds are connected (or not). Thinking of patients' narrating as presented here assumes that a patient's offline experience ('lived experience' in Ricoeur's terms) provides materials that are woven into a story she produces online. In this

sense, through narrating, and particularly the second moment Ricoeur calls 'configuration', offline experiences feed into online experiences. This moment leads to the third moment of refiguration which 'opens the kingdom of the *as if*' (Ricoeur: 64). That is, through configuring their experience into a story online, patients are allowed to think of themselves beyond the condition and constraints of their lives, and appropriate the new structures they create to refigure their lives.

This claim describes a clearly utopian moment. Arguably, however, it might not necessarily correspond with patients' offline lives; a patient might construct her experience into a 'workable framework' online, but may not be capable of translating it into her 'real' everyday coping with the illness. This is indeed a wider conceptual difficulty, in assuming that the moment of emplotment unproblematically leads to an actualisation of the structure (the plot). While I do not deny this difficulty, within the scope of this thesis I do not intend to resolve it. My aim is to use this conceptual proposition to enlighten possible ways in which patients' narrating online might connect to their offline world. In particular, how materials from their offline lives are woven into their online narrating and how the stories they try to construct online help them organise a structure by which they can think and live their offline worlds. True, without ethnographic material it is impossible to claim that the moment of refiguration indeed takes place, and that the online experience of narrating affects, in any way, patients' offline experiences. By drawing on patients' accounts of their online experience, I merely wish to entertain the possibility of thinking about narrating as a process that can potentially interweave their online and offline worlds.

This line of thinking links to a wider critique of much of the existing literature on CMC and Internet use. This literature tends to posit the 'online' and the 'offline' as a dichotomy, regarding the online space as a space *apart* from social life. Such critique includes that recently raised by Miller and Slater (2000; in press), (Slater, 2002), Wynn and Katz (1997), Baym, (2000) and Hine (2000) who criticise the earlier generation of Internet writing for its focus on terms such as 'cyberspace', 'virtuality', 'spatiality', 'disembedding' and 'disembodiment', terms that imply a separation of the offline from the online. Such writing, claim Miller and Slater, portrayed the Internet as a kind of a 'placeless place', a space *apart* from social life, rather than an integral part of it.

Other works perceived the relationship between online and offline as the relationship between phenomenon and context. Accordingly, the offline was often treated as that which makes sense, or explains, the online. As a result,

Putting the online into the offline reifies both: it assumes a thing called the Internet and a thing called society, or community, or social relations, and at best investigates how one affects the other (Slater, 2002: 544).

Again, without sufficient ethnographic material it is impossible to convincingly claim for the inseparability of the online and the offline. Notwithstanding, in describing patients' online experience of narrating, my aim is to follow this line of critique and open up the possibility for thinking about this process as a site where the online and offline can connect. Along these lines, I purposely avoid treating the experience of breast cancer as the context for the phenomenon of online narrating. Rather, the two are seen as contextualising each other: women's experience of the illness provides the context for understanding their online experience, while at the same time it is a phenomenon that can be explained in light of the context of their online experience.

The exclusion of narrative from the Internet debate

The internet is counternarrative, shaped in part by rumour, fantasy and mystical reverberation (DeLillo, 22 December 2001: 1-2).

Celebrating the Internet as the manifestation of post-modern culture, much of the debate on the Internet (both popular and academic), has been overwhelmingly focused on terms such as 'cyberspace', 'virtuality', 'spatiality', 'disembedding' and 'disembodiment', terms that implied a dichotomous separation of the offline from the online, portraying the online space as an autonomous, self-contained 'placeless place' (Miller and Slater, 2000; Slater, 2002).

One of the theoretical and analytical implications of this line of thinking has been the almost complete exclusion⁹ of ideas on narrative and narrating from academic accounts of Internet research. This theoretical and analytical neglect is not accidental, however: underlying it is the claim for the novelty of virtual worlds that afford the

possibility of doing things differently with narrative than ordinary face-to-face language allows (Webb, 2001). Stressing its distinctive features, 'cyberspace' has been often depicted as a space where narrative cannot exist.

This argument was largely fuelled by studies that focused on the nonlinearity of 'hypertexts' (e.g. Nelson, 1995, mentioned in Tabbi, 2000). The word 'hypertext' has often been used with the intention of supplanting the notion of narrative as a linear, page-by-page movement from a clear beginning through intermediate complications to an ultimate resolution (Tabbi, 2000: 138). Hypertexts were depicted as challenging the presumption of linearity (with which we are familiar from our 'offline' 'real' world), presenting the reader with a completely different set of assumptions. Firstly, as Mitra and Cohen (1999) argue, the fundamental presumption that there needs to be a well-recognised beginning and end is problematised. In hypertexts it is impossible to determine what can be the authentic beginning of the text.

Second,

Unlike other texts...the WWW text is self-consciously intertextual, constantly inviting the reader to move to another textual node. The presumption of reading to the end is replaced by the expectation that the reader will "explore" and "surf" to follow the links that appear in the text. (Mitra and Cohen, 1999: 186)

As a consequence of the 'overt nonlinear connections the text provides', so the argument goes, 'the reader is liberated to produce whatever text the reader pleases' (Mitra and Cohen, 1999: 186). To put it simply, for scholars like Mitra and Cohen (1999) or Nelson (1995, paraphrased in Tabbi, 2000), there is an inherent contradiction between 'cyberspace', along its particular features, and the capacity to produce a narrative.

Tabbi (2000) contests the celebrated nonlinearity of hypertext and the consequent conceptual separation between narrative and online space. He insists that we need to continue speaking of 'narratives' (rather than hypertexts), considering them, however, in the different context of online space. For him,

The post-print medium's difference lies not in its linearity or non-linearity as such, but in this potentially infinite connectivity in which all writing exists simultaneously with all other

writing, so that one can no longer pretend to an objective position “outside” the written environment where life is increasingly lived (ibid.: 146).

Tabbi eschews the technologically deterministic trap of assuming an inherent contradiction between ‘cyberspace’ and ‘narrative’. However, in trying to explain what is new about narrative in this space he seems to fall into a different trap, one that we could call the ‘structuralist sin’. As the quote above shows, Tabbi seems to reify the online space as a monolithic space whose single significant characteristic is its multiplicity and simultaneity of sources, and, in light of this reductive definition, explains narrative as an online discursive form.

While I acknowledge the novel opportunities and forms of communication that are facilitated by the distinctive features of the online space, I think that arguments such as the aforementioned, (whether claiming for the impossibility of narrative in cyberspace like Mitra and Cohen, or reifying what is new about narrative in online, such as Tabbi) present too deterministic a view, failing to account for users’ actual experience of engaging in those online spaces. They attempt to specify the relationship between narrative and online space, independently of the particular social uses in which this relationship is embedded.

The current study seeks to overcome this inadequacy. Its point of departure is that the online space is a social space. To understand the properties of this space we must contextualise them in their social uses and relations (Slater, 2002). In the case of breast cancer patients, as will be argued later in this study, not only is the production of a narrative enabled and practised by patients who engage online but it constitutes a key process in their online communication. Recent studies of patients’ online communication corroborate this observation, showing not only the possibility for, but also the centrality of, narrating in online spaces (Hardey, 2002; Eley, 2003). In light of this observation the study highlights the need to pay sufficient attention to the potential significance of narrating and storytelling in users’ experience.

In an attempt to avoid deterministic generalisations about ‘what is narrating online?’, relatively little has been said in this chapter about the specificity of the online context. The aim of the chapter was to set out the theoretical foundation for a contextualised

examination of breast cancer patients' engagement in narrating in online spaces. The goal of this examination is to enquire into the significance of the process of online narrating and storytelling, to see what it entails and to discuss its consequences for the lives of patients. To meet this aim, in light of the empirical data, the following chapters will develop the concepts and issues outlined so far.

¹ a. Narratives are characteristic of the discourse of illness and breast cancer in general, and can commonly be found in other media such as diaries and autobiographies of illness published in books. However, I suggest, the process of narrating, as it takes place online, has specific significance which is worthy of exploration.

b. In this study, the notions of 'narrative' and 'story' are often used interchangeably. It should be noted, however, that in some schools of narrative analysis, the terms have come to designate two quite distinct phenomena. Whereas narrative often refers to discursive rendering, 'story' refers to the underlying events that the narrative recounts (Mattingly and Garro, 2000: 12).

² Although I use Silverstone's work here to exemplify a structuralist narrative analysis of media texts, it should be said that Silverstone's approach is not purely structuralist. Rather, in his work Silverstone (1988, 1994) combines an acknowledgment of the structural elements of television, with a view of media consumers as crucially engaged in interpretative processes.

³ Kozloff (1992), who uses a Proppian analytical framework for her study, herself admits to some limitations of this approach.

⁴ a. Thompson also draws on the works of Gadamer and Geertz, to establish a useful theoretical bridge between the hermeneutic account of narrative and the activity of media consumption.

b. The notion of appropriation has been used before in reception studies and audience research (e.g. Miller, 1992; Silverstone, 1994).

⁵ The growing theoretical importance of the narrative concept in the field of illness research reflects the increasing emphasis on suffering as a point of departure to the study of illness (Hydén, 1997: 52) and the increasing focus in medical Sociology upon people's subjective experiences within the contexts of their daily lives, their culture and biographies (Lawton, 2003; Bury, 1982; Williams, 1984; Radley, 1993).

⁶ See Hydén (1997) for a comprehensive review of how social scientific studies of illness and biomedical studies have made use of the narrative concept.

⁷ In employing this notion, Ricoeur is highly influenced by Heidegger's existential analysis of *Being and Time* (1962).

⁸ Rosenblum (2000) particularly examines the narratives of two holocaust survivors, Primo Levi and Sarah Kaufman.

⁹ The only study I came across that provides a consistent account of the issue is *Hamlet on the Holodeck: The Future of Narrative in Cyberspace* (Murray, 1998). This study provides useful insights into the ways in which computer mediated communication changes and shapes narratives and stories. It is limited, however, particularly in light of the approach of my study, in two main respects. Firstly, its focus is on narratives rather than narrating. It is clearly written from a literary perspective, examining what happens to narratives when they move from classic formats (e.g. novels) into computer-mediated forms. Secondly, Murray's analysis is primarily concerned with digital environments of interactive fiction: stories in which participants engage in role-playing, interacting with automated characters on imaginative online landscapes. In this sense, it aligns itself, to a large extent, with other studies that focus on notions such as disembodiment and virtuality, a focus of which this thesis is highly critical.

Chapter Two

The Story of Breast Cancer in Contemporary Culture: Narrativity and the Discourses of Breast Cancer

Life stories must mesh, so to speak, within a community of life stories; tellers and listeners must share some “deep structures” about the nature of a “life” (Bruner, 1987: 21).

At the heart of this thesis is the interlinking of three key components: the online experience, narrating, and breast cancer. While the previous chapter established the framework for accounting for the relationship between the first and second components, i.e. between the online experience and narrating, the present chapter focuses on the third component, i.e. breast cancer, and its relation to narrating.

The particular context in which users’ narrating and storytelling take place, and, more precisely, the particular *content* of the communication – namely, the experience of breast cancer – is highly pertinent. It is not an arbitrary backdrop to the emergence of patients’ engagement in the production of stories and of their telling online. Rather, the discourses of health and breast cancer shape and construct users’ online participation in particular and significant ways. Closely drawing on Ricoeur, the premise of this discussion is that people adopt and appropriate certain templates, which are provided by public discourses, into their self-narratives. Thus, the process of narrating and storytelling in patients’ online participation cannot be exhaustively explored and fully understood if the public discursive context of this communication is not made explicit.

This chapter seeks to introduce the reader to some salient features of the discourses and ‘culture’ of breast cancer, which will be reflected upon in the analysis of patients’ engagement in online narrating. In particular, in considering the discourses of breast cancer, I wish to focus on narrativity as a central feature of the culture of breast cancer, and show how the particular historical context of its construction has led to the

emergence of personal narratives as significant discursive forms. The centrality of narratives is only a token of the broader discursive context of breast cancer. Thus, while this chapter underscores narratives and narrativity, it is important to bear in mind that the social and cultural construction of breast cancer in contemporary society comprises more than that. The discussion of this chapter and its focus on the aspect of narrativity is aimed to illuminate, in later chapters, the analysis of breast cancer patients' accounts of their experiences of Internet use.

Narrating and storytelling are not exclusively characteristic of, and significant for, the experience of breast cancer. Illness narratives have been claimed as a significant feature of chronic illness in general (see Chapter One). In this chapter, however, I seek to highlight the distinguishing features of the discourse of breast cancer and its relation to narrativity. To my knowledge, there has been very little research on this link, and none of it seems satisfactory. Perhaps the most coherent account of this issue is Potts' essay *Publishing the Personal* (in Potts, 2000), in which the author accounts for the significance of personal illness narratives for the discourse of breast cancer. Too often, however, Potts seems to regard aspects of narratives and narrating that are actually applicable to any chronic illness, as distinctive and unique to breast cancer without justifying the claim for their specificity.

Thus, what follows below is not a comprehensive account of the cultural (and, particularly, the discursive) context of breast cancer, but an overview of several fundamental features. These were selected for their relevance to the discussion of women's online experience in this context, particularly in narrating and storytelling.

The place of breast cancer in contemporary culture

Today breast cancer is the biggest disease on the cultural map – bigger than Aids, cystic fibrosis or spinal injury. It is bigger even than those more prolific killers of women – heart diseases, lung cancer and stroke. There are hundreds of web-sites devoted to it, not to mention newsletters, support groups, a whole genre of first-person breast cancer books; even, in the US, a glossy, upper-middle brow, monthly magazine. There are pink ribbon days and an annual “race for the cure” in the US which attracts a million people.

(Ehrenreich, 8 December 2001: 1a).

Breast cancer, as a subject for sociologists and social historians, has received fairly little scholarly attention. However, this void in the academic literature stands in stark contrast to the extremely visible and voluble presence of the disease in contemporary culture. Notably, for instance, there has been over-coverage of breast cancer in the media, compared to incidence of the disease in the population (Saywell et. al., 2000; Seale, 2001). This prominence of breast cancer in contemporary culture has to do with, among other factors, the paramount attention that the breast attracts, the breast being a site of conflict for so many of society's values and beliefs (Yalom, 1997; Leopold, 1999).¹

Images of ideal femininity may have changed in the two last decades, however they remain unexceptionally informed by an ideal of two-breasted symmetry. The dominant discourse of breast cancer is consequently still highly governed by the desirability of retaining woman's 'wholeness' and 'femininity' by conservative surgery and the construction of prosthetic breasts. Since the breast features in iconic images of idealised femininity, the asymmetry (of mastectomy or lumpectomy) represents an assault on beauty and perceptions of normality (Saywell et. al., 2000: 43). Evidently, the representation of breast cancer in the media is influenced mainly by perceptions of femininity which focus on the breast as an icon of feminine worth, perceptions that often obscure other dimensions of the experience of illness (ibid.: 59).

In a nutshell, the preoccupation of contemporary culture with aspects of embodied femininity, the breast being particularly prominent, has inevitably resulted in breast cancer 'taking residence in every cultural medium, from soap operas to sculpture' and so 'There is no public forum now in which breast cancer is not at home' (Leopold, 1999: 2).² This, however, has not been the case until quite recently. During the nineteenth century, and through the first half of the twentieth century, breast cancer 'has been cordoned off from society, a private experience suffered by women individually, at the margins of public consciousness' (ibid.: 3). A key characteristic of the social and cultural construction of breast cancer is a process of the unveiling of the disease: from the reign of an almost complete silence and taboo to the emergence of the disease into the limelight.³ And this transition, metaphorically described by

Leopold as a move 'from the closet to the commonplace' (ibid.: 215), was facilitated, to a large extent, by the media.

I suggest that the shift 'from the closet to the commonplace' is a process that, in crucial ways, frames the meanings of breast cancer in contemporary culture, embracing the key aspects of the cultural meanings of the disease. Hence, I will employ this shift as a framework to discuss those key aspects. To do so, I will first briefly and loosely outline the historical narrative of the illness from the nineteenth century to 1970s, highlighting the process of breast cancer's 'coming out of the closet'. In light of this emphasis, I will then move on to discuss key discursive features of the disease. These features appear central to any critical account of the social and cultural context of breast cancer; however, they are particularly illuminating in relation to the subject of this enquiry, namely: narrating and storytelling in the online communication of breast cancer.

The unveiling of breast cancer: From the closet to the commonplace

Breast cancer was a problem that the culture had rejected. It was impenetrable. The encounter between a newly diagnosed patient and her doctor really *was* private, desperately so.

(Leopold, 1999: 213).

During the nineteenth century, breast cancer was a taboo. Since diseases such as breast cancer in postmenopausal women played no role in the dynamic of social reproduction, they hardly attracted any attention. The failure of medical science in the nineteenth century to cure or even manage breast cancer led eventually to its disappearance from family physicians' areas of competence. Furthermore, the disease challenged the very femininity that Victorian culture worked so hard to promote and preserve (Leopold, 1999: 10), hence it was silenced and it became a taboo.

Cancer, in general, has been historically surrounded by conventions of concealment, motivated by a public sense of horror.⁴ Like any other taboo subject, breast cancer had to be hidden away from the public view. The disfigurement it brought was thought to be a precursor of certain death. Unlike other deformities such as the effects of leprosy, however, signs of breast cancer could be hidden away. Thus, a woman who suffered

with breast cancer was encouraged to disguise her pain and discomfort not only to the outside world but also to herself (ibid.: 204). As a consequence,

Virtually no woman with breast cancer was aware of anyone else suffering with it. And the language that would have enabled her to discuss her condition with a fellow sufferer, to exchange, for instance, information about symptoms and the side effects of treatment, was not available to her. (Leopold, 1999: 204).

In other words, during the nineteenth century and the beginning of the twentieth century, there was no infrastructure for women to communicate the disease (ibid.: 213).

Although a gradual change started to take place by the turn of the century, especially with the increasing availability of surgery and the introduction of the radical mastectomy as the 'gold standard' (that is, the dominant model of treatment for breast cancer) (ibid.: 10), by and large, women's experience of the disease still remained sealed off from the public arena. What is more, since radical mastectomies were seen as life-saving procedures, a woman's dependence on her doctor and her subservience to him was further enhanced. This fact, and the fact that it was medical men who governed the arena, meant that breast cancer remained secluded for much longer than many other women's health issues (ibid.: 204).

Perhaps the first significant landmark in the assimilation of women into the communication of the disease was the foundation of the Women's Field Army (WFA) in 1936, by the American Society for Cancer Control (ASCC). The WFA was an explicit attempt to challenge the passivity towards breast cancer and the fatalism that dominated both medical and public attitudes towards the disease. By raising public awareness about breast cancer and its curability, the WFA sought to fight the continued silence and stigma that surrounded the disease. Indeed, the WFA's official goal was to promote 'trench warfare with a vengeance against a ruthless killer' (Lerner, 2001: 43).⁵

Despite the support garnered by the WFA, by the mid 1960s, the number of American women dying from breast cancer every year had surpassed 25,000 and seemed to be

rising. Notwithstanding the large number, it appears that the women had no idea of how large a sorority they belonged to (Leopold, 1999: 153). It was not until the early 1970s that the illness significantly emerged within the public cultural arena.

From the early stages of the debate on the illness, the media played a highly central role in its 'publicisation'. Already in the late 1930s, first person cancer narratives written by women began to appear in popular magazines, starting to switch the perspective from the impersonal medical (predominantly male) authority voice, to the more intimate voice of personal experience. Those early stories, however, were still very much dominated by the medical voice, and the heavy-handed presence of the American Society for Cancer Control in them was often obvious (ibid.: 183). The stories kept portraying the doctor as the main, if not the exclusive, source of information and knowledge that a woman has (ibid.: 219). Consequently, the knowledge that women had was of a 'need-to-know' nature, with doctors conveying just enough knowledge to gain the women's cooperation while sustaining their status as patients rather than as partners (ibid.: 183).

It was only in the 1970s that a more momentous challenge to the dominant medical and impersonal discourse of the disease was offered by the publication of personal stories. Highly prominent among those stories was *Why Me?* (Kushner, 1977), an account written by Rose Kushner, a Baltimore journalist diagnosed in 1974, who turned her breast cancer into a public crusade to inform women about the disease and their treatment options.⁶ A subsequent contribution to the opening up of the discussion on the illness was *First, You Cry* (Rollin, 1976), a vivid account of Betty Rollin, an NBC correspondent, of her experience with breast cancer (Lerner, 2001: xii). Perhaps most influential, however, were famous American women such as Shirley Temple Black, Betty Ford, and Happy Rockefeller who, during the 1970s, revealed their diagnoses in the media (Lerner, 2001: 7). Leopold (1999: 231) summarises the significant role played by the press in that particular moment:

...In these early days of public discussion, the press served as a critical intermediary between the closed world of medical science on the one hand and the equally sequestered world of breast cancer patients it was deemed to serve on the other.

Apart from the print media (books, magazines, and newspapers) that provided a central platform for invigorating the communication of the illness, television also played a central role in bringing the disease into the open. Reaching out to mass audiences, television broadcasting considerably extended the public's awareness of the disease (Leopold, 1999: 238). Highly significant was the first televised portrayal of breast cancer in the soap opera *The Young and the Restless* (broadcast in 1974), giving rise to many more occasions for breast cancer to appear on television and be incorporated into many dramatic series (ibid.: 241). Particularly pertinent to the current discussion is the focus that representation of breast cancer on television gave to the personal experience of the illness and its reinforcement of breast cancer as a *personal narrative*. The raising of the visibility of the illness, and the opening up of its discussion, are closely tied in with the increasing emphasis on (and consequent availability of) narrative as a central discursive form that 'carries' the meanings of the illness. This is not to deny that other discursive forms occupied the representation of breast cancer in the public arena and enhanced its communicability. Campaign slogans, for examples, were increasingly circulated by different organisations in the public domain (see next section), raising public awareness of the illness and its detection. Unlike personal stories, those slogans encapsulated information in a short, to-the-point and clearly non-narrated fashion. So while the discussion of this chapter emphasises personal narratives, they should not be mistaken to represent an exclusive or a primary mode of discourse in the social construction of breast cancer. They are, at the same time, claimed to be significant. I will return to this point at the end of the chapter.

As far as the unveiling of the illness is concerned, it is also interesting to regard the influence of the discourse of AIDS on the construction of breast cancer. In many ways, it seems that the gay movement, in its political struggle, constituted a 'role model' for the political path undertaken by breast cancer activists. As Love (2000: 591) relates (referring to the work of the AIDS movement):

For the first time we were seeing people with a killer disease aggressively demanding more money for research, changes in insurance bias, and job protection. Women with breast cancer took note of that – particularly those women who had been part of the feminist movement.

They were geared, as were the gay activists with AIDS, to the idea of identifying oppression and confronting it politically.

What seems significant for the purpose of this discussion, is that the driving force which underpins the 'coming out of the closet' of both the discourses of AIDS and breast cancer, is an attempt to break the silence that surrounded the diseases and voice them in the public arena. The 'coming out' of the disease is crucial for the understanding of its current discourse. It seems that, inherent to the discourse of breast cancer, is that tension between the private and the public — the hidden, silenced taboo on the one hand and the public, out in the open, on the other. As will be discussed later, this 'double stranding' as Potts (2000) has it, runs as a thread in women's personal narratives of their experience with breast cancer.

This tension between the concealed, intimate aspect of the illness and its public dimension frames, in many ways, the discursive features of the illness. Keeping this framework in mind, I now wish to turn to discussing key features of the discourse of breast cancer.

The dominant story of breast cancer: Agency and responsibility

Over time, as the campaign to alert women to the danger signals of cancer broadened...there was a clear suggestion that women who failed to avail themselves of treatment in a timely manner were themselves to blame for the consequences.

In this construction, **the focus is on women and how they respond**, not on treatment, which is taken as a given. (Leopold, 1999: 172, my emphasis).

The discourse of breast cancer is clearly one of personal responsibility, a notion strongly embedded in the focus on early self-detection of the cancer as the key element to cure. Of course, this aspect should be located within its wider ideological, and, particularly, cultural context. As Leopold (1999: 172-173) observes, the insistence on personal responsibility that dominates so many aspects of American life has a clear part in this construction. In a culture that has always valued the virtues of self-help, says Leopold, one finds it hard to escape the self-blame that accompanies failure.

‘America had become a Persian bazaar of self-help’ (Albom, 1998: 65). Indeed, despite the growing evidence from advanced liberal democracies other than the US of the spread of ‘individualisation’ (Beck, 2001) and the ‘enterprising self discourse’ (Rose, 1992), the latter is still notably an American phenomenon. A belief in self-determination and autonomy has always been part of the ideology of the United States, following Benjamin Franklin’s notion of autonomous self-help, that is, the idea that ‘one could help oneself’ to shape a life uniquely satisfying and unfettered (Grodin and Lindlof, 1996: 5). The discourses of breast cancer work by the same cultural rationale: to internalise the problem and to search for its remedy within one’s body.

With the focus on the illness as a private experience on an intimate scale, women were encouraged to look inward rather than outward (Leopold, 1999: 184). Indeed, since their early days in the 1920s, breast cancer public education campaigns, conducted within the scope of consumer culture, and provoking a clear association between beautiful breasts and healthy breasts, conditioned women to accept responsibility for whatever calamities befell them (ibid.: 161). For instance, as Leopold shows in her analysis, the recommendations set out for women in a pamphlet produced by the American Society for the Control of Cancer in 1929, clearly conveyed the full range of responsibilities enjoined upon women (1999: 162).

The message of personal responsibility is embedded in a cultural ethical regime that is governed by ‘survivalism’ (Lasch, 1980), the ‘autonomisation’, ‘responsibilisation’ (Rose, 1992) and the ‘individualisation of the self’ (Beck, 2001),⁷ by which people no longer perceive themselves as subjects with duties and obligations, but as individuals with rights and freedoms, with the powers of personal choice, self-fulfilment and initiative (Rose, 1992; Beck, 2001). A key site where the vocabulary and discourse of the self are exercised and constructed is health. Patients are depicted as ‘health workers’ (Stacey, 1988), actively seeking to understand and make sense of their illness and treatments (Lambert and Rose, 1996).

‘In the early treatment of cancer lies the hope of cure’:

*The campaign for early detection*⁸

The 1950s seemed to have been an even riper time to promote the message of self-responsibility, by focusing on breast self-examinations. The cervical cancer campaign

that prefaced that of breast cancer provided an essential background for the American Cancer Society's fierce advocacy of breast self-examinations and particularly its explicit call for individual responsibility (Lerner, 2001). Fundamentally, the latter campaign was set in a very particular historical context:

Having emerged from the Depression, defeated the Germans and Japanese in World War II, undergone an economic boom, and invested in scientific research, the United States suddenly seemed within reach of making cervical cancer a curable disease (Lerner, 2001: 51).

Following the lines of the campaign against cervical cancer, the campaign to promote breast examinations in the United States relied heavily on the language of personal responsibility. This strategy drew on three factors (ibid.: 59):

- (1) the growth of 'new public health' after 1920, encouraging the public to be informed and adopt healthier behaviour;
- (2) American individualism which prized initiative and action in the face of uncertainty;
- (3) familiar gender roles, in which women were perceived as accountable for maintaining health and preventing disease.

A particularly common approach in the 1950s was to tell the story of a woman whose recent death had resulted from her unwillingness to participate in breast cancer detection strategies. Thus the line between responsibility and blame was extremely thin (ibid.: 59), and the relationship between the two was encapsulated in the form of a personal story. Many women indeed approved of breast self-examination, seeing as empowering the idea of taking action in an uncertain situation (ibid.: 55).

Later, as the techniques grew more sophisticated, moving from breast self-examinations to screening mammography, the survival rates did improve but the underlying strategy remained unchanged: the emphasis on early detection shifted attention and accountability away from the medical profession and towards the patient and her personal behaviour (Leopold, 1999: 174). So, with the move into a more patient-centred model, choice and control have been further devolved to the patient and away from the medical profession (Potts, 2000: 5). This claim is corroborated by a recent study (Charles et. al., 1998) that examined women's perception of their

treatment options and decision-making in the early stages of breast cancer. The governing construction of treatment decision-making among those patients was, as the researchers describe it, that 'doing nothing is no choice'. Indeed, a central issue that emerges from this research is patients' internalisation of the idea that *they* are responsible for their treatment and cure: they have to constantly reassure themselves that they have done everything possible to maximise their treatment (and thus their healing) options.

The emphasis on personal responsibility goes hand in hand with what Leopold (1999) identifies as the 'privatisation' of the disease. Part of this process is the change in the approach to treatment of breast cancer from the 'one-size-fits-all' approach that characterised earlier treatment, to 'targeted therapy aimed at correcting the key defects in that particular cancer cell' (Love, 2000: xviii). The open recognition of the disease, argues Leopold, has not been accompanied by the emergence of any sense of social responsibility. The stress has been increasingly on the intimate, individual struggle between the disease and its victim, with a focus on breast cancer being predominantly a domestic drama. Consequently, it is the individual control of the disease, rather than the social control, that has been foregrounded.

The message of personal responsibility and enhanced involvement of the patient implies, among other things, a shift in the control of the discursive space of the disease, primarily from the hands of the medical profession to those of the laypersons. The consequence of this shift is that embodied knowledge often turns out to be more reliable than biomedical knowledge, particularly for women who experienced technological or biomedical failures (e.g. detection failures). This is a shift of the common hierarchy of credibility⁹ by which biomedical knowledge is far more reliable than knowledge gained through personal experience (Fosket, 2000).

Challenges to the dominant discourse of self-help and agency

The centrality of the notion of personal responsibility in the discourse of breast cancer notwithstanding, the discourse of risk in relation to breast cancer is not entirely amenable to the same analysis as that posited in other recent critiques of health risk discourse. The latter depict risk analysis and management as the responsibility of the actively vigilant consumer (Lupton, 1995; Lupton and Petersen, 1996 in Potts, 2000:

9). While women are urged to manage risk through techniques of self-surveillance, the governance of the risk remains the responsibility of science and technology (Potts, 2000). For one, all knowledge about risks and causes of breast cancer are uncertain and up for debate (Fosket, 2000: 19).

Another challenge emerges from the implicit link between information and empowerment. 'Information is power' was an implicit slogan of the 1980s Women's Health Movement, with an allied assumption being that empowered women would have more control over their lives and their bodies (along with the renowned critique *Our Bodies Ourselves*).¹⁰ While information is commonly seen as empowering, and essential in order for one to be able to take responsibility and action, the other aspect suggests that the discourse in which it is constructed, demands of women a confrontation with their own 'dangerous' bodies and potentially compromised sense of femininity (this argument is made by Hallowell, in Potts, 2000). In other words, information can also constitute an obstacle to agency, resulting in feelings of disempowerment.

Such alternative voices still remain largely in the margins of the breast cancer debate. While the online environment is often celebrated as a discursive space that allows for alternative (and even radical) messages to dominant discourses to be communicated, I remain unconvinced of this claim in the context of breast cancer. In accounting for the online communication of breast cancer, I will consider the extent to which competing voices such as those outlined above are indeed heard in this communicative context, and the role they play in it. In particular, to what extent do the existing frameworks of meaning and the discursive structures available online allow expression for patients who do not fit the dominant discourses of breast cancer? I tackle this question especially by drawing on the experience of two of my interviewees (J, interview 10 and K, interview 11) who refused to classify their experiences among what they considered the mainstream stories communicated online.

Discourse of cure, triumphalism, cheerfulness, hope and survival

...in the seamless world of breast cancer culture, where one website links to another – from personal narratives and grassroots endeavours to the glitzy level of corporate sponsors and celebrity spokespeople – cheerfulness is more or less mandatory, dissent a kind of treason.

(Ehrenreich, 8 December 2001: 1a).

...breast cancer talk on the Internet is a self-directed rhetoric of hope and enablement...

...its many threads form a blanket of nurturance that helps to promote the transformation of vulnerability into strength, and negativity into hopefulness

(Sharf, 1997: 78).

As both quotes usefully observe, the discourse of breast cancer (in its offline and online manifestations), is clearly governed by optimism. This utopian politics of empowerment and cheerfulness is deeply implicated in the discourse of agency. Self-help and personal responsibility are constructed as key to hope and enablement. The following extract from one of my interviewee's online narratives is testimony to this claim:

I was diagnosed on 7/8/99 with invasive lobular breast cancer. It took a couple of days for the news to "sink in" and then I felt I had a choice.

I could be a "victim" of this disease...or I could face it head on ~ with a positive attitude and "just do it". I chose to be bigger than the cancer and face it head on.

(Online narrative 14, my emphasis).

The notion of one's capacity to 'just do it' has been incorporated by patients (or, in a Foucauldian sense, one might say 'interpellated'), drawing largely on the utopian discursive 'baggage' carried by the illness throughout its history. The latter is replete with examples of seemingly objective terminology that actually reflect the cultural context into which they were introduced (Lerner, 2001: 11).

For one, the portrayal of the disease as curable owes itself greatly to the use of the seemingly 'objective' notion of 'cure', which, in the public mind, refers to *permanent* disappearance of the disease, but which, medically, signifies that there is no clinical evidence that the cancer has returned (ibid.).

The motifs of hope and the 'triumphalism of survivorhood', as somewhat cynically described by Ehrenreich (8 December 2001: 1a), are not unique, however, to the discourse of breast cancer. Stacey (1997), for instance, has shown how the dominant

cancer narrative is one of heroism, of confronting the monsters, battling against the odds, and of triumph, a construction evident in a number of different genres (popular culture, medical, feminist) of different kinds of cancer.

Sontag's well-known analysis of *Illness as Metaphor* (1978) also accounts for the 'triumphal' dimension as constitutive of the construction of cancer. She fascinatingly demonstrates this point by reflecting on the association of the cancer personality with one of life's losers:

Napoleon, Ulysess S. Grant, Robert A. Taft, and Hubert Humphrey have had their cancer diagnosed as the reaction to political defeat and the curtailing of their ambitions. And the cancer deaths of those harder to describe as losers, like Freud and Wittgenstein, have been diagnosed as the gruesome penalty exacted for a lifetime of instinctual renunciation (ibid.: 48).

In the case of breast cancer, claims Potts (2000: 111), this triumphalism often takes the form of

a trajectory in which the heroine emerges richer for her experience, a 'better person', the kind of woman we are all supposed to be, who copes with whatever life throws at her.

While alternative kinds of narrative do emerge, for example such that explicitly state they do not want to speak of bravery and courage in fighting the disease, these voices are still contained, and even within these voices the notion of the courageous fighter is coming through 'the back door' in more implicit ways (ibid.).

One of the implications of a discourse governed by such notions is the almost complete exclusion of death from the discussion. It appears as if, in the culture of breast cancer, death is a taboo:

Why is there no room in this cult for some gracious acceptance of death, when the time comes, which it surely will, through cancer or other misfortune? (Ehrenreich, 8 December 2001: 1a).

Sharf's analysis (1997) of the online communication of a breast cancer mailing list bears out this observation:

...it seems clear to me that participants have decided to emphasize hope, tempered by realism, and to make this a colloquy about living with breast cancer, rather than dying from it
(Sharf, 1997: 73).

Another aspect tied in with the governance of hope of the discourse of breast cancer is the construction of the illness as a site of continuous change, rather than as a fixed, determined experience. That is to say: it is only by regarding the illness experience as constantly and dynamically changing, that hope and cheerfulness can have meaningful room in its representation. The Introduction to *Dr. Susan Love's Breast Book* (Love, 2000),¹¹ a breast cancer guide often referred to by patients as the 'bible of breast cancer', is a good demonstration of this idea:

The major theme of this third edition is that all of medicine and science, and especially the study of the breast, is a **work-in-progress** (Love, 2000: xvii, my emphasis).

Love's account, a primary text in the discourse of breast cancer, epitomises the dominant way in which the scene of breast cancer is portrayed in the public discourse: dynamic and ever-changing.¹² By the same token, a common metaphor used to describe one's experience with breast cancer (and cancer in general) is that of a 'journey' (e.g. McLellan, 1997). Implying movement and change rather than fixity and fatalism, the metaphor of a journey is underpinned by the motif of hope. The cover of a book which is a collection of women's accounts of their illness (Eckess, 1998) illustrates this point explicitly: on a background of the rainbow colours (conveying a cheerful message) appears the text '*Rainbow of Hope: Seventy Women and their Journey with Breast cancer*' (Appendix 3).

Military discourse and the language of warfare

War metaphors fit well the cancer society's goal of maintaining "optimism in the face of danger and threat"
(Lerner, 2001: 45).

Hand in glove with optimism and triumphalism goes the language of warfare and struggle. In the years after World War II, to motivate American women to participate in the effort of early detection of breast cancer, combat metaphors were used, linking the 'war' on breast cancer with recent American military triumph. For instance, the

cover of the Women's Field Army pamphlet showed a picture of a sword, titled as the 'Sword of Hope'. Even more obvious is the very choice to form a body of women volunteers, under the name of 'Women's Field Army'.

As evidenced by the 'war on poverty' and the 'war on drugs' (and more recently the 'war on terror'), Americans often characterise efforts to combat social problems in terms of battle. Hence, the Cancer Society's use of a war metaphor since its early days is hardly surprising (Lerner, 2001).

It is useful to digress for a moment to consider more closely this cultural (American) dimension, which emerges as an implicit thread in the discourse of breast cancer. Although the ideology of self-help and the language of war are not exclusive to the American cultural milieu, the historical and cultural context in which breast cancer emerged is significantly American. While other western countries had established cancer control by the 1930s, the emphasis on mobilising the public against the cancer nemesis was most pronounced in the United States, with its rich historical legacy of citizens forming interest groups in order to promote social reform. Anti-cancer organisations outside the United States (e.g. England's Imperial Cancer Research Institute) tended to focus more on promoting research than waging a war of propaganda against the disease. 'Europeans' stated the director of the American Society for Control of Cancer in 1939, 'have toward the cancer problem a much more patient, long-time attitude than we do in America' (cited in Lerner, 2001: 45).¹³

However, beyond the cultural specificity of the language of warfare used in the post-war years in the United States to promote awareness of breast cancer, in contemporary culture, the language of war is characteristic of the discourse of cancer in general. Sontag's seminal work (1978) provides a thoughtful analysis of the prevalence of warfare language in the construction of cancer in our culture. Cancer, argues Sontag, fills the role of an illness experienced as ruthless, secret invasion (ibid.:5). It is commonly described as a process in which the body is consumed (ibid.:10), 'invaded' by alien cells (ibid.:13), and 'with the patient's body considered to be under attack ('invasion'), the only treatment is counter-attack' (ibid.:63). So, both the disease and its treatment are described by military rhetoric. Treatment aims to 'kill' cancer cells and the fight against cancer often sounds like a colonial war (ibid.:65). Seale (2001)

too, in a recent account of the predominance of sporting language in news reports of cancer experience, reflects on the domination of military connotations in current representations of cancer.

The Feminist context¹⁴

The dominant representations of breast cancer have often linked the language of war specifically to women:

“It was a women’s war”, noted a WFA pamphlet, “because they have the patience, devotion, and the courage needed
(Lerner, 2001:46, citing a WFA pamphlet).

In fact, cancer in general has been seen historically as a ‘female disease’:

Women have long been taught that cancer is their special concern and that, indeed, to worry about cancer is their duty
(Reagan, 1997, cited in Lerner, 2001: 46).

The decision to designate women as ‘volunteer soldiers’ for the War Field Army in the 1930s did not necessarily have to do with the high prevalence of the disease,¹⁵ but with women being relegated to the private sphere of the home and their citizenship being tied into the production of other healthy citizens (their families, their communities, etc.) (Lerner, 2001: 46).¹⁶

Notwithstanding the explicit connection between women and breast cancer, breast cancer entered the public debate as part of the Women’s Health Movement only in the 1990s (Leopold, 1999: 190-191). This delayed response enabled breast cancer to exploit the feminist principles that early women’s health movements’ campaigns brought into the public arena and legitimised, namely: the idea that women have ‘the right to choose’, to determine the outcomes that might affect their own health (ibid.: 194).

So, the communication of issues such as abortion during the 1960s and the 1970s paved the way for breast cancer’s projection into public debate. The media coverage of women’s health related issues tended to focus on specific *personal stories* that were exceptional or sensational enough to be newsworthy (Leopold, 1999: 192). This pattern seems to have been ‘imported’ later to the representation of breast cancer,

although this time it exploited the advantage of technological innovations (such as national television news networks, and, currently, online communication), which were not available for early women's health movements' campaigns.

Breast cancer, the feminist context, and the centrality of narratives

Implicated in the feminist project of the Women's Health Movement in the 1970s and 1980s to expose the 'socially constructed and punishable shamefulness of all aspects of female embodiment' (Potts, 2000: 99) is the pivotal role personal narratives of breast cancer have in the social construction of the illness. This feminist tenet of 'consciousness raising', emphasising women's connectivity and solidarity, required discursive forms that would enable the exercise of shared meanings and experience. One of these forms was women's personal stories of their illness (the diary style being the most favoured form for these stories), which ideally served this purpose: personal insights gave new meanings to what had previously seemed to be isolated and discrete, allowing the emergence of a sense of sisterhood between women (ibid.).

Other discursive forms were more informational in character, and were published as pamphlets, leaflets, reports or books, often by official bodies (for example, as mentioned earlier, the pamphlet of the American Cancer Society for the Control of Cancer). A more recent example of such informational texts is *Dr. Susan Love's Breast Book* (Love, 2000), which was mentioned earlier. It is a highly detailed guide, which informs patients, their caregivers, and women in general about different aspects of breast cancer and its treatment. The book is a key source in the discursive terrain of breast cancer, whose contribution to the awareness-raising of the illness has been invaluable (to judge merely by the numerous times it was mentioned in patients' and critics' accounts I came across, both online and in my face-to-face interviews). Clearly, it constitutes a very different discursive form than that of narrative. So while the emphasis in this chapter is on the centrality and significance of narrated forms for the feminist project of fighting the disease, it should be seen in the wider context, in which different non-narrative forms are at play, working towards that goal. Personal narratives did not gain their recognition and legitimacy in a vacuum. Rather, it is precisely because other kinds of expression, information and meanings were increasingly communicated, that the acceptance of personal illness stories into the public domain was fostered.

This growing recognition of the illness and the significance of its communication in the public realm are manifested, among other things, in the emphasis on patients' writing. Often this activity is interlaced with the feminist project of patients' bonding and camaraderie. As Potts (2000) observes, writers of their personal accounts of breast cancer often describe their search for other women who had had breast cancer and who could help them in their own understanding of the illness. Furthermore, breast cancer authors tend to depict their stories as gifts to their readers and to construct themselves as guides (ibid.: 100-101).

The notion of writing appears to be a central thread running also through Love's (2000) account of the politics of breast cancer. After describing the pivotal role of Rose Kushner's book *Why Me?*, Love recounts a project which was carried out in 1991 by the National Breast Cancer Coalition, under the title: 'Do the Write Thing' (ibid.: 592). The idea of the project was to collect 175,000 letters from women from all over the US, representing the 175,000 women who would be diagnosed with breast cancer that year, and to deliver those letters to Washington.

Over the last decade, numerous personal accounts of the experience of breast cancer have been published, many by women who previously would not have identified themselves as writers (Potts, 2000: 98). Recently, the online space has become a significant location for the production and circulation of such texts. (Having said that, as we can see in the previous paragraph, writing does not necessarily have to do with personal narratives, but can relate to other discursive forms such as letters).

To fully get to grips with the central role narratives and storytelling seem to play in the construction of meanings of cancer and breast cancer in particular, the discussion has to be complemented by the centrality of narrating and writing in the wider cultural context.

First, the notion of writing has been generally central in feminist discourse, underscoring the public and political significance of women writing their lives, 'taking the power of words, of representation, into their own hands' (Friedman, 1998: 40). Second, beyond the feminist agenda, contemporary culture is increasingly characterised by the flourishing of different culturally mediated forms of disclosure,

confession, and self-revelation. The act of writing is often seen (particularly in relation to chronic illness) as a crucial affirmation of living, a statement against fearfulness, invisibility, and silence (Lorde, 1980: 61) and as a way to give meaning against the meaninglessness of the disease experience (Acker, 1997).

True, writing does not equal narrating. As has already been mentioned, it can produce various discursive forms that are clearly different from narratives, such as letters. It is not my intention to colour every aspect of breast cancer discourses with the notion of narrativity and suggest that no other important forms of discourse and communication exist. In different places throughout the chapter I showed how non-narrated structures and processes are equally at play, for instance, informational texts, promotional materials (campaigns etc.), and personal letters. My aim has been to provide a purposive rather than exhaustive account, focusing on narrativity as one of the important and interesting features that emerged in the communication of the disease into the public arena. In the remainder of the chapter, linking back to the different features that have been discussed in relation to the discourse of breast cancer, I try to shed further light on two questions: Why do personal narratives appear so prominent a form in the public communication of the disease? How do patients' personal narratives incorporate the abovementioned discursive features into their own representation of the illness' experience? My aim is twofold. First, to show that the specific cultural and discursive context of breast cancer as described thus far, to a large extent provided an appropriate (if not an ideal) platform for the emergence of narrative as the central discursive form of the disease. Second, I wish to indicate preliminary directions to thinking about the implications of the cultural context of the disease (particularly its emphasis on narrativity) for patients' CMC.

Coming out of the closet: Visibility through verbalisation and publication of personal accounts of breast cancer

Against what Lorde (1980: 64) calls the 'wipe-out of self in which women are constantly encouraged to take part', and especially against the silencing of their personal experience which held sway for so long, women with breast cancer are now encouraged to 'become visible to each other', as a way to 'translate the silence surrounding breast cancer into language and action against this scourge' (ibid.: 61, cited in Potts, 2000: 122-123). Writing personal accounts is often seen in this context

as a way to promote visibility, the authors acquiring authority through the process of writing and publication (Potts, 2000: 123). Furthermore, since the stories of most people who suffer from cancer have hardly any circulation – if they are heard at all – the act of publication bestows status in a very different way from other forms of public recognition (Stacey, 1997: 21). Arguably, online communication is one way to enable the popularisation of the capacity to publish personal stories. This idea is critically examined throughout Chapters Five to Seven, through focusing on the process of narration.

The 'double stranding' in breast cancer narratives: Personal and private/connective and collective

In her critical examination of key texts of breast cancer, Potts (2000: 102) shows how the *personal* experience of breast cancer is fundamentally constructed (and thus lived) within a historical frame of reference, as a *collective* experience, through a context of community. The location of personal experience in a social and collective context is closely tied in with the issue discussed before of the tension embedded in the history of breast cancer between the silenced and the sounded, the intimate and the public. As neatly captured by Potts (2000: 104):

...while the texts tell a *shared* story, breaking down the isolation of the women's experiences of breast cancer with an assertion of the connective and collective, they also assert the unique and *individualized* self.

In Chapter Seven I develop this aspect, showing how patients' act of narrating constitutes a site for the negotiation of the dual meaning of their illness.

Realising agency through the construction of linearity and chronology

The representation of the experience of breast cancer is commonly shaped by reference to several common and pivotal moments: discovery, diagnosis, decisions about treatment, confronting possible death and life after treatment (Potts, 2000: 114). This chronologically linear narrative is particularly typical of patients' personal accounts, and is clearly embedded within the wider discourse of agency, self-help and control. The capacity to construct a coherent linear story implies one's capacity to control and contain one's experience. Crucially, the starting point of a personal story

is commonly the author's discovery of a lump in her breast(s). That is, the personal story one produces replicates the implicit public message that one is responsible for one's illness and so one has consequently to look inwards for cure.

In Chapter Five, I explore the possibilities and challenges embodied in patients' construction of narratives online, focusing particularly on the issue of emplotment and the construction of closure, as a means of gaining control over one's experience and one's body.

Extending the language of warfare: Dissociation and displacement of cancer

Breast cancer is often depicted, whether in patients' personal narratives or in other modes of discourse (e.g. campaign texts, see example later in this section), as a central and separate protagonist (Potts, 2000: 115). Cancer appears to have a clear identity, and the text often establishes an epistemological opposition between the woman and the disease. Often there is an elevation of the disease to the status of an animated identity in the text (Potts, 2000; 116).

Although the language of warfare no longer necessarily dominates current discourse as it used to, the notion of a clear-cut separation between the cancer and the self is still implicit. This notion could be well recognised in *Avon Breast Cancer's* slogan in 2001, namely: 'Kiss Goodbye to Breast Cancer'. Depicted as something separate to one's body, that one can simply 'kiss goodbye' to, breast cancer, the 'alien', can easily be beaten and forgotten. The explicit, violent, military connotations might be more implicit and contained, but the triumphal discourse of cheerfulness and hope is constantly at work.

In the analytical chapters I will consider the implications of 'survivalism' and 'triumphalism' for patients' online communication. In particular, in what ways does online narrating (among other processes) enable patients to dissociate themselves from the illness and 'displace' cancer, as a way of coping and asserting themselves as cured?

Experiencing breast cancer as a site of change through construction of a dynamic subject

Central to the construction of the image of the self in relation to breast cancer is the idea that the subject who suffers from breast cancer is not fixed by the illness. Personal narratives are thus one way for the patient-author to insist that a 'woman with breast cancer' is not an ontologically discrete category, but rather is open to constant changes (Potts, 2000). This issue is highlighted in Chapter Five, where I suggest that the online context has communicative potential that allows an ongoing construction of one's self-narrative.

The privatisation of the illness in and through telling personal stories

Leopold critically contends that the rise of the self-healing movements of the 1980s and the 1990s is evident in personal breast cancer memoirs, 'in their almost ritualistic patterns of self-interrogation and sometimes self-incrimination' (1999: 255). On a more positive note, Potts (2000) discusses how authors' assertion of the 'I', commonly through the use of the First Person, is crucial to the political purpose of those texts. That is, says Potts, through those private 'I' stories, women with breast cancer position themselves as they understand themselves, in public. Even when they seek to locate themselves alongside other women with the disease and acknowledge the powerfulness of that shared identity, at the same time they recount the process of coming to a new personal identity (ibid.: 105). These concerns are discussed in relation to patients' online communication in Chapters Six and Seven: how is the tension between the private and the public negotiated through online storytelling? How can we account for patients' exchange of their stories online, in light of Leopold's view of the privatisation of breast cancer and the growing emphasis on self-interrogation? Needless to say, the process of narrating and storytelling is only a token in the broader context of patients' attempt to handle the tension between the private and the public, the latter being a central feature of the illness' experience.

What emerges from the account of the aforementioned aspects is the significance of narrativity and narrating for the construction of the cultural and social meanings of breast cancer. If the story of breast cancer in contemporary culture can be encapsulated by the metaphor of coming out of the closet to the commonplace, personal narrative as a discursive form, and narrating as a communicative process, are

key facilitators of this transition. Notwithstanding the centrality of narrativity in the existing discourse of the disease, however, its scope has been restricted insofar as the process of unveiling the disease remained highly mediated. As the historical account has shown, the projection of the illness into the public debate was primarily carried out by the mass media, the press and television serving as the main conduits. In other words, despite the increasing eminence in the media of personal stories of illness, and the subsequent emergence of the patient's voice as pivotal to the discourse of the disease, the framework that organised the patients' narratives and the production of those same narratives was still fairly institutionalised and mediated by others. It is with this insight in mind that I wish to explore the role of online communication in relation to the significance of narratives and narrating for the experience of breast cancer and its meanings in the twenty-first century.

The intention of this chapter has been to identify the underlying cultural ideas and meanings of breast cancer, in order to understand how they frame and shape (as well as are shaped by) patients' online experience of communicating this illness, particularly their engagement in online narrating. Shedding light on the cultural discursive context of breast cancer is essential for understanding the significance and the consequences of online experience for women who suffer from the disease in the twenty-first century. However, far from exhausting the characteristics of the cultural and discursive context of breast cancer, the discussion presented in this chapter has attempted to highlight one element, namely narrativity, and demonstrate its centrality in the construction of the meanings of the illness. This purposeful discussion provides the basis upon which the issue of narrating will be explored in later chapters in the context of breast cancer patients' online communication.

Given the historical context of the silencing of breast cancer and its very recent unveiling, the question of the roles played by patients' communication of the disease and their participation in telling their stories seems ever more salient. For many decades, breast cancer patients had no infrastructure to communicate their illness. It is therefore highly significant to ask the following questions. What kind of communicative infrastructure does the online environment furnish to patients today? What makes the online environment so attractive to them? Why does the online communication fit so well with the existing discursive features of the disease? What

kind of discursive space do the processes of narrating and storytelling constitute for patients to communicate their experiences? What are the specificity and the significance of this emerging space?

It is these questions that I wish to address in analysing the accounts of breast cancer patients of their online experience and in examining texts of breast cancer websites. The issues touched upon in this chapter regarding the discursive construction of the illness will be a secondary, but nonetheless significant thread woven into the analysis of the dimensions of patients' online narrating, presented in the chapters that follow.

¹ Within the limited scope of this discussion, the issue of the status of the breast in contemporary culture will not be developed. For a fascinating account of the breast and its cultural meanings, see Yalom (1997).

² The discussion of this chapter may seem too heavily dependent on Leopold's account *A Darker Ribbon* (1999). However, among the very few social and cultural critiques that exist on breast cancer, Leopold's seems highly salient to the purpose of our discussion, hence its predominance.

³ Similarly, breast cancer as a subject has been separated from the mainstream literature of history and sociology. This thesis joins the endeavour of critics such as Leopold and others, to reincorporate a critical discussion of the social and cultural aspects of the disease into a sociological analysis.

⁴ In the UK, for example, a well-known euphemism for cancer is 'The Big C' (Saywell et. al., 2000: 39).

⁵ This text was taken from the WFA's official documents, cited in Lerner (2001). I discuss later the significance of the language of warfare and militarism in the discourse of the disease.

⁶ In *Why me?* (1977) Kushner argued passionately that it was important for the woman to have her biopsy, learn if she had cancer, and if she did, decide what avenue to pursue (Love, 2000: 590).

⁷ Each of these notions has, of course, its specific meanings and implications, and I do not mean to discount the crucial differences between them and the approaches they represent. However, what all these notions enlighten, is the idea that contemporary everyday life has been increasingly patterned by techniques of self-management and self-steering.

⁸ This was the slogan of the campaign of the American Society for the Control of Cancer (Leopold, 1999: 12).

⁹ Termed By Becker (1967), in Fosket (2000: 24).

¹⁰ Philips and Rakusen (1989).

¹¹ Indeed, Love's book was mentioned by almost all of my interviewees.

¹² Communications technologies would presumably play a central role in enabling this 'work-in-progress' of the meanings of breast cancer. One can already think about the role the Internet could potentially play in this scene, for immediacy is one of its clearest characteristics.

¹³ The cultural (American) aspect has significant implications for the topic of this research and will be reflected upon in the concluding chapter.

¹⁴ Breast cancer has been claimed as a feminist issue in different ways. For a collection of essays on feminist perspectives of breast cancer see Potts (2000).

¹⁵ During the nineteenth century women supposedly accounted for three-fifths of all cancer cases (Lerner, 2001: 46).

¹⁶ The recent figure on women being the main seekers of health information online is consistent with this construction. Women appear to go online not only for their own health-related issues, but also as caregivers (for family members and friends) (Pew Internet & American Life, 2002b).

Chapter Three

Methodology and Methods:

A Phenomenological Approach to the Internet and to Breast Cancer, and its Implications

This chapter provides a detailed introduction to the empirical design of the study. It seeks to be both descriptive and critical regarding the methodology and the methods employed in the present research. It starts with an account of the phenomenological approach to the study of Internet use taken in this study. This introductory account offers a critique of approaches that seem to have overwhelmed the Internet research field so far, as well as reflects on the appropriateness and salience of the methodology employed in this study. In discussing the implications of a phenomenological approach for the study of online contexts, the discussion focuses on the need to break down the online/offline distinction, both conceptually and methodologically. The chapter then moves on to a detailed presentation of the empirical and methodological framework that was designed in line with the study's goals and theoretical concerns. This part concerns the first steps of the empirical process, namely: getting to know the environment of the experience, defining the relevant social group, and gaining access to its members. Crucially, all these methodological aspects were initiated and pursued online. The discussion then reflects on the need to bring the ethnographic context into the empirical enquiry. The latter implies the second key stage of the empirical process, that is, moving the research from online to offline. The section that follows traces the main methodological issues considered in the move to the offline context, and the limitations of this design: the decision to conduct face-to-face interviews, the particular type of interview chosen, the interview topic guide, the recruitment of interviewees, and specific aspects related to the procedure of conducting the interviews. Next, I include some reflexive notes about the move from online to offline, stressing the conceptual turns made necessary by this shift. Finally, matters concerning the data analysis are discussed briefly, focusing on the notion of narratives as methodological artefacts to be analysed. The remainder of the chapter presents the key ethical considerations of the research.

Phenomenological approach

As stated earlier, the aim of this study is to examine the Internet as a social and cultural process in the experience of women with breast cancer while at the same time understand the experience of breast cancer as being shaped by processes of online communication. The theoretical concerns that stem from this goal, and which were presented in previous chapters, are closely coupled with a phenomenological approach. By attending to how participants perceive their activity, and what *meanings* emerge around their online *experience*, it is possible to develop a framework that accounts for the role the Internet plays in the management of those patients' lives. Furthermore, enquiring into the ways in which social meanings are bedded down in participants' forms of experience is the key to foreclosing the reification of notions such as 'CMC' or 'the Internet'.

In taking a phenomenological approach to the experience of online communication, I follow Rojek in his criticism¹ of the 'gladiatorial paradigm' by which experience "...is 'read off' from a person's sex, race, age, income level, regional location and so forth..." (Rojek, 1995: 102, cited in Bull, 2000: 11). Notably, in much of the work on Internet use and CMC, especially studies of patients' online communication in the context of illness (and even more particularly the few done in relation to breast cancer), the online experience is often explained by the kind of analytical practices described by Rojek. For instance, in accounting for patients' participation in computer mediated support groups of women with breast cancer over the Comprehensive Health Enhancement Support System ('CHESS'), Shaw's (2000) main concern is with the prediction of the volume of 'insightful disclosure' of participants, using variables such as age, race, income etc. This is indicative of a broader analytical preoccupation, especially within American-based Internet research, with establishing 'Internet user typologies' based on whether demographic variables or experiential variables, a tendency fuelled particularly by the 'digital divide' debate (e.g. Howard et. al., 2001; Nie and Erbring, 2000; Hoffman et. al., 2001; Anderson and Tracey, 2002; Shaw et. al. 2000).

Although many of these studies associate themselves, explicitly or otherwise, with a phenomenological approach (e.g. Shaw et. al. 2000; Anderson and Tracey, 2002), in focusing on the characterisation of Internet use and CMC along rigid typologies, they

assume experience as a given category, falling short of taking into account its multi-faceted character. What is more, since many of those studies aim at producing answers to *why* questions, they overlook questions of *how*: that is, the actual processes that constitute the online experience (the latter being the primary concern of phenomenologists).² Fundamentally, those thematic and analytical foci have specific methodological implications. For one, in this kind of study (which is mainly US-based) surveys are often employed as the main method of researching the experience of Internet use and CMC (the work of Pew Internet & American Life project is probably the most prominent in this context).³

Phenomenological methodology and its implications for the study of online contexts

This study suggests a rather different version of an empirically oriented phenomenology: one with a mind to the need for a methodology that can encompass the way participants perceive and construct their experience of online participation in relation to their illness, and that would sensitively capture the contradictory and many sided nature of this experience. Such an approach is implicated in a commitment to relate the phenomenon that is being studied (herein: 'breast cancer online') to wider contexts, avoiding notions such as 'virtuality' or 'cyberspace' which involve a methodological presumption that the Internet inherently comprises 'virtual relationships' and can therefore be treated as a self-contained and autonomous setting (Miller and Slater, in press).

Those methodological foci go hand in hand with the wider theoretical concern, with which this research is highly sympathetic, with the inextricable relationship between the online and the offline, and with the attempt to break down the lines between the online and the offline. These lines, as Slater (2002) observes, are drawn '...as much by methodology as by theory, politics and culture' (540).⁴

So, breaking down the online/offline distinction cannot be pursued only in theory; it is a project substantially implicated in methodology. If we are to understand participants' online context, we have to have knowledge of their offline contexts – that is, of their everyday lives, and, in this particular case, their experience of breast cancer. The opposite is also fundamental: to make sense of patient-participants'

experience of breast cancer, we need to get to grips with their online engagement as a significant part of their experience of coping with their illness. The ability to access offline environments provides particularly useful insight into the connections between online and offline interaction (Kendall, in Jones 1999). As stated in Chapter One, the concern with participants' online/offline connections is closely tied in with the conceptual foundations of this thesis, namely narrating and agency. *Theoretically* patients' engagement in the act of narrating online, is perceived as inextricably connected to the constitution of their agency, hence the significance of *methodologically* gaining access to both their online and offline environments and to the connections (or disconnections) between the two.

Following from this is the necessity of 'capturing both sides of the screen', as Bakardjieva and Smith (2001) have it, i.e. of combining onscreen and offscreen methods. In employing both online and offline methods, this study positions itself in contrast to the tendency to rely merely on 'virtual methodologies' (studying Internet-based phenomena through methodologies implemented by and through the Internet), a tendency that seems to have overwhelmed the Internet research field since its early days (ibid.).

Employing both online and offline methods of studying Internet users means that the researcher is engaged in both online and offline interactions with her informants. Thus her experience becomes an inevitable part of the story that is being told: the empirical process itself, and the particular relationships that emerge between the researcher and her informants (both online and offline), entail substantial meanings that are inextricably related to the actual phenomenon being studied.

For instance, as I reflect on later in this chapter, the online interaction of participants with me as a researcher, reveals much about what influences their willingness to disclose their personal experience (e.g. anonymity) in the general online context of breast cancer. The latter point implies, of course, a constant effort to be sensitive to, and highly reflexive of, my own research experience, and to consequently allow meaningful room for what emerged from my own experience when accounting for patients' experience of the Internet.

This reflexive aspect is tied in with the way the research employs narrating as a methodological strategy. As was discussed in Chapter One, the interactions between the researcher and the participants (which were carried out both via e-mail and face-to-face) are themselves considered as sites where patients engage in the actual phenomenon that is being studied, i.e. narrating and storytelling. So beyond a mere tool of yielding participants' personal accounts, the actual research interactions with the participants are treated as part of the data, that is, as sites of narrating and storytelling.

The following section presents in detail the empirical and methodological framework that emerged from what has been discussed so far, and was designed to support the goals of the research.

Point of departure: The online space

Getting to know the environment of the experience

Over a period of three years, I followed different breast cancer online forms and activities. This included participating in breast cancer online message boards (albeit mostly by lurking), reading patients' personal online diaries, participating in breast cancer chats, browsing through informative sections in different breast cancer websites, and maintaining long-term e-mail correspondence with patient-users.

However, a neutral observer of breast-cancer websites would find it difficult to completely make sense of what goes on there. What motivates patients to go on-line in relation to their health condition in the first place? What causes them to actively participate, for instance, to disclose their experience on breast cancer message boards? When do they go online, and how does the specific timing of use relate to the stages of their illness? What do they do with the information they find online? Merely observing messages and logs on breast-cancer websites cannot provide satisfactory answers to this kind of questions. It is limited in its capacity to reveal the more complex story that lies behind these online appearances. For one, since the language of computer-mediated communications is intended for people directly involved in interaction, it tends to lose part of its sense and meaning when re-read later by *neutral* observers (Reid, 1995, in Paccagnella, 1997).

Hence, although this 'loose' participant observation of different online breast cancer spaces was absolutely necessary as a point of departure (and it was significant to maintain it on a continuous basis as the research progressed), it was obviously insufficient on its own. There remained the need to obtain participants' constructions of their online experience. To do so, the first step was to define the relevant social group of the study and then gain access to its members.

Defining the relevant social group: Who should be studied?

The relevant social group of this study, by which I mean 'the actors that participate in the negotiations or controversies around a specific technology' (Bijker. et. al., 1987) is women who suffer/ed from breast cancer and experienced the Internet in the context of their illness. Although breast cancer also affects men this thesis focuses exclusively on the online experience of female cancer patients. Given the association of the female breast, and therefore mastectomy and its consequences, with sexuality, femininity, intimacy and motherhood, a focus on women is essential to this story (Lerner, 2001).⁵ What is more, empirically women constitute the majority of participants in breast cancer related online forms.

Focusing on this group inevitably involved the exclusion of other groups as well, e.g. women who do not have access to the medium, women who failed, for different reasons, to use it in the context of their illness etc. However, women who have breast cancer but did not go online in the context of their illness were irrelevant insofar as they do not enlighten the concern of this study.

Gaining access to participants' lives: The online space as a point of departure

Given that the key factor in the definition of the relevant social group was the subject's online experience, the online space was the place where informants were initially recruited. In order to obtain participants' constructions of their experience, I posted messages on online breast cancer message boards on health-related websites,⁶ expressing my interest in women who would agree to share with me their experience of using the Internet in the context of their illness (See Appendix 4). In addition, I directly e-mailed women who provided their e-mail addresses with the message they posted on those boards. I repeated this procedure twice: I first posted messages on different breast cancer online forms and e-mailed online participants directly during

December 1999-January 2000,⁷ and then did a similar round of message posting during June-July 2001.

In the message that was published on message boards or sent directly, I requested women to share with me their experience of Internet use in relation to their illness. More specifically, I provided several general questions to which they might have wanted to refer in their account:⁸

1. When did you first use the Internet?
2. What made you turn to the Internet in the first place?
3. What made you turn to the Internet for your health problem?
4. What did you expect to find on the Internet?
5. What information did you get from the Internet about your health problem and where did you find it?
6. At which points/stages and for how long did you use the Internet?
7. Did you get any information from the web that you did not get from your doctor?
8. Did you feel that the information that you got from the web was trustworthy?
9. Supposing there was no Internet, what are the things that you would miss the most in the context of your medical problem?

Following the notes I posted and the personal e-mails I sent, I received in total eighty-three replies. I believe that my receiving so many replies largely owes itself to elements such as availability, degree of anonymity, high control of one's participation in the online interaction, as well as feeling at ease with the medium – similar factors arguably motivated these women to participate online in the context of their illness. In particular, many scholars suggest that anonymity provided by electronic communication encourages the extent of self-disclosure and the degree of intimacy (Rheingold, 1994; Jones, 1998; Sharf, 1997). However, as I discuss later in the thesis, in the case of the patients studied here, anonymity seems to take quite a different meaning from that of a capacity to invent personas and disguise one's real identity.

All replies were sent to me by e-mail (with the exception of one woman who sent her account via snail mail, narrative 3). In some cases I re-contacted women who initially replied and asked them to elaborate their account. Remarkably, most of the accounts were constructed as stories: rather than answering the guideline-questions in a

question-and-answer format, or providing a brief informative report, most e-mails consisted of a fairly elaborated account, telling the *story* of their online experience following the diagnosis with breast cancer.⁹ They were often long accounts constructed as narratives: a constellation of events, embedded in time and space, constituted by causal configuration of the different events into a whole, directing them toward a conclusion (based on the definitions of Somers, 1994 and Polkinghorne, 1991, see Chapter One). Take, for example, the following e-mail account:

Exposition
the cause of the
events to come).

{ I received my diagnosis (over the phone) on a Friday afternoon.
By 5 PM I was online, searching for all the info I could find.

I am computer literate and comfortable surfing the web. It was comforting to know that I could look up whatever I wanted and do it in my PJs at 3 AM if I felt like it. I expected to find a lot on the web, what I did find and was not expecting was a HUGE group of breast cancer patients and survivors who became great sources of information and some became permanent friends. I started by typing BREAST CANCER into my search engine - and it just took off from there.

There are medical links, chat rooms, message boards, you name it - you can find it! Tons of information you get from other women who have dealt with BC is different from what the doctor tells you. He tells you what the treatment should do, lists the possible sideeffects, recommends medications to combat the side effects, etc. The ladies have BEEN THERE, DONE THAT - they give you an honest accounting of how it happens, what it feels like, what side effects are and how to handle them.

Medical information I printed out and discussed with my doctor if I thought article was valid. I did NOT follow any medical regime without discussing with my doctors first. All the info from the BC ladies is their personal account of how they felt or dealt with BC and its treatments. Once in a while they would suggest something that I felt I had to ask my doctor about. (Example: BC warrior ladies tell you to shave your head at first sign of going bald - they say it is less itchy that way) Nothing I had to confirm with my drs. Some recommended soy. Checked some articles on the Web and soy and phyto-estrogens are controversial, so I checked with my doctor and then made my decision.

I did find a ton of information at the local public library. The difference between the library and web - library - I have to wait till they are open; they do not always have the book you want; I have to be presentable in public to go there.

{ There is a ton of info on the web - there are also many quacks out there - just like in life, you have to decide what is real, what's valid and what has value FOR YOU PERSONALLY. I have continued in my support groups on line and now help other newly diagnosed women. The internet is one of the greatest resources of our times.

Constellation
of events,
embedded,
however
loosely, in time
and space.

Conclusion

(Online narrative 2).

Receiving participants' e-mail replies in the form of a story was a significant factor leading to the decision to focus on narrating as a significant process in patients' online communication. Clearly, it was in accordance with the prominence of this discursive form on breast cancer related online forums such as message boards and personal

homepages. While the breast cancer online environment is characterised by diverse communicative forms and processes, of which narrative and narrating are only one, in the context of this study and its research experience, narrating appeared as the most central of patients' communicative processes, and thus worthy of exploration.

I chose twenty nine accounts that were rich enough in both length and content for analysis purposes (see Appendix 5). In the analysis, I refer to those accounts as 'online narratives' (to distinguish from the narratives I later obtained via face-to-face interviews). Those accounts constitute the preliminary data of the research as they provide an initial access to patient-participants' constructions of their experience of online participation in relation to their illness (breast cancer).

Of course, the data collected at this stage, which constitutes the basis for the next stage of the empirical research, suffers from a self-selection bias: for different reasons, many women do not have the capacity to reply and provide personal accounts. Of those who replied, generally speaking, these were mostly 'successful stories': i.e. women who (1) have access to the Internet; (2) are computer literate; (3) had a positive experience with using the Internet in the context of their illness. Indeed, there is an inherent bias within this research: it is about people who engaged with the Internet positively, whereas other groups such as those who do not have access to, or competence of CMC, or those who did not get the support they needed via CMC, are inevitably excluded. One of my interviewees, whom I recruited via face-to-face snowballing rather than through online communication, implied as much when she said: 'You would have never found *me* online'. Meaning that, given her critical perception of the breast cancer online landscape, and her not necessarily positive experience with this communicative context, she would not have participated in related message boards, nor replied to my online request for women who are willing to participate in the study.

However, while the study might be criticised for this bias and its implications in terms of lacking a representative sample,¹⁰ the absence of negative accounts (e.g. cases of patients who failed to use the Internet for illness-related purposes) should be understood as a token of a broader picture of the online colloquy on breast cancer, and, more generally, of the public discourse of breast cancer, the latter being about

'living with breast cancer rather than dying from it' (Sharf, 1997: 73). As Sharf (1997: 78) rightly concludes: '...breast cancer talk on the Internet is a self-directed rhetoric of hope and enablement'.

By the same token, the sample of the respondents suffers also from a *cultural* bias: the majority of my respondents are from the US. Interestingly enough, while I did try to recruit women from the UK by posting messages on UK breast cancer websites, I found it fairly difficult. I hardly received any replies from UK sites, whereas when I posted messages on .com/.org websites – generally considered to be US websites – I received many, and very prompt, replies.

While this bias challenges the idea of the Internet as a truly global medium that crosses national boundaries, it is actually indicative of the phenomenon of breast cancer online, the latter being clearly dominated by US websites and fundamentally by a North American discourse. What is more, in terms of the cultural dimension of the actual online communication, there seem to be significant differences in the patterns of communication, the content, the style, the format, and the discourse that are typical of US breast cancer websites and of UK breast cancer websites.

The methodology employed in this study is thus significantly informed by the specificity of participants' cultural location, which facilitated their online recruitment and their collaboration in being interviewed first online and then offline. Indeed, the methodology itself could be regarded as culturally specific. It is located in a prominently North American cultural communicative space, implicated in the online colloquy which is governed by the American English language, and in the discourse of breast cancer, which is in itself significantly framed within the US-American culture (as discussed in Chapter Two). The way in which I approached participants and the manner in which I pursued and managed the communication with them thereafter, was profoundly informed by my knowledge of their cultural background. Respondents' generally informal style, and particularly the friendliness, openness and ease with which they very quickly disclosed their intimate experience, owe themselves, to a large extent, to their US-American cultural context.¹¹ Given that, the procedure of enquiring into the specific issues in which I was interested ran fairly smoothly. Most importantly, it is these aspects of participants' discourse and style of communication (being culturally specific) that allowed me to ask respondents, with

little difficulty, to move from online to offline, i.e. to meet me for a face-to-face interview after we had corresponded online for a time. And it is the 'American factor' that can largely explain most of the participants' agreement (and even eagerness in some cases) to elaborate their personal stories in a face-to-face meeting with me.

The 'Interview society' (Silverman, 1993) is first and foremost American: most of my respondents appeared fairly experienced in the practice of being interviewed, and more specifically in telling a story. In a more substantial sense, then, the US-American specificity of the methodology is highly pertinent in understanding the focus of this thesis on narrating and storytelling, and the employment of narrative as a methodological artefact. I come back to this issue in the concluding chapter.

To summarise, the Internet is not an undifferentiated space outside of 'real' space; equally, the methodology used to investigate Internet space is not 'placeless', but rather has social and cultural borders.

Bringing in the ethnographic context: Moving from online to offline

So, the empirical process started in the online space: obtaining participants' constructions of their experience of online participation was carried out completely by and through the Internet. However,

Obtaining information about someone's off-line life through on-line means of communications [...] is always a hazardous, uncertain procedure, not simply because of the risk of being deliberately deceived but also because in such cases the medium itself increases the lack of *ethnographic context* (Paccagnella, 1997:4).¹²

The need for ethnographic context, tied in with a phenomenological approach, implied the *methodological* need to extend the research into offline context and to obtain offline accounts of participants' online experience. More specifically, given the theoretical focus on patients' online narrating as a key site where they constitute themselves as agents, it appeared necessary to methodologically yield insights into their offline contexts. How do the online experience of narrating, and the narratives patients produce (or seek to produce) online, connect (or not) to their offline realities? One way to address this question could have been to conduct an ethnographic study

which would have involved an observation of patients' everyday lives. Underlying this approach is the claim that without ethnographic material it is impossible to claim for connections between the stories women tell online and their offline realities. Put more crudely, without ethnographic evidence we cannot claim for the significance of what is going on online for the way patients' manage their illness. For one, numerous studies have documented how people's construction of their fictive selves online is disconnected from their offline selves and their sense of agency (e.g. Stone, 1995; Turkle, 1996).

I fully recognise the merit of this ethnographic approach. At the same time, to look for ethnographic material of patients' reality 'out there', 'outside' storytelling, seems inconsistent with the notion of narrating to which this study adheres. Theoretically, narrating and agency are seen as mutually implicated, and the very act of narrating is understood in this thesis as transforming the narrator. Action is assumed as embedded within thought and discourse, rather than occurring in a separate 'everyday' realm. Therefore, to methodologically go and look for 'evidence' of agency outside the realm of storytelling, seems to imply the opposite: that 'narrating' and 'agency' are essentially separated; that storytelling happens in one place, and agency can be affected or not by it, in a different life context.

What is more, to try and obtain ethnographic data from patients' daily lives is highly problematic from a reflexive, feminist ethical standpoint, to which the current study subscribes. The reality of these patients is not simply 'out there', at my disposal (the researcher), for interpretation. Even the use of online interactions is not unproblematic, as I discuss in the end of this chapter, let alone using elements from their day-to-day interaction. Hypothetically, to examine whether and how the stories patients tell online connect to their 'offline' lives would mean following them in their everyday contexts, in sites such as their homes, with friends, their medical encounters and their face-to-face support groups. Observing participants in this manner appeared highly inappropriate, insensitive and impractical in the context of this study, which involves an experience that is extremely intimate and sensitive.

Thus, to take a methodological approach in accordance with the way the thesis conceives narrating, while maintaining a reflexive ethical stance, it seemed most

appropriate to rely on the accounts patients produce (in the research situation, by e-mail and face-to-face interviews, and in online interaction – to each other) as data. Geared towards mapping and understanding the respondents' life world frameworks, and more specifically the relation between their action (online participation) and their situation (chronic illness), the main offscreen method employed in this study was *qualitative interviewing*.¹³

Face-to-face interviews with participants

In contrast to the 'gladiatorial paradigm' mentioned earlier, and underlying a qualitative interviewing methodology, is the assumption that the social world is not an unproblematic given: it is actively constructed by people in their everyday life (Bauer and Gaskell, 2000: 38). The interviewee has a 'subjective theory': a stock of explicit and implicit knowledge about the topic (Scheele and Groeben, 1988, in Flick, 1998: 82). The interview constitutes the methodological tool for yielding insight into that knowledge; it supports the interviewee in articulating her knowledge.

Type of interview

The individualistic character of patients' Internet use and online participation, espoused with the private nature of the illness experience, led to the decision to conduct individual interviews, rather than, for example, focus groups. Embedded within a phenomenological approach, the research style of this study moves towards the interpretative. Thus, the face-to-face interviews were designed as open in-depth interviews, semi-structured (leaning to unstructured), using only the most general of guides in a highly interactive fashion, in order to help the interviewee construct a sense of her experience. On a continuum of interview forms, the interviews conducted in this study followed the lines of what Plummer (2001: 141) describes as the 'Interpretative pole': they were flexible and shaped by checklist of general themes and questions rather than standardised through a questionnaire; they were idiographic, designed to use for fewer people; they were open, allowing the interviewer to follow her 'hunches', rather than focused and leading to planned answers. The interviews were designed to create a situation where patients are invited to construct and recount their story. In this sense, as discussed in Chapter One, narrating was employed as a methodological strategy. That is, beyond a methodological means to elicit data (patients' accounts), the interview situation itself constituted part of the data; it

provided a site where patients engage in storytelling. As such, the interview situation itself becomes part of the actual phenomenon being studied.

Hand in glove with this kind of interview, is an emphasis on the reflexivity of both the interviewee and the interviewer. Such qualitative interviewing forces the interviewee to reflect on her experience and her implicit knowledge. It is geared towards gaining a social understanding of implicit knowledge through the interviewee's explicit voice. The researcher, on her part, is also called on for reflexivity: since the interview is treated as a site of storytelling, and narrating a methodological strategy, the research experience becomes part of the data that is being analysed; so the empirical process itself, and the particular relationship that emerges between the researcher (the listener) and her informant (the narrator), enlighten in significant ways the actual phenomenon being studied.

The interview topic guide

The interview was designed in light of the research questions, exploring the different aspects of *why* and *how* women with breast cancer use the Internet and participate in online activities in relation to their illness. It particularly attempted to 'fill in' the gaps that emerge from the online written accounts, in order to provide an adequate understanding of participants' experience. Roughly speaking, the interview guide (see Appendix 6) was designed with the intention to touch upon the following themes: motivations for using the Internet in relation to the illness, expectations from the online experience, the actual uses made and the particular online forms used, time and temporalities of online participation, exchanging experience with other fellow-sufferers online,¹⁴ and the expression of one's experience of illness in writing on online forums. Each of these topic areas was introduced by an open question.

Recruiting interviewees: Who and how

The recruitment of the face-to-face interviewees was based on the initial contacts with online participants (i.e. women with whom I have been corresponding via e-mail). In June-July 2001, I contacted fifteen of the women who replied to my message and with most of whom I maintained correspondence since their first response to my request, asking if they would agree to meet me for a face-to-face interview to follow up their written story in greater depth (see Appendix 7). The particular women whom I

approached with a request for a face-to-face interview were selected according to three main criteria:

1. Women whose online accounts were rich enough in terms of the information they provided on the experience of Internet use. (Some respondents elaborated on the experience of their illness, but their account of Internet use in relation to their illness was not rich enough).
2. Women whose accounts demonstrated a reasonable capacity of expression in writing.
3. Women who lived within the area of New York State and its neighbour states. This was of course a convenience sampling consideration, given the time and budget limit of my fieldwork.

Needless to say, these are explicit biases of the sample, and hence the reader should keep them in mind as they qualify the data that is analysed later.

All fifteen women whom I approached replied to my note. Some of them expressed their agreement to be interviewed face-to-face immediately. Other were ambivalent at first, stating that they do not feel they have anything new to tell that they did not already tell in their online account. It was only after a few e-mails were exchanged that I managed to convince most of those who were initially ambivalent that a face-to-face interview would be extremely significant, even if they thought that all they could say would be a repetition of what they had written in their e-mail account. Eventually, of the fifteen to whom I referred, only one strictly refused to be interviewed face-to-face, explicitly saying (in her e-mail):

I am a bit leary of meeting people I've just met on the Internet. I would be willing to answer any further questions you may have online.¹⁵

It should be noted that the latter respondent was recruited on the second round and my request to interview her came after an exchange of only four e-mail messages.

The latter point raises an important distinction: as far as respondents' initial willingness to be interviewed is considered, there was a clear difference between women whom I have known from the first 'round' (December 1999-January 2000)

and with whom I have been corresponding (albeit not frequently) for a year and a half, and those whom I 'met' only following the second 'round' in June 2001, and whom I asked to meet me face-to-face after a relatively short period of e-mail correspondence.

Notably, all of the women who knew me from the first round of online recruitment expressed willingness to meet face-to-face, in most cases without a need to negotiate the issue at all. Their positive attitude and readiness to collaborate owes itself to a combination of several factors. Firstly, in September 2000 I sent all my first-round respondents a copy of my MSc thesis report, which was based on the analysis of their online accounts. This constituted a significant element in the establishment of trust: for them, it was a 'proof' that I fulfilled my part in our online contract, and kept my promise to send them the report once completed. What is more, seeing their personal experience being transposed into an academic context, produced, I think, a certain reassurance and, consequently, appreciation of my seriousness as a researcher of the issue. Secondly, the temporal dimension played a crucial role: the fact that I have been working on this project for a substantial period of time was, for them, an indicator of my genuine interest in the issue and my serious motivation to further develop the research by interviewing them face-to-face. Thirdly, some initial offline components were incorporated into our relationship already before the face-to-face meeting. First, the thesis report was sent as a hard copy via snail mail. Then, in response, some women sent me Christmas cards later in the year. In a sense, these two offline components enhanced the 'realness' of our relationship beyond its primary online setting.

Those recruited online on the second round with whom I did not establish a long-term relationship, were generally more suspicious of my intention to meet them and thus expressed ambivalence towards the possibility of being interviewed. This constituted a challenge that required me to establish rapport instantly, an endeavour that did not prove consistently successful.

Another bias embedded in recruiting interviewees from online spaces should be taken into account. While many online participants are only 'lurkers' who do not participate in interactive online activities such as posting messages on message boards, my initial access was limited only to those who *do* post messages on message boards (and

therefore are 'visible'). In order to overcome this bias, at a later stage of the face-to-face interviews, I recruited some interviewees also by snowballing. That is, initial contacts with women whom I met online (and particularly B', who constituted a key informant) were exploited in order to recruit their acquaintances as other interviewees who participated online but not necessarily in interactive forms. This enabled access to an appropriate range of participants engaged in different levels of involvement in different kinds of online activities and practices in relation to their illness. I will discuss the conceptual implications of this methodological aspect in the concluding chapter.

Conducting the interviews

Moving from an online relationship to offline interviews with the respondents has implications that are distinctive to this shift. However, the actual procedure of the face-to-face interviews primarily involved issues of the 'traditional' kind. I will discuss those aspects first. I will then reflect on some unique aspects that are implicated in the move from long-term online relationships with the informants (mainly through e-mail) to face-to-face interviews. Although this move from online to offline is a methodological issue, it had substantial implications for theory and concepts, and for their consequent analysis.

Interview: Aspects and challenges of the 'traditional' kind

As Jones (1999: 17-19) argues, the Internet is a form of 'personalised' mass media, hence we should focus not only on community but on individuals within social groups, while at the same time maintain the capacity to think beyond individual desire. Jones' assertion seems ever more relevant in the case of this study. Since the context at issue (breast cancer) is extremely personal and intimate, and since the experience discussed (that of online participation) takes place on an individual basis, it was only natural that the interviews would be carried out on a one-on-one basis.¹⁶ In total, I conducted twelve face-to-face interviews. Each interview lasted between one hour and a half and two hours.

The setting of the interview

All interviews took place at a location chosen by the interviewee. In most cases the meeting was in a public space such as a diner or a coffee shop; in other cases it was at

the interviewee's home. As Plummer (2001) observes, "...the more interpretative the interview, the better it may be to see the subject on their own 'turf'" (ibid.: 144). However, the 'principle' by which one feels at greater ease in one's own domain, (hence the desirability of having the interviews in the respondent's homes) seemed to work somewhat differently in this study. It seems to me that one reason why most women suggested the place of the interview to be *other* than their home, was because of the explicit connection between their home and their illness. That is, particularly since the topic of the interview was so personal, intimate and *private*, the interviewees needed a *public* space (yet, one that still offered some intimacy) to articulate their experience freely. Furthermore, it is my assumption that the choice of having the interview in a place out of the home is unconsciously driven by a need for a certain distance from the primary environment in which the experience took place. It arguably enhanced the interviewee's capacity for reflexivity. Another possible explanation why women preferred having the interview in a public place, rather than their homes, has to do with the issue of security. Although none of my interviewees expressed explicit suspicion of or distrust in my real identity and genuine intentions, there was the obvious fear that the person they had been corresponding with was not who she was claiming to be. After all, the fact is that the interview was the first time they met me face-to-face, after a relationship which was maintained, often entirely through e-mail.

The course of the interview

The interview started with introductory comments about the research, stating the interests of the research, speaking about myself, thanking the interviewee for agreeing to talk, and generally demonstrating as much reflexivity as possible. In particular, to create an open and unthreatening atmosphere, I explicitly stated at the beginning of the interview that I regard it as an open conversation, and that everything that is important to the interviewee was of interest for me. I believe the fact that I am a woman was also helpful in creating an open atmosphere and generating an initial level of trust. Informed consent for recording the interview was secured when setting the specific details of the interview via e-mail correspondence. All interviewees seemed quite at ease with the presence of the tape-recorder, a fact that can be explained by (1) their familiarity with similar situations [an aspect related to what is commonly referred to as the 'Interview Society' (Silverman, 1993)¹⁷]; (2) their advance

knowledge that the interview would be recorded, and the way I justified the need for tape recording as an *aide mémoire* for later analysis, emphasising the importance of what they have to say, and my will to concentrate on what they say rather than on taking notes; (3) the unobtrusiveness of the recording equipment due to small size of the mini-disc used.

Ad hoc decisions had to be made during the interview: whether a question had already been answered; when to enquire in greater detail and support the interviewee in roving further afield, or when to return to the interview guide when the interviewee digressed. These decisions require a high degree of sensitivity to the concrete course of the interview and the interviewee. In particular, since they tended to easily regress to discussing their illness rather than concentrating on the experience of using the Internet, I had to continuously turn their focus back to the Internet part. Concurrently, I remained wary of applying the interview guide too bureaucratically, especially since discussing the illness constituted the context in which their experience of Internet use is located. At times I felt as if I was not rigid enough in terms of focusing the interviewees on the aspect of the Internet experience. However, in retrospect, after transcribing the interviews, it seems that the decision to allow them to regress a little to discuss their illness was appropriate, particularly since this enabled them to disclose later significant information on their Internet use. More generally, as I hope to show in my analysis, it produced rich material that suggests interesting links between the experience of the illness and the online experience.

In general, I tried to be as empathetic and as good a listener as possible, stimulating the interviewee's motivation through the expression of interest, reducing any form of threat by providing support and giving confidence, and stimulating the memory of the respondent by providing probes to take them back further, particularly by linking to things that were raised in or omitted from the written online accounts (based on Plummer, 2001: 144-145).

Use of language

'Respondents may be fluent in the language of the interviewer, but there are different ways of saying things, and, indeed, certain things should not be said at all, linking language and cultural manifestations' (Fontana and Frey, in Denzin and Lincoln,

1998: 58). Indeed, a basic familiarity with the interviewee's argot was a prerequisite, particularly given the specific medical jargon with which patients become very familiar during the course of their illness and treatment. Despite the preparations I had made, there were still quite a few instances in which I was not familiar with the jargon the interviewee used. Decisions about whether to interrupt the interviewee and ask for clarifications during the interview were made *ad hoc*, according to how crucial it was to understand the specific term on the spot. In some cases, I checked the meaning of terms with which I was not clear only when transcribing the material.

In addition to the matter of the medical jargon, there were particular *cultural* linguistic forms of which I had to become knowledgeable. These were mainly the language and discourse of breast cancer, and, even more particularly, the distinctive features of the discourse of breast cancer online. For example the name 'BCANs' stands for a specific online message board (www.bcans.org); 'BC ladies' commonly refers to breast cancer patients who are regular participants on breast cancer interactive forms. Spending extensive time in breast cancer online forms was crucial in this respect and indeed equipped me with most of the necessary language to enable me to make sense of the interviews. Even then, there were several idiosyncratic linguistic forms that I learnt only during the face-to-face interviews themselves.

Beyond the methodological issue of language, the latter has, of course, obvious contextual significance for the understanding of the online experience and breast cancer. The different online spaces in which the experience of breast cancer is communicated, contain social and cultural sites where such meanings are produced, circulated, and consumed. This aspect will be elaborated later in the analysis of texts from interviews as well as breast cancer websites.

Going native

There exists the danger of 'going native' i.e. losing a neutral perspective in describing and analysing the data as a result of over emotional involvement. This concern is not exclusive to Internet research, however it seems ever more salient when the issue of the study is people's intimate experience such as going through breast cancer, and where the methodology employed involves personal contact between the researcher and the informants.

I tried to be as aware as possible of this risk, particularly by maintaining a consistently formal style in my correspondence with my respondents, even when they seemed to shift into a very friendly and open style and extended the content of their messages into personal matters other than breast cancer and Internet use.

From online to offline and back: Reflexive notes

The move from online to offline was extremely influential in determining the course of the interview. As has already been shown, the specific background within which the online relationship emerged defined in very significant ways whether the respondents initially agreed to be interviewed face-to-face or not. The way in which the relationship was established online also had important implications for the actual course of the interview.

Moving relationships from online to face-to-face generally proved to be a smooth transition.¹⁸ Needless to say, there were certain surprises. Especially after an extensive period of online contact, it was surprising to see the person whom I had imagined on the basis of the impression created through our online communication. However, these aspects were incidental and I do not wish to dwell on them, particularly as I do not think they provide any meaningful insight beyond the specific context of one individual or another. I do wish, however, to focus on the main implications of moving from online and offline, and the consequent implications for going back online, i.e. how the move from online to offline reflects back on the online phenomenon being studied.

The major turn that my research has taken, following the move from research online relationship to offline relationship, is recognition of the complexity of the relationship between the lives of the patients and their online experience. While from the very beginning of my research I was aware of the need to supplement the data obtained online with data that originates in participants' offline contexts, it was only after coming back from my field work, having done the face-to-face interviews with my informants, that I could see the full significance and contribution of the latter. In retrospect, I realise that, so long as I had access to participants' construction of their online experience only from their online (e-mail) accounts, my capacity to perceive

the relationship between patients' lives and their online experience was somewhat limited. The latter seemed fairly palpable and straightforward. The face-to-face interviews were invaluable insofar as they enlightened connections that remained obscure in the e-mail accounts, between patients' online and offline experiences.

In the following account I will show how the *methodological* shift from online to offline informed some *conceptual* turns that the research has taken.

Before

Generally speaking, the online accounts that emerged from my email correspondence with breast cancer patients (both those sent to me in relation to their experience of using the Internet, as well as the ones they post on websites about the experience of their illness), produce a somewhat limited understanding of the experience of Internet use. In the accounts sent to me, the patients constructed their relationship with the Internet in a fairly coherent way; they were constructed as narratives in which the author (patient) is the protagonist, and the Internet appears as a means at her disposal, enabling her to cope with the illness in different ways. While I never took a deterministic view of the relationship between the Internet and the participant, and although I was aware of the danger of reifying the Internet as a singular, undifferentiated technology, my perception of 'the Internet' was informed primarily by women's accounts, and the latter portrayed 'the Internet' in a fairly 'reifying' view: either in emancipatory ways, as 'a miracle', and 'dazzling', or in a reductive tone, as nothing but another source of information about cancer. In so doing, these accounts provide limited access to the complexity and the nuances of the relationship between patients' lives and their online experience.

After

While the online *written* accounts foregrounded the role of the Internet in patients' experience of coping with the illness quite explicitly and consciously, the face-to-face *oral* accounts referred to the online experience more implicitly. The face-to-face accounts were closer to what is often regarded as a 'project of the *self*' (Thompson, 1995): they were primarily stories about oneself, and so the online experience is embedded in the story, most of the time in implicit ways. In this respect, the meetings with the informants and their face-to-face accounts provided a much more complex and rich picture of the relationship between their lives and their online experience.

Shifting from online to offline and gaining access to a significantly different set of data, namely face-to-face accounts, implied the need for two key conceptual turns that the research's framework has since taken. The first is concerned with the shift from a notion of empowerment to that of agency, a shift that is closely linked to the kind of politics within which the research is framed. The second move regards the question of representativeness and suggests replacing the latter with a focus on the stories being told and their significance, rather than on the representativeness of the sample.

From empowerment to agency

To a large extent, as long as I had access only to data that derived from online sources (websites and women's e-mails), it was quite tempting to conceptually frame breast cancer patients' online experience as one of *empowerment*. Basing my view primarily on women's online accounts, and buying into common claims in the literature about patients' Internet use, the liberating potential of online participation seemed to frame the understanding of their experience: participants' online accounts maintained the focus on an external source ('the Internet') by which she (i.e. the patient) has been empowered. Some accounts even used the verb 'empower' explicitly in relation to their reflection of their Internet use. Such a view positions the research within utopian and even emancipatory politics, underscoring the online experience as essentially resistant, compensating for the lack of alternative sources in participants' lives. This aspect has not disappeared, of course, following the move from online to offline. Patients' interview accounts still maintain a strong, if not utopian, sense of agency. However, as the access to face-to-face accounts provides a more complex picture of patients' online experience, the politics within which the questions of research should be framed are more complex. This is not to say that the empirical data from the interviews are concerned much about negative experiences with the Internet. However the 'emancipatory' tone seems to be relatively more contained, and consequently it seems appropriate to replace concepts such as 'empowerment', 'resistance' and 'liberation', with notions that would account for a more nuanced experience, encapsulated in the concept of *agency*.¹⁹ True, although the interview accounts reveal a more complex picture than the one the e-mail accounts do, they are still limited in their capacity to reveal patients' sense of agency in offline contexts beyond the construction of their narratives. Clearly, in most of the cases, in both their e-mail and

face-to-face accounts, women present an inspiring, if not utopian, sense of themselves as agents who have control over their lives. Indeed, a central claim this thesis advocates is that it is through these narratives that women construct, such as the ones they told me as a researcher, that they constitute their sense of agency. At the same time, this pressure to present an inspiring sense of agency in their self-narratives – both online and offline – might have a problematic relationship to their realities, and to their actual capacity to realise this constructed agency. Relying merely on participants' accounts, as this study does, allows a limited view of the actual connections between patients' online and offline worlds. Having recognised this limitation, one should also understand the rationale behind designing a study whose core data is participants' constructions, and the reasons for rejecting ethnography as a methodological option (as explained earlier in this chapter).

From representativeness to clarity

The problem of representativeness and particularly of 'how many interviews are enough?' is familiar to any researcher who is engaged in a qualitative study. Following Plummer's discussion of this issue, (2001: 154) I suggest that, in the case of this study, the question of representativeness might be reconsidered. Rather than asking questions along the lines of: 'who do these women represent?' or 'do they constitute a representative sample?', the question may be simply put as: what do these *stories* actually represent?

While I cannot (and do not) claim that the interviewees that I chose constitute in any way a representative sample of a specific population, I do claim that they define a group whose voice is clear, definite and significant. Such an approach signals a move from a concern with *representativity* to *clarity* (Sennett, 2001). The unit of analysis is peoples' constructions – in this case, narratives – rather than the population they represent. In short, my intention is not to construct a representative account of breast cancer patient-users of the Internet, but rather to say something meaningful about how they experience online communication.

I wish to devote the remainder of this chapter to a brief discussion of matters related to the analysis of the data.

Narrating as a methodological strategy, narratives as methodological artefacts

In Chapter One, I discussed how the concept that underlies the research, of narrating as a site for the constitution of personal agency, implies the use of narrating also as a methodological approach. In short, the study employs a methodology that not only observes and analyses patients' engagement in the act of narrating online in existing sites (message boards, personal homepages etc.), but also creates situations in which patients are invited to recount their experiences, whether by e-mail, face-to-face (interviews), or both. True, in these methodological sites of expression (e-mail and face-to-face interviews) patients can recount their experience in various ways, narrating being merely one possibility among a diversity of modes of expression at their disposal. For instance, patients could have easily followed the structure of questions I provided them with in my recruitment message (see p. 88), and articulated themselves in question-and-answer format. However, interestingly enough, the majority of the accounts I received, following my invitation to participants to share their experience with me, were constructed as stories. By the same token, the transcriptions of the face-to-face interviews contain clear characteristics of a narrative, and, therefore, are treated as such.

In addition to the e-mail and face-to-face accounts which seemed to follow the structure of a narrative, a textual analysis of a few popular breast cancer websites has shown that narrative is a prominent discursive form among the diverse discursive forms in which patients communicate their illness and that participants often perceive what they post and read online as 'stories'. I have already discussed and demonstrated this point in Chapter One. What I wish to emphasise is that the decision to treat the data as narratives was not arbitrary or predisposed, but rather emergent from the research experience. This methodological choice was further endorsed by the extensive theoretical writing about the significance of narrating and narratives in coping with chronic illness (Bury, 1982; Williams, 1984; Kleinman, 1988; Becker, 1994; Frank, 1995; Hydén, 1997; Mattingly and Garro, 2000, see Chapter One), as well as by recent studies specifically on the centrality of narratives in patients' online communication (McLellan, 1997; Walstrom, 1999; Hardey, 2002; Eley, 2003, see Introduction).

Analysis of the data

The data analysis examines three different sets of texts: (1) e-mail accounts²⁰ (2) face-to-face interviews (3) online texts from breast cancer websites. A complementary text that was analysed is a fictional book titled *Dearest Stranger, Dearest Friend* (Katz Becker, 2000) that recounts an e-mail correspondence between two breast cancer patients who 'met' on an online message board. Given that this is a fictional text, and thus has a different value from that of the other texts obtained through ethnography, it was treated only as secondary data. Nonetheless, its invaluable contribution was in allowing access to the kind of online activity that is highly central to patients' experience (namely, e-mail correspondence between fellow sufferers), that otherwise, for obvious reasons, would have remained completely inaccessible.

Twelve face-to-face interviews constitute the core data in the analysis (see Appendix 5). However, the analysis attempts to combine the different texts rather than treating them separately according to type i.e. as e-mail, face-to-face, or website narratives. Also, no hierarchy is implied among the different texts; all three kinds of text are treated equally in terms of their contribution to the data analysis. As Hine (2000) suggests, discourse analytic approaches to Internet texts could be usefully combined with ethnographic approaches to Internet interactions (ibid.: 53-54). I used the discourse analysis of website texts to contextualise patients' accounts (both e-mail and face-to-face) of their online experience, and vice versa: the discourse analysis of website texts has been rooted in the everyday meanings that participants have of their interactions, as they emerged from their face-to-face and e-mail accounts. For example, a common feature was that, in their interviews, participants understated or even denied their participation in posting personal stories online, while an examination of their e-mail accounts and an observation of the websites they visited showed that, in fact, they were quite actively engaged in doing so.²¹ What is more, the face-to-face and e-mail accounts were produced for me, the researcher: they are the stories of patients' online experience in relation to their illness. The online texts taken from breast cancer websites are stories about the experience of illness and coping that patients produced and published for their online fellow-sufferers. The significantly different audience of the various stories has crucial implications for their content and form.

Another difference arises from the timing in which the different texts were created: the online narratives women posted on websites were often created when they were going through the illness and treatment. The e-mail accounts they wrote me were often still temporally close to their experience of use (since I recruited interviewees from the actual websites where they posted their story, usually close to the time of posting). The face-to-face interviews, however, were mostly conducted at least a year later. Naturally, women often had a very different perspective of their experience of illness, and inextricably of Internet use. For all those reasons, it appeared crucial to integrate the different kinds of stories into an understanding of the communicative context that has been examined. Indeed, as Hine (2000: 54) points out, the combination of a discourse analysis of Internet texts and the analysis of ethnographic texts (online and offline interviews) helped maintain analytic ambivalence about what the phenomenon being studied *really* is.

All three kinds of data were treated as narratives, insofar as they were seen as part of the wider process of narrating and storytelling in which patients engage in different sites of their lives. At the same time, their analysis was **not** conducted using the formal method of 'narrative analysis'. The latter, as Bury (2001) indicates, treats the text (e.g. interview) as a whole, identifying longer stretches of talk that take the form of narrative. This analytic technique suits a conceptual emphasis on the *form* of narrative. The prime question it seeks to explore is 'why was the story told that way?' (Riessman, 1993, in Bury, 2001: 281). This study, however, as stated in Chapter One, places the emphasis on the *process* of *narrating*, rather than on the *form* of *narrative*. This conceptual shift infers the need for an analytic methodology, whose aim is to capture the communicative experience in which patients engage, of producing and publishing stories online, rather than a methodology concerned with the structural properties of the text. Furthermore, narratives, whether produced and communicated online (the e-mail narratives and the narratives patients publish on message boards or on personal home pages) or offline (the face-to-face interviews) are both texts and interactions. Hine (2000) suggests that the distinction between the textual and the interactive is blurred in the case of online objects. I think this observation is applicable to an offline interview context as well: it is a textual record of an interaction between the interviewer and the interviewee. Thus, it seemed inappropriate to use formal narrative analytic techniques that do not allow meaningful room for

considering the texts also as dialogic interactions rather than mere monologic texts. This methodological consideration goes hand in hand with the conceptual proposition I present in Chapter Four and develop throughout the thesis, of attempting to bridge the dichotomous thinking about communication as *either* dialogic *or* disseminative.

Therefore, for the analysis of patients' engagement in online narrating (Chapters Five to Seven) I use a qualitative procedure that does not concentrate on a specific narrative as a whole, but rather various themes are identified in relation to the process of narrating, and then illustrated with quotes from across the different data set.²²

The analytical discussion is organised by three dimensions of online narrating and storytelling, as identified in Chapter One (emplotment and construction of closure, exchange and reciprocity, and the negotiation of public and private). These dimensions served as broad analytical categories for examining the data. These categories were not informed only by theory. Crucially, they constitute the key aspects that emerged from patients' accounts and from observing their online participation as most significant and meaningful in their online experience. Each text (twelve face-to-face interviews, twenty-eight e-mail accounts and one letter, and various texts from breast cancer websites) was then coded according to those three categories. When analysing the texts, the aim was to identify participants' understandings of their online experience, in relation to each of the three categories. For instance, when examining the issue of exchange and reciprocity (discussed in Chapter Six), I looked for the different manifestations, as well as absences of this aspect in patients' accounts and in other texts on breast cancer websites (e.g. a website's instructions for how to post a story). The kind of questions I asked, in reading the texts were: What do they say is significant about exchange? What do they emphasise and what do they omit or understate? What is surprising about what they say on exchange online? What is problematic? The intention was to move beyond the face value of participants' accounts. A statement such as 'the love and acceptance of each other's differences is almost overwhelming' (Online narrative 24) is presented first in Chapter Six to illustrate the notion of *communitas* and bonding online. However, then it is revisited in Chapter Seven, to suggest a more critical understanding of patients' online communication as quite homogenous and standardised, rather than allowing uniqueness and difference.

Ethical considerations

One of the most contested areas in Internet research involves ethical considerations for conducting online studies (Jankowski and van Selm, 2001; Elgesem, 2002). The debate centres on issues of privacy and confidentiality, informed consent, appropriation of others' personal stories (Sharf, 1999: 245), and, more generally, commonalities and differences between the ethical considerations for doing research in virtual and 'real' worlds (Jankowski and van Selm, 2001). Clearly, the field is currently in a formative phase where no clear guidelines have been set, and by which Internet researchers are bound.²³ While, as far as possible, I did follow existing guidelines and learnt from what has been done to date, there were many grey areas, and, ultimately, ethical decisions were made on the basis of my personal judgment within the specific context concerned.

Despite the specificity of ethical aspects of doing Internet research,

It's important to remember that all 'Internet research' takes place in an embedded social context. To understand Internet-based phenomena, you need to understand that broader context. Consequently, most 'online research' really also should have an offline component, and many ethical issues become identical to those for traditional research" (Bruckman, 2002: 3).

In what follows, I reflect on the key ethical concerns which were apparent in this study, and which were involved in conducting the research both online and offline.²⁴

Privacy and confidentiality

Privacy and confidentiality are central considerations in Internet research because of the blurred boundaries between the private domain and the public domain in online spaces. Bruckman (2002) suggests that researchers should determine when members of an online list have a reasonable expectation that their communication is private and when they do not, and act accordingly. In particular, she refers to a study of a group with a serious illness as an example of a 'high risk' study, insofar as issues of privacy and confidentiality are concerned. Bruckman (2002) provides fairly strict guidelines for treating material from online resources, suggesting that the latter may be freely cited only when (1) it is officially, publicly and permanently archived; (2) when no

password is required to archive access; (3) when there is no site policy which prohibits it; and (4) when the topic is not highly sensitive. In other cases, according to Bruckman, permission must be requested.

In this study, participants' personal accounts (both the online accounts that were sent to me via e-mail and the offline accounts of the face-to-face interviews) were treated in the strictest anonymity and confidentiality. The information obtained about a participant was treated as confidential, and remains so, unless otherwise agreed in advance. During the analysis of the data, all possible appropriate precautions were taken to protect the confidentiality of the participants.

As far as the online colloquy on breast cancer message boards is concerned, although the latter does not constitute the main data of this research, some references to those discussions have been used in the analysis. I attempted to use those references with the highest degree of sensitivity, to avoid identifying links between the quotations and their respective sources. I made an effort to contact directly the individuals who had posted a message that I wished to quote, in order to seek their consent.²⁵ However, I still used material from postings whose authors' consent I could not obtain, when I found it significant and salient enough to risk the fact that I had not received prior consent. In such cases, I attempted to provide as much as possible the context in which the text was communicated. I often edited the text in a way that it would demonstrate what it was meant to, while at the same time make the original text as untraceable as possible. When I quote from personal texts that were posted on online forums (personal homepages, message boards etc.), I deliberately do not provide their URL. It should be also noted that in treating such online postings the perspective taken is sociological rather than psychological. I am not interested in the specific story of a specific individual, but rather in what it represents and how it enlightens our understanding of the social and cultural context of the phenomenon under scrutiny. This goes hand in hand with the strategy of analysis that was conducted: rather than focusing on each personal narrative as a whole, the different texts were analysed in an integrative fashion.

Nevertheless, and although the content of the discussions on those boards is highly private and intimate, it should be remembered that it is open and accessible to

anybody. The discussion in Chapter Seven reflects on patients' ambivalent perception of their online communication as both private and public. In so doing, it sheds a critical light on the seemingly seductive claim (made by Bruckman and others) that researchers should not use any material without participants' consent, since the latter perceive the texts they post online as private and restricted to specific audiences. While I made any possible effort to ensure respondents' anonymity and a proper ethical consent, I think that Bruckman is posing an unrealistic and unsustainable set of rules.

Informed consent

The participants in the research were informed at the outset about the aims and purposes involved in the research. In the message initially posted, I clearly identified myself, and explicitly declared my interest and aims. I then repeated my self-introduction in the first e-mail to those who replied to my posting. Initial consent was obtained electronically. Consent regarding face-to-face interviews was obtained separately (also via e-mail) from the interviewees involved. In obtaining the research participants' informed consent, I used language that is reasonably understandable to them (i.e. non-academic terminology).

In both the online stage and the offline stage, participants were informed that things they said might be quoted in my doctoral thesis. Furthermore, they were informed of the expected date of the completion and the production of the actual thesis and were offered the possibility of receiving a copy of the research report once it was completed. This seemed to be an informal incentive for their participation in the research, as no financial inducement was involved in obtaining their co-operation.

With regard to the face-to-face interviews, at the stage of setting them up via e-mail correspondence, the interviewees were informed that the interview would be recorded by tape. In addition, in the beginning of the interview, I made it plain to the participants that they were free to participate in, or withdraw from the interview at any time.

Appropriation of participants' stories

The issue of appropriating someone else's personal narratives is a concern inherent in the nature of qualitative research, whether mediated or face-to-face (Sharf, 1999: 248;

Plummer, 2001: 216-217). On a broader level, *reflexivity* was a key practice throughout the research and, in the process of writing, as a way of considering questions that emerged from the process of imposing my own framework of analysis on the stories of other people. The following chapters illustrate the findings that emerged from the application of the methodology described above. I have done my best to cause as little harm as possible to all the individuals whose online and offline stories I incorporated into my account.

¹ Rojek originally raised this criticism with regard to work in the field of leisure, but I think that it has much to offer in the context of Internet use research.

² In making this observation I draw loosely on Plummer's remark about the difference between positivists' tendency to focus on *why* questions and phenomenologists' concern with *how* a person lives a life in a culture (2001:140-141).

³ See: www.pewinternet.org

⁴ This is not to imply that combining online and offline methods should be an end in itself, nor do I claim that offline information is always necessary to make sense of online sociality. As Slater (2002: 542) and Hine (2000) contend: it depends on the question we ask and the context we study. For the purpose of this study, the need to contextualise the online information gained from the e-mail account by the offline constructions of the face-to-face interviews was essential.

⁵ This aspect was discussed in Chapter Two.

⁶ For example: 'Shared Experience' (www.sharedexperience.org), Yahoo Breast Cancer Club (www.breastguide.com), 'Breast Cancer Survivor Network' (www.acscsn.org).

⁷ This was part of my research for an MSc dissertation

⁸ Those questions were provided only in the messages and e-mails sent on the first round, in December 1999-January 2000. In the second round, I left only the actual message that declares my interest in their account of the experience of Internet use in relation to their illness.

⁹ A similar experience was indicated by the researchers of Pew Internet & American Life (2003), where interviewees were sent a semi-structured questionnaire about their health-related Internet use. Rather than follow the question-and-answer format, respondents elaborated on telling their personal stories. This aspect of storytelling was not developed, however, by the researchers.

¹⁰ I will come back to this point later in discussing the question of representativeness.

¹¹ Throughout the thesis I use 'American' to mean North American and mainly US-American.

¹² Hine (2000: 76-77) criticises Paccagnella's observation, claiming that in stressing the need to obtain offline ethnographic context, Paccagnella implies that the standards of authenticity for the ethnographer should be different to those of informants. While I accept this critique, I wish to stress that in this study, for the reasons I discuss in the chapter, obtaining participants' offline accounts was necessary in order to enquire into the ways in which the online and the offline connect in participants' experience.

¹³ This reflection is based on Bauer and Gaskell (2000: 39).

¹⁴ As e-mail is one of the most prominent online forms of communication between fellow sufferers, and as I have no access to the correspondence, the interview was used to obtain information about this aspect from participants' reflections. In addition, I draw on a book which follows the e-mail correspondence of two breast cancer patients who met online. Although it is fictional, it yields insight into this experience in a fairly realistic manner. See: Katz Becker (2000).

¹⁵ This e-mail is from a breast cancer patient whom I did not interview eventually.

¹⁶ There was only one exception: one interview was conducted with two interviewees (# 8 and # 9) who are sisters and insisted on being interviewed together.

¹⁷ There is a broader interesting issue here in relation to the notion of 'Interview Society' that links to the idea of storytelling as a practice with which those patients are highly 'exercised' and which is central to the experience of illness.

¹⁸ Neice (2000) reflects on a similar experience.

¹⁹ See Chapter One for a discussion of the concept of agency and how it is construed in this study.

²⁰ Except for narrative 3 that was sent via snail mail.

²¹ I discuss the implications of this issue in Chapter Five.

²² The only place where I cited almost the whole text of a patient's story (with hardly any editing) was in Chapter One, where I wanted to demonstrate why I consider this kind of discourse to be a narrative [i.e. how it is organised around time and consequential events in a 'world' created by the narrator (Reissman, 1990 in Bury, 2001: 282)].

²³ See the Association of Internet Researchers' ethics recommendations:
www.aoir.org/reports/ethics.pdf

²⁴ In considering the ethical aspects of the research I relied chiefly on two ethical sources: (1) Outline of Proposed Research for Ethical Approval (Institute of Education, UK, 2001). (2) Ethical Guidelines for Research Online (Bruckman, 2002). I wrote an ethical statement written and had it approved by my supervisor before starting the fieldwork that involved face-to-face interviews.

²⁵ This was in addition to my contact with my direct informants, whose consent I obtained as a matter of course.

Chapter Four

Online Narrating and Other Models of Communication

The issue is not so much the inherent properties of the medium as the social constellation of speakers and hearers that became enforced as normative

(Peters, 1999: 195).

Narrating and storytelling, as argued in Chapter One, is one of several varying communicative processes in which patients engage. The goal of this chapter is to locate online narrating in a wider context of thinking about communication. By locating the model of online narrating within a broader context of communication processes, I wish to clarify why and how this concept is particularly helpful in studying the processes of online communication of breast cancer patients, and how it helps overcome some of the limitations of existing paradigms. At the same time, positioning online narrating in relation to other models available for studying CMC reveals its conceptual weaknesses, and I will try to address those towards the end of the chapter. The integration of the discussion of narrating (that was developed in Chapters One and Two) with the model of online narrating (suggested in the present chapter) provides a theoretical context for examining the empirical data in the following chapters.

The point of departure for the discussion is: what do women who suffer from breast cancer do online? How can we describe the communication in which they engage? More specifically, what models or paradigms are available to explain their communicative activities?

Breast cancer patients engage in different kinds of communication online: they chat, they ask questions, they exchange experiences on message boards, they lurk, and they tell stories. This kind of interaction, whether of patients or other online participants, has been commonly understood in existing studies in terms of 'interactivity'.¹ The latter has placed a great deal of emphasis on aspects of exchange, reciprocity, responsiveness, and feedback. More specifically, I suggest, online interactions in sites

such as mailing lists, news groups, MUDs and chat rooms have often been examined and explained with a conversational metaphor in mind. This paradigm of 'interactivity' and 'conversation' shaped the CMC research field in significant ways, and was particularly influenced by the sociological Conversation Analysis (CA) tradition (Hutchby, 2001: 181). True, only a strand of studies drew *explicitly* on the sociological model of face-to-face conversation to analyse online interactions. However, I would argue, even when other types of analysis were performed, for instance discourse analysis of online interactions, the concepts of conversation and interactivity were an influential prism through which many researchers understood (and still do) the ways in which participants manage their online interaction. So although alternative models of understanding online interactions have developed (for example, online presentation of the self, see Chandler, 1998), the interactive conversational model has been probably the most central one, and therefore is worthy of attention.

I acknowledge the relevance of the conversational model for studying online interactions, and the usefulness of the concept of interactivity for understanding CMC. However, for the case of this study, I argue, conceiving the communicative interactions of breast cancer patients only in terms of online conversations and interactivity is relevant, but insufficient. Crucially, it does not get to the heart of things. That is, it fails to account for the salience and the significance of the communicative context under scrutiny.

The first part of this chapter introduces in detail the 'conversational model' and the ideas on interactivity that shaped the conceptualisation of CMC. When considering the application of the conversational / interactive model to the study of breast cancer patients' online communication, several limitations arise. The aim of the part that follows is therefore to offer a critique of the possible pitfalls of that paradigm, in view of the specific purpose and context of this study.

Following this critique, in the second part of the chapter, the concept of online narrating is presented. It is suggested as a particularly helpful way of illuminating the specific processes of patients' online communication. The purpose of this part is to highlight why narrating can serve as a useful communicative model to understand

patients' processes of online communication. The potential merit of online narrating for the examination of patients' online communication is further endorsed in the remainder of the chapter, where online narrating is located in relation to other existing models of communication. In particular, I highlight how accounting for patients' communication as online narrating might potentially integrate tensions that characterise the dominant thinking and modelling of media and communication.

The discussion of online narrating in the present chapter is the basis on which, in subsequent chapters, I examine the online communication of breast cancer. In particular, to what extent what is happening on breast cancer related websites is indeed narrating, what the qualities of this process are, and in what sense the websites themselves furnish a framework of story.

Interactivity and online conversation

The concept of conversation has largely governed the way in which online communicative interactions have been understood and analysed (Baym, 2002). While to the best of my knowledge, there is no coherent definition in the literature of what is online conversation,² what is common to the different accounts of online conversation is that they position it (often implicitly) in relation to an idealised model of face-to-face conversation. This is a token of the broader theorisation of online interpersonal relationships, especially of the early 'reduced social cues' model, which is biased towards face-to-face communication (Lea and Spears, 1995). As the field of CMC research developed, more complex approaches were introduced. In particular, there has been a shift from a concern with face-to-face as the basis for comparison in understanding CMC, to a view of CMC as a cross between interpersonal and mass media (Baym, 2002). Nevertheless, I would like to suggest, the foundations underlying the paradigm of interactivity and conversation still strongly resonate in current thinking about CMC. It is therefore worth looking at the key dimensions of this paradigm and their implications for understanding CMC.

Online conversation is a communicative model that describes a qualitatively different kind of interaction from that possible in face-to-face conversation. The latter is regarded as a communicative situation in which 'individuals interact directly with each other bypassing central controls or intermediaries', choosing their

communication partners as well as the time, place and topic of communication (based on Bordevijk and van Kaam's typology, in McMillan, 2002: 273). This nature of an 'ordinary conversation' (i.e. face-to-face conversation) is construed as the baseline to understand what online interaction is. In this sense, the majority of the accounts of online conversation follow the view of 'technologised interaction' (Hutchby, 2001: 5) which examines technologies (e.g. the telephone) and the communication they facilitate with a conversational metaphor in mind. This line of thinking is embedded in the perspective of Conversation Analysis (CA) which is ethnomethodological in its theoretical underpinnings (ibid.: 76). The implication of applying this framework to the online context is a concern with the ways in which users utilise certain conversational norms and conventions (with which they are originally familiar from 'ordinary conversation', for example turn-taking) to engage in the online interaction. The underlying assumption is that online conversation, whether as a result of the technology's configuration of users, or users' configuration of the technology, is significantly different from face-to-face conversation (Hutchby, 2001: 181). Consequently, research concerning online conversation has sought to explore the differences (and to a lesser extent the similarities) between face-to-face and online conversations.

Following from the comparison between a face-to-face and an online interaction (that takes place in IRC) are a set of features that characterise what is 'online conversation' and distinguish it from face-to-face conversation. Crucially, these features represent 'a version of conversational interaction, but only within technologically circumscribed interaction' (Hutchby, 2001: 183). In other words, online conversation is constructed as a *constrained* version of face-to-face conversation, the latter being implicitly elevated to a supreme status of an idealised communicative interaction. In what follows, I will briefly discuss the pertinent aspects on which the model of online conversation centred. These aspects have shaped, to a large extent, the conceptualisation of CMC, stretching beyond those writings which followed a Conversation Analysis approach. So, while the following overview describes the key features of the model of online conversation, it actually points out elements that are characteristic of the wider study of CMC and the way online interactions have been conceived. On the basis of this overview I will then present a critique of the model,

indicating its fallacies and inadequacies for the purpose of studying the processes of online communication of breast cancer patients.

Embodied vs. disembodied

Disembodiment has been understood as the key determining factor of online conversation. Disembodiment was often seen as an intrinsic property of 'the Internet', independent of the particular uses in which it is embedded (Slater, 2002). Consequently, explorations focused on essential questions about the possibility for communication without bodies or presence: What is interaction without bodies or presence? How binding is an online relationship that lacks any contract or mutuality, and is based on disembodied interaction(s)? What kind of moral or political obligation can 'virtual' contact compel?³ These questions stemmed particularly from a conception of CMC as a constrained version of face-to-face interaction. However, they frame much of the broader debate on CMC, for example, the discussion of online communities (e.g. Wellman and Gulia, 1999).

Synchronous vs. asynchronous

Since the implied point of reference for thinking about online conversation is face-to-face conversation, early explorations of online interactions tended to focus mainly on synchronous environments of Internet Relay Chat (IRC).⁴ IRC seemed particularly appropriate a form of online communication (among other alternative forms such as e-mail) since it 'enables participants to be online simultaneously and to interact with one another in a way that approximates real-time turn-taking'⁵ (Hutchby, 2001: 173). More generally, and not just strictly in Conversation Analysis studies, the concept of interactivity has been usually associated with real-time contexts. There have been some challenges to the linking between interactivity and synchronic communication, underscoring the significance of asynchronous characteristics for interactive communication (e.g. Rheingold, 1994). However, the view that seems to have overwhelmed accounts of interactivity in general (e.g. Rice and Williams, 1984) and in relation to CMC in particular (e.g. Rafaeli and Sudweeks, 1997), is of interactivity as based on an immediate, synchronous interaction (Downes and McMillan, 2000).

Textual vs. oral

Online interaction is carried on through the means of typed text rather than speech (Hutchby, 2001: 173). In examining the consequences of the textual dimension of the interaction, questions concerned the issue of intimacy and impersonality. Often the textual is equated with the impersonal and inauthentic while the oral is depicted as the genuine and intimate.⁶ More context-sensitive models departed from the hypothetical theorisation of CMC on the basis of its textual property. In accounting for the particular uses people make of the Internet, they acknowledged CMC as a hybrid communicative situation, containing both oral and written characteristics (e.g. Baym, 2002; Fernback, 2003). Notwithstanding this, they often remained captured by the idea that the oral is the authentic, interpersonal and interactive. 'Like speech', explains Baym (2002: 65), 'much CMC is direct, contextualized and interactive', implying that, the textual is necessarily *not* all these things. So even when accounting for CMC as entailing oral qualities, the sense is usually of restoring an idealised face-to-face interaction.

Lack of control/constrained control vs. high degree of control

The primary model for 'ordinary conversation' is a dialogic two-party interaction. Online conversation is commonly depicted as inevitably more complicated, because (among other reasons) it is often multi-party conversation (Hutchby, 2001: 184). For example, while in face-to-face conversation the locus of orderliness for a current turn is, largely speaking, its relationship to the prior turn, in online conversation, for technical reasons, this is not necessarily the case. This challenges participants' capacity to control the interaction. The stress on the lack of control of participants in online conversation is a corollary of a comparison between CMC and an idealised model of face-to-face conversation. The latter portrays the exchange between participants as one that 'can be straightforwardly managed' (Hutchby, 2001: 186), allowing its participants a high degree of control. Online interactions are thus understood as the opposite.

Because (face-to-face) conversation is regarded as a communicative situation in which 'individuals interact directly with each other bypassing central controls or intermediaries', choosing their communication partners as well as the time, place and topic of communication (based on Bordevijk and van Kaam's typology, in McMillan, 2002: 273), accounts exploring online conversation focused on the *challenges*

introduced to this definition. What kind of controls and intermediaries that do *not* exist in a face-to-face context are present online and how do participants deal with them? What are the implications of participants' incapacity to choose and to fully control the different elements of the communicative interaction (their partners, the time, place and topic of the conversation)?

Loosened coherence vs. coherence

Entwined with the issue of control is the question of how users compensate for the lack of coherence online, through the practice of conversation (Erickson, 1999). Drawing closely on the CA perspective, textual online conversation has been claimed to enable participants to have a low degree of control and to be interactionally incoherent, due to two obstacles in the properties of the medium: *low degree of adjacency* (messages are posted in the order received by the system without regard for what they are responding to) and *reduced feedback* (lack of audio-visual cues and the fact that messages cannot overlap) (Herring, 1999). Consequently, 'violations of sequential coherence are the rule rather than the exception in CMC' (ibid.: 9).

To summarise, table 4.1 presents the key features of the online conversation model, positioned in comparison to the (idealised) interaction of face-to-face conversation.

Table 4.1 Comparison between face-to-face and online conversation

| Face-to-face conversation (<i>idealised</i>) | Online conversation |
|---|--|
| Embodied | Disembodied |
| Oral (the Socratic notion) | Textual |
| Soul-to-soul, intimate. | Lack of intimacy, impersonality. |
| Control | Lack of control/constrained control - participants' incapacity to choose and to fully control the different elements of the communicative interaction. - lack of physical/audio-visual cues. |
| Coherent | Loosely coherent/incoherent - low degree of adjacency. - reduced feedback. - violations of sequential coherence. |

Critique of online conversation

The model of online conversation is highly useful in illuminating the ways in which participants manage their interactions at the interface between the norms of conversation and the communicative properties of the online space. However, for the purpose of studying the online communication of breast cancer patients, it seems limited in several respects. I now wish to discuss four key limitations of the conversational paradigm. Against this backdrop, I will then present online narrating as a more appropriate and useful way of elucidating the specific processes of patients' online communication examined in this study.

First, the model of online conversation is clearly framed by a *dialogic* perception of online communication. It assumes a necessarily two-way, dynamic, interdependent reciprocal process between senders and receivers (Kiousis, 2002: 359). As I have shown, this conception is tied in with the notion of interactivity which has largely

framed the thinking about online communication. The latter was influenced by Rafaeli's (1988) early account of interactivity in relation to CMC, and the focus on *feedback* as the key signal of the concept (Kiouisis, 2002). Consequently, investigations of different online communication contexts focused on examining the responsive dimension and the interconnected relationships among exchange messages online (ibid.).

The problem with this paradigm is that it does not allow enough room for communicative processes and practices which are not necessarily dialogic or interactive. In the context of the online communication of breast cancer patients, I suggest, there is a range of activities and processes in which patients engage that cannot be explained by the notions of 'conversation' and/or 'interactivity', at least not in the way they are defined by this paradigm. While the reciprocal dimension plays a central role in patients' online communication, as I explore in Chapter Six, there are also significant non-interactive processes, such as lurking, for example, that need to be accounted for. This kind of process, however, is overlooked by the conversational model. More generally, while the technological development of the Internet is increasingly following the broadcast model of one-to-many (Fidler, 1997; Roscoe, 1999; Mansell, 2002), and so there is a growing presence of *disseminative* elements in the communication on the World Wide Web that do not involve feedback,⁷ the predominant characterisation of online communication (in both academic and popular discourses) has leaned towards the *dialogic* conversational model.

The conceptual preoccupation with the dialogic aspect of online communication is interlinked with a second inadequacy of the model of online conversation. As argued earlier, online conversation is constructed as a *constrained* version of face-to-face embodied conversation, the latter being implicitly elevated to a supreme status of an idealised communicative interaction. Accordingly, *disembodiment* (to distinguish from embodiment of face-to-face interaction) has been considered a determining dimension of online communication (Slater, 2002). While traditional conversation analysis depicts face-to-face conversation as a dialogic embodied, private, authentic, and controlled interaction, it is cast in opposition to the disembodied, public, inauthentic online conversation.⁸ As a consequence, the focus has been on the

question of how users compensate for the lack of engagement, or of the capacity to engage, in dialogue in online environments.

There is a moral implication to this conceptual preoccupation: Whether celebrating the capacity to experience identity in new ways, that is, online communication as re-authenticity, or decrying the loss of 'real' 'genuine' communication, i.e. de-authenticity,⁹ the underlying agenda of research on online conversation (and CMC more generally) has been the need to restore a dialogic relationship of body to body, the latter likened to authenticity. Recent research casts a critical light on the concern with authenticity (see Hine, 2000), suggesting that the question should not be whether online interaction is more or less authentic than a 'real' interaction, but rather where and when identities are made available on the Internet (ibid.: 118). More specifically, I suggest, in the context of this study, rather than asking whether patients' online interactions are 'authentic', it seems more appropriate to focus on the question of how online interactions are experienced as social processes that are meaningful for the patients who participate in them.

The conceptual limitations of the model of online conversation also have analytical implications. As mentioned earlier, since face-to-face conversation serves as the baseline to understand online conversation, explorations of online conversations tended to focus mainly on *synchronous* environments. For the purpose of studying breast cancer patients' CMC, this focus on synchronous forms is problematic in two respects. First, it does not give sufficient attention to asynchronous forms which are very central in patients' online experience. Asynchronous forms might have quite different (as much as similar) consequences from synchronous ones, for the communicative situation. This is even more salient given recent figures which indicate that the majority of American Internet users communicate via *asynchronous* rather than real-time online forms (Pew Internet & American Life, 2000). Second, in focusing almost exclusively on synchronous forms, accounts of online conversation suffer from a deterministic element. Rather than asking what specific technological uses and communicative processes are evident and where (whether in synchronous or asynchronous environments), their starting point is simply to specify the features of synchronous forms, in order to explore how their 'inherent properties' affect the conversation. In so doing, they often overlook the particular social uses in which these 'inherent properties' are embedded. To follow Slater's line of

critique, the result is a body of research that reifies the notion of 'the Internet' as a singular thing that has singular consequences for a singular kind of communication, namely online conversation. Therefore, in examining the characteristics of breast cancer patients' online communication, my intention will be to look at processes in which patients engage, without predefining whether they take place in synchronous or asynchronous contexts.

A fourth limitation of online conversation as a way to understand patients' processes of online communication derives from its underlying view of communication as a *process*. It assumes that communication is the transfer of a message between two parties or more. Its main concern is consequently with describing *how* the process in which a message passes into the online space occurs. It thus focuses on issues such as the disembodied nature of the flow of the message, the textual characteristic of the message and its implication for the relationship between user and sender, the levels of feedback, coherence and control (of sender / receiver), for these are all terms relating to the *process* of sending a message online.

As shown thus far, these issues are relevant and profound. However, they do not provide a satisfactory account of the actual *significance* of the communication for its communicators. To put it crudely, in the context of this study, analysing the degree of adjacency of messages posted by patients on online forums, or the dynamics of turn-taking in an online interaction, does not adequately tell us *why* this communication matters for the patients involved. Nor does it tell us what the consequences for the patients involved in the interaction are.

Narrating and storytelling

So while the model of interactivity and online conversation has considerable explanatory power, for the purpose of this study, it seems to yet deprive us of an understanding of several important aspects. I wish to introduce an alternative paradigm to address this challenge. I suggest calling this communicative model "narrating and storytelling". This model offers a particularly helpful way, I believe, of elucidating the processes, practices and structures of communication in which breast cancer patients engage. Far from proposing narrating and storytelling as a communicative model in its own rights, or claiming for it universal and privileged

status, the following section should be read as an attempt to identify a specific model that seems useful for the context of this study.

Narrating and storytelling suggests a different conception of communication from that of the conversational paradigm: one which acknowledges that communication is a process, but at the same time emphasises the notion of communication as the *generation of meaning*. Like discourse analysis, the conventional model that has been traditionally counterpoised with conversation analysis,¹⁰ the model of narrating challenges online conversation's sole focus on questions of *how* the interaction takes place, proposing a broader engagement, with the question of *what* meanings are being generated in this interaction and *how*. This focus, I suggest, would enable us to adequately account for the salience and significance of the communicative context of breast cancer patients.

One should bear in mind, however, that the distinction between narrating and other forms of communication, is, to a certain extent, an analytical distinction. In practice, different forms of communication (such as conversation and narrating) can take place at the same time. The model of conversation and interactivity has much to suggest for getting to grips with the context of breast cancer patients' online experience. Indeed, as I will demonstrate throughout the analysis, and particularly in Chapter Six, aspects of exchange, reciprocity and conversational interaction are central to this communicative context. Nevertheless, I suggest that narrating constitutes a more appropriate way to account for patients' online communication.

To fully ascertain the proposed model of online narrating, it is useful to briefly remind us of the broader discussion of narrating and its significance as a communicative process, beyond its online context. The focus of this study is how narrating works as a communicative tool that has significance for the agents involved in its production and reception. Narrative is a mode of description or discourse. Narrating is the production (or the attempt at producing) of that mode. As already presented in Chapter One, to address this area of concern, I adhere to one definition of narrative that provides a useful framework for the exploration of narrating as a communicative model. Closely drawing on Ricoeur's ideas on narrative, narrative is regarded as the 'constellation(s) of *relationships* (connected parts) embedded in *time and space*, constituted by *causal*

emplotment' (Somers, 1994: 616, italics in original). Emplotment is the 'procedure that configures temporal elements into a whole by 'grasping them together' and directing them toward a conclusion or ending' (Polkinghorne, 1991: 141). It is through the operation of emplotment that particular actions take on meaning as a contribution to the unfolding plot of the story (Polkinghorne, 1991, based on Ricoeur, 1984).

In what sense is this communicative model, with its emphasis on the act of configuring different elements into a coherent framework and gearing them towards a closure, different from other models of communication? In particular, for the study of patients' online communication, what is helpful about narrating that the conversational model does not tell us?

Firstly, given that emplotment is the syntax of narrative, 'to make something understandable in the context of narrative is to give it historicity and relationality' (Somers, 1994: 617). This is significantly different from making sense in a context of other modes of discourse.¹¹ Whereas narrativity demands that we discern the meaning of any single event only in temporal and spatial relationship to other events (ibid.), other modes of discourse do not require a necessary temporal or spatial connectivity between their different parts. For example, studies that looked at online interactions as conversation showed how coherence in a conversation depends primarily on a certain temporal relationship between the *turns* being taken, however not necessarily on a temporal relationship between the actual *meanings* being communicated. Other studies, which did give attention to the meanings or discourse communicated online, often explored discourse in more general terms, but were not concerned with the generation of a particular structure of meaning, namely narrative. So the emphasis I propose for studying patients' online communication is on the production of meaning, which is intended to elicit meaning ordered in the form of a narrative.

Secondly, and closely related to the latter point, is the notion of *coherence*. Coherence has very different implications for the model of narrating than for that of conversation. The essence of narrating is the imposition of structures of meanings, that is, of a coherent framework that organises the events (Brooks, 1994). Thus in the context of narrating, coherence involves the work of making sense. In this sense,

narrating can be seen as part of other communication models, such as discourse analysis, which put the emphasis on how meaning is generated and structured. Conversation analysis is also concerned with the issue of coherence, however in a very different way. For conversation analysis, coherence is based on sequential principles, namely adjacency and relevance. Adjacency refers to the ways in which turns that belong together in the interaction will occur adjacent to one another in temporal sequence. Relevance implies the expectation that adjacent turns will relate to one another, in keeping with the pragmatic principle of relevance (Herring, 1999: 9). Again, while the emphasis in examining conversation is the *course* of the interaction, to explore the processes of patients' online communication, I suggest, it seems that the concern should be with the *meanings* that emerge from and through their interaction.

Thirdly, thinking about patients' online communication in terms of narrating, rather than, say, conversation, might help avoid the unfruitful question of authenticity. Implicit in the depiction of online conversation as disembodied and inauthentic, separated from the offline world, is the notion of authenticity. The embodied 'here and now' of a face-to-face conversation is equated with authenticity. This might explain the concern with aspects of disembodiment and inauthenticity when conversation is transferred to the online space and the 'realness' of the interaction is presumably under threat. More generally, the concern with authenticity has occupied much of the writing on Internet interactions, beyond accounts concerned with the conversational model. Most typical of this literature is the fascination with online identity play and the construction of identities (Hine, 2000).

This is not to say that applying the conversational framework to the analysis of online interactions necessarily entails a view of the latter as inauthentic. There are definitely accounts that work with a conversational metaphor to explain different CMC contexts, and do not fall into the trap of asking whether online interaction is authentic (e.g. Baym, 2000). However, as long as the conversational model (or any other paradigm) is established as an opposition to face-to-face conversation, it is doomed to be captured in questions of authenticity. Thinking about participants' processes of communication in terms of narrating allows a focus on how online interactions are experienced as social processes that are meaningful for their participants, rather than whether those interactions are more or less authentic than 'real' (offline) ones.¹² For

narrative, the implicit assumption is that the form of communication (a story) has to make sense for the teller and listeners. It has to constitute a plausible framework that generates 'narrative truth', but this framework is not dependent on an embodied face-to-face context. Thus, a discussion of online narrating would not concern questions of whether this mode of communication is authentic or 'real', but rather whether it is useful and significant in helping the narrator to make sense of her experience.

Analytically and empirically, the exploration of online narrating does not restrict itself to a specific kind of environment. This is unlike the model of online conversation, which focused almost exclusively on synchronous forms, since the latter provided a convenient platform to examine how online conversation differs from a face-to-face conversation. The model of online narrating chooses the environment in which to explore, according to where the communicative process is actually evident, be it synchronous or asynchronous environments.

This is not to say, however, that in accounting for online narrating we ignore the specificity of technological properties of the communicative space and their impact on the communicative process. Indeed, most of the online narratives appear to be published on asynchronous, rather than synchronous forms. Notably, rather than a predetermined factor, this finding emerges from an observation of the actual communicative activities that take place online and is grounded in users' experience.¹³

More broadly, narrating as a communicative model can help us understand *how* patients communicate, but crucially, also *why* their communication matters. The model of narrating is linked to the wider theoretical assertion about the centrality of narrating in constituting agency (as discussed in Chapter One). In other words, thinking about patients' communication in terms of narrating (rather than, say, conversation, on the one hand, or generation of discourse, on the other) carries with it ontological claims about this process: that it is through narrating that we come to understand and make sense of the social world and it is through narratives and narrativity that we constitute our social identities. In this sense, the model of narrating is proposed not only as a descriptive model that can elucidate what patients do online, but also as a model which explicates the significance of their online activities.

To summarise, in several ways narrating seems a particularly useful model in order to consider the processes of online communication of breast cancer patients. First, it describes the characteristics of this communication while at the same time telling us why this communication is meaningful. In other words, it illuminates the question of *how* the message is being transmitted and received, but at the same time elucidates also the *significance* of this process. Second, thinking about participants' online communication in terms of a narrating process, helps shift the concern from one of authenticity to an empirical focus on how the communication actually occurs and what its consequences are. Thirdly, the framework of narrating allows room for exploration of different kinds of online environment, rather than focusing exclusively on asynchronous forms.

Locating online narrating in relation to models of communication

I now wish to move beyond a consideration of online narrating only in relation to other models of *online* communication (in particular, interactivity and conversation). I wish to try to locate online narrating within the broader context of models of communication. By so doing, I attempt to contextualise the exploration of this study – of breast cancer patients' processes of online communication – within a wider agenda of models of communication. This, I believe, will help us consider the communicative context we study as part of the long-lasting study of communication processes, rather than treating it solely as a novel phenomenon, separate from communication processes and patterns that characterise our social lives, and that have been studied for the last few decades.

I wish to focus on two main features of models of communication that have been developed to date. I start by critically examining these aspects and the way in which they have shaped our thinking about communication. I then move on to discussing how the model of online narrating can be related to these two features.

The dialogue / dissemination dichotomy

Existing models of communication have been largely captured by thinking about communication in dichotomous terms of dialogue and dissemination. As the field of communication emerged, more recursive models have been developed, and I will account for them later. Nevertheless, I argue, existing models of communication still

largely adhere to a framework of regarding communication as either dialogic or disseminative. Peters' (1999) seminal account is a decisive point of reference here. Reading Plato's *Phaedrus* as a normative grid of communicative forms, Peters (1999) suggests a key distinction between two forms of communication: *dialogue* and *dissemination*. I will first briefly present this distinction, purposively holding to its *analytical* dichotomous framework. I will then locate existing models of communication in relation to this dichotomy, and reflect particularly on the way in which online communication has been modelled in light of this dichotomy.

Introduction to Peters' account of dialogue and dissemination (1999)

To put Peters' analysis into focus for the purpose of the current discussion, I present the scheme below (table 4.2), by which I shall examine his distinction between the two models of communication: *Dialogue* - based on the Socratic notion of the communication between philosopher and pupil, and *Dissemination* - based on Jesus' synoptic Gospels, in which Jesus is represented as delivering the parable of the sower to a vast and mixed audience (Peters, 1999: 51). It is important to bear in mind that this account is merely analytical, and will be examined critically and empirically later in this chapter, and throughout the thesis.

Table 4.2 *Dialogue and dissemination*

| | Dialogue (Socrates) | Dissemination (Jesus) |
|-------------------------------------|--|---|
| <i>Direction of communication</i> | Reciprocal, one-on-one. | One-way act. |
| <i>Sender-receiver relationship</i> | - Instructions and directions are offered by a guiding father/teacher. - Give-and-take | - Audience members make of the message what they will. - Diversity of interpretation. -No instructions as to intended meanings. |
| <i>Exclusion vs. inclusion</i> | Selective. | Democratically indifferent to all. |
| <i>Intimate vs. public</i> | - Private esoteric mode of communication. - Intimate hermetic setting. - Reciprocal symmetrical relations. | - Radically public. - Exoteric mode of dispersing meanings. -Asymmetrical relations in public. |
| <i>Embodiment vs. disembodiment</i> | Must be among embodied live people. | No essential privilege of the body. |

As one can see from the table above, dialogue and dissemination constitute two dichotomous and mutually exclusive processes that can be distinguished along the following aspects.

Direction of communication

While dialogue is a reciprocal flow, dissemination, a non-dialogic form, is based on a process of distribution that is equally gracious to all. The model of dialogue is based on the Socratic notion of the communication between philosopher and pupil as a one-on-one, interactive, live, unique and non-reproducible communication (ibid.: 35). The model of dissemination, on the other hand, is based on Jesus' synoptic Gospels in which 'the sower (Jesus) engages in a purely (reproducible) one-way act' (ibid.: 53, my brackets).

Sender-receiver relationship

For Socrates, in dialogue, the living, spoken word is 'always accompanied with directions for use offered by a guiding father or teacher' (ibid.: 53). In contrast, in three of the Gospels (Matthew, Mark, and Luke) the diverse audience members are left to make of it what they will. The sender (Jesus) has no control over the 'harvest' (ibid.: 51). Dissemination is thus 'about the diversity of audience interpretations in settings that lack direct interaction. The sender and receiver are loosely coupled and it becomes the hearer's responsibility to close the loop without the aid of the speaker; the recipient is made self-active' (based on Kierkegaard, in Peters, 1999: 52). In this kind of communication, there is 'no give-and-take, no instructions as to intended meanings' (ibid.: 53).

Exclusion vs. inclusion

Hand in glove with the abovementioned characteristics, goes the notion of dialogue as fundamentally *selective*, while the model of dissemination presents a mode of distribution that is *inclusive*, democratically indifferent to who may receive the 'precious seeds' (Peters, 1999: 51).

Intimate vs. public

Socratic dialogue privileges a private and esoteric mode of communication: an intimate setting in which the receiver is carefully selected by the speaker in advance and carefully brought to understand. Dialogue is a mode of reciprocal and hermetic relations. Jesus, in contrast, performs a radically public, exoteric mode of dispersing meanings, in which the audience sorts out the significance for itself. In short, dissemination favours relations that are asymmetrical in public. (ibid.: 53).

Embodiment vs. disembodiment

For Socrates 'communication must be soul-to-soul, among embodied live people, in an intimate interaction that is uniquely fit for each participant' (ibid.: 47). Unlike this concept of dialogue, the model of dissemination assumes no essential privilege of the body as a carrier of personality.

The dialogue / dissemination dichotomy in models of communication

Early models of communication (e.g. Lasswell, 1948; Gerbner, 1956) regarded the process of mass communication mainly in disseminative terms. Influenced by the experience of World War II, these models conceived communication as a linear one-way process, with very limited possibility for feedback. Since then this view has been continuously altered,¹⁴ most significantly by Hall's encoding/decoding model (1980), which conceives communication as a cyclical process, recognising the receiver's capacity for negotiation over the transmitted meanings, even alluding to her potential capacity for feedback.¹⁵ This shift from a disseminative model of communication to a dialogic model that stresses the active responsive role of the reader is inextricably interlinked with the move away from effects to audiences. The latter shift has had substantial impact in the last two decades, to the extent that audience researchers have elaborated their interest in the audience almost to the exclusion of the text (Livingstone, 1998: 174).

Thompson's influential model (1995) of interactional situations created by the use of communication media manifests that the dichotomy of dialogue and dissemination has resonance in current analytical approaches to communication. A key distinguishing element between the three types of interaction that Thompson introduces (face-to-face interaction, mediated interaction and mediated quasi-interaction) is the

dialogical/monological 'axis', the two first types of interaction being mainly dialogical in character, while the latter is characterised as monological (disseminative). Thompson admits that in practice, everyday interactions may have a hybrid character, involving a mixture of those analytical interactional categories. Therefore, Thompson asserts, such categories are intended only as a heuristic device that should be valued by its usefulness. Notwithstanding Thompson's acknowledgment of the need to evaluate the analytical dichotomies of his model, I contend that in offering an analytical tool that is based on the dialogue/dissemination distinction, this distinction is actually being reproduced rather than altered. In the end of the day, Thompson's model is about the *distinction* between *dialogic* and *disseminative* types of interaction, rather than about a *hybrid* kind of interactional situation.

The prevailing conceptualisation of online communication, as shown earlier, testifies to this observation. Thinking about CMC in terms of conversation and interactivity is clearly biased towards a dialogic conception. Alternative views, as discussed earlier, often tend to represent an opposite model: one-to-many, informational, monologic, or, in other words, disseminative. In short, the dialogue/dissemination distinction has coloured to a great extent the way in which online communication has been understood. Even among researchers that take a more integrative approach, which recognises CMC as hybrid in character, the separation (and often opposition) between dialogue and dissemination is evident. Consider, for instance, the following apparently straightforward observation made by Baym (2002: 62). I have *italicised* the part that indicates the disseminative model, and **bolded** the references to the dialogic component of CMC:

Even aspects of the Internet that *do not seem particularly social*, such as *business sites, online magazines and information services*, have integrated **social opportunities** such as **chat spaces and bulletin boards** into their sites

Baym's statement demonstrates, how despite a seemingly complex understanding of CMC, thinking about CMC is still framed, to a large extent, within a view that regards certain spaces as inherently 'social', that is, dialogic, conversational and interactive, while others such as business sites and information services as intrinsically

disseminative. However, as Hine (2000: 50) usefully points out, there is little to be gained from itemising (like in Baym's observation) which aspects of the Internet are 'interactive' (or 'dialogic'), and which are not (i.e. 'disseminative').

The split between media-based models of communication and models of communication

Most existing models of communication suffer from another limitation. Notably, there is a split between models whose perception of communication depends on the specificity of media or technology, and models that concern communication in its larger sense. The latter, however, often overlook the relationship of the concept of communication to the media. Among the former kind of models one can find, for instance, Carey's model of transmission and ritual (1992), which is grounded in thinking about communication in relation to mass media, assuming the notion of audience as an integral component in the communicative process. It therefore fails to sufficiently account for *contexts* of communication such as interpersonal interactions, which are not defined by a producer-audience relationship. By the same token, Thompson's (1995) distinction of 'three types of interaction' namely face-to-face, mediated, and quasi-mediated interactions, is based on the specificity of media. Like Carey's model, it is grounded in thinking about communication in relation to media, and thus is limited in its capacity to adequately account for communication in non-media contexts. Other kinds of models suffer from the opposite problem. These models present an account of communication that is not dependent upon the specificity of technology, but rather enquires into the meaning of the process of communication in its larger sense. However rarely do these accounts develop the implications of their communicative model to include conceptions of media. Martín-Barbero's (1993) account is one such example. It offers enlightening insights into the notions of mediation and communication, however, remains relatively underdeveloped as far as these notions relate to media and technology. Another example is a recent account by Finnegan (2002) that purports to uncover the multiplicity of humans' creative ways of communicating across time and space, but gives very little attention to the centrality of the media in it. Peters' account (1999), mentioned earlier, is the only model (that I came across) that develops the concept of human communication in its larger sense, while, at the same time, providing a

compelling account of the case of the radio in the light of this model, with some suggestive insights about media and technology more generally.

Online narrating and storytelling

So far I have discussed two key tensions that have largely governed the theorisation of communication. In the remainder of this chapter I would like to link up these conceptual tensions and the specific exploration of narrating in breast cancer patients' online communication. I hope to show how the analysis of patients' processes of online narrating – to be explored in the following chapters – might suggest a way of encompassing some of these larger conceptual tensions. In other words, by juxtaposing the general discussion on dichotomies in models of communication and the particular case of patients' online narrating, my aim is to open up a possibility for thinking about how these dichotomies might be integrated. To unfold this proposition, it seems useful to follow the schematisation of Peters' model of dialogue and dissemination, as presented in the beginning of the previous section.

It should be said, however, that the following discussion of online narrating as a way of easing theoretical tensions between existing communication models is, of course, hypothetical. This proposition needs to be qualified and substantiated in light of the analysis of the empirical data in Chapters Five to Seven. Hence, rather than assertions, the following observations should be read as initial suggestive directions, to be further addressed in the subsequent analytical chapters.

Online narrating and the dialogue/dissemination dichotomy

Direction of communication, sender-receiver relationship

As stressed in Chapter One, theoretically narrating is predicated upon a promise for *exchange* (following Barthes' and Brooks' theories of narrative). That is, the narrator has an implicit knowledge that others would read her story and has an expectation that they would reply. Empirically, as will be demonstrated in Chapter Six, patients' online narrating has indeed a significant dialogic dimension. In many instances, the 'mentoring' relationship that emerges online between survivors and newly diagnosed patients echoes the Socratic view of a one-on-one interactive relationship between philosopher and pupil!

At the same time, on a theoretical level, narrating in the online context is a process which also contains significant disseminative components. This is primarily due to its textual characteristic, as Ricoeur observes: "In writing, the 'narrowness of the dialogical relation explodes. Instead of being addressed just to you, the second person, discourse is revealed as discourse in the universality of its address...An unknown, invisible reader has become the unprivileged address of the discourse' "(in Peters, 2001: 150). How is this manifested in the case of breast cancer patients' engagement in online narrating? As I will aim to show, the potential global scale of readers, promised by the World Wide Web, plays a significant role in motivating patients to write their story and publish it online. So, while reciprocity and exchange are central to the experience of online narrating, there is a significant monologic dimension to this communication. Patients' personal homepages that recount the 'journey of their illness' are a good case in this point. These are often a kind of 'personal performance', disseminative in nature, where it becomes the reader's responsibility to interpret the text, with no necessary capacity for aid from the narrator.

In short, rather than *either* dialogue, *or* dissemination, in exploring patients' processes of online communication I will try to show how both attributes can be present, often at the same time. The notion of narrative as a gift captures this duality neatly: '...a gift always hovers somewhere between unprovoked generosity (one-way) and the call for a later return gift (reciprocal)' (Peters, 1999: 58). Take, for example, a message posted on a breast cancer message board. It is at the same time a creature of dissemination, whose addressee is polygamous, and a creature of dialogue, often leading to a one-on-one correspondence (usually via e-mail, after the initial message was posted on the public board) and to the emergence of a reciprocal relationship.¹⁶

Intimate vs. public, exclusive vs. inclusive

The second tension that will be addressed during the exploration of patients' communication as online narrating is that between the private and the public. Patients' participation in online narrating happens privately and publicly at the same time. Patients' performance of their illness' stories on breast cancer related websites is radically public; it is 'out there', inclusively indifferent to all. At the same time, there is a strong sense of intimacy in this mode of communication: participants share some of their most private experiences, anxieties, thoughts and feelings on this public space.

What is more, as already mentioned, often the relationship that emerges in the public space (e.g. on a message board) moves into e-mail, which constitutes an exclusive intimate setting, allowing a private mode of communication.

Jacques Derrida has famously argued that all mailed correspondence has the implicit structure of a postcard, that the attempt to restrict the reception of a message to one recipient is always undermined by the scatter of all textuality. Derrida's argument, claims Peters, was historically possible only so long as the postal system was not made a secure private channel (Peters, 1999: 166). The case of patients' online communication, especially on forms such as message boards and discussion groups seems to reopen this question, allowing the production of a message which is addressed to a particular recipient while at the same time implicitly inviting the engagement of other readers by the publicity of the text.

The issue of inclusiveness and exclusiveness goes, however, beyond the question of whether the setting of the communication is public and inclusive (e.g. message board) or private and exclusive (e.g. e-mail). The discourse of the communication, and, particularly, the form of a narrative which organises this communication, are also on the one hand inclusive, ostensibly open to all, while at the same time consist of 'hidden rules' (as put by one of my interviewees) that exclude certain meanings and certain forms of expression. For example, there is an almost complete exclusion of death from the online discussion (Sharf, 1997).¹⁷ In discussing narrating as a central process in patients' online communication, I will attempt to highlight how it works to include, while at the same time exclude, certain meanings; how the act of narrating furnishes an accessible framework for any participant to construct her experience, while at the same time it latently functions to produce certain meanings and exclude others, inevitably excluding particular users from participating.

Embodiment vs. disembodiment

Interestingly enough, the online experience allows patients the communication of a highly embodied experience in a disembodied space of communication. Socrates' notion of embodied communication as the prerequisite for soul-to-soul intimate interaction might be challenged in that case: while online narrating is indeed disembodied (its communicators are spatially disjointed), its qualities, as I will argue

in the data analysis, are those commonly associated with embodiment: intimacy, sincerity, reciprocity and bonding. Needless to say, this is not unique to the process of narrating. Previous studies have already shown how intimacy and bonding are forged specifically in an anonymous disembodied context such as the online space (e.g. Baker, 2002; Ben-Ze'ev, 2004). However, in analysing patients' online experience, I will try to consider the role that the particular process of narrating might play (or not) in that. I will particularly explore narrating as a way of providing a framework for one to construct one's 'self' in a very detailed and vivid fashion, bringing the actual embodied personality into the interaction (often including very specific descriptions of bodily aspects). This is not to say that other processes of communication are not equally relevant to understanding how the tension between the embodied and disembodied is managed, but merely to highlight the potential salience of narrating in this context.

Juxtaposing the particular context of this study – that is, patients' experience of online narrating – with the broader conceptual dichotomies of models of communication reveals a potentially complex picture. It shows that we cannot speak of either dialogue or dissemination, but rather of a 'hybrid middle', in which supposedly dichotomous processes exist simultaneously. In the analytical chapters that follow, I will seek to explore this complexity further. I shall ascertain the extent to which the conceptual tension between dialogue and dissemination can indeed be integrated by using narrating as a model for understanding patients' online communication.

Online narrating and the media/communication split

The account of patients' online narrating will also seek to encompass the tension between models whose view of communication is dependent on the specificity of technology and media and models that overlook the centrality of the media in accounting for communication. On the one hand, as already discussed, the model of online narrating is engendered by the broader theory of narrative and narrating. It enquires into the essence of narrating as a *communicative process*, which is embedded, in the case of this study, in patients' engagement in the social world. Clearly, this theoretical and conceptual perspective is *not* restricted to a specific technological context. At the same time, the exploration of patients' online narrating will address the implications of the *specific technological context* in which narrating

takes place. It will concern the ways in which the nature of narrating shapes and is being shaped by, the online space.

Conclusions

The aim of this chapter has been to position the discussion of patients' online narrating in relation to other available models of online communication, and of communication more generally. Interactivity and online conversation were discussed as the central paradigm that was developed to account for online interaction. I argued that, despite its explanatory power, this paradigm is insufficient to account for the processes of communication among breast cancer patients. Against this backdrop, I introduced online narrating as a more useful way to account for this specific context. Following this proposition, I then highlighted possible ways in which online narrating, as a model for explaining patients' online communication, can potentially integrate some broader conceptual dichotomies that characterise existing models of communication.

Although online narrating has been advanced as an appropriate way to explain the communicative context under scrutiny, it should not be seen as if it was proposed as some kind of a privileged model that resolves the pitfalls of all other models. As I stated in the beginning of the chapter, breast cancer patients engage in a wide range of communicative activities that can therefore be understood and explained in various ways, using different models. Online narrating is proposed here as a specifically helpful way to account for what seems to be central in the case of breast cancer patients' online communication. Much of what has been suggested here in relation to online narrating is definitely not distinctive nor exclusive to narrating as such. As I mentioned, the model of online narrating bears similarities to the traditional approach of discourse analysis, insofar as they both emphasise the way meanings are being generated. Furthermore, by no means do I suggest that there is something inherent in the model of online narrating that can essentially resolve the dialogue/dissemination dichotomy and the split between media-based and communication-oriented approaches. Arguably, any sensitive empirical account of communication processes can show how, in actual contexts of communication, these conceptual tensions do not necessarily emerge as such. My modest aim has been to offer online narrating as a

conceptual tool to enlighten how this kind of dialectics takes place in the case of breast cancer patients' online communication.

The proposal of a communicative model that resolves, or at least eases, conceptual tensions that exist in other models, is considerably seductive. Having said that, this very aspect is also its weakness: describing patients' online narrating as give-and-take and at the same time a one-way-act private and exclusive while at the same time public and inclusive, disembodied and embodied – runs the risk of lacking a clear focus. As a result, some might argue, it is hard to tell what the consequences of such a fundamentally dialectical process are. For instance, does narrating work mainly to allow participants to exchange experiences and information in an inclusive way, or is it largely a one-way process, allowing only a few voices to communicate and govern this communicative space? I do not intend to offer decisive answers to this kind of question. I do, however, wish the reader to bear this criticism in mind, while I will attempt to address it throughout the analysis.

The aim of the following chapters is to examine the proposition made in this chapter: to what extent is online narrating a useful way to examine the communication that takes place among breast cancer patients online? How far are these conceptual dichotomies indeed integrated in this context? In the light of the proposition of this chapter, the analysis in the subsequent chapters will focus on three dimensions of patients' online narrating. These dimensions represent the ways in which patients construct and present narrative through their online experience. The aim is to show how online narrating works to furnish patients with a communicative tool that is meaningful for their everyday lives and for the management of their illness. **Chapter Five** discusses the issue of emplotment and the construction of closure. It highlights how users perceive this process as both 'monologic' and 'dialogic; how the process of emplotment and closure construction contains 'disseminative' attributes such as asynchronous communication, while at the same time necessitates dialogic interaction, based on exchange with other fellow-sufferers. **Chapter Six** explores the dialogic component of patients' CMC, and specifically their engagement in narrating. In so doing it casts critical light on many presumptions about what we consider as dialogic. For example, it illustrates how the act of lurking is central in patients' development of reciprocal relationships, while at the same time it contains clearly

monologic aspects. **Chapter Seven** takes this argument one step further. It illuminates patients' perception of their Internet use, and especially the act of narrating their experience online, as both private and public. In other words, in patients' actual experience the relation between the private and the public is not necessarily mutually exclusive, nor is it inevitably dichotomous.

Through exploring those three dimensions in depth, the analysis also seeks to integrate an understanding of communication as embedded in the specific context of the Internet, with a broader understanding of communication as a social process. Fundamentally, rather than specifying the intrinsic properties of the medium, the point of departure for the analysis is the particular social and communicative processes in which patients engage online. It is only this way that we can say something meaningful about the communication under scrutiny and seek to transcend the separation between a media-based view of communication and an approach to communication as a social process.

The distinction of the three dimensions is, of course, merely analytical. Nevertheless, it is useful as a framework to account for the nature of online narrating and its significance. It is through the separate exploration of each dimension that I also wish to pursue the argument for narrating as a process through which the online and the offline are interwoven.

At this stage, the account of online narrating lacks sufficient self-criticism. A detailed critique of the usefulness of the model of online narrating (as suggested in this chapter) will follow the analysis of the empirical data in the concluding chapter.

¹ 'Interactivity' has been often elevated to a kind of a mythical property of CMC: 'a theoretical construct that grapples with the origins of captivation, fascination, and allure that can be inherent in computer mediated groups' (Rafaeli and Sudweeks, 1997, cited in Downes and McMillan, 2000: 159).

² For example, the issue of JCMC titled 'Persistent Conversation' presents a collection of essays concerning online conversation. However there seems to be a very weak link between the different definitions and perspectives of online conversation that are suggested in the different essays. Consequently, online conversation seems to have too many meanings, with no clear reference.

³ Similar questions and concerns to those were raised during the introduction of the telephone (Marvin, 1988) and the radio in the 1920s and the 1930s (Peters, 1999).

⁴ Empirically, online conversations have been examined also in asynchronous systems such as e-mail, mailing lists, news groups, and message boards (Erickson, 1999); however it seems that the body of work that has substantially shaped the theorisation of online conversation is that on synchronous forms.

⁵ Turn-taking is the central aspect with which the CA approach is concerned, referring to conversational phenomena such as asking and answering, offering options and choosing preferences etc. (Hutchby, 2001: 9).

⁶ This observation resembles the Socratic model of an oral dialogue (to be mentioned later in the chapter) which rejects writing, the latter claimed to be to be inhuman, impersonal and destroying authentic dialogue (Peters, 1999: 47).

⁷ Several analyses of CMC accounted for the disseminative form, using concepts such as 'monologue' (McMillan, 2002), 'transmission', 'allocution' (Jensen, 1998, in McMillan, 2002), 'static texts' (Hine, 2000) and 'broadcast' (Fidler, 1997). However, relatively little attention has been given to the examination of CMC as a disseminative process, and what has been written seems generally limited, commonly focusing on commercial and organisational contexts of CMC.

⁸ Peters (1999) calls this a 'moral tyranny of dialogue'.

⁹ I thank Roger Silverstone for this insightful observation.

¹⁰ I thank Don Slater for this comment.

¹¹ Hayden White (in Mitchell, 1980), in his famous account, discusses the distinction between three modes of historical discourse: chronicles, annals and narratives.

¹² This argument goes hand in hand with the ethnographic shift from asking whether Internet interactions are authentic to an empirical focus on how, where and when identities are made available on the Internet (Hine, 2000: 118).

¹³ As I discuss in later chapters, for most breast cancer patients whom I interviewed, online synchronous forms seemed inappropriate environments to communicate their personal experience of illness.

¹⁴ Gerbner modified his stance through time, acknowledging more room for the capacity of viewers to interact with media texts.

¹⁵ However, this aspect remains undeveloped in Hall's model.

¹⁶ Based on Peters' (1999: 167) analysis of the post office.

¹⁷ This observation is corroborated by my analysis of online discussion on breast cancer.

Chapter Five

Emplotment and the Construction of Closure

I don't know how many people search for 'cancer experience' but it's more likely they'd search for 'cancer story'. (E, the designer of a cancer patients' website, interview 5).

While for E, a cancer website designer, the centrality of illness narratives online is common sense, it is striking how little research has been done on this issue. The very few works done on online illness narratives (McLellan, 1997; Hardey, 2001, Hardey, 2002) represent the view that 'on-line narrative of illness is the electronic counterpart to published accounts of one's own illness' (McLellan, 1997: 89). Consequently, these works are concerned with exploring the differences between 'conventional' and 'online' narratives of illness. They regard traditional written narratives of illness as a baseline to examine online narratives. There are, however, two main problems with this approach. First, they compare online narratives only to *written* texts. In so doing, their analysis falls mainly in the literary domain, concerning the text as a fixed product. It overlooks, however, the process behind the construction of these texts: how and why do these narratives evolve? What drives patients to produce such stories? What is their significance for the patients who produce them? Furthermore, in focusing on the analysis of the textual properties of online narratives, studies such as McLellan's or Hardey's fail to recognise the oral qualities of these texts, an aspect I will aim to show in my analysis.

Second, construing offline 'conventional' illness narratives as a 'baseline' might be a useful point of departure. However, thinking about online narratives only in relational terms, that is, against conventional (offline) narratives, constrains our ability to recognise the former's distinctive qualities that are not necessarily comparable to those of 'offline' narrative. Hardey (2001; 2002), for instance, treats online illness narrative as simply another form (albeit with some novel qualities) for patients to communicate their illness.

The following chapter aims to account for the specificity and the significance of the processes and forms of narrating that emerge in patients' online communication of breast cancer. Rather than written narrative of illness, my point of departure for this exploration is the notion of narrating (as introduced in Chapter One). That is, I start by

examining how patients' online experience facilitates the production of their self-narratives: constellations of *relationships* (connected parts) embedded in *time and space*, constituted by *causal emplotment*' (Somers, 1994: 616, italics in original). In light of this definition, to fully account for the centrality of narrating in patients' online experience, and its significance for their coping, we need to ask: how does a process of emplotment take place in online spaces? How are elements of one's experience being configured into a whole on online sites, and how do processes of online communication work to direct them towards closure?

To address these questions I present an analysis of patients' accounts of their online communication of the experience of their illness. I focus particularly on their reflections of the ways in which they engage(d) in the processes of emplotment and construction of closure. Unlike the abovementioned authors, I do not pursue a consistent comparison between online and traditional narratives. My aim is to appraise what is distinctive and significant about the process of narration when it takes place online.¹

To go about this task, I start by discussing patients' need to make sense as the primary condition for their decision to engage in online narrating. I then move on to exploring the ways in which the online communication of breast cancer acts to furnish patients with frameworks of meaning for the construction of their narrative. I focus on four key aspects that underlie these frameworks of meanings, namely: (1) locating experience in time and space; (2) the 'gluing' of elements by an overriding topic; (3) the kind of environment as an organising principle of meaning; and (4) establishing a narrating authority, reflecting on the distinctiveness of the online context in relation to each aspect. While each of these dimensions is explored specifically in relation to the discussion of narrating, at the same time they relate to other communicative processes, which, where relevant, I acknowledge.

Next, I examine the ways in which patients' online experience directs them towards a construction of closure. The notion of closure construction is seen as central, and to a large extent distinctive, to the process of narrating. As implied in the conceptual exploration of narrating and emplotment in Chapter One, one of the key features that characterises the process of narrating (and distinguishes it from other communicative

processes) is the imposition, or the attempt to impose, closure on the account of events. Patients' struggle to construct closure is discussed in light of the notion of survival as a dialectical process that entails remembering the painful experience, while at the same insists on a closure of the painful chapter and moving on towards an optimistic future. In particular, I examine the inextricable link between narrating and survival, and its significance in patients' online narrating. Finally, I explore situations in which patients stop engaging in online narrating. Looking at why patients stop engaging in the interpretative work of narrating enlightens our understanding of the meaning of the act of online narrating, and helps to further clarify its scope and limits. I conclude by integrating the different aspects discussed in the chapter into an argument about the function of online emplotment and its consequences. Significantly, the rationale for the thematic organisation of this chapter (as well as those which follow) is an enquiry into the social practices and processes in which patients engage, rather than an exploration of how the technical properties of the medium create, shape or determine patients' experience.

How does the online experience work to facilitate a process of emplotment?

A fragmented reality, a fragmented representation

I would like to open the discussion of this question with two extracts from patients' accounts. The first excerpt is the opening paragraph of an e-mail account of a 51 year-old breast cancer survivor (herewith: B), who relates her online experience in the context of her illness. The second excerpt is part of a face-to-face interview with J, a 44 year-old breast cancer survivor.

(1)

I was Dx 10/98 - I found the lump in my breast; mammography failed to detect it. Ultrasound with guide wire confirmed lump. Lumpectomy 11/98 - results invasive ductal carcinoma and DCIS (ductal carcinoma in situ) - pre-cancerous cells. Lumpectomy did not achieve "clean margins"-when they slice the tumour for pathology they ink the edges. If edges are "clean" they have gotten all the cancer. 11/98 had a wide excision (large lumpectomy) and axillary dissection (lymph node removal). No positive nodes (good sign that cancer has not spread further than the breast) but unclear margins again. 12/98 had mastectomy. (B, online narrative 2).

(2)

Q: What kinds of things were you looking for (when you went online)?

J: I wanted to know, really: Me! (laughs). 43 old male, oh female! pre-menopausal, has this kind of cancer, at this stage, several lymph nodes, what's going to happen? And of course, I was probably looking for the impossible. (J, interview 10)

In the first excerpt, B starts her account with a detailed report of her diagnosis. The different elements of her diagnosis constitute the backdrop for her experience of going online. Similarly, in the second excerpt, J describes her expectations from the Internet and her actual online experience as being directly framed by the specific elements of her diagnosis.

What notably emerges from both B's and J's accounts, and is corroborated by accounts of other interviewees, is the fragmented way in which the diagnosis is represented. The diagnosis appears as a set of terms and elements which are totally foreign to the patient/author's life, lacking any meaningful connection between them. Had B's account not been written in the first person, one could have easily thought it were part of a laboratory medical report; the language is highly medical and the style extremely informative, laconic and impersonal. By the same token, J's description of her diagnosis constitutes a set of elements which appear totally disjointed: 43-old female/pre-menopausal/breast cancer/stage X/several lymph nodes. This kind of representation resembles what Hayden White, in his seminal essay *The Value of Narrativity* (1980), referred to as *annals*. This form of representation 'possesses none of the attributes that we normally think of as a story: no central subject, no well-marked beginning, middle, and end, no peripeteia, and no identifiable narrative voice' (ibid.: 87). It does not suggest any necessary connection between one element and another, and all elements seem to have the same order of importance or unimportance. Finally, it 'does not conclude; it simply terminates' (ibid.: 8).

However, for a breast cancer patient, unlike the historian annalist,² it is often impossible to sustain her experience in such a disjointed form. To manage the disturbance posed by the cancer to the 'normality' of her everyday life, she seeks to connect the fragmented elements of her diagnosis into a coherent and plausible framework. Such a framework is geared towards making sense of her experience and directing its seemingly unconnected elements towards a closure, namely (as J put it): 'what's going to happen to me?' The argument of this chapter is that among the frameworks of meaning available to patients online, one of the frameworks the online

communication furnishes them with is narrating. This framework enables them to emplot their experience and direct it towards a certain closure. In what follows, I wish to account for the ways in which this process works.

Going online as a means of dissipating 'the fog of confusion and fear'

...I have found the internet to be extremely useful and have found several sites [...] that have helped me through the fog of confusion and fear. (A message posted by a breast cancer patient on a message board.)

The quest for sense-making is a central factor in women's motivation to go online in the context of their illness. Interviewees' descriptions of the situation that prefaced their referral to the Internet portray a fairly chaotic state of mind, in which they had many questions and unknown fears. Indicative of this total confusion is J's comment (interview 10), that recounts how despite her familiarity with the illness (both her mother and grandmother suffered from breast cancer) when she first went online to search for information about the disease, she had to find out how to spell 'breast cancer'. The following online account is a neat testimony of the uncertainty that governs patients' condition following the diagnosis of breast cancer (note the repetitive use of three dots, indicating confusion and uncertainty):

...everyone is afraid and wants to know what the other has gone thru what they should do... where they can get information, so they can make the right choices for them... what to ask their doctors...how to be their own advocate...how to deal with side effects, and what side effects to expect? How are we dealing with the trama of losing our hair and being bald... Our families, relations with our spouses, our children, friends, our jobs, insurance, indifferent doctors, or bosses... Depression, fatigue...where to find local support...dealing with the loss of their breast/breasts... to reconstruct or not?... there are million questions... (Online narrative 15).

Significantly, these questions arise at different stages of the illness. Indeed, the diagnosis is perhaps the stage where confusion and uncertainty are acute (as has been shown in the previous accounts of B and J). Unsurprisingly, it is often the time when women refer to the Internet and start engaging in an attempt to make sense of their situation. However, since confusion and uncertainty are lurking features of the experience of the illness, especially since the reality of breast cancer does not allow final closure – there is always the risk of recurrence. Therefore, the project of 'making sense' (and consequently of narrating) is continuously a work-in-progress.

So, a major motivation of patients in going online, whether consciously or not, derives from the need to organise and make sense of their experience. A key procedure that enables this process is that of narrating, and more specifically emplotment: configuring elements into a whole by 'grasping them together' and directing them toward a conclusion or ending (Polkinghorne, 1991: 141).

Frameworks of Meaning

The online experience enables patients to grasp together the different elements of their experience by furnishing them with 'ready-made' frameworks of meaning. These frameworks are constituted by other women's stories and by the visual and textual manners in which breast cancer websites are structured. On some sites, when a breast cancer patient goes online, she is implicitly directed to insert her personal experience into publicly available frameworks that help her configure and order her experience. These frameworks evolve according to four key principles: (1) locating experience in time and space; (2) the 'gluing' together of elements by an overriding topic; (3) the kind of environment as an organising principle of meaning; and (4) establishing a narrating authority. In what follows, my aim is to demonstrate how these principles facilitate patients' online narrating. While I do not suggest that they are in any way exclusively tied in to narrating, the discussion of this chapter underscores the ways in which these four principles create a particularly fertile context for the production of patients' narratives.

(1) 'An easy structure to work with': Locating experience in time and space

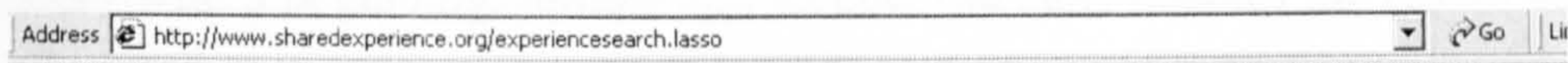
...let's try and organise the thoughts...chronologically it's probably the easiest thing, isn't it? It's an easy structure to work with. (K, interview 11)

It is not accidental that the above quote is the way in which K started her account in her interview. Breast cancer patients look for an 'easy structure to work with', that is, to organise their experience within a coherent framework which they can inspect, think about and plan actions around. As K suggests, one element that may provide this 'easy structure' is a temporal (and inevitably also spatial) ordering of the 'experience of the illness'. A visit to various breast cancer websites in which patients publish the stories of their illness reveals how patients' narratives are given coherence and order by the way that events are linked together within a broader sequential framework.³

However, beyond the fact that these stories are performed on the online space, there is nothing new in arguing that the narrative orders the experience in time and space. At stake is the question of the specificity of the online communication in enabling this ordering of experience in space and time. What is it in the online environment that facilitates the construction of an ‘easy structure to work with’?

‘Shared Experience’ website (www.sharedexperience.org) furnishes a useful example to start addressing this question. It is defined as a ‘Cancer Support Knowledgebase’, designed to enable cancer patients and their caregivers to share their experience of illness online.

Figure 5.1 ‘Shared Experience’ search page (<http://www.sharedexperience.org/experiencesearch.lasso>)



Search the Shared Experience Pages

Try searching using different words in the form fields. You can narrow the search by selecting a specific cancer type from the "LIST All" pop-up menu below, then after viewing results, return to this page and try other words in different fields to broaden or narrow your searches.

| Search Experiences Database | |
|--|-----------------------|
| Cancer Type: | BREAST |
| Diagnosis: | DCIS |
| Chemo Drugs: | Tamoxifen |
| Treatment: | mastectomy, radiation |
| Quality of Life: | Fine |
| Information Gathering: | Susan Love, Internet |
| General Comments: | Never give up hope |
| Page Number: | |
| <input type="button" value="Find All"/> - or type keywords above and click: <input type="button" value="Search"/> <input type="button" value="Reset"/> | |

As can be viewed in figure 5.1, to search the website’s database of patients’ stories of their illness, or, alternatively, to add one’s personal story to the existing database, one has to choose a particular cancer type from a dropdown list. Rather than using an open form, one enters one’s personal story into a structured form, which contains a range of possible ‘stories’: Acute Myeloid Leukaemia, Brain Tumours, Breast cancer and so forth. Below this dropdown list there are open text fields for categories such as ‘diagnosis’, ‘chemo drugs’, ‘treatment’, ‘quality of life’ and so forth, to allow entry of particular details. Visually, these categories appear as text boxes. They are static ‘grids’ of meanings that help the patient (both as narrator and as reader) to impose meaningful order on the incoherent experience of her illness. This technical structure,

which is repeated in different variations in different websites,⁴ helps to turn the flux of the experience into narrative and provides the patient with a tool to master events that are ordinarily beyond her control.

A different way to construe this personal stories database is as a tool of translating narrative structure into forms of information. That is, rather than presenting each patient's personal story as a whole, that is, as a coherent framework which configures different events on a temporal order and directs them toward a conclusion, the personal story is actually fragmented into small units of information which are clustered under a fixed range of generic topics (e.g. 'diagnosis', 'treatment' or 'quality of life'). The poster dismantles her experience into 'chunks' of information that she can fit and insert into the table's rows. Rather than reading a posting 'vertically', as a story with a beginning, middle and an end, the table enables the reader to view many postings in parallel, reading information on one aspect, e.g. 'treatment', 'horizontally', that is, across many postings. In this way, the process of narrating is actually transformed into a process of information seeking.

Another online element that provides patients with a sequential and spatial framework to organise their experience, is the actual interaction with fellow sufferers through message boards and e-mail correspondence. I will discuss in depth the aspect of patients' interactions on the breast cancer online forums in Chapter Six, as this is a substantial feature of patients' engagement in online narrating. For the purpose of the current discussion, I wish to highlight one point that is related to patients' interaction and exchange of experiences on the online space.

The process of locating one's experience in time and space is based primarily on the interaction between 'veteran' online participants (who are also veteran in the experience of illness and treatments) and 'newcomer' patients. It is often the case that women who join the discussion on message boards and similar breast cancer online forums, are welcomed by 'veterans'. The work of 'welcoming' entails the implicit provision of a sequential framework, to guide the newcomer about the way in which she has to organise her experience. As B relates:

...AOL had some boards for breast cancer. That one had all these people that were there that had been through it or were still going through it and I remember typing in

questions there and those people answered me. Somebody answered me right away and then I got hooked on to go and talk to these people. I remember the whole time I was going through the treatment, they would tell me: you've got to do this, and I would tell them tomorrow I'm going to have this, and they would tell me what it was. (B, interview 2)

A posting of a newcomer's story is usually followed by replies from other members – whether on the public space of the message board or privately via e-mail - who draw on their own experience to help the newcomer order her own experience. The work of 'ordering' is based on women who draw on their past experience telling the newcomer what to expect at which stage. For instance, should she get a wig before or after her hair falls out because of the treatments? An issue such as the timing of getting a wig is key to one's configuring of one's experience into a framework that one can practically think about and plan actions around.

Arguably, this kind of communication does not necessarily take the form of narrating. In the example above, communicating issues such as purchasing a wig is more likely to be done by a straightforward exchange of questions and answers on a message board or by e-mail correspondence. That being said, I suggest that narrating entails a different element, which goes beyond mere information exchange, insofar as it enables the communicators to order their experience in time and space. B's above quote alludes to the centrality of the temporal dimension and thereby the significance of a communication process that helped her to order her experience temporally. The communicative situation she describes involves, undoubtedly, information exchange. However, I wish to argue, it consists of more than that: B's comment points to an ongoing communicative interaction which enabled her to configure the events she has gone through in the past, is going through in the present, and is about to go through in the future, into a comprehensible framework of meaning. This process, I propose, following the theoretical assertions presented in Chapter One, can be usefully understood as narrating.

The asynchronous form of the communication is another element that fosters the process of locating patients' experience in time and space.⁵ The narrator addresses the posting she publishes online to certain readers, whom she assumes (given the asynchronous nature of the communication) would not be necessarily present online at the time she posts her message. Consequently, the author of the message

unconsciously fills in gaps and orders her account coherently, so that the readers are able to relate to it without the author being necessarily present at the time they read it. What the author has to tell is inevitably made more explicit and coherent, primarily by ordering her experience in time and space, than if it were communicated in an asynchronous interaction such as conversation. In other words, the asynchronous context of the communication seems to gear the messages being posted into a narrated form, or at least a discursive form which is more ordered, coherent and explicit than what would have been posted had the setting been synchronous. This does not suggest that all postings on asynchronous forums are narratives, but certainly there is an implicit pressure in asynchronous communicative contexts to produce texts that have narrative components, in particular, a temporal ordering of events.

A useful example of this point is given in the fictional (though highly realistic) account *Dear Stranger, Dearest Friend* (Katz Becker, 2000). The book recounts the story of an e-mail friendship that emerges between two breast cancer patients: Susan, a survivor, and Lara, a newly diagnosed patient. They meet on a breast cancer related message board and develop an intimate exchange of emotions and experiences that gradually extends beyond the mere experience of the illness. Immediately after coming back from a mammogram, where the doctor suspected her to have breast cancer, Lara e-mails Susan, her veteran fellow-sufferer, recounting her experience of the mammogram. She opens her letter by saying:

I'm tempted to simply skip the details, but I know you'll write with questions about why and how and when, so I'm going to force myself to slow down, *breathe* and tell you what happened, in the order that it happened. (Katz Becker, 2000: 87).

The fact that she addresses her text to a certain reader and the knowledge that her reader would read her message in her absence, *forces* the author, as Lara puts it, to order her experience in a coherent sequential framework, that is, to narrate. Indeed, in her e-mail she produces an extremely coherent account that configures the different details of her mammogram experience into a plausible narrative.

(2) *The 'gluing' of elements by an overriding topic*

The procedure of locating one's experience in time and space involves the assignment of importance or significance to the different elements of the account. Their significance derives from their relation to an overriding subject that organises the story. As White (1980: 15) observes:

...the capacity to envision a set of events as belonging to the same order of meaning requires a metaphysical principle by which to translate difference into similarity. In other words, it requires a "subject" common to all of the *referents* of the various sentences that register events as having occurred.

In other words, for a text to become a narrative there has to be an organising principle of meaning that 'glues' the different elements into a whole. The thematic structuring of the online communication serves to facilitate such an overriding subject that assembles the different referents into a whole. The online space is compounded by topics: website names, names of discussion groups, titles of the messages' subject on message boards, e-mail subject titles etc. Every discursive element belongs to a subject that works as an organising principle of meaning. It allows patients to envision a set of personal events belonging to the same order of meaning, and by so doing furnishes them with tools to narrate: to assemble separate elements into a meaningful whole.

In A's experience, for instance, age constituted the overriding principle of meaning. Having been diagnosed with breast cancer at the age of 31, age constituted the primary factor that governed her experience. She therefore sought a communicative framework that centred on the subject of breast cancer at early age:

I didn't go to the support group nearby my house, because they were all from different ages, [...] whereas [at] Young Survivors Coalition [a breast cancer website] they're younger and that was much more comforting, because I was able to interact with people who were at the same age who understood the... (A, interview 1).

The key words A typed in into online search engines, namely 'breast cancer' and 'young' constitute the organising theme of her story. It lead her to communicative spaces that would potentially provide her with a relevant framework of meaning, to which she could relate and into which she could fit her experience. Significantly, A

highlights the capacity to reach specific communicative forums that are relevant to her personally as highly advantageous, in contrast to the face-to-face support group that was available to her in her geographical area. While a face-to-face support group is, of course, also organised by an overriding theme, it is often too general and hence limited in its capacity to help a patient to make sense of her specific circumstances. In this respect, the embodied nature of a face-to-face support group is constrained, insofar as it depends on the physical location of the patients, rather than on the thematic specificity of their experience. This significance of the flexibility of the online communication and patients' capacity to find a personalised context of communication is a notion that recurs in patients' accounts. As the following patient stresses in her e-mail account, by using capital letters to signify shouting:

There is a ton of info on the web - there are also many quacks out there - just like in life, you have to decide what is real, what's valid and what has value FOR YOU PERSONALLY. (Online narrative 2).⁶

Even F, who denies the centrality of Internet use in the experience of her illness, actually implies in her interview the usefulness and significance of the personalised aspect of the online communication. That is, the capacity to 'tailor' the communication 'out there' to one's personal concerns and needs:

I guess I'm not that into the Internet thing, except for what I want it for, for specific things. What I look for, for specific things (emphasises 'I'). (F, interview 6).

K's experience (interview 11) seems especially enlightening in this regard, as it manifests a case of a failure of the frameworks she encountered online to help her in making sense of her experience. Since she found the dominant online frameworks incompatible with her personal experience, K failed to engage in narrating. K first went to Susan Love's website. Susan Love is a breast cancer doctor whose offline and online resources are commonly considered by breast cancer patients as the 'bible of breast cancer' (see Love, 2000; www.susanlovemd.com). She found it difficult to 'fit in' her experience to the dominant meanings that frame this website, as she relates:

It was OK [Susan Love's website] [...] but the targeting really...you kind of look at things, and think: who's this for and what's this for? Am I in this target group or not? (K, interview 11).

She identifies two main frameworks of meanings that govern the online communication of breast cancer, however she cannot relate her experience to either of them:

I think there is a kind of terrorizing of women that's going on around breast cancer on the one hand. And on the other hand, there is an awful sentimentality about it. I just felt I couldn't relate to either of those really (laughs). (K, interview 11, my emphasis).

Following the failure of 'fitting in', she stops her online engagement in relation to breast cancer:

The reason I stopped looking at that stuff and didn't find it useful was that I found that around the time I was interested in having surgery, 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, it did come across like that. [...] At the same day [of] the appointment I found out that I've had breast cancer, the consultant actually wanted to start a conversation with me about reconstruction, and I didn't want to have this conversation at all! (K, interview 11).

K's online experience reveals patients' capacity not only to choose the frameworks that are relevant to their experience, but also to eschew those that they find irrelevant and futile. This capacity is depicted by K as unique, in contrast to offline contexts, such as her interaction with the consultant, in which frameworks are often inflicted on the patient. So, the flexibility of the online communication works in both ways: whether to enable a patient to relate her experience to a specific topic or to allow her to avoid altogether the available frameworks of meaning.

The thematic organisation of online sites and the capacity for conducting a personalised search prove highly significant in allowing patients a structure for the narrating of their experience. These organising principles, however, are not specifically connected to narrating. They can equally act as facilitators of other communicative processes. For example, the comment cited earlier of a patient who emphasises the personalised aspect of online communication, refers to her experience of information search rather than to that of storytelling. Hence, my aim in accounting for these elements thus far and in the following sections is not to claim that they are exclusive to the process of narrating, but rather to highlight their potential relevance and usefulness in enabling this process, among other communicative scenarios.

(3) *The kind of environment as an organising principle of meaning*

Another element that demarcates what is a 'relevant framework of meaning' for a breast cancer patient to communicate her illness is the *form* of communication in which the discussion takes place. In the previous section I discussed the notion of a 'subject' that glues different referents together and constitutes an organising principle of meaning in relation to the *content* of the communication. The organising principle I wish to discuss now has to do with the actual *medium* through which the communication is facilitated. I argue that elements are organised not only by overriding themes that glue them together, but also by the technical properties of the interaction. In this context, the key distinction that emerges from patients' accounts is between synchronous and asynchronous forms. Women's core engagement in the online communication of breast cancer seems to be in asynchronous, rather than synchronous forms. While the latter exist, mainly in the form of IRCs, they seem to attract a limited 'hard core' of members of online breast cancer groups. Unlike these participants, for most women whom I interviewed, chats represent an inappropriate platform for the kind of communication they seek.⁷ Chats are often depicted as an 'unknown territory' from which breast cancer patients deliberately exclude themselves. Tellingly, when interviewees mentioned chats they often expressed embarrassment. For instance:

I have never been into one of these chat-room things. I don't plan on going into it. I mean, I've heard some really wild stories! (laughs). I don't see that that would be interesting to me at all. (F, interview 6).

Even women such as the one quoted below, who are highly computer-literate, expressed their reluctance to use chats in relation to their illness:

I don't go on chat sites because I do not fully understand what is going on in those rooms. I go in to some chat rooms to see what they are talking about but it mostly seems to be people who are angry and need to vent or young people being ignorant. (Online narrative 14).

So, chat rooms appear as an environment that many breast cancer patients do not relate to. Arguably, unlike the woman quoted above, the perception of many women of chats is based on mediated representations of chats such as the discussion on sexual harassment and paedophilia on online chats, rather than an actual personal experience. What seems significant for the purpose of the current discussion is the way in which

the very kind of online form of communication constitutes a 'filter' that channels women to engage in communicating their experience elsewhere, that is, in asynchronous rather than synchronous forms.

Women look for a place where they can make sense of their experience. The work of making sense requires the patient to 'slow down and breathe', as described by Lara in her e-mail to Susan (see Katz Becker, 2000: 87). Indeed, the capacity to 'slow down and breathe' is a repetitive theme in patients' accounts in relation to their online experience. Women often stressed the significance of their ability to communicate online at their convenience in terms of time and space:

I could surf on my own time [...] when I was in the right frame of mind [...] and when the house was quiet so I could concentrate (Online narrative 7).

Never had to leave the house & go to the library had it all at my fingertips!!!! (Online narrative 8).

...the benefit of finding that information and support in the comfort of one's own home (Online narrative 24).

It was comforting to know that I could look up whatever I wanted and do it in my PJs [pyjamas] at 3 AM if I felt like it (Online narrative 2).

Chats do not allow one to 'slow down and breathe'; they demand instantaneousness and swiftness. Hence patients' preference of asynchronous forms such as e-mail or message boards.

In contrast to synchronous chats, the 'chattiness of e-mail', as G observes (interview 7), makes it a 'natural vehicle' for women to communicate their experiences. Asynchronous forms, and e-mail in particular, constitute an ideal platform for storytelling. On the one hand, they contain a dialogic dimension, which plays a crucial role in motivating women to narrate their experience (an issue that will be developed in the next chapter). At the same time, unlike synchronous online conversation, they provide the narrator with a monologic communicative structure that allows her a relatively high degree of freedom and control. The following extract captures this hybrid nature of asynchronous forms, as encompassing a communicative space that is both monologic and dialogic (the split into two parts is mine, to highlight the idea of duality):

monologic { When your in this situation you're on such a roller coaster it's nice to calmly sit down and search with out some one over your shoulder. And you don't have to talk to any one at that time. Grieve is a big part of the process and sometimes you just don't know how it will play in it. So there is no pressure [...]. And you can deal with it on your own time and own way.

dialogic { But if you need to talk your a click away. (Online narrative 25).

The following quote further endorses the potency of asynchronous forms in facilitating a space where a patient is neither dependent on immediate interaction with others, nor is she limited in time, or in space, and where she can arrange her thoughts independently and in isolation, before a correspondence starts.

Probably the best part of the internet is that you need to type your question or feeling before you can share it and sometimes just writing it down is a therapy of its own. (Online narrative 21).

In an online conversation, on the contrary, patients are far more dependent on the reactions of the other participants. However, to fully appraise the capacity of asynchronous online forms to allow a patient a communicative situation in which she can have a relatively high degree of control, we need to position it not just in relation to online synchronous forms (such as online conversation), but also against other offline communicative situations in which she could potentially engage. For instance, E, who is the designer and the owner of an online (asynchronous) website of cancer patients' stories, explains the significance of his online project precisely in relation to the limitations of (synchronous) face-to-face support groups:

Talking to strangers...that type of encounter in a physical place, it's so much about unconscious reactions to people! Body language and all that stuff...I think it's a very rare type and I don't think many people do that. (Interview 5).

In short, the combination of a space which allows participants to 'slow down and breathe', which contains both dialogic and monologic qualities, and is anonymous and disembodied, serves as a suitable place for the production of self-narratives. As has been discussed thus far, patients' engagement in the emplotment of their experience online entails the imposition of meaningful order on the incoherent experience of their illness (Brooks, 1994). Underlying this process is an attempt at gaining control over an experience where patients often do not feel in control.⁸ A key element that

facilitates the process of emplotment online, and enables the construction of control, is the establishment of a narrating authority.

(4) Establishing a narrating authority: The protagonist who propels the plot

I am sorry you had to join the ranks of women fighting the dragon

(A message posted by a veteran breast cancer patient-participant on a breast cancer message board, in response to a message of a 'newcomer' patient, who has been recently diagnosed).

Images of that kind are not rare on the online pages of breast cancer. In fact, I suggest, the online communication of breast cancer, through the act of narrating and storytelling, enables a process of establishing the breast cancer patient as a forceful heroine 'fighting the dragon'.⁹ This process is achieved through the establishment of the patient as a narrating authority, or, to put it differently, as the protagonist who propels the plot of her own illness. The significance of this process lies in the hermeneutic relationship between narrating and agency (as discussed in Chapter One): through the act of telling, the authority of the narrative becomes the authority of reality itself. Following the theoretical assertions that were discussed in Chapter One, a patient's construction of herself as an active agent on online sites is seen as an action; she asserts herself as an active patient, informed and involved in the course of her illness and healing. The subsequent quote is a useful point of departure for substantiating the claim for the mutually implicated nature of the story one tells and one's identity as a patient:

There are women on the message board in all stages of breast cancer. The ones who stick around 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 narrative 15).

The author 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.

For a patient to constitute herself as an active online participant, she has to make her participation visible. 'Leave your footprints' as 'Shared Experience' website encourages its visitors, and do it in a very particular way:

Add to this Shared Cancer Knowledgebase
Please don't think of this as "filling out a form". Be **conversational**, and write as much as you want, and say whatever you want.

(www.sharedexperience.org)¹⁰

In other words, the way to construct oneself as an active participant, and thus an active patient 'fighting the dragon' is through writing. Of course writing is not the same thing as narrating. Writing can be involved in various ways of online participation and self-presentation in which patients establish themselves as authorities through text, narrating being only one such way. Thus the discussion of narrating should be qualified and understood within the wider context of patients' engagement in various online textual activities in which they seek, whether consciously or not, to assert their agency.

Personal homepages are probably the clearest manifestation of a monologic space where a breast cancer patient constructs herself as an active agent who propels the story of her illness. One of the informants of this study launched her personal homepage where she traces the experience of her illness and healing. Clearly, her website can be seen as a 'symbolic project of the self', and more specifically a project of establishing herself as an authority. The slogan she made up is reflective of her attitude: 'Only in silence can breast cancer continue to kill'. The word is seen as magic, online narrative as the cure technology. Indeed, women often describe the Internet as a magical tool. For example:

It is always shocking to me how many people are affected by cancer and have no strong support system and especially for those women the internet is a miracle tool. (Online narrative 27).

Technology, storytelling and magic are inextricably interlinked. This 'miracle tool' provides patients with a space for storytelling, an act that

[...] creates and occupies the territory of the 'as-if': inviting wishes, possibility, and desire; raising questions, seeking answers (Silverstone, 1999:41).

The act of voicing one's experience through its narration is magical insofar as it promises an illusion: control and mastery of the uncontrollable; authorship implies

authority. The following extracts from a patient's personal website put a gloss on this argument:

Welcome to my journey.

[...] Many times I have been asked by authors and journalists just "... what spurred you on?" **I did it for, and by myself.** I wanted the cancer OUT of my body! (emphasis in original).

[...] The amazing aspect of this experience with cancer is that I personally witnessed the power of the universe!

The e-mail account that the author of this website sent me performs the same process of constituting herself as an independent active agent who refuses to take ownership of cancer. Referring to my question 'could you tell me about the relationship between the Internet, the disease and you', she replied:

Relationship implies a human interaction, and I do not take any ownership of the disease, hence: My experience with breast cancer - not my breast cancer, and the Internet is a vehicle which may or may not be permanently available as a means of communication, therefore, I'm not sure of your question. (Online narrative 6, underlining in original).

The marginalising of the role the Internet played in coping with the illness is a recurring phenomenon in women's accounts. When asked to reflect on the place of the Internet in the experience of their illness, interviewees often depicted their online experience as insignificant. However, comments such as 'I'm not that into the Internet thing' (interview 6), 'it didn't fulfil my needs' (interview 10), or 'there is not much to tell' (online narrative 1) are often contradicted by what emerges from their account as a rich experience of Internet use in which the online participation played a central role in the management of the disease.¹¹ This could be explained as patients' unconscious attempts to construct themselves as the key exclusive agent who 'made it', reducing the role of other possible factors (such as the Internet) that might have helped them in their battle against cancer.¹²

However, individuals' engagement in the establishment of their selves as narrating authorities goes beyond the explicit manifestation of personal homepages. Arguably, the very individualised and particularised nature of the online experience enhances this 'I mode' in which one positions oneself in the centre of the story, marginalising or excluding altogether other factors which might constitute driving forces of the plot. It would be inaccurate to say that women do not give credit to their doctors, their

family members and other caregivers in their stories. However, I suggest that the individualised self-centred experience of a woman using the Internet on her own, translates, to a certain extent, to her capacity to establish herself as an active heroine fighting the cancer, almost in a Proppian sense. In the interviews I conducted, it is noticeable that women who have not used the Internet personally (those whose husbands or other family members have used it on their behalf)¹³ tended to construct themselves in far less active terms than women who have been directly engaged in the experience of online self-presentation (on message boards, e-mail or personal homepages). While the latter clearly located themselves at the centre, propelling the plot of the course of their illness, the former's accounts often foregrounded their doctors as the central agent of the plot. By no means do I suggest a deterministic view of women's online participation as conditioning a self-narrative of active agency. Nor do I imply that narrating is in some way an exclusive or privileged way of patients to constitute their agency. Rather, I want to highlight the important role the process of narrating may play in patients' management of their 'project of the self', through online participation.

In this context, the apparent variety of the available voices on the online space and the capacity of one to choose among them paves the way for one to establish oneself in her own terms, as an active agent. As the following patient reflects:

Originally I went to a support group for women with cancer but found out early that it wasn't for me. Most of the women sat around crying about their situations, yet took no active part in their treatments and just believed whatever their doctor told them. [...] These were not ignorant women, but I think most of us have been trained to believe that doctors know best. This is the reason I went on the internet to look for a sight where women talked about their experience. [...] I think I am hoping to find someone who did the same thing as I and had a successful outcome. (Online narrative 14).

Even if one is satisfied with the medical treatment she gets and pleased with her doctors (which appeared to be the case for most of my interviewees), the online context furnishes a discursive space where patients, implicitly, have more freedom and more opportunities, to bring themselves to the fore, and establish themselves as self-responsible agents, rather than as passive patients who are dependent on their medical authorities. An example of this observation is provided by L (interview 12). L recounts how, when she used to meet her doctor, she would be often at a loss for

words, despite the many questions she had prepared at home that she meant to ask him. Once she went online, she would look for answers to her questions, whether from other fellow sufferers or from online medical sources of information. In the online space it is easier to take the active role, be it through narrating, or other communicative practices such as information seeking, as in the abovementioned example of L.

This observation does not suggest, however, a separation between the offline and online experience of breast cancer patients. On the contrary, patients' engagement in their self-establishment as active agents, through online narrating, is part of the wider cultures and wider experiences in which their lives and identities are embedded. Recalling the discussion in Chapter Two, the discourses of agency and self-responsibility which embody the culture of breast cancer (and more generally the culture of health and self-help) in contemporary society, should be seen as the 'umbrella framework' within which patients' construction of their selves as narrating authorities online is ingrained.

In light of this emphasis, I wish to move on to discussing the ways in which online communication enables patients to construct closure. As stressed throughout this thesis, the construction of closure is one of the key aspects of the process of narrating. The struggle to achieve closure distinguishes narrating from other communicative processes in which patients engage online, for example, information exchange. While the latter is based on the communication of contained units of information, which by and large have to stand independently and be understandable in themselves, storytelling involves the configuration of separate events into a plausible whole, and their direction towards an ending. The project of a breast cancer patient directing her story towards closure is part of the wider story of survival and cure that governs the discourse of breast cancer (see Chapter Two).

Directing towards closure: A story of survival

...I am cured but I'm not sure anyone can actually say they are cured when they've had cancer. I AM a survivor, tho. ;). (Online narrative 18).

The above perceptive comment shows an awareness of the paradoxical experience of a breast cancer patient. On the one hand, the reality of the illness does not allow final closure, as there is always the risk of recurrence. Since an absolute cure from breast cancer is never guaranteed, one can never completely end the story of one's cancer. At the same time, a patient is constantly seeking to reach an end of the illness, that is, to impose a closure on the story of her cancer.

As encapsulated by the patient cited above, for many patients the way out of this paradox is the adoption of the role of a survivor. The discourse of survival (which is highly central to the culture of breast cancer, as discussed in Chapter Two) does not deny the experience of the illness. Rather, it acknowledges the traumatic experience of the illness and its continuous consequences for one's life in the present. At the same time, however, it insists on a closure of this chapter, stressing the end of the 'battle' and the patient's triumph over the cancer. The emphasis is on the future, hope and optimism. The following message of a breast cancer patient captures this duality neatly:

...if my CAT scan next week comes back normal, like expected, my Cancer Treatment Experience is supposed to be finished on April 1st [...] Seriously, that's the date of my last radiation treatment! After that, I will be somewhat sunburned and sore cancer survivor!!!!
(A message posted on a breast cancer message board).

The above message is an attempt at constructing a closure: the patient announces her arrival at the finish line of her 'Cancer Treatment Experience'. She thus claims the role of a survivor. At the same time, a 'survivor' does not imply forgetting the experience of illness. Her sunburned and sore body, and hence her story, are a living testimony of her pain. What is more, while the message is clearly cheerful, hopeful and optimistic towards the future, it is framed as an uncertain situation, using the conditional 'If'.

The production of a narrative on online sites is one way of enabling a patient to actualise this dialectical role of a survivor. It offers a path out of the pain and, at the same time, a guarantee that it will not be forgotten. In other words, I suggest, the process of narrating is restorative in that it guarantees the remembering of the experience, and thus remembering as healing, but also writing to forget, or at least

contain the experience, by placing it firmly in the past (Stacey, 1997: 242). Stacey's (1997) conclusive chapter of her book *Teratologies* unfolds these dialectics very sensitively:

Do I hesitate to finish this book for fear of what might follow? Has it protected me from death? As long as I keep writing I might indulge in a fantasy of control, of authorship of the narrative trajectory of my health, a fantasy that contradicts my knowledge of my own mortality. Or does this piece of writing display a lingering fear of death's imminence: having said my bit, must I prepare to die?...Or is the writing itself a sign of life: I must still be alive, I am producing – 'I write therefore I am'? (ibid.: 242).

Stacey's reflection relates to the connection between writing and survival. Within the wide range of communicative possibilities that fall into the category of 'writing, I wish to focus on online narrating as a specific experience that offers patients the dialectical process of survival. How does the online communication work to enable patients to perform the role of survivors? In particular, how does the online experience direct patients' stories towards closure, while at the same time perpetuating a sense of openness, hope and continuation towards a desired future? In what follows, I present several observations that tackle these questions. The discussion seeks to account for the ways in which breast cancer patients' online narrating constitutes what Stacey describes as a 'symptom of not dying'. In so doing my aim is to identify the distinctiveness of narrating and storytelling on the online space in offering patients the possibility of performance of a dialectical process of survival.

A space for testimony

The online communication of breast cancer constitutes a discursive space of testimony where, through engagement in online communication, patients perform their roles as survivors. Storytelling is one activity in this context. Theoretically, as Frank (1995) contends, in telling the story of her illness a patient actually becomes more than a survivor – she becomes a witness. Survival, Frank argues, does not include any particular responsibility other than continuing to survive, whereas becoming a witness assumes a responsibility for telling what happened (ibid.: 137). While I think Frank pushes too far the distinction between 'survival' and 'testimony', in making this

distinction he nonetheless draws our attention to the centrality of the act of telling and narrating in the actualisation of the role of survivor.

The significance of the online space as a space for testimony and thus the exercise of the role of 'survivor', is epitomised in B's account. B, who explicitly identifies herself as a breast cancer survivor, and who performs this role primarily through her active online participation, stresses how her survivor identity is constructed upon the commemoration and the celebration of the triumph over cancer:¹⁴

A couple of people will say: why do you want to talk about that? There are some people, and not even just breast cancer [patients], but relatives and stuff, would say: why don't you just... it's over and done. Put it behind you. Pretend it never existed. I can never answer that to anybody's satisfaction. It did happen, so you can't just sweep it under the rug and say: no, it never did. (B, interview 2).

A 'queendom' of survivors: Been there, done that

A straightforward observation to begin with is the recognition of the dominance of survivors, and the governance of the discourse of survival, of the online space of breast cancer. In this sense the online interaction on breast cancer websites resembles tribal power relations, where the old and experienced people have a privileged voice. In other words, the discursive online space of breast cancer is implicitly structured by a hierarchy of voices, where survivors determine the tone. This is not to say that newly diagnosed patients or patients who are in the course of their illness cannot voice their experience. On the contrary, they are encouraged to do so. However, their experiences are not voiced into an open neutral space, but rather one that is dominated and framed by a discourse of survival. Indeed, many websites and online communicative forums are effectively run and owned by survivors.

Underlying the dominance of survival and the foregrounding of survivors in the discussions on breast cancer online forums is the 'been there done that' principle:

Tons of information you get from other women who have dealt with BC is different from what the doctors tells you. He tells you what the treatment should do, lists the possible sideeffects, recommends medications to combat the side effects, etc. The ladies have BEEN THERE, DONE THAT - they give you an honest accounting of how it happens, what it feels like, what side effects are and how to handle them. (Online narrative 2)

Women often stress the significance of the ‘been there done that’ component of much of the representations they encountered online (constituted usually by fellow-sufferers’ first-hand experiential stories), especially against the kind of representations furnished by the medical authority (commonly embodied by their doctor).

Fundamentally, the ‘been there done that’ element is not ‘neutral’. Rather, it is geared to implicitly construct a story of survival and direct new stories to a sense of closure. It is geared to the temporal ordering of the events involved in the experience of illness and their configuration toward a closure. These elements, as I argued in Chapter One, are closely tied in with the production of narratives, rather than any other discursive form. J’s description of her encounter with fellow-sufferers’ stories on breast cancer online forums illuminates this observation:

...it’s comforting to read: oh yes, this is supposed to be happening...another woman goes through this, you do get a certain matter of strength, because you read things from women, I’m one year out, I’m five years out, I’m eight years out. **You know that there is an end** and these women live healthy normal lives, **it’s all over**. (J, interview 10, my emphases).

The shaping of patients’ stories by survivors

So the governance of survivors’ voices of the online space of breast cancer invigorates the continuous production of more stories of survival. However, it is not merely survivors’ implicit dominance that directs patients to produce closure and a discourse of survival. Survivors are actively shaping patients’ accounts, through their online interaction with breast cancer patients who are going through the course of illness and treatments. In Chapter Six I will discuss in detail the ways in which the process of exchange and communal storytelling occurs, and what its consequences are. At this point, I want to highlight one aspect of this process in relation to the ‘joint authorship’ of survivors and patients of the stories produced online.

The interaction and exchange of experience between fellow sufferers, commonly on message boards or via e-mail, usually occurs between patients going through the illness and survivors who have ‘been there’. The communication is initiated by the patient who is new to the board, who presents her experience of diagnosis and illness. This initial account is, of course, not free of influence of discourses and cultures in which it is embedded. It often contains elements of the ‘grand narrative’ of breast

cancer, namely self-help and self-responsibility, hope, survival and agency. However, what it often lacks is a sense of closure. It is an account of a patient in a liminal stage, for whom the future is completely unknown. These postings are often replete with three dots ('...'), question marks and explicit expressions of fears and anxieties. For instance:

[...] I was hoping you would be able to help me [...] when I should get a wig...should I get it now or wait until later. I have been reading some of the messages and they made me cry...so many people going through the same thing, how ignorant I was before this and still feel I'm in the dark. I think sometimes I choose to be an ostrich! :) [...]
My mind is rambling on with things I want to say, a part of me just wants to scream. (A message posted by a breast cancer patient on a message board).

Such postings are a call for experienced patient-authors to 'intervene': to help the inexperienced patient-author to shape her story, and particularly to help her construct a closure (rather than being an ostrich, as the above quote puts it).¹⁵ A (interview 1) conveys this very well when she proudly tells that the message she posted following her medication treatments engendered 19 responses. This was the goal of her posting: to prompt the production of other postings that will reassure her she is not alone and help her direct her story towards a desired end. For the same reasons, when she was about to go through a second mastectomy she did not need to invite others to help her construct her story, since, as she says, she has been there and knows what's ahead (interview 1).

Survivors' responses direct the patient in terms of practical issues, such as when to get a wig, whether to participate in a clinical trial or not, how to deal with the kids, but also direct her as to her self-identity and what she should expect of herself. For example:

[...] your attitude sounds great. Do not feel bad if some days is not so great. You will have both days where you will be strong and then of course there will be days where you will look elsewhere for strength. (From a message posted on a breast cancer message board).

It is fascinating to trace such 'threads' of discussion that are composed of an initial posting of a patient who is going through a stage of pain and uncertainty, followed by a chain of stories she gets in response that help her shape her own story, and then view the patient's reformulated story, which carries the 'footprints' of the survivors'

replies. In fact, the message that was quoted earlier, of a patient who describes herself quite cheerfully as a soon-to-be ‘sunburned and sore cancer survivor’, is a ‘product’ of a message whose original meanings (i.e. when it was first posted on the message board) were negotiated and re-shaped by the help of other survivors. As I have been arguing throughout this chapter, this directing and redirecting of patients’ accounts toward closure are central to the process of narrating.

The organisation of websites by themes, structures and symbols of survival

The eminence of the discourse of survival is manifest also in the actual visual and textual ways in which many breast cancer websites are designed. This design accommodates a variety of discursive forms, narrating being a central one. In the following section I wish to illuminate the ways in which the ‘survivalist’ design of many breast cancer Internet sites specifically shapes patients’ posting as narratives of survival.

Perhaps unsurprisingly, the dominant colour of many breast cancer websites is pink. This alludes, of course, to the Pink Ribbon, which symbolises the fight against breast cancer. In broader symbolic terms, it induces an atmosphere of optimism, hope and cheerfulness.

‘Young Survivors Coalition’, which is a website focusing on breast cancer at an early age, is a good case in point. First and foremost, its name and URL contains the word ‘survivors’. Second, its homepage displays a list of words, in different font sizes, namely: challenge, inform, act, support, question, empower, inspire. These words are all verbs rather than nouns. Typical of the discourse of the ‘enterprising self’ (Rose, 1992), they call on patients to fulfil their potential as agents.¹⁶ More particularly, I suggest, they call on patients to move from ‘passive’ online participation to active participation in the form of expressing themselves online. Moreover, this kind of design and use of rhetoric implicitly direct patients to express themselves in similar terms to the ones the website employs, i.e. to depict themselves in active terms as ‘empowered’ ‘active’ and ‘informed’. Indeed, there is a similar rhetoric and a clearly utopian and inspiring sense of agency in many of the patients’ postings on that site.

Another interesting example of the ways in which breast cancer websites are structured to direct patients to construct a story of survival is the format that 'Shared Experience' website provides its visitors in order to fill in their personal information. While the first pivotal moment in a breast cancer patient's experience is commonly the patient's discovery of a lump in her breast(s), this moment is skipped in the story-form provided on 'Shared Experience'. The first category to which the narrator is asked to refer is diagnosis. In this way, this structure directs the patient to begin with a moment of certainty. The diagnosis may be a threatening or a frightening moment, yet it is a moment of relative control, compared to the moment of discovery, which is characterised by total uncertainty, confusion and anxiety. Although this decision to skip the discovery and start from diagnosis was made unconsciously by E,¹⁷ the designer of 'Shared Experience', when asked to reflect on his decision reveals, in his response, the discourse of survival and hope that has unconsciously underlain it:

Gosh...should I actually change that? [i.e. add a category of 'discovery' before the on of 'diagnosis']...But that would be very scary, wouldn't it? (Interview 5).

In her study of an online discussion group called the Breast Cancer List, Sharf (1997) testifies to the notion that patients' communication seems to be tempered by hope, and 'to make this colloquy about living with breast cancer, rather than dying from it' (ibid.: 73).

The ongoing nature of the communication as a sign of survival

As has been stressed thus far, patients' online communication is orientated towards the production of a story of survival. This is a dialectical process: on the one hand, it aims at imposing closure while on the other hand it aims at maintaining a sense of openness and continuity. A key feature of the online communication that acts to facilitate these dialectics is the ongoing nature of the online communication. Here I depart from accounts such as McLellan's (1997) and Hardey's (2002) that underscore this feature only in view of how it facilitates the emergence of a dynamic, open, unfinished and 'unruly' text. I argue that this aspect is only one side of the coin and that we need to understand the ongoing nature of online communication as a dialectical framework: one that sustains openness and continuity while at the same time constitutes a structure for the construction of closure(s).

The ongoing nature of online communication furnishes patients with the capacity to constantly rework their story; they can update it, edit it and change it over time. This technical capacity allows them to claim their role as survivors, that is, to effectively confirm and reconfirm: I'm still alive. In fact, women often explicitly use this notion in their online posting as well as in their e-mails. For example, one of the women whom I contacted following a message she originally posted online a year before, replied in an e-mail letter that starts with the sentence:

I am still alive and well in Northern California. (Online narrative 15).

The capacity for immediacy of publication, i.e. avoiding the usual lapse of time between experience and book publication, yields a distinct meaning to the act of writing online. A patient can effectively come back to the online space and make herself visible on the online space, confirming and reconfirming (both to her readers and to herself): 'I write, therefore I am'. Indeed, women often revisit online forums to tell their continuing story. By being present online, they claim their survivorship, a year, five years, ten years and even fifteen years after being cured. The five-year milestone has a particular significance in the context of breast cancer as it is considered to be the threshold of a reduced likelihood of recurrence.

One of the temporal milestones in which patients engage in online narrating is the eve of their annual mammography. The latter is part of the regular follow-up that women who suffered from breast cancer have to go through each year. Commonly, women who retired from online participation once they were 'cured', go back online before their mammography 'because you get nervous around those times' (B, interview 2). The online space is always there: one can join in, leave and come back at any time. This unlimited availability enables patients to engage in the dialectical process of survival: to open, close and then re-open and re-close their story in their own terms and their own time.

B describes patients' maintenance of their online participation, and particularly online storytelling, even long after they have been cured, as a 'knock-on-wood' effect:

I think that a lot of the people that have survived it...I think...they're proud of it, part of it is like a 'knock-on-wood'. If I say I had it 20 years ago, and I keep coming (to the online support group) maybe I won't ever get that. (Interview 2).

Perhaps, as B observes, patients unconsciously regard the sustenance of an ongoing online participation, and of storytelling in particular, as an 'insurance' policy. This policy enables them to manage the difficult task of bringing an end to an experience that in fact cannot be ever fully closed, as there is always the risk of recurrence. Fundamentally, the ongoing dynamic nature of the online communication and its features of immediacy and availability go hand in hand with the construction of breast cancer as a site of continuous change.¹⁸ The emphasis on patients' experience of the illness as never fixed and determined but, rather, a 'work-in-progress' (Love, 2000: xvii), seems to be facilitated and endorsed by their capacity to engage in the online space on an ongoing basis. In particular, their capacity to construct and re-construct their self-narrative: to change, edit, and update, on an immediate basis, at any time.

Writing as the triumph over the body

The joy of writing.

The power of preserving.

Revenge of a mortal hand.

The Joy of Writing / Wislawa Szymborska (1993)

The discussion in the previous section highlighted the ongoing changing dynamics of online communication and particularly of online narrating. To a certain extent, these dynamics contain the qualities of an oral situation, that is, communicators' ability to change and rework their narrative 'on the go' on an immediate basis. In this sense, patients enjoy 'the joy of talking'. In this section I wish to focus on the significance of 'the joy of writing', as Szymborska (1993) has it, for patients' project of survival and the construction of closure. In other words, of concern here is the written aspect of patients' engagement in online narrating.

Szymborska's poem eloquently implies how the act of writing entails a triumph of the text over the body: the actual writing has the power of making the mortal immortal.¹⁹ The notion of the act of writing as an attempt to subjugate the body to the narrative

emerges as a central (albeit implicit) theme in breast cancer patients' accounts of their writing on the Internet.

The idea of writing as a way to enable the body to prevail appears extremely interesting in the context of the online space, given the latter's profoundly disembodied character. To put it simply, a patient seeks to contain (if not subjugate) her bodily experience by presenting herself in writing, in a disembodied medium. At first sight, bridging this tension between an embodied experience being constructed and performed on a disembodied space might seem impossible. However, attending closely to the voices of the individuals engaged in this experience, we realise that it is precisely the production of an *embodied* account on a *disembodied* discursive space that enables them the 'revenge of their mortal hand'.

I wish to begin this discussion with the example of a breast cancer patient who recounts how during the surgery she went through, she was planning the way she would describe her experience in writing, in her online breast cancer diary:

[...] The anticipation to write makes me happy and keeps me occupied. Yesterday I went through transplant surgery, as the surgery takes place, under local anaesthetic, on the verge of falling asleep, I went over in my head the way I'll put in writing the event I'm going through, I planned how I will write it, and in what order I'll describe the events. I do it often [...]. (Narrative 3).

What this story exemplifies so intelligibly is the way in which the act of narrating, and even more specifically the ordering of events in time and space, already in its very early stages when the ideas are 'cooking' in the author's mind, enables the patient to 'leave' her body and disconnect from the actual corporeal experience she is going through. This capacity for displacement and dissociation, through the act of narrating and storytelling, has a central role in the patient's therapeutic process. 'The analysand is to be witness to his/her own mind' (Schafer, 1980: 38). The teller of the story can empower himself/herself 'by stepping back from the mesmerizing power of events' (Sennett, 1999: 12). In other words, by dissociating oneself, the narrator is capable of reflecting on her painful situation. Frank (1995) encapsulates this inextricable link between storytelling and dissociation when he describes his experience of writing his illness:

I felt written from the outside, but my own voice was doing the writing (ibid.: 71).

The online environment constitutes an ideal site for this process of dissociation and disembodiment through the act of narrating. To a large extent, the situation of being 'behind the screen' when one is not physically visible, and where one can remain anonymous, constitutes an appropriate context for one to step back from one's personal experience. In particular, the ability to remain anonymous enhances the process of disembodiment. As A reflects, for her, remaining anonymous on online forums signifies detachment from the cancer:

Sometimes I'll say Anne or Marie, but... I find that a lot of young people do want to leave the breast cancer behind. (Interview 1).

Notions of 'anonymity' and 'disembodiment' in cyberspace are often related to the idea that virtual and fluid identities can exist with no necessary link to the physical body. However, for A, as for many other breast cancer patients, rather than experiencing a 'virtual' fluid identity in the post-modern sense, the capacity to tell her personal intimate story online and at the same time remain anonymous, is a way to 'leave the cancer behind', to dissociate herself. This is unlike other contexts of her life in which she is often labelled as the 'one with breast cancer' (as she puts it), and hence is constantly being reminded of the cancer, 'component' of her identity.

In the story *Dear Stranger, Dearest Friend* (Katz Becker, 2000) Lara, a breast cancer patient, writes in her e-mail to her fellow-sufferer Susan:

I still have that out-of-body experience from time to time. You know, like I'm watching this happen to me instead of it really happening to me (Katz Becker, 2000: 111).

Women often refer to the posting they published online as if they were an independent entity, which exists outside of their bodies and their selves, 'floating' in cyberspace. In the body of their online messages, patients often provide links to other online sites where they published other similar messages. For instance, a woman who has her personal website, sent me a reply e-mail (following my request for her participation in my study), in which she constantly refers to other online links of her story (e.g. 'see IMPORTANT UPDATES on my website/Updates', online narrative 6). By the same

token, in her interview (interview 2) B kept referring me to the breast cancer related column that she writes online. Another woman, responding to my request for her participation in my study wrote:

Thank you for your interest, please send me the link to shared experience board, I need to review what I had submitted. (Online narrative 29).

In this way, it seems to me, breast cancer patients enact and re-enact this out-of-body experience, watching their own story as if it were happening to someone else. The ability to disembodiment herself plays a central role in the patient's capacity to claim herself as a survivor who remembers and preserves her painful corporeal experience and, at the same time, can leave cancer behind, avenging her mortal hand.

The stop of online narrating as a sign of survival

In order to fully grasp the significance of the process of patients' emplotment and storytelling on the online space, it is also useful to examine situations in which patients choose to stop their online communication. In examining patients' decisions to withdraw from online participation, I focus on their disengagement from actively participating in online forums, in other words, from voicing themselves through writing. While patients might keep participating through lurking, for instance (as I discuss in the next chapter), it is the discontinuation of narrating that I wish to highlight here as a particularly consequential decision. Understanding why patients stop engaging in the interpretative work of narrating could shed light on the meaning of the act of online narrating.

For different patients, at different stages of illness and treatment, both the *act* of writing online and *stopping* it constitute a way to claim their identity as survivors: 'I write therefore I am'. A's comment about breast cancer survivors who keep participating on online discussion forums illustrates this observation:

They're five years survivors and they're still on the Internet?!! (Interview 1).

Earlier in her interview she criticises more generally breast cancer survivors who remain active in communicating breast cancer, even years after being cured. Her

comment usefully contextualises the notion of retiring from online communication as a signal of survival:

...that's the problem I think I have with breast cancer survivors. There's something of a victimness about it, you know...for the rest of their lives, they have this label they wear the pink... (A, interview 1).

What A suggests is that to sustain active online participation (which, among other things manifests itself in narrating), is like continuing to wear the pink ribbon, rather than moving on and 'leave cancer behind', as she has it. For her, once a patient is cured, the motto should be: I don't write therefore I am.

A's perspective is emblematic of the view of many breast cancer patients. For instance:

...the more you talk to people about it the more depressed you would get (F, interview 6).

When I first got diagnosed, all I did was talked about cancer and researched cancer. Now, I'm in remission, thanks god, I don't want to talk about that at all. I'm so happy to be alive, that I want to live life! I don't want to talk about it. (E, the founder of a cancer website quotes a friend who suffered from cancer, interview 5).

B, for instance, following her diagnosis used to post messages on breast cancer message boards, asking other participants about aspects of the illness and its treatment. After she was cured, she stopped participating in discussion on those boards, though she did keep engaging in other kinds of online activities. By disengaging from message boards, and especially from telling her story, B conveys a significant message to herself and to her environment, namely: I am a 'patient' no longer.

A chose to follow the path of her online pal with whom she corresponded via e-mail until the latter signed off once she got cured and got back to normal healthy life. As soon as A got 'cured', the online experience had fulfilled its role; to some extent, the act of storytelling as an attempt to regain mundanity had translated into life and had become reality, so she retired from her online storytelling activities. The way she describes the time when she stopped her online participation (in relation to breast cancer), epitomises a moment of 'coming back to normality':

I followed that (breast cancer message boards) I'd say for a year and a half, and after that point my menstruation came back, my hair grew in, chemo was over, radiation was over, so I really had no more questions. (A, interview 1).

A second reason why patients stop engaging in online forums, particularly by withdrawing from narrating, reflects the other side of the coin. Patients often retreat from participating in online forums when they feel that they are incapable of sustaining a 'cheerful' trajectory in which the heroine emerges 'richer for her experience', capable of coping with 'whatever life throws at her' (Potts, 2000: 111). As discussed in Chapter Two, the motifs of hope and 'triumphalism of survivorhood' (Ehrenreich, 8 December 2001: 1a) are deeply ingrained in the discourse of breast cancer, and women's online stories are certainly governed by these motifs. When a breast cancer patient is incapable of 'fitting' her story into this framework, she often stops narrating online. This decision to stop the act of online narration is often linked to the actual physical circumstances that technically disable one's ability to go online. Many women said that during periods when they were weak from chemotherapy, they usually did not go online and if they did it was only as 'lurkers' rather than as active participants.

In short, patients' decision to disengage from online communication sheds light on the complex meaning of online narrating. When the perpetuation of the act of narrating signifies 'victimness', as A puts it, stopping this act embodies survivorhood – I don't write therefore I am. When the act of writing represents a sign of life (I write therefore I am), being incapable of claiming herself as truly 'alive', a patient stops narrating. Each of the scenarios highlights the centrality of the act of writing in patients' actualisation of themselves in the dialectical process of agency and survival.

Conclusions

From annals to narrative

Narrative becomes a *problem* only when we wish to give to *real* events the *form* of story. It is because real events do not offer themselves as stories that their narrativization is so difficult. (White, 1980: 4).

Patients' experience of breast cancer does not offer itself as a story. Rather, the initial representation of the illness, as it is given by the medical authority, is often closer to the form of annals: a set of laconic medical details, that seem to possess no central subject, no clear relations and no identifiable narrative voice (based on White, 1980). In engaging in the online communication of breast cancer patients endeavour (among other things) to construct a coherent story which will order their experience in time and place, assign significance to the different elements of their illness by linking them with an organising principle of meanings and direct them towards closure.

White (1980) views narration and narrativity as the instruments by which the conflicting claims of the imaginary and the real are mediated, arbitrated or resolved in discourse. If we follow this view, patients' online narrating could be seen as a means to bridge the imaginary and the real: it arises out of patients' desire to impose coherence, integrity, order and closure on an experience of life that is rather chaotic, incoherent and does not allow a final closure. As has been discussed throughout this chapter, this process is closely entwined with the notion of survival: a dialectical endeavour to remember and forget, to keep the painful experience open and accessible, while at the same time close it and move on. As has been argued in this chapter, the online environment constitutes a suitable site for patients to mediate and resolve the dialectics of their situation, through, among other processes, the production of narratives.

The mutual shaping of patients and the online space

The more general argument that emerges from the discussion of this chapter is that breast cancer patients and the online discursive space in which they engage, are mutually shaping each other. As I have shown throughout this chapter, the process of online narrating is the product of the interplay between participants and the online space. Patients are actively constructing the online landscape of breast cancer: in choosing specific forms to communicate their illness and avoiding others (e.g. asynchronous versus synchronous forms); in developing interactions with other fellow-sufferers which adhere to implicit power relations of survivors and patients (as much as to the unwritten hierarchy of online veteran participants and new joiners); in communicating their experience in their own terms, at their physical and temporal convenience; in appropriating the disembodied features of the online space to

dissociate themselves and 'revenge their mortal hand'; in enjoying the act of writing and the capacity to stop and resume it, to convey themselves and their environments their survivorship.

At the same time, the online space of breast cancer, and more generally the ways in which the online communication is structured, shape and condition the experience of breast cancer patients. The unlimited availability of the online communication; the flexibility it allows users in choosing what, how and when to use it; the thematic organisation of the World Wide Web and other online features such as the e-mail; the variety of interactive structures it furnishes to users, which consist of both oral and literal qualities; the disembodied nature of the online communication and the ongoing nature of the communication – all aspects are interwoven into patients' online experience, and direct it in particular ways.

The proceeding chapters follow this 'structural' view of the relationship between patients and their engagement in online narrating, focusing on two substantial aspects of this experience namely: exchange and reciprocity (Chapter Six), and the public and the private (Chapter Seven).

¹ While the focus of this chapter (and the thesis as a whole) is on narrating, it should be remembered that patients engage in communicative processes other than narrating and that the process of narrating is undeniably related to other communicative processes and discursive forms. For instance, in this chapter I will discuss patients' writing as a key activity in which they participate. Writing involves the fabrication of both narrative and non-narrative forms (e.g. writing a question). I want to argue that patients' online writing is particularly interesting and salient when it is entwined with narrating.

² White (1980) claims that, in the historical documents he examines, the representation of events in the form of annals is a conscious and purposive 'refusal to narrate' (p. 14) on the part of the annalist.

³ In his study (2002) of homepages of people's illnesses, Hardey demonstrates how patients order their experience in a sequential framework. However, he fails to account for the specificity of the online communication in enabling this process.

⁴ See for example: www.breastcancer.org 'Biographies of breast cancer survivors' message board and www.breastcancergroup.org/ourstories.html.

⁵ Most of my interviewees have not participated in synchronous forms such as IRCs (Inter Relay Chats), as they found them inappropriate for their needs, as I discuss later in this chapter.

⁶ This comment raises a significant question about trust, particularly: what makes patients trust specific materials that they encounter online rather than others? Why do patients find online narratives of other patients trustworthy? I intend to develop this issue in Chapter Six.

⁷ An exception is online narrative 24, whose author tells about her active participation in a chat called 'OncoChat' (www.oncochat.org).

⁸ For example: 'Having that power also made me feel like I had some control during a part of my life which I felt was completely out of control' (Online narrative 13).

⁹ The image of a battle against monsters and dragons is part of the wider dominant cancer narrative, as discussed in Chapter Two (see also Stacey, 1997).

¹⁰ Last accessed 14 August 2003. This text seems to have been recently removed.

¹¹ In this respect, the face-to-face interviews were crucial insofar as they exposed the centrality of the online experience in patients' coping, while the same interviewees dismissed the role of the Internet in their coping, in their online accounts.

¹² An interesting contradiction in patients' relationship to the media is revealed here. On the one hand, patients regard the Internet as a magical tool, providing them with reassurance, legitimisation and validation of their experience and thereby a sense of control over their lives. On the other hand, they marginalise its importance, depicting it as insignificant, as a way of constituting themselves as the propelling protagonists of the story.

¹³ Interviewees 4, 8, and 9.

¹⁴ While B speaks in more general terms about writing and self-expression on online message boards, I wish to highlight the act of narrating in this context.

¹⁵ Indeed, the story cited above generated a dozen of other women's stories in response.

¹⁶ The appearance suggests an organisational discourse, as if what comes next were about a business project rather than a personal health project of the self. The informal but professional appearance reinforces the optimistic atmosphere of the content.

¹⁷ E was my only male interviewee. He is not a breast cancer patient himself, but rather the founder of a breast cancer website, a project he initiated following the diagnosis of his mother with breast cancer.

¹⁸ See discussion in Chapter Two.

¹⁹ While this idea has been developed in numerous accounts, both academic and popular, reflecting on patients' writing in traditional forms (Frank, 1995, Stacey, 1997, Bury, 1982, Rosenblum, 2000), my concern is with the specificity of patients' engagement in *online* writing in enabling the 'revenge of their mortal hand'.

Chapter Six

Exchange and Reciprocity

First what you do when you get diagnosed, you look for people who have been through or going through what you do. Then when you're done with it, people contact you. (A, Interview 1).

Exchange is a central feature of the online communication of breast cancer.¹ As the above excerpt of a breast cancer patient's account implies so neatly, underlying the interaction between patients in the online space is a promise (whether implicit or explicit) of exchange between participants.

Patients' engagement in exchange online can be framed in various ways. A common agenda has been patients' exchange of information. In particular, studies looked at how patients exchange medical information and first-hand knowledge through different online structures and applications (e.g. McLellan, 1997; Eastin, 2001; Pew Internet & American Life, 2003). Another framework with which patients' processes of online exchange have been explained focused on the emotional level, exploring the exchange of experience and feelings (e.g. Sharf, 1997; Preece and Ghazati, 2001). These frameworks are clearly relevant to the case of this study. As this chapter reveals, the exchange of information and experience constitutes a pivotal element in breast cancer patients' online communication. Nevertheless, I suggest, emerging from the analysis of breast cancer patients' engagement in online exchange is also another focus, which has not been explored yet in this context, namely narrating and storytelling. The intention of this chapter is to enlighten this aspect and illuminate narrating and storytelling as processes central to, embedded in, and enabled by, structures of online exchange. This conceptualisation should not be seen as superseding the other frameworks, but rather as a different way of framing patients' online exchange, which seems particularly helpful to explain the experience of breast cancer patients in this study.

The aim of the following exploration is to highlight the significance of the online reciprocal platform and its distinctive properties, for the production of patients' stories, and thereby for their capacity to act. Without ignoring other possible

frameworks, I show how patients' dynamics of online exchange enable them to engage in a meaningful process of storytelling, one that endows them with powers to cope with their new station in life.

The brief introduction shows how deeply the principle of exchange is embedded in the experience of breast cancer patients' online communication. Following is an account of the key properties of online exchange. From separating the structure of online exchange into its component parts, I move to the core endeavour of this chapter, namely an analysis of three key processes that constitute patients' online exchange. Each of these processes, I suggest, shapes in significant ways the particular experience of patients' narrating and storytelling: (1) engagement and disengagement; (2) anonymity, disembodiment and re-embodiment; and (3) *communitas*. Fundamentally, these are dialectical processes, which allow for a hybrid communicative experience, in the form of narrating. The latter claim leads the discussion to its concluding part, where I re-evaluate the proposition made in Chapter Four, of online narrating as a model that might resolve certain conceptual tensions. Finally, I close the discussion with preliminary reflections on the link between trust and the narratives that patients post online.

Introduction: The principle of exchange

Patients' online participation exists in a situation of exchange from its early stages. In posting their message online, patients seem to have a kind of a tacit knowledge that there is an audience out there, to read and respond to their posting:

I **knew** that if I went online, somebody out there would know. (G, interview 7, my emphasis).

At first, it was comforting to hear other people, you know, you're asking people, especially on BCANs like [a breast cancer bulletin board], something that you noticed, whether it'd be a rash, or waking, nausea...**You know** that after medication people would respond and that was very comforting. (A, Interview 1, my emphasis).

In Blau's terms,² underlying women's engagement in this exchange is their expectation to derive something from this association, to *profit* and be rewarded in certain ways for their act. While women would rarely articulate their behaviour explicitly in terms of profit, most of them did express implicitly the expectation of

getting feedback from other patients as their underlying motivation for sharing their experience online. Posting any kind of text on an online site entails probably an expectation for some feedback. However, I suggest, constructing a personal story and communicating it online involves a heavier investment (emotionally, temporally, textually) than say, posting an informative question. Hence the expectation for a reciprocal act, i.e. for someone to respond to the posting, is arguably amplified if the message posted is a personal narrative, rather than other discursive forms such as a short note or a question. This assumption is endorsed by Barthes' (1974) stress of the contractual notion of narrative: a patient's decision to narrate her experience and tell her story online, Barthes would have argued, is underpinned by the implicit assumption that she would get 'something' in return from her listener(s): a response, a comment, or another story.

Patients often express their expectation for feedback overtly in their postings. Take, for instance, the following excerpt from a posting of a patient on a message board. After telling her readers about her positive diagnosis with breast cancer, the author closes her message with a humorous call for responses:

Thanks for your continuing words of support. You are the most sensational group of women. Now, enough of this seriousness. Get over on the off-topic³ and respond to my subject post over there if you there! LOL! [Laughing Out Loud]. (Posted on a breast cancer message board).

Even N (online narrative 6), a breast cancer patient who stresses her altruistic motivation in launching her personal website on breast cancer, ('I was not using the Internet as a resource for my personal use [...] ...people need help, and that is what I'm dedicated to'),⁴ states, in the end of her e-mail account, that she expects me to respond to her e-mail in return.

Accordingly, when patients indeed receive feedback to their posting, they feel a sense of achievement :

I got 19 responses so that was very good! [proud] [...] People from Australia! Yah! That was good, very good! (A, Interview 1, my emphasis).

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! Oregon... (F, interview 6).

It's [B's online column on breast cancer] averaging like 2,000 hits a month, which I think is fine for just a little column on breast cancer. (B, interview 2).

Yielding a large number of replies, especially from respondents across the globe,⁵ constitutes a confirmation that the patient's message has been received, in the technical sense, but more significantly, in terms of its meaning. It is an affirmation that its message came across, and that the construction was 'correct' insofar as the readers were able to infer its meaning.

An examination of breast cancer websites reveals how the specific ways in which those websites are structured, serve to furnish a framework of exchange. While visitors to these websites are encouraged to produce their personal stories, the stress is that, rather than simply being monologues, the purpose of the stories is dialogic:

Your words are for others who follow after you and the more you describe your experience, the easier it will be for others to relate. (www.sharexperience.org/experienceadd.lasso)

Women are often surprised, especially in their first encounters, by the prominence of exchange on breast cancer online spaces:

I expected to find and did find answers to all my questions from statistics to definitions of doctor's terms that I didn't understand. Something I didn't expect to find were so many people who had been through breast cancer who were so eager to share their experience and be there to encourage others. (Online narrative 13).

I expected to find a lot on the web, what I did find and was not expecting was a HUGE group of breast cancer patients and survivors who became permanent friends. (Online narrative 2).

However, very quickly they come to learn about this exchange-based space, and seem to regard it as an obvious taken-for-granted structure in their lives:

[...] I read the letters from people. I just went by breast cancer, or something like that and then I just read all these different women's letters and then I somehow got into submitting my own letter. (F, interview 6).

What is curious about the way in which women like F describe their decision to engage online is this almost mindless mode that 'somehow' got them into submitting their message. After all, people do not disclose an intimate experience such as breast

cancer so easily, in a public space, in front of readers whom they do not know.⁶ I want to argue that the way patients regard the act of sharing their experience online, as trivial and taken-for-granted, is a manifestation of their trust in the online discursive space and particularly in the structure of online exchange. In other words, for a patient to 'somehow get into' disclosing her intimate experience in a public online discursive space (albeit in an anonymous and disembodied fashion), she has to feel comfortable enough; she has to trust it. In particular, she has to trust the specific structure of exchange: to trust her readers to be able to infer the meaning of her story 'correctly', to trust that they would respond to her posting, and to trust the 'system' for being capable of facilitating this exchange.

What makes a patient simply 'know' that if she posted her message, she would get feedback from the readers 'out there'? What is the basis of this tacit promise of exchange? What makes women trust the structure of online exchange? What do patients expect to derive from their exchange and what things do they actually find as significant in this exchange?

To adequately address these questions, and to be able to account for the significance of patients' online interactions, a characterisation of the properties of patients' online exchange is in order. Such a characterisation will enable us to understand how the way participants interact, particularly (although not exclusively) through narrating and storytelling, is fundamentally shaped and facilitated by the specific ways in which the online spaces are structured and organised.

Therefore, the first part of the following discussion revolves around the form of patients' online relations. In particular, what are the specific characteristics of patients' online exchange relations, and how do they produce specific communicative processes, particularly narrating? Based on this introductory account, in the second part I will then discuss the significance and the distinctiveness of the interactional situations in which patients engage, and how they are embedded in these structural properties. The following analysis stresses the ways in which the process of online exchange (with its particular properties) and patients' online communication (narrating in particular) are mutually implicated. Online exchange is understood as a

platform for patients' engagement in storytelling, among other communicative processes such as information seeking.

The structure of patients' online exchange

Breast cancer patients exchange their experiences, using a variety of discursive forms such as question-and-answer, informative reports, notices and stories, on various online forums including message boards, e-mails, and news groups.⁷ There are, of course, significant differences between these various settings, for instance the number of participants and the extent to which they enable a private or public interaction. I will indeed touch upon these differences throughout my discussion. At the same time, these different sites in which women exchange their experiences share fundamental similarities that constitute a framework for a structure of online exchange.

In order to understand how this framework of exchange shapes women's experience, I wish to separate the structure of online exchange into its component parts. Each of the following observations reflects a specific element of patients' online exchange. The distinction between the different elements is merely analytical and the order of their presentation is arbitrary. These elements exist and take place simultaneously and it is their confluence that creates a framework for patients' interactions. However, to adequately account for the significance of this framework, it is necessary to untangle its different features.

1. The exchange occurs mainly between patients. While other actors such as friends, caregivers, family members and medical professionals are also involved in those exchanges, the most prominent actors (quantitatively as well as qualitatively) are patients. Although most websites allow people who are not breast cancer patients to participate in their interactive forums, their spaces are nonetheless implicitly designed almost exclusively for patients. For example, the following are the instructions for participants who want to participate in the 'BCANS' (Breast Cancer Action Nova Scotia) message board:

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. Posters may be be [sic.] in any stage of breast cancer - newly diagnosed, advanced breast cancer and long time survivors.
[BCANS Board Etiquette & Policy, <http://bcans.ca/forum/help.htm>].

Ostensibly, the board is open to people 'from all walks of life and from all over the globe'; however, effectively it does not allow room for non-patient participants. In this sense, online spaces such as the BCANS website provide a fundamentally different setting of interaction from those of other exchanges in which patients engage. They furnish a basis for an egalitarian communicative space, intended for patients only. This is a significant factor, especially given the prominence of patients' interactions with health professionals, in which power relations are clearly hierarchical. This claim will be further examined (and challenged, to a certain extent) in my discussion of the egalitarian dimension of patients' online exchange in the last section of the chapter.

2. The exchange is transacted through text. Patients' online experience is usually the only textual exchange in which they engage; the rest of their exchanges are oral. As already discussed in Chapter Five, and will be developed in this chapter in light of the process of exchange, the written medium has significant implications for patients' interactions. There are various discursive written forms that patients exchange (for instance, a question, an announcement, a notice). The analysis of this chapter will focus on the exchange of narratives. The narratives patients post online may include non-narrative elements such as informative questions or other pieces of information, for instance, the details of their diagnosis. What distinguishes a narrative, however, from other kinds of postings is that it constitutes a text that can be described as a coherent account which organises the author's experience in time and space and assembles the different elements of the reported experience into a whole, usually directing them towards an ending or conclusion. Earlier in this thesis (Chapter One) I explored the definition of what this study counts as narrative, and provided some examples.

3. The exchange is voluntary. Online exchange forums would normally have a certain policy and etiquette that instruct participants regarding their participation in the interactive forums. However, these instructions are very general. Overall, the exchange is open insofar as formal obligations or commitment are concerned. There are no formal contractual obligations between the online participants. The obligations incurred in the interaction between patients are not specified, or at least are defined very loosely.

4. *The exchange commonly takes place in asynchronous settings.* Such settings include message boards, mailing lists, e-mails, discussion groups and newsgroups. While there are synchronous forms of patients' online exchange such as chat rooms (e.g. OncoChat, BCANS chats), the kind of exchange that facilitates a communicative space for narrating and storytelling seems to be fundamentally asynchronous rather than synchronous. Hence the current discussion centres on asynchronous contexts. I have started developing this claim in Chapter Five, and will elaborate it in this chapter in relation to the process of exchange.

5. *The exchange is temporally unspecified.* This means that the time of the exchange is not contained or defined. A patient can contact other patients at any time of the day, and there is no specific time in which a reply to her posting is guaranteed (this is due to the asynchronous nature of the communication, which I discuss in the next article).

The time period of the exchange relations is not specified either. Some exchanges are short-term, consisting of a few turns only (e.g. F, interviewee 6, and G, interviewee 7), while others develop into long-term relationships that often last for years (e.g. A, interviewee 1, and B, interviewee 2).

6. *The exchange takes place on both dyadic and multi-party levels.* Exchange between patients often evolves on a multi-party level, usually when a patient posts her message on a public forum such as a message board to an unknown audience of readers (universal readers, as Ricoeur would have called them). It can then emerge into a multi-participant discussion and/or, often, to a one-on-one exchange, commonly conducted via e-mail. As I will discuss later in this chapter, there are crucially different implications for multi-party and dyadic interactions in the different settings in which they take place.⁸

7. *The exchange is anonymous and disembodied.* Unlike other exchanges in which patients interact during the course of their illness and treatment, the online setting is the only space where their interactions are disembodied and anonymous. Although they may extend into embodied relations (some women, for instance, meet their online pals later in a face-to-face interaction), for the most part, online exchange

relations emerge, develop and are sustained in a disembodied manner. The disembodied nature of the interaction implies the anonymity of the participants. Some participants reveal their real identity (usually as the interaction evolves); however, arguably, a certain degree of anonymity is sustained as long as the interaction is disembodied. Noticeably, veteran online participants who are often breast cancer survivors, and who participate in online interactive forums on a regular basis, tend to reveal their personal details such as their real name, home address and telephone number. Against much of the writing on disembodiment and anonymity online, which focuses on participants' capacity to invent personas and disguise their real identity, these features seem to take quite a different meaning in breast cancer patients' online experience.

The confluence of these eight features creates a structure for patients to engage in exchange relations with fellow sufferers. How can we explain patients' online exchange in light of these features? What do women perceive as significant and distinctive about their online interactions? In what ways does the structure of online exchange facilitate a process of narrating?

1. Engagement and disengagement

A key aspect that patients appreciate as special and significant in their online exchange is their capacity to experience a hybrid condition in which they interact, concurrently engaging and disengaging. The key facilitator of this condition is the capacity to lurk. Lurking enables the online participant to be there and yet at the same time not be there: to observe the social interaction and its dynamics, while at the same time remain invisible, without having to interact.

A careful analysis of women's accounts reveals the centrality of the condition of lurking in their experience. Significantly, most women do not engage in exchanging their experience immediately after their first online encounter. Rather, they usually start participating in breast cancer online interactive forums as 'lurkers', reading other patients' postings, however refraining from voicing their own. Some remain lurkers during the whole course of their illness and it is only after they get cured that they start actively engaging in the exchange. Others start exchanging their experience at earlier stages of the illness. As I will show, whatever the time period of the lurking, it

often constitutes a fundamental preparation period for their 'real-time' engagement, in which one of the central activities is storytelling. Clearly lurking and storytelling are two different communicative activities, and should not be confused. My aim in the following section is to highlight their possible interrelationship, and particularly demonstrate how lurking can constitute a significant process that paves the way for patients' participation in storytelling at later stages.

Lurking as a preparatory stage for exchange

In any interaction, while actors have to have a certain level of trust *before* they start engaging in the exchange, their ability to make judgments about the actors and the interaction is quite limited prior to the actual exchange. One has to actually participate in the interaction in order to learn to trust others. As Blau (1968) observes, trust develops mainly as the exchange relations evolve.

Unlike other kinds of exchange relations in which patients engage, in their online relations patients are capable of establishing a relatively high level of trust in the actors and the form of the relations, *before* they actively engage in the actual exchange. Through lurking, patient-online participants gain familiarity with, and consequently trust in, the exchange relations, before actually getting involved in any kind of transaction. As Silverstone (1999: 119) acknowledges:

Trust is [...] achieved and sustained through the ordinariness of everyday life and the consistencies of both language and experience.

Through lurking, patients become familiar with the modes of discourse of the interaction. A prominent form they encounter on online forums is narrative: patients sharing their personal experience in the forms of a story (as argued in Chapter One). When they start to actively engage in the exchange, they follow the patterns they have learnt during their lurking period. This way, they often imitate the narrative form (among other forms they encountered) and participate by producing their self-narrative. Thus narrative becomes a taken-for-granted form in their online communication. This is evident in most of the interviews I conducted, where women referred to the notion of story as the obvious object of their communication: 'I posted my story', 'I read women's stories'.

The only interviewee who was reflexive on this aspect is K (interview 11), who remained a lurker and never participated in exchange relations online:

I didn't ever post any messages. [...] it just seemed like these women were...[silence, K thinks] **involved in a form that was about mutual support, it wasn't about having arguments.** (K, interview 11, my emphases).

Unlike most of the patients I interviewed, for K, lurking was a process of critical reflection on breast cancer online spaces, by which she felt quite alienated. It is precisely the fact that she remained a lurker, and never got into actually exchanging her experience with other patients online, that enabled her to take a critical distance from the interactions that went on these spaces.

However, for most of my interviewees, lurking constituted a key process in the formation of their trust, in both their online pals and in the online structure that facilitates the exchange. Through lurking, the unfamiliar becomes familiar; the foreign language and the culture of breast cancer online, become something ordinary and consistent. Consequently, patients appear to 'somehow' (as F put it) get into telling their personal story to other participants in this space.

Lurking gives patients the privilege of getting to know and trust their partners in the interaction, without actually having to risk anything. This advantage is particularly notable in relation to face-to-face interactions in which patients engage, such as support groups. The following account highlights this comparison:

Originally I went to a support group for women with cancer but found out early that it wasn't for me. Most of the women sat around crying about their situations, yet took no active part in their treatments and just believed whatever their doctors told them. [...] This is the reason I went on the internet to look for a sight where women talked about their experiences. [...] Reading these different experiences [...] proved very helpful. (Online narrative 14).

The capacity to lurk, before actually getting involved in exchange relations with other actors, enabled this patient to minimise her risks. She could 'window-shop' the available discursive spaces, to decide which communicative framework suits her best, without having to actually pay any price. With the face-to-face support group, paying a certain price is inevitable: she had a limited way of knowing the particular nature of

that face-to-face support group ('women crying about their situations') without actually engaging in the exchange. Following the lurking period, some patients, like the one cited above, decide to move from passive to active participation, whether by posting a comment, a question, informative text, or a story. Others, like K, whom I quoted earlier, for various reasons remain lurkers and decide not to move onto storytelling, or any other active participation that involves posting.

Lurking during exchange

Patients can step back and disengage by lurking also during the actual exchange. Their stepping back does not necessarily result in a ceasing of the relations: they can engage in ongoing exchange relations and yet at the same time, when they choose to, step back from the interaction to the position of a lurker. The capacity to maintain this hybrid condition, in which one is both engaged and disengaged at the same time, facilitates patients with very distinctive qualities, such that they usually cannot experience in other interactions in their lives.

A few women noted that at certain periods of their illness, particularly when they were physically weak (often during chemotherapy treatments) they did not have the physical and the mental ability to participate actively in online forums. During those periods, patients often find exchange to be a burden:

I was really exhausted and I had kids at home [...] I didn't even have the desire to share any part of myself with anybody at that point. The phone was always ringing, my family was always...in terms of my emotional view to people, I was already maxxed out. (G, interview 7).

Yet, at the same time, patients desire a continuity of communication, support and reassurance. Lurking proves invaluable in this respect: it enables patients to keep engaging in the communication, however as readers rather than as active participants. While they do not produce online messages during these periods, they engage in the reception of others'. The act of reading others' postings, I suggest, is a meaningful part of the wider process in which they engage, of the ongoing construction of their self-narrative. In making this observation, I draw on the theoretical ideas discussed earlier in the thesis about the self-reflexive nature of the process of storytelling: individuals weave their understanding of themselves by working and reworking their

interpretation of their own biography in the form of a narrative and a story (Giddens, 1991). This self-narrative is nourished by symbolic materials which they encounter, the latter being increasingly mediated materials (Thompson, 1995). In light of this theoretical assertion I argue that through reading others' stories, the patient negotiates the meanings of her own experience, and unconsciously reformulates her own self-narrative. Brooks (1994) develops the notion of the transferential condition of narratives, to illuminate the potential cure of the *narrator* that emerges from the dynamic interaction of the production and interpretation of the narrative (ibid.: 50). The idea of lurking extends the transferential notion of narrative also to the *listener*: the listener too is being transformed, through interpreting her partner's story. This view echoes the emphasis on the constructive nature of reading in literary theory and the notion of the 'active viewer' in media audience studies, by which the reader/viewer is seen as actively engaging in the interpretation of the text, despite her apparent passivity.

This idea is represented aptly in the case of J and K, two breast cancer patients who continued lurking throughout the whole course of their illness and did not post anything online:

I guess I got the most benefit out of reading women who were five years out, eight years out, ten years out. And were living healthy lives, and had children subsequently, just knowing there was an end to it. (J, interview 10).

[...] looking at these sites, I remember just starting to see these other accounts and I'm going through this myself...One of the things that it really brought home to me, was that I am extremely well-resourced in comparison to lots of women. [...] Once you start encountering other women's stories, you realise that there are a lot of situations of people actually losing their incomes, marriages are breaking up, or they are completely on their own, or they're facing a future of never being able to have children or whatever. [...] I don't know what's going to happen to me... [...] But I know that I'm well off in comparison with a lot of other women that have had it. (K, interview 11).

Lurking enables patients like J and K to engage in a meaningful interpretative process of their own experience: appraise their personal experience, locate it in relation to others and consequently reformulate and rework their personal story. In this sense, lurking constitutes a significant online practice embedded in the larger ongoing process of patients' formation of their self-narratives. The act of lurking online, particularly reading other patients' postings, feeds into patients' reworking of their

personal stories, primarily by validating their personal experience and conveying a message: You are not alone. The following extract demonstrates the significance of lurking for the process of validation and legitimisation. A breast cancer patient who returns to her regular online message board after a period of absence writes:

I didn't use my computer for a few days and was blown away by all the news I missed. Reading this forum has helped by reminding me how normal my feelings are. (A posting on a breast cancer message board).

True, this study lacks sufficient ethnographic evidence of these lurkers' lives to validate the claim that their lurking process and the materials they encounter online have indeed translated into the self-narrative they construct and tell in other (offline) sites of their lives. At the same time, as I explained in several places in the thesis, the approach taken by this study is that the accounts informants give of themselves to the researcher is a way to yield insight into their selves. As evident in the quotes above, patient-lurkers such as J and K explicitly reflected in their interviews on how fellow-sufferers' stories that they read online (as lurkers), affected the interpretation of their situation. Furthermore, despite the lack of evidence from other offline sites of patients' lives, this study conceives the interviews themselves as an offline site of storytelling (see discussion in Chapter Three). In their interviews, patients – whether those who remained lurkers or those who participated actively by posting – often wove materials they came across online into their self-accounts.

Lurking as a strategy of survival

Finally, many women keep lurking after they get cured. The capacity to be present and at the same time be absent, to concurrently dissociate and associate, fits like hand in glove to the dialectical process of survival. Reading other women's accounts guarantees the lurker the remembering of her own experience (as others' mirror her own), but at the same time it enables her to remain remote from the scene. This 'behind the screen' position of lurking, where a patient does not participate in online discussions, is a way for a patient to signify to herself: I am a patient no longer. Although patients do not continue actually telling their story in online interactive spaces, their online lurking contributes to the ongoing story they keep telling themselves and their environment, in other sites and contexts of their lives.

More generally, this means that the process of narrating stretches beyond participants' actual production of a narrative and its telling in the online space. The act of storytelling can take place in other sites of patients' lives (and not necessarily online) however the production and construction of their story is shaped, among other factors, by their online experience. For instance, the story patients told me about themselves in the interview was shaped in significant ways by the stories of other patients whom they encountered online, often only as lurkers.

By carefully examining the condition of lurking, and scrutinising its different types in the complex situation of patients' online exchange, we are able to appraise its significance for patients' experience. As Thompson (1995: 86) points out, such an analysis

[...] enables us to analyse these situations with some degree of rigour and precision, and thereby to avoid some of the misunderstandings that could arise from a hasty characterization of the interactional situations created by the media.

Getting to grips with the meaning of the practice of lurking in patients' experience enables us to escape the commonly negative connotation of the act of online lurking, to which many studies seem to fall too easily. Lurking is often depicted as a practice of surveillance and voyeurism (Murphy, 2002), charged with normatively negative meanings. Illustrative of this view is the recent debate on lurking as an unethical practice in doing Internet research. Even Baym (2000), who acknowledges a more positive dimension of lurking in her study of the online communication of soap opera fans, remains restricted to a utilitarian and functional level of explanation of participants' reasons to lurk and not post:

Uncertainty about how to post, a sense of not knowing enough about the group to speak, the feeling that one has nothing new to contribute, and a lack of time (ibid.: 144).

In short, for breast cancer patients, lurking constitutes a 'licensed position', which can be empowering. The mythic link between invisibility and omnipotence gains a specific value in the context of patients' online communication; in particular, in the

ways participants' invisibility contributes to the therapeutic process of the ongoing construction and reworking of their self-narratives.

Having said all that, lurking is not necessarily a social position distinctive to the online context. Although it has specific meanings in users' online experience, in fact, people keep engaging and disengaging all the time. This movement is emblematic of social actions in general; we lurk in many ordinary situations in our daily lives, although we might not refer to it that way. In this sense, online lurking should be understood as a continuity of offline social processes, rather than a completely distinctive and novel feature. The special and significant value of lurking in the online experience of breast cancer patients derives from patients' specific situation. Given their inability to be *other* than the cancer patient that they are in their offline world, lurking is hardly a possibility. They are always recognised as 'the cancer patient'. Online, lurking enables them to avoid the inevitable identity of 'a cancer patient'.

2. Anonymity, disembodiment, and re-embodiment

Over time, individual personalities emanate from the BCANS Forum [online message board], without influence of physical form. [Extract from the introduction to the BCANS message board, www.bcans.org].

Anonymity

Closely interlinked with the experience of lurking and patients' capacity for invisibility, is the disembodied and anonymous nature of the online interaction. B's account is a useful starting point for this discussion. Although she personally reveals her real name and identity on the online column that she writes, she acknowledges that anonymity plays a role in encouraging other patients to disclose themselves and participate in her column:

[...]at least half of the questions at 'Ask me' [her online column], the writer is listed as anonymous. [...] most people who are online are very open about whatever they're saying. I don't know if they were that open if they were in person. (B, interview 2).

The author of *Dearest Stranger, Dearest Friend* (2000), a fictional book on breast cancer patients' e-mail correspondence, supports this observation when she admits that if the characters of her novel, who met as patients on an online forum, had met each other face-to-face they would have been 'more guarded about what they say'.

Indeed, as other studies have shown, anonymity provided by online communication encourages individuals' self-disclosure (Rheingold, 1994; Jones, 1998; Sharf, 1997).

Sennett's observation (2002) regarding the ethnographer's interaction with her unfamiliar informants is particularly illuminating in the context of this study, as it sheds light on the role that anonymity plays in shaping people's stories:

[...] a speaker is more likely to go into things when talking to a foreigner or stranger than to a familiar. The reason is that the speaker uses the occasion to convert tacit understandings and assumptions into explicit, conscious statements, thereby objectifying and exploring the patterns of behavior for him or herself. For both speaker and witness, this kind of communication incorporates personal difference, social distance, and cultural dissimilarity into the communicative process. (ibid.: 17).

Indeed, as has been already discussed in the previous chapter, the need to write to an anonymous Other, forces the patient to convert her implicit tacit experience into an explicit coherent text. This process was notably evident in the e-mail responses that women sent me upon my request for their participation in my study. My respondents commonly provided a very detailed account, often richer than what I asked for, replete with conscious statements about their illness. Similar statements can be often found on messages posted on breast cancer online boards. For example:

I believe that physical healing goes hand in hand with spiritual healing. [...] above all we need to stay positive. our words and [t]houghts affect us more than anything else. What goes on in our thoughts and attitudes often shows up in our bodies. (A message posted on an online message board/author of online narrative 15).

Such statements are often part of an account that seeks to make sense of one's personal experience. They often serve to create a closure, to gear the account toward some kind of a moral conclusion, which reflects the author's self-realisation of a wider fundamental (often spiritual) principle. This pressure to construct closure, as I discussed in earlier chapters, is emblematic of the process of narrating.

However, it is not anonymity alone (like in the case of an ethnographer and her unfamiliar informants of which Sennett talks) that shapes the way patients share their experience online. Disembodiment has crucial consequences for this process. G

accounts for this aspect when she described the nature of the online relationship of the characters of her novel:

The women talk about how their relationship and how they would have been different. Lara says maybe it's easier to pull your heart out when you know you will never gonna have to run into them at the AMP. And I think that that kind of anonymity is a wonderful thing because it allows you to just say what's on your mind. (G, interview 7).

Crucially, it is not only the anonymous context in which the relations emerge that incites patients to engage in the interaction and disclose their experience in a way they would not have done in a face-to-face situation, but also the promise of disembodiment: that they 'will never gonna have to run into them (their online pals) at the AMP'.

Disembodiment

To fully understand the significance of disembodiment for breast cancer patients we need to contextualise it in relation to the wider experience of the illness and its implications for patients' social relations. Breast cancer is a highly embodied illness. Unlike other types of cancer, which are invisible, breast cancer is located in a clearly demarcated part of the body: the breast. Its discovery is often a result of the patient physically feeling a lump in her breast. The experience of the illness and its treatments is an extremely embodied experience. As A's comment relates so eloquently, the self-identity of a breast cancer patient is established to a large extent on the basis of her appearance:

[...] there's so much cosmetics that occurred: your brows, your eye lashes, your pubic hair, your hair...I look at the mirror and I wouldn't even recognise myself!
(A, interview 1).

In a sense, the disembodied nature of the online interaction compels the patient to confront the changes she has gone through. Paradoxically, the disembodied setting enforces her to bring in the body by textual means. She has to explicate bodily elements that are tacit in a face-to-face interaction. Spelling out her bodily features (e.g. 'I am bald') often leads the author to a process of self-exploration of her feelings and of behaviour. The need to communicate her self to the other, who is anonymous and disembodied, creates a very different situation from the monologic situation in which a patient stands in front of the mirror, where she does not recognise herself.

Through spelling out how she looks and what she consequently feels, the patient goes through a process of self-discovery and recognition. Narrative serves as a particularly useful tool in the articulation of this self-reflexive process. For example, through her e-mail correspondence with her online fellow-sufferer, A (interview 1) reworked the trauma of going bald, making sense of her new situation to her online pal and thereby to herself. Given the dramatic changes in patients' physicality during the illness, their relations with people in their everyday life are fundamentally framed by their appearance:

It's very difficult, because cosmetically [emphasises 'cosmetically'] that's what people notice.

[When] I was first diagnosed I'd wear a wig [whispers] and people would go: something is different! [...] but you know, I can't control what other people do or say. (A, interview 1).

The online exchange facilitates a different kind of relations. Rather than her physical appearance, the object that embodies a patient's 'self' is symbolic, namely: her story. Online, the story is the exclusive conduit of a patient's identity. Unlike embodied situations in their lives, where they 'cannot control what other people say', because their self-identity is overwhelmed by their appearance, in the disembodied exchange with other online participants, patients can better control the interaction and what they will receive from their partners in return. A patient's control of the interaction derives from her capacity to control her story: (1) she can choose whether she wants to reveal her identity/story, something many patients describe as very difficult to control in their local community, where the story of their illness spreads through the grapevines; and (2) she can decide what kind of identity she wants to construct, rather than be dependent on her physicality. This capacity provides a patient with a sense of omnipotence and control, especially in comparison to other interactional situations in her life.

Indeed, for some patients, anonymity and disembodiment online provide a path where they can engage in exchange, while evading encounters with others in their locale:

[...] my friend Nancy she does not want people to know she was sick. Not even people in her community know.

Q: So she types in as anonymous?

A: I guess because of her profession partly, she doesn't want people in her community to know about her illness. And she has cut back a lot of her hours, so I think the Internet was helpful for her in that respect as well. (A, interview 1).

For some patients, the anonymous and disembodied nature of the interaction constitutes a constraint:

...you don't know who these people are, you don't...their opinion or their...evaluation of something...I don't know who they are. I don't know where they're coming from. So I would sort of need to judge them before I could judge... (J, interview 10).

What J regards as an impediment, that is, the lack of information on her partners of exchange, is often seen by patients as a facilitator. They feel it allows them the freedom to 'hit it off' potentially with anybody who was affected by breast cancer, regardless of other identity-factors (place of living, class, education). Indicative of this feeling is the way women describe their connection with particular online pals as completely spontaneous and arbitrary:

Eventually, I think, you just hit it off with some people better than others. [...] I don't know what it was or why we decided...we have nothing in common. She's this Southern type Georgia bell person and I'm this rough New Yorker! (B, interview 2).

I am trusting God to put the 'right people' with the 'right people'.
(Online narrative 10).

However, there has to be certain compatibility between patients who engage in exchange relations. Even B, who insists on the arbitrariness of her online relationship with her friend, admits:

She's a single mother, which I was for many years, and she works in a...so we had some things in common. (B, interview 2).

G (interview 7) endorses this point when she insists that the characters of her novel (two breast cancer patients who meet online and maintain an intensive e-mail correspondence) had to share enough commonalities in order to be able to connect and maintain the exchange-based friendship:

The only reason that they could become friends is because there were enough similarities that enabled them maintain the e-mail back and forth. If one had been very intelligent and the other one had minimal education, or one was a lesbian who hadn't had the experience of being a parent or being married and that kind of a relationship, then to me, it wouldn't have been realistic, that the other one could really relate to her completely as they did. So in some ways they were similar in that they

both were married, they both had responsibilities of children, they both were concerned about their illness is affecting their children, and yet their backgrounds were very different. In my mind their physical appearance was also quite different. I don't think that if they had met or lived in neighbouring towns they would have been the kind of women who would have been friends. (G, interview 7)

The disembodied nature of the interaction may enable patients to overcome constraints that they would have faced in embodied interactions (being judged by their appearance, for instance). Arguably, the universal nature of the illness enables breast cancer patients to share their experience with other fellow-sufferers beyond cultural, physical, economic and social boundaries. However, their self-representation online cannot be and is not naked of their embodied 'real' identity. Patients' online communication (and thus their stories) is significantly shaped by these boundaries, for instance, by the medical services that are available to them nationally. Their narrative is an imprint of their selves, and their selves are a product of 'conventional' identity factors such as education, class, culture etc.

Patients' preference for a disembodied interaction has another dimension, which is aptly captured by the following excerpt:

If there was no Internet, I might have chosen to tell the story of cancer and coping through lectures and talks with other patients, however that would have required physical and emotional powers that are not always at my disposal. (Narrative 3).

Like the capacity to lurk, at times when a patient is physically and mentally weak, the anonymous and particularly the disembodied nature of online exchange appears highly valuable. The capacity to engage in meaningful exchange relations that do not require physical presence is discussed by many patients as a significant advantage.

Paradoxically as it may sound, it is the lack of involvement and disclosure that is ingrained in the idea of anonymity, that enables the opposite to take place. The fact that one can sit at her home, behind the screen, seemingly with no pressure for commitment and engagement (such that she often has in her local context) encourages her to get involved and committed with greater ease than if it were an embodied interaction.

Being able to empathise and reach out for the other, and yet at the same time remain comfortably installed behind the screen, in the comfort of one's home is a key dialectic in patients' online experience. It implies patients' capacity to embrace two opposite feelings at the same time: detachment and empathy, dissociation and camaraderie.

G reflects on the emotional detachment that is enabled through patients' disembodied online exchange:

There's a whole other side to it too, that strangers can give to one another that good friend and family members can't. That's that sort of **emotional detachment**, at least in the beginning. [...] Once you have your neighbour, your sister, or even somebody who lives in your town, as soon as they start to express their own fears, they're falling apart. You spend so much time trying to comfort them, and that's not what you need! You need somebody who's going to support you, who's going to be strong, and that you're not going to want to look across to see the fear on their face. The Internet gives women the chance to do that. Because even if it's *killing* [emphasises 'killing'] you that somebody else is going through a bad time, you can tell them, type them a letter and say: "I'm sitting here, crying for you, that's so bad. I wish there was something I could do to help". (G, interview 7, my emphasis).

Other patients articulate the advantage of being able to maintain a certain level of detachment in less explicit terms. Patients emphasise the comfort and convenience of their spatial environment during interactions, as an element that allows them a certain distance from the situation:

When your in this situation you're on such a roller coaster it's nice to calmly sit down and search with out some one over your shoulder. (Online narrative 25).

Re-embodiment

Ironically then, patients enjoy the capacity to distance themselves from their physical presence, while at the same time they try to make themselves present. However, while disembodiment is not specifically related to the production of narratives (i.e. disembodiment facilitates patients ability to exchange diverse discursive forms), the process of re-embodiment seems to be especially tied in to the act of narrating. Narrative constitutes a highly useful tool in making oneself present in the disembodied space. It provides a discursive framework for the author to make her body and her self visible. Unlike informational forms which patients post online, a self-narrative is probably the textual form which is most capable of making its author present. What Redford (1986) noticed about the eighteenth-century familiar letter, is

to a large extent true for the online dialogic narrative: 'the voice of the letter-writer makes distance presence' (ibid.: 2). In other words, through the production of the online dialogic narrative patients pursue a process of re-embodiment: bringing the body into a disembodied space. The following are two typical excerpts from narratives in which the narrator devises different discursive techniques, emphasising the corporal context, to re-embody the disembodied interaction:

I have never had lymphedema before, so I don't know what to expect. I didn't get one of those sleeves [...]...last night I started getting a tingle and numbing sensation and it's getting worst today. It doesn't seem swollen, just the "asleep" feeling, like you've slept on your arm. (A posting on a breast cancer message board).

...I'm happy to hold your hand until you get the all-clear (an e-mail from Susan, a breast cancer survivor, to Lara, a newly diagnosed patient, in Katz Becker, 2000: 13).

Another common device used in patients' online stories is emoticons, particularly emoticons that signify bodily gestures such as { } to signify hugs, {{{HUGS}}}) to signify intense hugs, or kisses *xoxox*. There are also common 'bodily acronyms' such as 'LOL' (Laughing Out Loud), and metonyms like ****sniff**** (to denote crying). Such emoticons and acronyms can be used in independent messages, not necessarily as part of a narrated account, but they are often incorporated into patients' narratives, endorsing the re-embodiment project that the story pursues as a whole.

This dialectical condition of disembodiment and embodiment works to enhance a story of survival: it enables patients to talk about their body and other bodies, and thus remember and relive the experience of the illness, while at the same time remain disembodied and detached, as a way of forgetting. In other types of interaction patients seem to have this capacity to a far lesser extent. Offline, their bodies must be present, especially in their medical encounters in which they cannot escape the body.

To this point, I have considered two key dialectical aspects of patients' experience of online exchange: engagement and disengagement, anonymity, disembodiment and re-embodiment. These hybrid processes have to be understood as intricately embedded in the liminal phase of patients' experience. Echoing van Gennep's renowned account of *rites de passage* (1960) and its extension by Turner on the link between liminality and *communitas* (1969), patients can be described as 'passengers'⁹ who go through a

transitional phase. Detached from an earlier fixed point in their social structure, in which they were healthy persons (separation), patients pass through 'a cultural realm that has few or none of the attributes of the past or coming state' (margin/liminality) (Turner, 1969: 94). The liminal phase is one of betwixt and between, neither here nor there, 'a moment in and out of time' (ibid.: 96). Patients' online social processes, as we saw, particularly lurking, anonymity and disembodiment are embedded in patients' 'liminal' social processes. Invisibility,¹⁰ anonymity and disembodiment, are appropriated by patients to facilitate their transition: From a set of cultural conditions (health/embodiment/engagement/visibility) to a place where they are 'to be fashioned anew and endowed with additional powers to enable them to cope with their new station in life' (Turner, 1969: 95). Central to this transition through which 'passengers' go in the liminal phase is a process of *communitas* (ibid.). This process acquires significant meanings in the online experience of breast cancer patients. This is the focus of the next section.

3. Online *communitas*

The camaraderie is amazing, the love and acceptance of each other's differences is almost overwhelming. (Online narrative 24).¹¹

Perhaps the most central aspect in women's accounts of their online experience is their recognition of a special kind of interrelatedness and bonding that emerges from their online exchange with fellow-sufferers. The notion of '*communitas*' aptly encompasses this experience. Largely borrowing from Buber's concept of community, Turner (1969) introduced the notion of '*communitas*' to refer to a specific modality of social relationship that emerges recognisably in liminal periods. *Communitas* implies a sense of being '*with* one another of a multitude of persons' (ibid.: 127), with an emphasis on the 'spontaneous, immediate, concrete nature of *communitas*, as opposed to the norm-governed, institutionalised, abstract nature of social structure' (ibid.). Indeed, women often describe their experience of *communitas* online in relation to, if not in opposition to, institutionalised structures of exchange that they encounter in the context of their illness.¹²

Therefore, in the remainder of this chapter I wish to show how *communitas* evolves through patients' social uses of these online structures. The discussion will

particularly focus on the ways in which patients' liminal condition and their experience of *communitas* online generate a process of narrating and storytelling.¹³ This process, as I argue throughout this thesis, endows them 'with additional powers to enable them to cope with their new station in life' (Turner, 1969: 95).

Unstructured bonding: Immediacy, spontaneity and quick human interrelatedness

As opposed to the institutionalised medical structure that patients encounter in the course of their illness and treatment, the *communitas* they experience is largely characterised by spontaneity and immediacy:

I think you start out when you ask questions and go online to a group, looking for somebody who had, at least the procedure that you're dealing with at that time, whatever it is. When I was having the mastectomy [...] All I wanted to know is that compartmental of time, did you have a mastectomy, **tell me about it**. And then when I got the kind of chemo I was having, then I wanted to know that. It didn't have to be the same person. Eventually, I think, **you just hit it off** with some people better than others. Some people also wanted just to ask their questions, and they would discuss their subjects again. **Get your information**, and then they want no connection. (B, interview 2, my emphases).

'Tell me about it' 'get your information' and 'just hit it off' are statements that capture the spontaneity and immediacy in patients' online communication. Beyond the general expectation of reciprocity, the nature of the communication is unspecified and unstructured: there is not a specified type of actor who is expected to give feedback ('you just hit it off with some people better than others'); there is no obligation to sustain the exchange on a long-term basis ('It didn't have to be the same person'); and there is even no clear obligation for truly mutual exchange, insofar as some participants act instrumentally and cease the exchange once they get what they want. The latter also suggests that the immediacy and spontaneity do not necessarily have to do with storytelling. In fact, B's account describes these qualities in relation to what might be seen as a counter case to narrating, namely a brief, straightforward and instrumental information seeking ('get your information and then they want no connection'). So immediacy and spontaneity, I suggest, characterise the nature of patients' online communication in general, and apply to a diversity of communicative processes, from short-term information seeking to elaborate ongoing storytelling.

The *immediate* character of the online *communitas* has particular significance for patients' liminal condition. In their encounters with the medical institutions, patients

are often made to wait without knowing what is to happen and when (Frankenberg, 1992). Thus, the immediate nature of the online communication, of 'being a click away' from other fellow-suffers with whom a patient can share her experience without having to wait, plays a key role in patients' coping.

As discussed in Chapter Five, the immediate nature of the online communication enhances patients' capacity to rework their self-narrative 'on the go'. However, the significance of the immediate character of the online communication lies in the dialogic nature of narrative. Immediacy would not have any value as a property of the online space if it were not embedded in a social process of exchange and *communitas*. It is patients' *exchange* of their narratives with other patients on an immediate basis that facilitates the continuous reworking of their narratives. The *communitas* that emerges online represents a sense of being *with* one another, on a spontaneous, immediate and concrete level. Unlike other kinds of *communitas* patients may experience, in order to experience online *communitas* patients do not have to be confined to a particular time or space:

[...] the idea that the women can reach out to each other whatever the day or time... You can go online when it's convenient, you're not tied to a support group that meets every Monday at 7 o'clock. You're not feeling well, not feeling up to getting dressed, putting clothes on getting into your car, you can still benefit from online support which is always there and **you can do it when you can do it.** (G, interview 7, my emphasis).

As far as patients' narrating is concerned, this special kind of *communitas* produces a 'you can do it when you can do it' narrative: a patient can narrate any time, and there is potentially a witness to her story any time. This is unlike the accounts told in other areas of patients' lives, particularly in front of doctors, where listeners are available at fixed, planned and non-immediate times and places. The accounts women tell their doctors are usually well structured and prepared in advance. Women told me how they used to plan in detail what they would tell their doctors during their consultation, taking notes and arranging their thoughts and questions as coherently as possible. Given the fixed and limited time and space they have for their interaction with their doctors, patients produce accounts that aim to cover as much as possible and capture the here and now. By contrast, the nature of accounts that patients tell online is less 'condensed': they usually do not attempt to capture the 'whole story', here and now, in its entirety, but rather represent part of the patients' experience, which is often

followed by more messages that are continuously produced. The fact that the space for storytelling is constantly available, with potential listeners at any time, allows the representation to be more fragmented. So patients' postings do not always constitute narratives in their own right; sometimes they are short messages or only a fragment of a patient's wider experience. The bigger story is being established on an ongoing basis through the process of exchange with others; an initial short message can be elaborated and formulated into a richer and more coherent self-narrative. Thus, patients' online narratives should not be seen as independent units but as part of a chain of narratives, composed of both the narrator's stories and those of her listeners who, through the act of responding, become narrators themselves.

Generalised exchange and communal storytelling

It is through this communicative chain of stories that *communitas* emerges. The primary mechanism that facilitates the creation of a chain of stories, and thus *communitas*, is the structural organisation of messages posted on electronic boards along 'threads'. An online 'thread' links different messages, by organising them under an umbrella topic. In this way, several different postings, often composed by two or more patients, are aggregated into a 'meta-narrative'. The following thread, taken from a breast cancer message board exemplifies this idea. Note how a narrative about the relationship between a patient, her cancer, and her mother (posting 1), develops into a narrative of another patient about her cancer, her family and the Internet (posting 2), closed (albeit never sealed, as one could always re-open this thread by adding one's story) by a story of a third poster about her cancer and her friendship with her online fellow-sufferer (posting 3):¹⁴

MOMS SAY THE DARNDDEST THINGS....WITHOUT THINKING

[Posting 1]

Yesterday, just my Mom and I went to [...] a [...] craft store. [...] I came across over 100 angels and had tears come to my eyes. I just stood there looking at all of them. My mom said, what's wrong, with you? and Why are you crying in this store? I told her, that everytime I see an angel, it reminds me of mycancer. She just said, I shouldn't LOOK FOR THEM. I told her, that I love angels, because, even though, it was a bad time in my life, it was a blessing, too. I think that just about, knocked her off her feet. She said, You are glad you got cancer? I said, no, but I'm glad it happened to me and [me and] not my sister, or her or anyone else in our family. Then, I said, I have so many friends that I love, so much and they all have helped me, in ways they will never know. Then she had to sit down, she was

confused.....Well just who are these new people that you say that you love??? I said, it was all of you. who are reading this, now. But, she says, you have never even, met these people and haven't had the time to really know, who they are...Yes, Mom I have. I have them all in a special place in my heart. [...] It was a very, special day, cause, it was about, my MOM, my CANCER and all my new FRIENDS. [...] That cancer, made me find, all of you. [...] hugs & love,

Nina

[Posting 2]

What a sweet message. It's nice when you can spend time with your mom and get along so good. My mom drives me crazy, and my kids don't even want to be with my mother. I'm so glad that I found these boards to chat on too. I don't know what I'd do without them. My husband was telling me that maybe we should unhook the Internet and I told him noway, nohow. I'm not about to give up my Internet. Well, talk to you later.

Jean

[Posting 3]

Wow Nina ****sniff**** (reaches for tissues). One thing I have found since I have had this "affliction" is missing having my Mother to share it all with. Keep those precious memories, they are important. PLEASE say "hello" to your mother from me here..seeing I don't have a mother. Show her the calendar too, then she will see what friends you have!!!!

Carol

*(Breast Cancer Online: In Our Own Words, www.bcans.org, 2003: 26-27).*¹⁵

While each independent message does not necessarily constitute narrative in its own right (for example, posting 3 in the above quote clearly cannot be considered a narrative), the act of exchange and the structure of a thread, create, I suggest, a wider story. In this sense, the whole is more than simply the sum of its component parts; from the aggregation of the different messages into a thread, a story emerges: a constellation of different parts into a whole. Such 'chains' are based on the implicit principle that the only confirmation a patient can have that her message has been correctly constructed and construed lies in the production of more story.¹⁶ In other words, the only way to confirm the acceptance of one's story is to generate more stories. This observation draws on the theoretical assertion that the construction of one story necessarily creates further patterns of interconnectedness and meaning (Brooks, 1994: 56-57). Once a personal account is introduced into the public space of a breast cancer message board, negotiations over its meaning start to take place. Other participants in that space, i.e. 'listeners', respond to the author's posting, either on the public forum (e.g. by posting messages on a message board), or via e-mail, contacting

the poster directly and privately. In so doing, they join in the act of producing a story. Through the negotiation of the meanings of her message, the author seeks to gain credibility for her personal experience.

This process resembles an oral situation of 'communal storytelling' (Ricoeur, 1980), 'collaboratively crafted by many different voices along the way' (McLellan, 1997: 98). The idea of storytelling as a communal action implies that, through its recitation, a personal story is incorporated into a communal communication, and it is through the communicative event that emerges that a closure is constructed. (As has already been explained in the previous chapter, through the exchange of stories between survivors and new patients, survivors implicitly direct new patients' stories towards a 'happy end' of cure and hope). The following account hints at this claim:

...every month I am doctoring somewhere, I end up turning into a basket case. All I have to do is get on there [BCANS online message board] and say I've got an apt. [appointment] coming up and I'm overwhelmed with responses and wishes. These ladies have all been there where I am now, and got through by talking it out with each other. (Online narrative 19).

Underlying this process is what Ekeh (1974) calls 'the Law of Extended Credit': a credit mentality where individuals have faith that they will take care of others and will be taken care of in return, although not necessarily by the same people. This kind of 'generalised exchange', as Lévi-Strauss (1969) contends, operates on the basis of trust: individuals usually do not receive benefits from those to whom they provided benefit. The following excerpts are testament to the kind of univocal reciprocity between breast cancer patients in online spaces:

All of the ladies on the AOL thing [breast cancer message board], most of them, when I go back every once in a while, go to the board, a lot of them have been out for 10, 20 years. This is their commitment to go back and help the new people. (B, interview 2).

[...] after I was done with chemotherapy I stopped really doing the Internet, but then people were contacting me who were going through, and wanted to find what lies ahead. I still keep in touch with one girl... (A, interview 1).

One of the communicative forms through which participants build their faith in each other, and so *communitas* emerges from the collective production of stories in online spaces.

Institutionalisation of communitas

Theoretically, while spontaneity and immediacy are key attributes of communitas, at the same time there is a latent tendency toward the sustainment of a certain degree of social order, what Turner (1969: 132) calls 'normative communitas':

[...] under the influence of time, the need to mobilize and organize resources, and the necessity for social control among the members of the group in pursuance of these goals, the existential communitas is organized into perduring social system.

However, while Turner's typology of communitas insists on a separation between 'existential spontaneous communitas' and 'normative communitas', implying that the two are mutually exclusive, I suggest that in women's online communication the two orientations exist at the same time. B's description of the communicative dynamics on the AOL breast cancer online board implies this dual orientation:

I remember the whole time I was going through the treatment, they [the other participants on the AOL breast cancer online board] would tell me 'you've got to do this', and I would tell them 'tomorrow I'm going to have this', and then they would tell you what it was. Or explained 'oh, I've been through it, this is no big deal'...

(B, interview 2).

The communication on message boards such as AOL or BCANS is strongly based on spontaneity and immediacy. At the same time, however, the online board functions as a framework that creates, sustains, and reaffirms a certain degree of 'social order'. Comments such as 'you've got to do this' 'I've been through it, this is no big deal' are not merely informative. Although this level definitely exists, patients' online communication goes beyond the transmission of information. It involves the construction and maintenance of a certain social framework that can serve as a control and container for B and her fellow sufferers' experience. The production of stories is one way through which the women on the message board direct and mobilise B's story towards the 'appropriate' line of narrative: a narrative of self-governance, agency, survival, hope and cure; 'I've been through it, this is no big deal'.

In this sense, online communal storytelling can be seen as a ritualistic process of communication in the Durkheimian sense: It plays a significant role in the creation, sustainment and reaffirmation of social order, while at the same time enables the

emergence of feelings of 'sharing', 'participation', 'association' (Carey, 1992: 18), camaraderie, bonding, and 'communitas'.

Emblematic of this dialectical process is the metaphor of a family that is often used in breast cancer patients' online spaces. For instance, the introduction to BCANS Forum (online message board) says:

One family of women

[...] Although we branch out all over the planet, we are a single family sharing unified roots.

[...] this forum is a source of simple sustenance for those whose lives have been touched by breast cancer. Where does a woman turn when her world is torn asunder with the dreaded diagnosis?

(www.bcans.org)

The message conveyed by framing online interactive spaces as a family is that of constant support, empathy and bonding. At the same time the 'family', in the form of a message board, is a significant agent of socialisation and social control.

A uniform condition: Egalitarianism and homogeneity

Another complex dialectic underlies the metaphor of a family, and more broadly the nature of patients' communitas online. On the one hand, there is a strong emphasis on the egalitarian and homogenous dimension of the 'family of women' and its communication. On the other hand, like in any family, there is a certain hierarchy that underpins the relations between its members. As already mentioned in Chapter Five, breast cancer online spaces are 'queendoms' of survivors, where survivors rule the discursive space and determine its orientation.

By virtue of their liminal conditions of illness, the patients' condition is rendered uniform:

In my opinion the internet offers one "choice" and sharing with others in the same position. (Online narrative 21).

It is almost as if the experience of breast cancer strips them of the other factors of their lives, reframing their everyday experience and identity. In this sense, cancer patients resemble liminal entities:

They have no status, property, insignia, secular clothing indicating rank or role, position in a kinship system – in short, nothing that may distinguish them from their fellow neophytes or initiands. (Turner, 1969: 95).

The situation of being reduced to a uniform condition is the basis for the emergence of a sense of *communitas*, where bonding and comradeship are established on commonality: everybody is going through a similar experience and pain.

The character of the online communication facilitates and enhances the egalitarian dimension of *communitas*. First, the anonymous disembodied character of patients' online communication furnishes an ideal platform for the exercise of egalitarian relationships. As has been discussed earlier in this chapter, anonymity and disembodiment give participants the capacity to interact while overcoming conventional identity factors that would have otherwise determined power relations in very significant ways.

Second, as noted in the beginning of the chapter, breast cancer online spaces are structured for the participation of patients only. Although occasionally actors such as caregivers and family members do participate in those spaces, the core of the communication is almost exclusively patients'.

Third, breast cancer patients' online forums utilise different mechanisms to focus the discussion only on aspects of the illness, avoiding 'extra-curricular' issues that might undermine the common experience-based communication. The BCANS Forum, for example, directs postings that are not dealing with breast cancer to a secondary 'off-topic' message board. This exemplifies how certain kinds of discourse are designated to certain communicative spaces, and how, consequently, uniformity and homogeneity is sustained in subtle but effective ways.

Therefore, patients' engagement in online exchange is significantly different from other kinds of exchange relations in which they engage in the course of their illness, particularly their exchange with medical professionals (experts). While the latter is predicated upon clear definitions of power (one might think here of Parson's typology of the 'sick role', 1964), patients' online exchange offers a potentially non-hierarchical structure of relations. Indeed, women often compare and contrast their

online exchange relations with online fellow sufferers to their face-to-face exchanges with non-patient actors, particularly with their doctors. They highlight the significance of the common experience as a basis for genuine *communitas*:

It has been my experience that only those who have had an intimate relationship with cancer can truly understand the stages a newly diagnosed patient will go through. (Online narrative 24).

However, the non-hierarchical dimension of patients' *communitas* online is only one side of the coin. The *communitas* between patients is fundamentally based on a clear hierarchical order, by which online newcomers who are newly diagnosed patients follow their instructors, online veterans who are breast cancer survivors.

*The high could not be high unless the low existed, and he who is high must experience what it is like to be low*¹⁷

Within the OncoChat and the breast cancer listserv Internet groups, the responses to my questions and expressions of fear and angst have been met with understanding. There is always someone who has walked in my shoes already and can say, with honesty and compassion, "I know just how you feel" (Online narrative 24).

To be able to 'walk in one's shoes', with honesty and compassion, there has to be a certain order of relations: on top of the hierarchy are those who have 'been there done that', i.e. veteran patients, commonly occupying the title of 'survivors'. Their role is to mentor newcomers who are relatively new in their 'breast cancer journey'. The latter are in the liminal stage: they must experience what it is like to be low, in order to be high; i.e. emerge and reach their mentors' position. This hierarchical principle frames, in significant ways, the *communitas* that is developed among patients online.

Online mentoring is a voluntary pattern of survivors who remain online – even years after being cured – to 'welcome' newly diagnosed women, and to guide them through the course of their illness. The implicit 'working assumption' is that, one day, when those newly diagnosed become survivors, they will do the same. It is primarily on the basis of this 'extended credit' framework of mentoring that a considerable sense of contract between the fellow-sufferers emerges:

So, my friend Nicole, she had mastectomy and hysterectomy... she is ahead of me in the reconstruction, she has the reconstruction done, and so she gives me feedback. It's kind of like a 'pecking order', because her, and me and then my friend Nancy.... (A, Interview 1).

Having said that, the idea of a 'pecking order' of mentoring between patients is not unique to the online communication. Indeed, many of my interviewees had a mentor during their illness, outside of the online space, and later, when they got cured, they often mentored newly diagnosed patients. The distinctiveness of the online context lies in the way mentoring is enacted: in a disembodied fashion, through the medium of writing.

To explore this aspect, I wish to open with an extract from a (fictional) e-mail written by Susan, (a breast cancer survivor, acting as the mentor) to Lara (a newly diagnosed patient, occupying the role of the protégée). Susan writes:

Dear Lara,

{{{ }}} Those are hugs. Cute, huh? Stick with me kid, I'll teach you all kinds of neat Netspeak.

(Katz Becker, 2000: 26).

Susan is capable of acting as an online mentor, mothering Lara the 'kid', not only because she is a breast cancer survivor, but crucially because she is also a veteran active online participant. As Lara goes through the course of her illness and treatments, Susan teaches her not only about breast cancer but also about the discursive rules of communicating breast cancer online. These rules consist not just of medical jargon and terminology, but also of specific forms and styles of expressions, such as the emoticon of {{{HUGS}}}'.¹⁸ These are discursive devices that are characteristic of the culture of breast cancer online. To be able to participate in the exchange in this community, one must have some knowledge of the discourse and the norms.

One of the things Susan teaches Lara is to communicate her illness through narrating. I have already shown a couple of examples in the previous chapter, of how Lara works on the narration of her experience in her e-mails to Susan. As their correspondence progresses, Lara becomes an experienced storyteller of her

experience. Hence Susan's role of mentor is twofold: she is Lara's guide to the breast cancer journey and concomitantly her instructor on the online journey.

Online writing, especially in e-mail narrated format, has interesting implications for the development and sustainment of the mentor-protégée relationship. The following (fictional) excerpt, in which Susan inserts her comment into a bit from Lara's previous e-mail, is a useful demonstration of this point:

Subj: Whoa
Date: 11-30
From: Susan P@aol.com
To: cre8f1@mindspring.com

On 11-29 cre8f1@mindspring.com wrote:

> (Please, God, help me to raise Wendy to be a more forceful
> and confident woman and not a dishrag like her mom. Amen)

Now cut that out. You are not a dishrag. A dishrag would not have immediately called her internist for more information. You took action and are not to be condemned. (Katz Becker, 2000: 62).

Susan creatively uses her capacity to edit Lara's textual self-presentation to help her reformulate her self-account and reassure her of her decision to get a second opinion about her diagnosis. Susan is rewriting – both technically and substantively – her fellow sufferer's story.

After Lara got the definite news she has cancer, Susan wrote her:

[...] So now that you think you've heard the worst possible news in the world ("It's cancer"), let me switch into my "I'm a survivor, but you can call me Pollyanna" mode.

- Breast cancer does *not* mean you're going to die. I can't repeat that often enough.
- Breast cancer is *not* synonymous with mastectomy. (Lumpectomies with radiation have been proved as effective as mastectomies for long-term survival. Example: Me!)
- Breast cancer does *not* necessarily mean you'll even need chemotherapy.

(Katz Becker, 2000: 105).

In the latter example, Susan employs simple technical capacities enabled in e-mail writing, such as using bullet points or emphasising certain words by *italicising* them, to switch Lara's narrative from one of 'cancer' into one of 'survival'. The form of bullet points visually gives the story a clear order, attributing to the content a sense of validity and formality (a sense a breast cancer patient lacks, in the face of the uncertainty imposed by the news of her diagnosis). These bullet points represent, if you wish, the 'legitimate' building blocks of a breast cancer narrative, that is, of a story of survival. E-mail seems to furnish an ideal platform for a mutual reconstruction of their self-narratives: the veteran patient, through exchange, helps her protégée to reformulate her story into one of survival. In so doing, she reconstitutes and reaffirms herself as a survivor.

Susan and Lara's relation exemplifies the way Brooks (1994: 57) characterised a teller-listener relation, as simultaneously one of collaboration and struggle: 'collaboration toward the creation of the coherent and explanatory text, yet struggle over its interpretation, and over its very constitution'. Asynchronous disembodied textual forms such as e-mail provide a useful space for the sustainment of this collaboration/struggle process. Each actor is on her own, detached spatially and temporally from her online partner, free to construct her personal account, under ideal 'individualistic' conditions ('without someone over your shoulder', as put in online narrative 25). At the same time, the teller and the listener share the same discursive space: they literally share a single electronic sheet, on which they can struggle over each other's interpretation, by means of editing, referring, commenting etc.

Communitas evolves through these mutual acts of online storytelling. However, as both Blau (1968) and Turner (1969) recognise, exchange relations often become institutionalised, and the spontaneity and immediacy of communitas can seldom be maintained for very long. Rather, free relationships between individuals often become converted into norm-governed relationships between social personae (Turner, 1969: 132).

There are particular spaces in which mentoring is structured in fairly formal kinds of online 'schemes'. One such example is 'Chemo-angel', an online form by which patients are assigned fellow sufferers as online pals with whom they can correspond

and exchange experience. There is an online team of breast cancer survivors who runs this service and monitors the assignment of 'chemo-angels' to patients. As described in the following online account:

I also have a chemoangel who was assigned to me for one-to-one support. She e-mails me weekly and we have a nice relationship going. The chemoangel group tries to match you up to an appropriate angel and they got me a good one! (Online narrative 11).

Another way in which exchange relationships and *communitas* between breast cancer patients become institutionalised is when survivors become semi-formal authors, and subsequently semi-formal authorities, of their experience. Examples can be found in patients' personal web pages, patients' online journals, and other kinds of online columns that patients write on a regular basis. The way B describes the online breast cancer column she writes manifests how *communitas* online can become governed and how certain resources are mobilised to enable social control:

For the column... Mostly, you can logon and they show you how many hits you have. It's averaging like 2,000 hits a month, which I think is fine for just a little column on breast cancer. [...] Now, at the beginning, there are obviously faithful readers, because they know when it comes out, it comes out every other Sunday, and there's always like 50 hits, for the new article the next day. But, and it's a wide variety, one is about diagnosis, one is about mastectomy, there's a couple about chemotherapy. Consistently over the year, you go back and the pages that had the most hits are the ones about chemotherapy, the ones about radiation. It's the ones about the things that people are going to have to go through: the treatments. [...] I did one on celebrities with breast cancer. The ones that people read the most, when they come and find the column, they go either to ones about what they're going to go through...the treatment (B, interview 2).

B's relationship with her readers (to whom she refers throughout her interview as 'the people' or 'the general public') becomes more like a producer-consumer relationship, than one of equal fellow-sufferers. Her authorship infers authority, and it is being reconfirmed through the communal act of storytelling: her readers respond to her semi-official online story, and she responds in return. Another patient who wrote an online journal of her illness endorses the nature of this process:

[...] I find that beyond the experience of writing, it is important to me to transmit my story to other women that have gone through, or might go through breast cancer, and I indeed get very encouraging reactions and letters, from people who thank me for the emotional support and the power that I pass through my words. (Narrative 3).

The implication of Turner's notion of 'normative communitas' is that as a consequence of the institutionalisation of patients' mentoring relations and their collective storytelling, their communitas becomes less 'genuine' and 'authentic'. In light of the increasing institutionalisation of online spaces, certainly there is potency in this claim, as I will argue in the concluding part of this chapter. Having said that, Turner's proposition should be taken with a deal of circumspection. Even more institutionalised relations, such as those between the author of an online journal and her readers, entail a genuine and spontaneous sense of bonding. Thus, while Turner's discussion of communitas is useful insofar as it draws our attention to the significance of the institutionalisation of relations, it is limited insofar as it perceives this process as necessarily destroying spontaneity and genuine human contact.

Furthermore, there is a significant normative message conveyed in a space that is organised by the idea that 'the high could not be high unless the low existed, and he who is high must experience what it is like to be low' (Turner, 1969: 97). The message is that there are no shortcuts; one has to go through the complete journey in order to be high, i.e. to reach the status of a survivor, and get reincorporated into the normal healthy social structure. The 'complete journey' dovetails with the journey of the illness and the journey of online communication. And narrating constitutes a central means in completing this journey and reaching the moment of re-aggregation (*à la* Van Gennep).

Conclusions

The illness brought two women,
Foreign, far and apart
into one room,
and ordered the Friendship:
Play!

Zelda (1975)¹⁹

Breast cancer brings women who are foreign to each other into online spaces, where they engage in a process of disembodied, anonymous and textual exchange with fellow-sufferers. This process generates feelings of bonding, sisterhood, camaraderie,

and strong empathy among the participants, inviting patients to locate their personal experience in relation to that of others, and consequently validate and legitimise their personal experience. Narrating, as I argued in this chapter, is a central element in facilitating this process.

Of course, not all patients interact in the same way. While some engage in multiple kinds of online exchange relations, dyadic and multi-party, whether on a spontaneous level or in more institutionalised forms, others prefer engaging in one specific kind of interaction. Some get involved in long-term relationships, while others perform a more instrumental kind of exchange, as described by G: 'Get your information, and then they want no connection'. Yet others, such as J and K, prefer not to get involved at all in exchanging their experience with fellow-sufferers, and remain lurkers.

I do not want to suggest that the kinds of interaction presented in this chapter are the only possible types. I have explicitly acknowledged that patients' online exchange involves a variety of communicative processes, and that narrating is only one of them. Nor do I wish to celebrate the online space as the ultimate communicative space for the materialisation of *communitas* and exchange between patients. As I have shown throughout the chapter, in specific contexts, and for specific individuals, online exchange might be constraining or irrelevant. However, in separating out the main interactional features involved in patients' online exchange, my aim was to account for their significance and distinctiveness.

The analysis proposed in this chapter invites a revisiting of some of the issues that were raised in Chapter Four, in my proposal for a model of online narrating that might resolve tensions between the dialogic and the disseminative.

Revisiting online narrating as a hybrid model: Between the dialogic and the disseminative

The first issue revolves around the disembodied nature of online communication. As mentioned in Chapter Four, the debate on CMC has been occupied with the question: what kind of moral obligation can a 'virtual' contact compel? The majority of studies of online exchange perceived the disembodied online interaction, particularly online conversation (as this has been seen as a central form of online interactions), as a

constrained version of face-to-face interaction. The underlying normative agenda of research on CMC has been the need to restore a body-to-body dialogic relationship. Indeed, notions of presence and embodiment lurk in most of the traditional theories of social exchange. The assumption is that 'in order to exchange affection, it is often necessary to be in presence of the other party' (Roloff, 1981: 18).

In line with recent studies of CMC (e.g. Baym, 200; Hine, 2000) the analysis of the online exchange of breast cancer patients casts critical light on the presumed inevitable link between exchange and embodiment. For breast cancer patients, disembodiment is often facilitating rather than constraining. For example, as shown in this chapter, the production of a self-narrative and its telling in a disembodied space enables patients to 'bring their bodies back'. In this sense, the production of patients' narratives online might produce a hybrid experience: allowing patients to avoid constraints that they often face in embodied interactions in their lives, while at the same involve themselves in meaningful interactions, representing themselves textually, by telling a story.

Recalling the model of narrating that was proposed in Chapter Four, and following the discussion of the present chapter, patients' online narrating emerges as a hybrid process in yet another way. On the one hand, as the analysis has shown, online narrating entails typical disseminative attributes: it is radically public, democratically inclusive and indifferent to all patients (unlike expert medical modes of discourse from which patients are often excluded). The inclusive dimension is particularly augmented by the anonymity of the narrators, as Sennett (2002), who was cited earlier, suggests. It incorporates personal difference, social distance, and cultural dissimilarity into the communicative process. At the same time, as stressed throughout this chapter, patients' online narrating is essentially dialogic, generating a strong sense of *communitas* between fellow-sufferers. In other words, while online narratives are ostensibly open to all, they are also selective, working as a mechanism of social exclusion. Patients like K, who want to use a different form of discourse (rather than her personal narrative), and articulate different types of content from those that constitute the mainstream discourses that dominate breast cancer online spaces, often find themselves excluded from the communicative process.

Third, while framing patients' online narrating as a process of exchange emphasises, of course, its dialogic dimension, the accounts presented in this chapter have shown how the very same process involves a fundamentally monologic aspect. The one-way-act of online narrating is encapsulated particularly in two interactional situations: lurking and self-presentation of patients as semi-formal authors. Lurking, an issue explored in depth in the beginning of the analysis, can be seen as a mediated quasi-interaction (Thompson, 1995). It involves a one-way act of the lurker observing the others, and in this sense, it is monologic; it does not have the reciprocity and interpersonal specificity of other forms of interaction. At the same time, the lurker is engaged in receiving symbolic forms (stories) produced by others, to whom she does not respond, but with whom she can form bonds of friendship, affection and solidarity. Patients' self-presentation on forms such as online journals, personal web pages, or online columns, constitute monologic spaces insofar as they disseminate a personal narrative in a public forum that is inclusively open to all. Such self-presentations can be seen as individuals' performances of their selves (a notion I will develop in the following chapter). At the same time, as I have shown in this chapter, even such monologic spaces, which are arguably independent of any reciprocal interaction, are intricately embedded in relations of exchange.

The characterisation of patients' online narrating as a process of exchange that encompasses the dialogic and the disseminative, enlightens a dichotomy which frames social exchange theory, and which more broadly typifies 'sociological theory in its two broad divisions' (Ekeh, 1974: 197): the collectivist (most associated with Lévi-Strauss' theory of social exchange) and the individualistic (notably represented by Homans and Blau). Drawing on Malinowski's infamous study of the Kula exchange, Ekeh (1974) suggests that these two divisions should be encompassed, since the individualistic and the collectivist processes are not mutually exclusive. In a similar way, patients' online exchange can be seen as a social situation that consists, on the one hand, of individualistic orientation – where tellers and listeners engage in mutual reciprocity to satisfy their psychological needs, such as establishing themselves as authorities, gaining reassurance, and making sense of their experience. On the other hand, patients' online exchange is a clear case of 'generalised exchange' and *communitas* where the participants have faith that they will take care of others and will be taken care of in return.

Narrating and Trust

Although one would assume that people sophisticated enough to be participants in this kind of forum would not blindly embrace just any suggested remedies, a kind of trust develops among participants that seems to create greater acceptance of the free advice that goes back and forth (McLellan, 1997: 104).

In her account of an online forum on the experience of a kid who suffers from leukaemia, McLellan (1997) recognises the significant aspect of trust in the participants' communication. However, like other studies of health-related online interactions, McLellan's analysis remains restricted to the informational level, chiefly concerned with the aspect of the trustworthiness and credibility of the information that is being transmitted. The analysis presented in this chapter sheds a different light on the issue of trust. It suggests that trust is not restricted to the information being transmitted in patients' online exchanges. Rather, it involves also an experiential communicative dimension, which is manifested in processes such as storytelling or lurking. In other words, beyond the issue of information and its content, patients also require and acquire trust in the actual human communication and particularly in the processes and structures that facilitate it.

In the context of this analysis I have shown how narrative constitutes a communicative form through which trust evolves between patients online and how the particular properties of their online exchange render trustworthy the narratives that patients produce. Patients' online narratives, in their hybrid character, seem to transcend much of the anxiety, mistrust and rejection that patients often feel towards other discursive forms and towards other interactions in their lives. For instance, while patients often regard the anonymous disembodied online narratives of their fellow-sufferers as authentic, non-mediated and thus trustworthy, they appear to mistrust similar narratives of patients who appear on television and tell their story. The latter performances of patients who tell the story of their illness (usually in talk shows) were often depicted by my interviewees as inauthentic, self-interested and untrustworthy. By the same token, patients often find it hard to trust discursive forms that are *not* personal narratives. The following account neatly summarises the kind of trust patients seem to have in the process of online narrating, in comparison to other

online discursive forms such as critical discussions in chat rooms, about which they seem generally less enthusiastic:

It was after the surgeries and chemo that I began to seek others though the internet. I tried to find sites that promoted positive 'stories' [...] [of] those who have experienced cancer. [...] My "Friendships" have come by way, mostly of a site called Hangthrough. I wrote a short story about my encounter with 'an angel' and it's impact on me and me mental state. From that I have heard from a variety of woman, but Sylvie and I have remained 'friends'. [...] The internet has given us a chance to pray and intercede for each other and our family members.

[...] I do not use 'chat rooms'. Every attempt I have made has been met with one another, just **arguing** an issue. I have not time for that. (Online narrative 10, my emphases).

¹ Exchange appears to be a more general feature in the communication of breast cancer, as discussed in Chapter Two.

² For Blau, who predicated his theory of social exchange on economic motives, the keynote aspect of social interaction is *profiting* (Ekeh, 1974: 170).

³ The BCANS message board is divided into 'on-topic' and 'off-topic' boards. I explain this later.

⁴ Resembling Benjamin's notion of narrative as a gift, N frames her own storytelling as a gift, as a way to present her personal experience as a contribution to others.

⁵ It seems that the sense of achievement that women attribute to the fact they got replies from different places in the world, especially if these places are remote from their locale (geographically and/or culturally), is interlinked with the view of the Internet as a global space. Although I did not enquire into this meaning further in my interviews, it is my suspicion that reaching readers on a 'global scale' is seen by the narrator as a sign that her story has value beyond her personal realm.

⁶ Evidently, in their accounts, women told me how they were reluctant on different occasions to engage in exchange relations, whether in specific online spaces (e.g. chat rooms, as indicated by F, interview 6, and in online narrative 10) or offline (e.g. at the workplace, as described by A in interview 1). Sharing one's personal story of breast cancer is not a trivial act, hence the significance of exploring why women are motivated to exchange their stories in specific online spaces.

⁷ Chat rooms are not in focus in this discussion because they did not appear as central in patients' experience. Arguably, their synchronous nature creates a significantly different form of interaction, in which the object of exchange is different from a narrative.

⁸ There are also differences among multi-party exchanges and among dyadic exchanges; however, these seem to be less significant in terms of their implications for women's experience.

⁹ Breast cancer patients often use explicitly the metaphor of *journey*, to describe the experience of their illness, in which they are the passengers.

¹⁰ Interestingly, invisibility is often likened to liminality (Turner, 1969: 95).

¹¹ I revisit this statement critically in Chapter Seven, when I discuss similarity and difference.

¹² This is not to imply that *communitas* is unique to patients' online exchange and cannot be found in other contexts of their lives, or that the online properties have inherent liminal properties that produce *communitas*. Rather, what I suggest is that the structure of the online exchange facilitates, in significant ways, the emergence of *communitas* between fellow-sufferers.

¹³ The linkage between liminality, *communitas* and narrating loosely evokes Turner's observation that liminality is a condition in which myths and symbols are frequently generated (Turner, 1969: 128).

¹⁴ The original authors' names have been changed.

¹⁵ *Breast Cancer Online: In Our Own Words* is a collection of postings from the breast cancer message boards of BCANS. Available at www.bcans.org

¹⁶ Following Brooks (1994), I use the notion of 'more story' to refer to the idea that all the individual stories make up a meta-narrative i.e. more story.

¹⁷ Turner, (1969: 97)

¹⁸ Similarly, through my e-mail correspondence with breast cancer patients, I have come to learn specific phrases and emoticons that are unique to breast cancer online storytelling.

¹⁹ My translation from Hebrew.

Chapter Seven

The Negotiation of Public and Private

Introduction

On Saturday there is a train coming from Penn. station [in NYC] picking up all breast cancer survivors and it is called the Victory train. They have it once a year [...]. **I don't participate in these things because I am more private.** (An extract from an e-mail message by A, Interview 1, my emphasis).

Incidentally, the day of my interview with A was 'Victory Day': an annual day in which breast cancer survivors celebrate their victory over cancer in different events across the US. The train that I took from NY, on my way to meet A, was called the 'Victory train', a regularly scheduled train with specific cabins for breast cancer survivors who are picked up on the way. The event is communicated in the public space: there are public announcements about the 'Victory Day' at every stop. All breast cancer survivors who go on the train wear special T-shirts representing the event. Their cabins are decorated with pink balloons, denoting the pink ribbon. Along the way, local supporters wait on the platforms welcoming the survivors with signs and posters. A, who gave me directions for the venue of our meeting, knew that the train I would need to take is the 'Victory train'. In her e-mail, which I cited above, as well as throughout the interview, she stressed that she does not participate in this kind of events, because she is 'more private'.

For A, such breast cancer related activities, which are outdoor and embodied, are considered a violation of the boundaries between the private and the public. However, to A, the online space represents a private setting, where she has participated quite actively, sharing the personal story of her illness with disembodied fellow-sufferers.

What I want to explore in this chapter is these kinds of meaning of public and private that emerge around patients' online participation. More specifically, the goal of this chapter is to explore the ways in which online narrating enables the negotiation of the public and the private in patients' experience of their illness. At the heart of the discussion are the questions: How are the boundaries between the private and the

public in patients' lives being negotiated through online narrating? What are the consequences of this process for patients' coping with their situation?

As will be evident from the discussion that follows, patients try to manage the boundaries of private and public in their lives in different ways, and through different activities, unconsciously or not. Online narrating is one such activity. The aim of this chapter is to highlight the potential role of this activity in the wider context of patients' attempt to negotiate private and public meanings, and in relation to other ways in which they try to pursue this project.

In dominant Western culture, the tension between the public and the private is a dialectic characteristic of illness in general. On the one hand, as Potts (2000: 102) observes, modern Western culture portrays illness as a private problem bounded to the individual. On the other hand, there is a strong unifying factor of illness: medical discourses tend to group all sufferers into a homogenous category defined by the disease (Lorde, 1980).

This dialectical relation between the private and the public has a particular resonance in the case of breast cancer. Recalling the discussion in Chapter Two, the central thread in the history of breast cancer is the move of the disease from the private realm to the public arena: from a disease sealed off from public discourse and public awareness, to being 'the biggest disease on the cultural map' (Ehrenreich, 8 December 2001: 1a). The tension between the private aspect of breast cancer and its public dimension has further resonance in the recent social and cultural meanings of the disease. On the one hand, there is a growing tendency towards the 'privatisation' of breast cancer (Leopold, 1999). This trend is endorsed by the emphasis on self-exams and self-detection, which constructs the disease as a woman's private problem and responsibility. At the same time, as Leopold observes, 'There is no public forum now in which breast cancer is not at home' (Leopold, 1999: 2). The fight against breast cancer is depicted as a collective endeavour, not only of women but also of society as a whole.¹ As Potts (2000) demonstrates in her account of breast cancer autobiographical narratives (see also Chapter Two), patients' personal narratives constitute a central discursive form that encapsulates this 'double stranding' of the disease, that is, being simultaneously private and public.

This chapter looks at online narrating as a particular communicative process that enables patients to manage this dual orientation of their illness. The argument of this chapter is that, through online narrating, among other processes, orientations of public and private, which are rooted in patients' everyday lives, are being redefined. On the one hand, the act of producing a self-narrative and publishing it online constitutes a clear way of transferring a private experience into a public form. In this sense, online narrating is a way of moving from private to public. At the same time, as I will show throughout the analysis, online narrating facilitates patients with new ways for the construction of 'the private' and of their privacy. That is, online narrating constitutes one possible way to redefine, and perhaps even reclaim, the private realm of their lives. As such, online narrating constitutes a potential site for transformation: enabling patients to move from private to public and back. It is through an active crafting of boundaries and definitions of the relations between 'private' and 'public' in their lives, that patients tell themselves and their environment who they are. In facilitating the negotiation of public and private, online narrating becomes a key process in patients' self-formation.

The enquiry of this chapter should be seen as a part of the broader concern of researchers with exploring the significance of the forms that emerge from individuals' online participation, particularly in enabling the negotiation of the private and the public:

...a continuum of forms of being and acting together is growing from the technology of the Internet. [...] The challenge to analysts is to understand and appreciate the significance of these various forms of transcending the narrowly private existence and navigating the social world for individual participants, for society at large and for the shaping of the Internet (Bakardjieva, 2003: 294).

More generally, the discussion of this chapter connects to the wider concern with the relation between the public and the private as a central feature of social life, and the role of the media in individuals' management of this relation. The critical literature on public and private is immense and it is obviously beyond the scope of this chapter. The intention of this chapter is to highlight the private/public relation, as it emerges in patients' online experience, particularly in the process of narrating.

To this end, the discussion that follows presents five aspects in which patients' act of online narrating can facilitate the negotiation of the public and the private in their lives. Each dimension represents a certain meaning that the relations between 'public' and 'private' can take.² Significantly, these are sets of meaning: each set of meaning consists of a 'binary pair' that embodies a facet of the relation between 'public' and 'private'. Ostensibly, these binary pairs are dichotomous. However, as Warner (2002) points out, these meanings of private and public are not simple oppositions. In fact, the contexts of public and private overlap, and 'most things are private in one sense and public in another' (ibid.: 30). In exploring each dimension separately, my aim is to demonstrate how the act of making a story and telling it online might facilitate these dialectics.

Patients engage in the negotiation of public and private – through the act of narrating – in different sites of their lives, both online and offline. So while the discussion focuses on the specificity (and hence the significance) of the online experience in this process, and even more specifically, of online narrating, it does not imply that this experience is disconnected from patients' offline lives. Patients define and redefine the private and the public in relation to what their social lives consist of, that is, in relation to both the online and offline experiences in their lives.

1. Rewriting space and time as a way of negotiating public and private

Time and space function as a segmenting principle, helping people to segregate the private and the public spheres of their lives from one another. Zerubavel's (1981) account of time (which can be extended to space)³ seems a useful entry point to our analysis. Zerubavel accentuates the centrality of time to the definition and regulation of social involvement, commitment and accessibility:

Our life is socially organized and temporally [as well as spatially] structured in such a way that, whereas during some time periods we must be accessible to others, there are time periods during which we may be legitimately inaccessible to them. (Zerubavel, 1981: 142. The bracketed text is mine; it is included to extend the scope of our discussion also to space).

So, certain spaces and time periods carry specific meanings of the public and the private, which become taken-for-granted meanings of social life (Zerubavel, 1981;

Warner, 2002). However, the experience of breast cancer challenges in significant ways the mundanity of patients' everyday practices. Consequently, commonsensical meanings of private and public in relation to given spaces and time periods are being challenged. It is in light of this fundamental change that patients' project of negotiating and redefining the boundaries of the private and public in their lives should be understood. The online space, with its particular spatial and temporal characteristics, furnishes a central site where this project takes place. The act of narrating online - an attempt to manage the disturbance and regain control over the boundaries of private and public - is fundamentally shaped by the temporal and spatial character of the online space.

Rewriting space

I would like to propose two key spaces whose meanings of public and private are negotiated through patients' online participation and narrating in particular. The first space is the body, the second is the home. Both spaces are associated in patients' quotidian practices with the private. However, in face of the illness, their meanings are likely to be altered. The making of a story and its telling online is a process that enables the rewriting of the new meanings of these spaces.

Body

While the body is understood as constituted within and through a system of boundaries, cancer violates these boundaries (Stacey, 1997). To a large extent, the experience of breast cancer expropriates patients' bodies from the private sphere into the public realm. The breast, a bodily site invested with meanings of the private (restricted to the sight of very few, concealed and extremely personal), is being transformed through the medical procedure of treatment into a public object.

Online narrating, I suggest, can serve as a means of negotiating the new meanings of the body: reproducing and reconfirming its 'publicness' on the one hand, while at the same time struggling to bring it back into the private sphere and, by extension, to bring back one's self from public to private. In particular, the act of online narrating can constitute a means for making the body public, at the same time it can allow patients to maintain what they perceive as the boundaries of their private sphere.

One of the clearest ways in which the act of telling a story online claims the body as public is the use of vivid, textual, corporeal description. The following comment reveals the author's awareness of the public meaning of the act of 'writing the body' online:

...if you want the graphic details of chemo, etc, let me know - I'm not shy - I am trying to write a book and volunteer and speak about breast cancer and breast health for all women. (B, online narrative 2).

For B, 'writing the body' in the online space is an integral part of a range of activities, all geared towards making her personal bodily experience public. Of course, 'writing the body' refers to a variety of ways in which participants communicate their bodies in text. Some patients choose to communicate their corporeal experience in a narrated form, that is, they order it in time and space by linking the different bodily experiences they went through along a temporal (often chronological) framework that leads the description to some closure. In chapter One I provided one such example of a posting that organises different bodily experiences and events of a patient's illness in a coherent temporal order, gearing them towards a clear ending. Other patients post online messages in which they describe their bodies in a very graphical fashion, however in a rather informative format, often as a report. For example:

I've now had 4x epirubicin and cyclophosamide (and will now have 4 x taxol) - I found that I lost varying amounts of hair at different stages in the three weeks between treatments - I used the cold cap for the 1st 3 treatments - but not the last one. Pre chemo I decided not to pluck/wax/shave so started with quite thick eyebrows - and still have eyebrows - although I did lose a few each treatment in my 2nd week post chemo. It really hasn't made much of an impact on the brows (but apparently the taxol will), I have noticed that this time (ie 2nd week post treatment 4) I have a few lower lashes missing (A message posted by a breast cancer patient on a message board).

Yet other patients extend the textual act of 'writing the body' into a use of visual materials, by incorporating photographs of their bodies into their online posts (these are often pictures of mastectomies or reconstructed breasts). By so doing, patients display their private selves on a public space: 'I'm on the board' says B, referring to the posting of her story on an online board. Their online narratives, among other discursive and visual forms, act as an extension of their bodies.

This line of argument is, of course, quite familiar in recent writing on CMC. There has been substantive discussion of individuals' self-presentation, especially with regards to personal web pages (Hine, 2001; Chandler, 1998), and more generally about the implications of displaying the body in a disembodied environment.⁴ Recently, Hardey (2002) looked in particular at patients' personal web pages, discussing the latter as a means of patients' self-presentation, by which they are transformed from consumers of health information and care to producers of information and care. Drawing on these works, I suggest reframing the argument about individuals' online presentation of their selves and their bodies, and understand this practice as a way for individuals to extend their private space into the public sphere. I also suggest complementing existing accounts by the notion of narrating as a possibly helpful way to elucidate participants' online self-presentation.

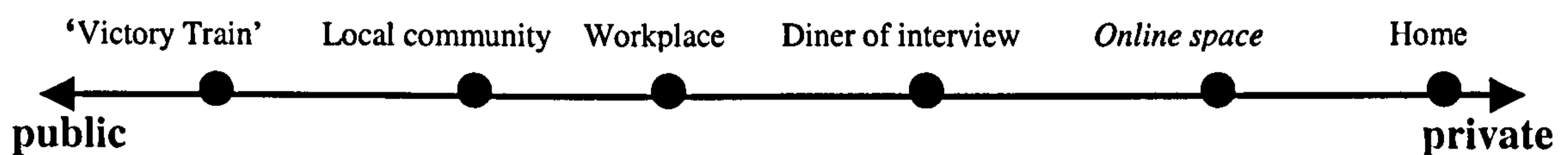
However, the experience of online participation, and particularly publishing one's story online, works in the other direction too: as a means to reclaim the body as private. To endorse this point, I wish to dwell on A's account (interview 1). Her account illustrates the distinctive value of online participation as an experience that, notwithstanding its clear *public* dimension, has also significant meanings of '*private*'. This distinctiveness is particularly illuminated in relation to other available spaces of storytelling in A's life. More generally, I suggest, to understand the meaning of the online space, and thereby of online narrating, as encompassing both the public and the private, it is necessary to understand it in relation to the wider process of storytelling and in comparison to other available spaces of storytelling in patients' lives.

Six sites appear in A's account as the most central spaces for the sharing (whether deliberate or not) of her experience of breast cancer: (1) outdoor spaces such as the 'Victory Train' (as described in the beginning of the chapter) where breast cancer patients advocate the fight against breast cancer by communicating their personal experiences and performing bodily activities (e.g. walks, races); (2) her local community (local grocery, the street etc.); (3) her workplace; (4) the diner where we had our interview; (5) online interactive spaces such as the BCANs discussion forum, where she participated quite actively; and (6) her home, where she continuously confronts the reality of her illness, by telling, among other things, the story of her

illness to herself (e.g. in front of the mirror) and to her husband and other intimates with whom she interacts in this space.

Each of the above six spaces could be located somewhere along a hypothetical continuum whose polarities are 'private' and 'public'.⁵ Of course, the polarities are never absolute and total: each space contains both private and public elements. Thus, the significance of each space derives from its relational position to the others. The meaning of the online space, and particularly of the act of online narrating, is defined in relation to the other spaces:

Figure 7.1 *The meaning of online space on a public-private axis*



At one extreme are spaces such as the Victory train (public transportation), which signify for A a clear public space. At the other extreme is the space of her home, whose boundaries delineate A's private sphere. Since A regards the experience of breast cancer as a totally private experience, for her the appropriate spaces for the enactment of this experience are those that are considered private. Hence her claim for a clear-cut separation between spaces such as the public train and the 'performance' of her illness. Indeed, after her diagnosis, she insisted on the containment of her experience within the boundaries of her most private sphere:

I just really grieved, I didn't really want to read the words 'cancer' when I first got diagnosed, I didn't want anyone to say it, just wanted to put my head in the pillow and cry 'why me?' (A, interview 1).

However, at a later stage A wanted to interact; she wanted to communicate the experience of her illness. Therefore, the private space of the home appeared insufficient; the separation between the illness and the public space could not be sustained. The act of going online and telling her story was an act of 'going public': A had to take her head out of the pillow, and necessarily break down the boundaries of her private sphere. At the same time, she kept struggling to preserve her privacy. Hence she sought a space that would enable her to enjoy both worlds: to tell the story

of her body, and thereby make it visible and public, while concurrently remaining with her head in the pillow to protect her privacy and stay out of public touch.

Telling the story of her illness in the online space enables this 'middle hybrid'. On the one hand, she insists that:

This [experience of breast cancer] is not information to share, no one should know that. It's a very personal thing (A, interview 1).

At the same time, she admits sharing her personal experience of breast cancer in several interactive online forums. Significantly, she does not see any contradiction between her perception of breast cancer as an issue that should not be shared publicly and her act of online participation. A found the online space a fruitful site that enabled her to share her experience and, at the same time, remain private. The online space offered her this public/private experience by allowing her to post online, whether 'information' as she relates in the above quote, or 'story' as she mentions in other places in her interview. The boundaries between what counts as 'information' and a 'story' are often blurred in A's perception. Indeed, any story contains some information, and personal information is often articulated in a form of a story. The key point is that the online experience comprises a variety of communicative opportunities for patients like A (narrating being one of them) to manage the public and the private, and to maintain this duality.

The key to explaining A's conception of the online space as a private space is, of course, the aspect of disembodiment. On the one hand, the disembodied and anonymous nature of the communication facilitates the capacity to maintain one's private boundaries. On the other hand, the written nature of the communication and the open-to-all character of the discursive space make the experience of online participation a significantly public one.

A implicitly highlights the link between disembodiment and privacy when she contrasts her online participation to other breast cancer survivors who 'go around wearing breast cancer T-shirts'. The latter, being a highly embodied act, represents for A, a violation of the boundaries between public and private. Online participation, on

the other hand, enables the maintenance of these boundaries. Another patient reflects on the distinctiveness of online communication as a way to transcend, on the one hand, the disembodiment and physical isolation from the public sphere, while at the same time maintain privacy:

It [the Internet] is a great way [to] avoid becoming isolated - which is so common for cancer patients as either you don't feel well due to surgery or chemo or radiation. or you don't always look good (I am bald now for the duration of the chemo tx) or just you don't feel like being social for whatever reason. The computer is a great alternative to face-to-face encounters with people at a time when you really value your privacy. (Online narrative 11).

Of course disembodiment is a general feature of the online experience rather than one that is specific to narrating. However, I suggest, the combination of the capacity for self-disclosure in a form of a story and in a disembodied fashion, seems particularly appealing to many patients, such as the one cited above. This observation is further enlightened in the following discussion of the redefinition of private/public boundaries around the space of the home.

Home

Perhaps the most central spatial category associated with the relation between public and private is that between outside the home (public) and the domestic (private). The habitual meanings of the home are often being significantly altered in patients' experience of breast cancer. During the course of treatment, patients are often physically confined to their home; they lose the capacity for an unrestricted movement between private and public spheres. Thus the boundaries between the private sphere – to which they are physically confined – and the public sphere are sharpened. Consequently, they attempt to bring the public home: to regain their access to the public, however in a way that would not necessitate embodied access. Online communication appears crucial in this context:

When I was unable to ride in a car for 6 months I got interested in the Internet to keep my sanity. I was confined to my home. I turned to the net for valuable Knowledge which is "power". I was able to hook up to lots of medical web sites to keep abreast of what was going on [...]. If you can't get over the fence than you go "under". I was out on the net for sharing stories w/breast ca[ncer] survivors [...]
[...] **There are still lots of "tools" in my box** to keep on going for remission!!! (Online narrative 8, my emphasis).

Thus, the Internet is a tool enabling patients to transcend their private boundaries by associating with other people without leaving their homes. This dual situation, in which a patient can participate in the public sphere and exercise a public discussion while physically remaining within her private sphere, is well captured in the following account (the split of the sentence into two parts is mine, to demonstrate the duality of public and private):

Public — [The internet is a place where treatments, definitions, and explanations
Private — [can be explored in the privacy of one's home. (Online narrative 26).

Bakardjieva (2003) describes this practice as 'immobile socialisation', in contrast to the condition of 'mobile privatisation'. The latter was termed by Williams (1974) to characterise a central feature of everyday life in industrial capitalist society, specifically following the move of families from the city to suburb. Williams argued that broadcasting was a product of the contradictory pressures generated by the condition of 'mobile privatisation': on the one hand there is enhanced mobility, while on the other, there is a home-centred way of living.

The experiences of breast cancer patients' online participation, and particularly of engaging in narrating in this space, show that, actually, 'immobile socialisation' and 'mobile privatisation' are two sides of the same coin. Like the woman quoted above, patients share their experience on the online space to connect and reach out, beyond the confines of their home. This use of the Internet is tactical in nature (in the sense that de Certeau defined 'tactic'): 'if you can't get over the fence then you go "under"' (online narrative 8, cited above). The Internet connection replaces the car; online written communication replaces face-to-face interaction. Indeed, posting messages online, especially personal narratives, emerges as an attempt at 'immobile socialisation', that is, a movement from private to public.

At the same time, patients equally reflect on the significance of being able to move from public to private, reasserting the private meanings of the home:

It was comforting to know that I could look up whatever I wanted and do it in my PJs [pajamas] at 3 AM if I like it. (Online narrative 2).

When your in this situation you're on such a roller coaster it's nice to calmly sit down and search [...]. And you can deal with it on your own time and own way. (Online narrative 25).

The home computer has pretty much replaced the local library as far as doing research and looking for information [is concerned], so it [going online] was the logical thing to do (Online narrative 15).

In this sense, patients' online communication could be seen as a resolution of 'mobile privatisation': offering them mobility at once (sharing their private experiences in a public space), and a home-centred experience, allowing the sustenance of meanings and feelings of confidence, comfort, convenience, and privacy.⁶

B. Rewriting time

The home designates not only a private space, but also private time. Indeed the temporal dimension of patients' Internet use is central to their attempts to negotiate the private and the public. Here, too, the negotiation of the two spheres works in both directions, and often concurrently: from private to public, and from public to private.

Private time is deliberately designed to prevent, or at least to discourage, the formation of human contact and to separate people from one another. Public time, on the other hand, is deliberately meant to promote the establishment of human contact and to draw people together (Zerubavel, 1981: 143).

Patients' participation in online sites is a way in which they transform the private time of home into a public time. They do so by going online from home to interact with others especially at unconventional times. In their accounts, women stressed that they tend to go online and participate in public discussions particularly during late night hours, times that are commonly associated with the private sphere. In these online discussions they talk, exchange information, share experience and tell their personal stories. Thus, as far as narrating is concerned, the actual time in which the story is being produced and told has a significant part in the construction of the act of online narrating as a way of moving from private to public.

So patients' online experience is an attempt at breaking through the boundaries between their private and public time. At the same time, however, the very same practice constitutes a way of reclaiming private time. That is, through interacting online, patients seek to re-establish 'time preserves' in which they have the right to be

inaccessible.⁷ This project of claiming private time ‘shields’ should be understood in the context of patients’ special situation:

...hospital patients [among other members of total institutions] are always socially accessible, and have no time whatsoever within which they can screen out nonintimates. (Zerubavel, 1981: 143).

Patients seek to reclaim their right to be inaccessible, to re-appropriate the control over their private time. Online communication, and particularly the capacity for lurking (as discussed in the previous chapter), is one way by which patients reclaim this right. G alludes to this idea:

If someone is giving you the story of her life and you’re interested, you can read. And if you’re not, you don’t have to! You can just skip it and move on to what you want to know (G, interview 7).

Patients’ attempt to reclaim their private time is also highly gendered. Women often regarded their online activity as a time devoted solely to *themselves*, a release from the other times of their everyday lives, where they often act as caregivers, concerned with *others* (family members, friends etc.). Among other online activities, for a breast cancer patient the act of narrating her experience online, often during late hours, delineates a private space and a private time, which are focused on the self.

Here again, the disembodied and anonymous nature of the communication appears central in enabling patients’ to negotiate the public and the private. It allows patients the freedom to be inaccessible, without having their behaviour considered inappropriate. Unlike other contexts in which individuals have ‘to go through social niceties’ (G, interview 7), the definitions of what is an appropriate or inappropriate time for communication are much more blurred online. In this context, the act of storytelling online often becomes a more flexible and simple experience than that of storytelling in other contexts of patients’ lives, where they have to be bodily accessible during the whole time of storytelling and afterwards (for example in a face-to-face support group, a patient cannot simply tell her story and disappear).

2. Online narrating: Everywoman's unique story

Another way in which the relation between the private and the public manifests itself in patients' online experience is the tension between the common and the particular. Generally speaking, the public is associated with the common and the general, whereas the private usually represents the particular and the unique. The tension between those meanings is at the heart of the social and cultural construction of breast cancer. As Potts (2000) suggests, the personal *unique* experience of breast cancer has been fundamentally constructed (and thus lived) within a historical frame of reference, as a collective (and thus *common*) experience, through a context of community. In her analysis, Potts shows how this dual character of the disease as both 'shared and unique' runs as a thread in breast cancer autobiographical narratives:

There is both the discrete and individualized experience of breast cancer, and the sense of it as a common shared story...a connective project, both 'shared and unique'

(Potts, 2000: 101-2, citing Friedman, 1988: 40).

I want to argue that the process of online narrating facilitates a significant site where patients experience the story of their illness as both common and unique. As such, it emerges as an interesting process in their endeavours to negotiate the private and the public in their lives, as part of their reconstructive 'project of the self'. I will first illustrate how, through communicating their experience online, particularly through narrating, patients frame their experience as an endemic one. Emblematic of this framing is a poem written by one of my interviewees (K, interview 11) titled '*The Common Cancer*'.⁸ I will then discuss how, through the very same process of online participation, patients come to think of their experience as highly special and unique. The discussion focuses on the ways in which the specific properties of online communication (and narrating in particular) are embedded in this dialectical process.

Everywoman's story:

Transforming the private and unique into a public and common text

...there are so many [breast cancer stories] out there! If you're Linda Ellerbe [an American television journalist and breast cancer survivor], people want to read it, because they know who she is. They're curious. But, who am I? Why would they be curious to read my story? **It's not that it's so terribly unique**, but it's also part of why I wanted to tell it. Because it's not so terribly unique! Yes, it's a little unique,

maybe the misdiagnosis, but you know what, a lot of women get misdiagnosed! I **really felt this could be the everyman, or the everywoman's story.** (G, interview 7, my emphases).

One of the most significant aspects that women mentioned in relation to their online experience is that, through encountering others' stories, they realised that they were not alone and that others have been going through a similar experience to theirs. Newly diagnosed patients might have been aware of the statistics indicating the high prevalence of the disease among women; however, it is only when they literally encountered stories of 'real' 'tangible' others, that they could experience a sense of commonality. The need to connect their private experience with others' is not distinctive to the stage of diagnosis. Patients continuously seek what Yalom (1970) calls 'universality': the realisation that others have similar problems. Thus, the significance of online communication during different stages of the illness. For instance:

...when the chemo starts, some physical change goes on your body and it's nice to go on and see that other women have gone through that. (J, interview 10).

The capacity to relate one's experience of illness to the 'public' and get a sense of commonality is facilitated primarily by the structure of exchange, and the notion of 'family of patients' which I have already discussed in Chapter Six. In this section, I want to focus on the ways in which the process of narrating – enabled by the structure of exchange – provides a framework to move from private to public. It does so by directing the teller to locate her experience *in relation* to the other. Online narrating, I suggest, is a process through which patients locate themselves (or are located) within a repertoire of emplotted stories. This process is part of the ongoing construction of their identity.

In exploring patients' negotiation of private and public online, the analysis will be informed by Somers' discussion of narratives (1994).⁹ Two key constituents of narrative that Somers discusses underpin the positioning of the private in relation to the public: historicity and relationality. *Historicity* implies the ability to locate oneself in relation to other women, on a continuum of experiences, and in relation to the history of the disease. *Relationality* infers the positioning of oneself in relation to others' stories. In what ways are patients' online narratives positioned relationally and

historically, both by their tellers and listeners, as well as by the structure of the online communicative space? What forms do the elements of historicity and relationality take in breast cancer Internet sites?

The graphic ordering of patients' stories in online forums is one such element. Whether patients' stories are ordered in discussion group threads (e.g. the forum of www.bcans.org, Yahoo Breast Cancer Club on www.breastguide.com) or in the form of a table (e.g. www.sharedexperience.org), their visual organisation on the screen generates historicity and relationality. Graphically, a message that is being posted on an online forum is inevitably historicised; it does not stand as a singular, private, unique, and independent message, but rather becomes part of a continuum of experiences

This graphic feature imposes itself on the meaning of those postings. Although each message is posted as a singular unique text, its meaning is significantly construed in relation to other texts. The structure of exchange, in which patients' communication is embedded, enhances explicit relations between messages. Authors often refer in their messages to other texts they have read, positioning themselves as similar or different to them. Furthermore, each story relates not only to the other stories in the specific forum, but also to the bigger story, the 'grand narrative', if you wish, of breast cancer. A good example of this claim is the way in which authors often describe their personal experience by positioning it in relation to the general statistics, the latter being a central component of the public discourse of the disease. Consider, for instance, the extract of this (fictional) e-mail:

Susan, let's face it, the odds that I am currently hitting are much less than 30%. To recap:

- 80% of the time lumps are benign. (Not mine.)
- More than half of all breast cancers happen in women over age 60. (Not mine.)
- Exercise and a low-fat diet are supposed to help reduce a woman's risk. (Not mine.)
- Pregnancy and breast-feeding reduce risk. (Not mine.)
- Beginning menstruation late reduces risk. (Not mine.)
- And doesn't low alcohol consumption also reduce risk? (Not mine.)

Do you see a pattern emerging? And let's not forget, I have no family history of breast cancer although I know that most people (85%) who develop BC don't have family history either.

(Katz Becker, 2000:117).

Of course, the online space is not an exclusive site where patients relate their personal experience in relation to the public discourse of breast cancer. Patients constantly refer to publicly available texts (such as statistical figures), interweaving them into their ongoing self-narrative, which they tell in different contexts and spaces in their lives. What is special about online spaces, however, is that they include various symbolic materials (both images and texts) within a contained discursive framework (commonly a website). The online space is all encompassing: it concentrates a wide range of symbolic materials, in a highly accessible way, on an immediate basis.

Interactive forums in which patients post their personal accounts are often only part of a whole website that is focused on breast cancer. Other features usually include informative sections about different aspects of the disease, as well as commercial features such as an e-store of merchandise related to the fight against breast cancer (e.g. www.thebreastcancersite.com). Consequently, in the process of constructing their message, patients often appropriate different materials that are available in the discursive space, incorporating them into their self-narrative, in a very immediate and direct fashion. When a patient writes online texts such as the above e-mail, in which she incorporates statistics of breast cancer (public discursive materials) into her message (private discourse), she often appropriates those materials directly from an informative section that she viewed on the same online space where she writes her story. In the example above, the author might have done it in a way of 'copy and paste': appropriating information from a statistical section of a breast cancer website, into the body of the electronic sheet of her message. Technically, patients usually first go through informative (and less often commercial) features, before getting to the interactive forums where they publish their account. Subsequently, whether consciously or not, they incorporate pieces from the information they encountered online (as well as offline) into the message they post. In this way, patients' online narratives become an integral part of a public discursive framework.

Indeed, women tend to regard personal accounts that they read on message boards as part of a 'larger story', which the website, as a whole, represents. This is manifested in their own choice of the particular forum in which to post their story. Patients' decision to post their message in one forum rather than another is often based on their judgment of the website as a whole. If they found the website that hosts that forum a credible, serious and trustable one (often judging by the information it provides) – they would be motivated to publish their message in it. In short, the all-encompassing nature of websites and the multiple structure of the World Wide Web, which consist of links to an enormous range of symbolic materials, augment the relationality and historicity of patients' online postings. Relationality and historicity, as Somers (1994) and others observe, are key characteristics of narratives. They make the texts patients post more than simple 'annals'; these texts are contextualised in time and space and become closer to what can be described as narratives: constellations of events and information ordered in time and space.

The insertion of a personal experience into a publicly available online form, similar to other forms, is yet another way by which uniqueness is erased and commonality enhanced. The idea that a personal disclosure is transmitted into an impersonal public form transforms something that is private and special into something which is public and common. Shared Experience website that was mentioned in previous chapters is perhaps the best example of the ways in which this process occurs. To enter a personal account, the author has to insert her text into an electronic form that is divided into different categories. This structure turns the unique into common, requiring the author to adapt her personal experience to existing categories of similarity. The display of patients' different stories appears in tabular format. The table's columns are the different categories (diagnosis, treatment, quality of life, etc.) and its rows are the personal stories:

Figure 7.2 'Shared Experience' cancer stories table

(<http://www.sharedexperience.org/experiencelist.lasso>)

| Page Number | Cancer Type | Diagnosis | Chemo Drugs | Treatment | Quality of Life | Information Gathering | General Comments |
|-------------|-------------|---|---|---|---|---|---|
| 4053... | BREAST | In 2001 at age 41, my wife was diagnosed with Duct... | Doing the Dose Dense regimen at the Mayo Clinic in... | Stated above. She had a chest film and blood work ... | Chemo has gone very well. She gets tired easily bu... | My wife did much of the research the first time ar... | We have a vary supportive church family who have b... |
| 4040 | BREAST | April 16 2002--my first born child's 12 birthday.... | fe5u? Epirubison & ? Every 3 weeeks for 6 trea... | Lumpectomy April 18,2002-- Intensive Chemotherapy ... | I'm Alive--- What else is there? Really I have had... | Some of my poetry; Hope it helps in some way ... | It seem's much more recent, but It was perhaps the... |
| 4018 | BREAST | Diagnosed on November 7, 2002 with medullary high ... | Adriamycin and Cytosan... | Lumpectomy, 4 cycles AC chemo and currently underg... | Fatigue. I had it before the cancer was found and ... | Joined the local cancer support group. This is one... | I think it is very important to have your own copy... |

The message this table conveys is a message of similarity rather than of difference. What organise the screen are the different categories that *unify* the different stories, rather than the specific one. Hence, this is a collective disclosure rather than a private one: it is about breast cancer and its different manifestations, rather than about a unique experience of a specific breast cancer patient.

It is through the implicit act of comparison between the different stories that the boundaries of the private and the public are negotiated, and that consequently the teller (as much as the listener) gains legitimisation and confirmation that her story is 'correct'. Since the quantity of patients' stories available online is enormous,¹⁰ a patient often finds other stories which relate a worse experience than hers. Indeed, women often describe their encounter with fellow-sufferers' online experiences as a meaningful reassurance of their own situation. For example:

When I went to the Internet it was just strictly for my own knowledge to see how many women had experienced this problem. And it was just shocking, really! You just don't imagine that...a lot of them were worse than I did, I mean I was lucky. (F, interview 6).

Seeing her story integrated into a table, a list, or a thread, which consists of numerous (often hundreds) of other similar stories, a patient is capable of connecting her private self to the public world. K neatly summarises this idea when she says:

...maybe that's what you want, you want the kind of distillation, rather than lots of individual experiences. [laughs]... which are all going to be very different, anyway. Perhaps you just want the general information. (K, interview 11).

True, as has been already discussed in Chapter Five, structuring patients' experiences in this table transforms complete stories – which have a beginning, a middle and an end – into fragmented units of information. At the same time, it is this structure of an informative table that seems to enable the personal to become public and to enhance its legitimacy and acceptance. In a sense, the narrating process is going through an un-narrating procedure, and it is through the transformation of the *personal narrative* into general *information* that makes this site so attractive and valuable to patients.

The disembodied and anonymous framework in which the narratives are produced and told enhances their generality and commonality. It blurs what makes an oral story distinctive: the embodied identity of the teller. Disembodiment has a homogenising effect insofar as it erases any uniqueness that derives from bodily appearance.¹¹

This is not to deny the space for multiple and changing nature of identities within a disembodied textual environment. However, the way in which online spaces are organised, as I demonstrated in the discussion so far, seems to be geared towards a focus on similarities, rather than differences, to create an existing repertoire in which the personal story (and thus identity) can be located. In this light, the following comment (which I cited in the previous chapter, to discuss the notion of online *communitas*) should be critically revisited:

The camaraderie is amazing, the love and acceptance of each other's differences is almost overwhelming. (Online narrative 24).

Rather than the *difference* between patients' online stories, the promise of acceptance lies, in fact, in their *sameness*: it is the *similar* rather than the *distinctive* character of the different personal stories, that enables their authors to communicate, and for camaraderie between them to develop. The move from private to public is thus essential in order for *communitas* to develop, and the online space, in its different features, applications and communicative processes, enables participants to make this move. However, for some participants the publicness of online spaces is constraining, whether in their generality, their adherence to dominant public discourse, or their

disembodied impersonal nature. Those patients, therefore, find it difficult to move from private to public and transcend their private sphere to move their stories into online public spaces.

J found the sheer quantity of stories and information in online spaces overwhelming:

...there's so much out there, and you only want to hear what applies to you. I don't want to hear about stage 3 to stage 4 [...] I just want to know what's going to happen to *me* [emphasises *me*], and it's very hard to find that. (J, interview 10).

For J, the online space appears to be too general. It thus fails in helping her connect her private experience to the public discussion. Consequently, J uses the Internet mainly for information seeking, and even this activity is limited in its extent. Clearly, she does not engage in narrating online. Although she is a very verbose storyteller (judging by her interview with me), she prefers sharing the experience of her illness only within what she considers private spaces: at home, with friends, and even at her local synagogue.

For K too, the online space appears inappropriate for the communication of her illness experience. However, unlike J, for K the problem is not with the generality of the discourses and information and their overwhelming amount. For K, the main limitation of the public nature of the online space is rather the opposite: its narrowness. She finds the existing repertoire of discourses and meanings in online public space extremely limited. She therefore cannot locate her own experience within this space:

There's a kind of a terrible hyping about how it [breast cancer] destroys a woman's life that goes on. Like your entire self and the meaning of what it is to be a woman is totally invested in the fact you have two breasts. [...] I just felt I couldn't relate [...] I felt it was pushed about women. [As a result,] I felt quite alienated by them [breast cancer online support groups]. (K, interview 11).

K specifically refers to what she encountered online and finds hard to relate to in terms of fellow sufferers' stories. From her interview it emerges that she was particularly looking for an alternative kind of discourse to that of personal stories, one that would allow a critical, rational and argumentative discussion. Rather than an experiential, subjective and personal discourse, K was looking for something closer to

the notion of scientific medical truth. However, 'narrative truth', recalling Spence's concept that was discussed in Chapter One, represents a significantly different kind of discourse:

Narrative truth is what we have in mind when we say that such and such is a good story, that a given explanation carries conviction, that *one* solution to a mystery must be true. Once a given construction has acquired narrative truth, it becomes just as real as any kind of truth; this new reality becomes a significant part of the psychoanalytic cure.

(Spence, 1982: 31, my emphasis).

Yet for others, the public disembodied nature of online communication is equated with impersonality. Indeed, as Warner (2002) notes, the dichotomy between the impersonal and the personal is commonly associated with the tension between the public and the private, respectively. In online narrative 9, for instance, the author asserts that 'The internet is totally impersonal'. She particularly compares the *public disembodied* and thus (for her) *impersonal* kind of online interactions between patients, to those she has had with fellow sufferers in her hospital. The latter are depicted as *embodied*, extremely *private* and *personal* encounters. She concludes her account of this stark contrast with a cynical comment:

Easier to talk to another human being than to a machine! (Online narrative 9).

Having said all that, writing the self in online space, particularly in the form of a story, is at the same time a central process in patients' attempt to assert themselves as unique selves. Against the one-size-fits-all paradigm (that is seen by many patients as the approach of governing professionals' and of the medical treatment), women regard their work of making a story online as an extremely personal, special and thus private act. As Potts (2002: 104) argues more generally about breast cancer autobiographical narratives:

...while the texts tell a *shared* story, breaking down the isolation of women's experiences of breast cancer with an assertion of the connective and collective, they also assert the unique and individualized self.

As already mentioned in Chapter Five, a recurrent theme in patients' accounts is the notion of the online communication, and especially the act of storytelling, as a highly personalised mode of communication. So, notwithstanding the recognition of the *public* dimension of the online space, patients' view of this space as a *personalised* communicative space frames the stories they produce in it as very *personal* and thus *private*. Beyond the fact that women often regard their experience as different and unique (Potts, 2000), the act of expressing this experience in the form of a story, in a space that is seen as highly personalised, invests the story with meanings of uniqueness. The following extract implies the interlink between the personalised character of the online space (an issue the author stresses throughout her account), and the unique value of the postings that are being published in this space:

After absorbing all of the information garnered from the net and from anecdotal information provided by the "people" genre, I've arrived at several personal conclusions [...]. The most important conclusion for me is that each person's breast cancer is uniquely their own. No two people reach the same medical treatment, nor do any two people with the same diagnosis and survival stats have identical chances of survival. (Online narrative 24).

Patients' conception of their online stories as authentic, unique and distinctive (notwithstanding the hundreds of other stories published in this space) is highlighted in their accounts, particularly in relation to their critical view of autobiographical stories that are told in mass media, especially on television. Patients often associated those mass media stories with negative meanings. Those stories were seen as populist, unserious, appealing to the lowest common denominator, misleading and consequently even dangerous (as they might influence women who suffer from the disease to take unreasonable decisions regarding their treatment). In contrast to this radically *public* storytelling in mass media, patients usually regard their own engagement in disclosing their experience online as having a clear sense of the *private*: intimate, related to a kind of inwardness and subjective experience and appealing to a specific public rather to the mass public. In contrast to the celebrity-oriented storytelling that takes place on television shows, where famous figures who are breast cancer survivors tell their story to the public, online storytelling is seen by patients as the 'people genre', as the patient in the quote above calls it.

The 'people genre' can contain various discursive forms. As the above patient relates, this 'genre' includes information, anecdotal information as well as stories such as the one the author herself tells. (The above quote is the ending of a full text in which the author recounts her experience in detail, ordering it in time and space. As a narrative, this account is geared towards the conclusion – which is explicitly articulated in the quote above). So narrative is one of the forms within this genre. What distinguishes this genre, and thereby projects upon the stories being told within this genre, is that it is perceived as authentic: interpersonal rather than mediated, one-on-one rather than one-to-many, restricted to some rather than open to all. These contradictions echo, of course, the distinction between a dialogic and a disseminative model of communication (see Chapter Four). I will return to this conceptual link in the concluding section of this chapter.

However, the distinction between online and mass-mediated storytelling as 'private' versus 'public' is not that clear-cut. A few of my informants also described patients' stories that they encountered online as 'public' in character insofar as they were seen as inauthentic and populist (e.g. see K, interview 11).¹² These kinds of online stories were often associated with a commercial motive. For instance, B (interview 2) describes one of the stories she read in a breast cancer website, as a means of 'cashing breast cancer', as she puts it. She accuses this kind of online narrative for its negative *public* characteristics: commercially driven (supported by some kind of medical organisation) and thus inauthentic and utilitarian.

What all this boils down to is the centrality of the negotiations of the meanings of private and public in patients' experience. Their online engagement in storytelling constitutes one of the sites where these negotiations take place. Another key aspect of these negotiations is the tension between the meaning of online communication (and by extension, online narrating) as a performative act, which is open to everyone, and the conception of the same act as rather concealed and restricted to some.

3. An open-to-all performance and a concealed interaction

The disembodied and anonymous nature of online texts clearly endows them with values of 'the private': they are seen by patients as confidential and concealed.

Crucially, online authors can restrict the distribution of their messages to specific listeners, for instance by using e-mail. These 'private' values are especially emphasised in patients' experience in comparison to embodied contexts in which their experience is being told. The latter contexts (and thus the narratives that are produced in them), in contrast to online spaces, are characterised by their public qualities. They are open to everyone, in physical view of others, and, as such, are beyond the control of their narrator. They can be expropriated from the private realm of the narrator, without her intention or will:

It gets me very angry when I hear people know my circumstances whom I didn't tell. [...] If I were a friend of them, I'd [have] told them, but if I'm just acquaintance with them, I didn't, because we don't know each other. So when I found out that they know, I get mad! [...] This is not information to share, no one should know that. It's a very personal thing... (A, narrative 1).

By contrast, online spaces are *perceived* by some patients as 'safe' spaces insofar as they guarantee a level of invisibility within visibility, and are *believed* to enable the restriction of the sharing of one's personal experience to a specific audience. Illustrative of patients' perception of the online space as private and safe is B's following comment:

I'm very loud within the breast cancer community, but not in the general public (B, interview 2).

Underpinning this statement is B's conception of the boundaries between what she considers to be a relatively intimate private space of the 'breast cancer community' and that of the 'general public'. Given her 'loud' (to use her words) activity within the breast cancer online space, it is implied that she considers the online space as part of that privately safe space of the 'breast cancer community', where she feels comfortable to 'shout'. It is through the delineation of the boundaries of online space as a closed, private community and its distinction from the 'general public', that B legitimises and confirms her online activity.

At the same time, patients perceive online spaces also as public venues that possess opposing characteristics: open to everyone, visible and performative. Indicative is patients' awareness of the risk involved in posting their messages in online spaces. Take, for instance, A's following reflection. Underlying her comment is an

acknowledgment of the inherently *public* (and thus not hermetically safe) character of online space:

...sometimes it's a little risky to put up yours [story, online], because some people kind of would talk about it. One girl suggested that so and so get in contact with the hospice. Now, I know hospice to be for terminally ill people, and then they were "oh, you know obviously nothing about hospice". Do you understand? She was recommending hospice for someone else, so I said I don't think that's a good idea, because this girl has a hard time coping with breast cancer and you're telling her to contact hospice? [laughs]. (A, interview 1).

However, patients' recognition of the *public* dimension of online spaces is not charged only with negative meanings. Central to their view of online space as public, is their appreciation of its performative dimension. Patients often refer to their own writing in online spaces in terms of performance. The following patient, for example, seems quite aware of her role as a performer, who has to appear reliable and trustworthy in front of her online audience:

[The Internet is] a vehicle to disseminate information quickly and practically in an honest, reliable, manner, and provide an opportunity for open communication to validate my experiences. After all, the users of my web site have no proof that I am even a breast cancer patient, author, female, caring, experienced individual. (Online narrative 6, italics in original, my emphasis).

B's account of her bi-weekly online column follows very similar lines:

Q: How people get to you?

B: It's on suite101, it's on 'Ask Me'. I'm on the board for the lymphedema thing, on that...it's out there (B, interview 2, my emphasis).

B then goes on to describe her engagement in writing her online column. Her description seems to meet precisely Goffman's (1969) 'criteria' of what constitutes a performance: her *continuous* presence as the *performer*, before *observers* (the online readers), on whom she supposedly has some *influence* (and for which reason she is concerned with their interests).¹³

...as human beings we are presumably creatures of variable impulse with moods and energies that change from one moment to the next. As characters put on for an audience, however, we must not be subject to ups and downs (Goffman, 1969: 63-64).

The performative dimension of CMC has been already discussed by several scholars in relation to a variety of communicative processes, discursive forms and online contexts (e.g. Chandler, 1998; Paccagnella, 1997; Turkle, 1996; Wynn and Katz, 1997). What seems interesting for the purpose of our discussion is the implication of the performative character of CMC for the act of narrating. Understanding the work of making a story as a performative act implies that the narrator has an implicit knowledge that her story is addressed to certain listeners. Consequently, since her story is to be presented before a particular (although implied and invisible) set of observers, it requires the maintenance of consistency and expressive coherence and control.

Tellingly, when I approached women via e-mail, asking them to participate in my study following the messages they had posted in online spaces, respondents would commonly reply asking me to first refer them to their original online posting:

I shared my stories on several sites and wondered which site that you read my story on? (Online narrative 13).

[...] please send me the link to shared experience board, I need to review what I hat submitted, and I will consider then sharing it with you, there are some updates I am sure since I wrote that. (Online narrative 29).

Arguably, then, patients seem to be aware of the publicly performative nature of their online participation and thereby of the act of telling their story online. They want to maintain a continuous presence before me, their audience, and display coherence and continuity with the story they have performed elsewhere in online space. Their online account constitutes a symbolic 'anchor', by which experience is constructed and organised. Thus, unlike the common view of online texts as fluid, dynamic and constantly changing, in this context patients' online accounts seem to represent the opposite. Their circulation in a public space endows them with certain fixity. Once a story has transcended the boundaries of a patient's private sphere ('back stage', in Goffman's terms), extended into the 'front stage', i.e. the public sphere of online space, it becomes a publicly available 'property', to which the author/performer is committed. The author can revisit her story (as suggested by the second quote above), however, she still needs to maintain continuity with the 'original' story she posted.

The need to maintain coherence seems to be particularly emphasised in the context of narrating, compared to, say, communicating information by posting a short answer to a question on an online message board. This is because a narrative constitutes a relatively detailed and coherent account, which configures a personal experience into a whole and directs it toward some kind of conclusion. Publishing such a discourse seems far more obliging than publishing a short informative text, insofar as it requires the author to maintain the coherence she created, to prolong the 'narrative truth' she constructed and to follow-up the construction she published in a consistent fashion. This is not to say that patients do not adapt and modify the stories they originally published. Indeed, as I discussed in Chapter Five, the dynamic character of the online communication facilitates an ongoing revision and adaptation of one's personal story. At the same time, there seems to be an amplified performative element, which requires the maintenance of consistency, to presenting oneself in a form of a self-narrative than to using other modes of discourse, which are often more fragmented and less ordered and coherent.

Still, the private/public meanings of online narrating are not defined only in relation to offline activities. The negotiations of the meaning of online storytelling as a private interaction, concealed and invisible versus a public act, performative and open to everyone, are significantly interrelated with distinctions participants make between different environments *within* online space. That is, the online space is not seen as a singular, monolithic entity. Rather, different venues and environments within the online space are associated with a range of meanings, from 'public' to 'private'.

The most important distinction patients make between discursive online spaces is that between message boards and e-mail. While the former is seen as utterly public, the latter is regarded as extremely intimate and private. A good example of this distinction is the way in which both B (interview 2) and G (interview 7) describe occasions in which they moved from communicating on a message board to communicating via e-mail:

Flora wrote a question to 'Ask Me' [online message board], and I answered her question. She asked me another question, and I said: you know, this is too cumbersome, why don't you just e-mail me direct? She did and then we started talking. (B, interview 2)

...along the way there were a couple of times I got involved with a couple of different women, where we e-mailed one another bypassing the board. (G, interview 7, my emphasis).

'Bypassing' the message board and moving to e-mail is a move from public to private. However, as we saw so far, the definitions of 'public' and 'private' are not fixed, but they are rather defined and redefined in relation to each other. For B, the space of 'breast cancer online' as a whole is private, when it is defined in relation to 'general public'. However, in a specific interaction with her online pal, B perceives an online message board to be public, and thus inappropriate for an intimate private interaction. Moving between different online environments is a way of moving between the private and the public. This observation is not specific to the act of narrating; however, it provides an important context for understanding narrating.

4. Expert and experiential voices

In the medical context, a central site of meaning where patients' negotiation of the private and the public occurs is the relation between expert and lay knowledge. Warner (2002: 53) carefully articulates this idea:

The epistemological leverage of medical experts [...] appears as a very public kind of knowledge and authority, objective and neutral where the patient's claims are understood to be subjective and interested, perhaps even pathological.

However, as recently recognised by much of the medical sociology literature, and as manifested in the experience of my interviewees, the classic polarities of 'expert' (public) and 'lay' (private) are becoming increasingly blurred. This blurring occurs primarily through patients' participation in online forums as 'semi-experts'. Such forms include patients' personal journals (e.g. online narrative 3), personal homepages (e.g. online narrative 6), breast cancer related online columns (e.g. B, interview 2), as well as message boards and e-mails. These are all spaces where patients, through the act of writing, often by narrating their experience, occupy the role of experts. McLellan (1997) and Hardey's (2002) studies of patients' online narratives corroborate this argument. They show that health care providers do not take centre stage in these narratives, but rather a multiplicity of experiential voices emerges. The

act of publishing their story, the format in which it appears, and the setting in which it is published, endow patients' narratives with a very different status from that of an oral story they would have told in a quotidian face-to-face interaction. Experiential knowledge is transferred into the informational, the subjective into knowledge, and thereby the private is extended into the public.

This is, however, not distinctive to the Internet. Recent literature on medical sociology has acknowledged the increasing blurring of boundaries between lay and expert knowledge (Lambert and Rose, 1996; Arksey, 1998; Bury, 2001; Prior, 2003). Health and communication studies in particular highlighted the role of the media in contributing to this process (Hodgetts and Chamberlain, 1999; Seale, 2002). Despite the important functions that lay depictions serve in the medicalisation of health representation on media, they still largely and mainly serve to support a medicalised perspective (Hodgetts and Chamberlain, 1999). In so doing, they reinforce and reconfirm the lay/expert dichotomy and its respective parallel, the private/public dichotomy.

It is in light of this limitation of mass media's representation of lay knowledge, that the potential significance and distinctiveness of the Internet should be appraised. Mass media, and television in particular, have specific, intrinsic, structural elements that do not allow laypersons a meaningful way to cross the boundaries and challenge the medicalised expert voice.¹⁴ The model of broadcasting is fundamentally based upon the separation of production and consumption. It is a predominantly one-to-many disseminative model of communication. As such, although it gives voice to laypersons, this voice is limited in its capacity to meaningfully challenge the lay/consumer/private versus the expert/producer/public boundaries. In short, although through broadcasting a patient is given a voice in the *public* sphere, it remains mediated, and crucially framed as *private*: subjective, experiential, interpretative and informal.

In light of the limitation within the televisual experience, the online space appears to suggest real opportunities for laypersons to participate as producers in a public domain, and thus meaningfully challenge the containment of their 'private' voice. As I have shown in the previous chapter, by engaging in writing online, especially of a

regular column or diary, patients develop a sense of being experts in the subject they write about. Indicative of the latter is the way in which B refers to the patient-readers of her online column as ‘they’, ‘the people’, ‘the general public’, regarding herself as apart from them. In distinguishing herself from her patient-readers, who belong to a private/subjective/experiential sphere, B constitutes herself as belonging to another sphere, where she exercises a public/objective/expert discourse: the public sphere. In so doing she conveys a significant message to herself and her environment, namely: I am a ‘patient’ no longer.

In this sense, the online space can be seen as a space for reversal: from lay into expert, from private expression into public discourse. Online storytelling is one of the communicative modes through which this reversal is enabled. The form of a personal *private* story published on an online *public* forum embodies the transition from public to private.

It is therefore not surprising that patients like K (interview 11), who insist on the maintenance of clear lay/expert private/public boundaries, do not engage in posting their experience online, neither in the form of a personal story, nor in any other form:

Women are trying to be each other's specialists, advisors when actually they're not in the position to do that. (K, interview 11).

5. Between the oral and the written, between the private and the public

In the previous chapters, I touched on the relation between the oral and the written in the process of online storytelling. In particular, I suggested that patients’ engagement in the making and the telling of their story in online spaces might constitute a hybrid form, containing both oral and written qualities. In this chapter, I wish to connect this observation to our discussion of online narrating as a process of negotiation of the public and the private. As acknowledged by Warner (2002: 29), one of the forms that the relation between public and private can take (and which appears central in the context of patients’ online communication) is that between the written and the oral. The public is often that which is circulated in print or electronic media, whereas the private is often thought of as circulated orally, or in a manuscript (ibid.).

Patients' online communication is a special site where these two components seem to exist at the same time. Perhaps the most useful manifestation of the oral-written nature of this communicative situation, is the ways in which users' descriptions of their online communication oscillate between the oral and the written:

Legend:

Bold = written

Italicised = oral

"I had two [online] **pen** pals. [...] if I click with a person, we **correspond** daily. [...] My friend **writes** me [...]" (online narrative 1).
"[...] we've been **talking** about the World Trade Centre [...] She'll [my online pal] **talk** about the length of her hair. And I **told** her [that] chemotherapy changes your hormones [...]. So she **said** : 'Oh, maybe I'll try it' ". (A, interview 1).

" [...] From 'Ask me' [B's online column] I get a lot of questions, a lot of people would also **write** direct. They'd **say** ' I saw your name here'. [...].

I have another friend [online pal] [...] we were both **posting** , and we started e-mailing [...] I've been **corresponding** with her for like three years. [...]. We're not **talking** about breast cancer anymore. Every once in a while we'd **say** ' I'm going for my mammo'. (B, interview 2).

I **talk** on a daily basis to 2 other ladies I met on the bcans website [...]. Even if I don't respond, I still **read** through everyones comments/questions. [...] Every time I have a doctor apt. [appointment], [...]., All I have to do is get on there [BCANS online forum] and **say** I've got an apt. [appointment] coming up and I'm overwhelmed with responses and wishes. These ladies have all been where I am now, and got through by **talking** it out with each other. (Online narrative 19).

That they use, interchangeably and seamlessly, words that refer to oral and written situations, demonstrates the hybrid nature of this communicative situation. The acts of writing (and especially typing), corresponding, posting and reading are acts of literacy. To an extent, they are associated with life contexts that are public, particularly in late modernity. This is particularly evident in some of the online forms into which patients are requested to insert their personal stories. These forms resemble 'public' forms that people usually fill out in daily public contexts (for example, financial forms). The instructions of 'Shared Experience' website refers to this resemblance directly:

Add to this Shared Cancer Knowledge

Please don't think of this as "filling out a form". Be conversational, and write as much as you want, and say whatever you want.

'Shared Experience' website tells its participants to move away from the public connotation of the act of typing and filling a form, into a private mode of orality: 'be *conversational* [...] and *say* whatever you want'. At the same time, this *oral* conversation has a fundamental *literal* component. To participate in this 'conversational' situation, one has to express oneself in writing. Recalling Chapter Four, unlike the conventional concept of online conversation, which takes place in a synchronous environment (and is often called 'chat', to connote an oral situation), this conversation takes place in an asynchronous environment. As such, it directs participants to textually recount their experience in a coherent way and at length, rather than just *chat*. Furthermore, unlike chats that can take place in *private* settings (closed chat rooms, restricted only to certain participants), the text produced by women on asynchronous forums such as 'Shared Experience' board, are *public*. They are open to everyone who visits the website.

Thus, online communication, and narrating in particular, offers a special interactional situation consisting of both the written and the oral. The written aspect has a significant role in enabling participants to connect the public. Even before an actual dialogic interaction takes place, the act of writing requires the narrator to step back, dissociate herself from her subjective private sphere, in order to display herself in the public realm. In this sense, as Bakhtin contended, the word is essentially dialogic, and by extension, as argued by Wittgenstein (in Warner, 2002: 25) all language and all thought are public. The following comment captures the significance of the *written* dimension of making a story online, in enabling the narrator to step out of the boundaries of her private self:

Probably the best part of the Internet is that you need to type your question or feeling before you can share it (Online narrative 21).

The *oral* dimension, on the other hand, endorses the private quality of the interaction. The chattiness enabled by communication via e-mail, or even on message boards, helps participants to delineate their communicative space as private and intimate. As G (interview 7) points out, the chattiness of e-mail also facilitates patients' translation

of medical expert discourse (public) into experiential first-hand discourse (private). In short, the oral nature of online communication, especially of storytelling, can be seen to redefine the private: communicating in a public space, but at the same time crafting a private interaction.

Arguably, the oral-written hybridity is not distinctive to the act of narrating. Rather, it is emblematic of various other communicative online processes, which consist of both textual and 'chatty' elements. For example, a similar claim about the enmeshment of the oral and the written in online communication has been recently explored by Fernback (2003) in his examination of discussion groups devoted to urban legends.¹⁵ Relying on Finnegan, who "urges us to move beyond the 'oral' and the 'written' dichotomy" (Fernback, 2003: 43), and drawing on earlier studies of CMC, Fernback shows how urban legends circulated in online spaces originate in literate culture (and hence are bound by the structures of literacy), but at the same time exhibit many of the characteristics of oral cultures.

However, the analysis presented in this chapter calls for a more elaborate consideration of the issue of orality and literacy in relation to online communication. First, it highlights the need to expand the scope of the discussion beyond synchronous online forums. In existing literature, the claim for online space as a locus for an oral culture appears restricted to real-time simultaneous online textual environments. Consequently, the kind of online oral culture that Fernback and others depict, is derivative of characteristics of synchronous environments: in particular, immediacy and ephemerality. In analysing patients' online communication, I have insisted on the significance of the oral component of communication also in *asynchronous* environments, e-mail in particular. Second, the analysis of breast cancer patients' online communication highlights *narrating* as a particularly interesting locus for the confluence of oral and written qualities.¹⁶

Lastly, and perhaps most significantly, the purpose of exploring the blurred distinctions between the oral and the written in patients' online communication, is to link it to the significance of their negotiations of the public and the private. Accounts of orality and literacy in CMC such as Fernback's seem to miss this point. Interestingly, for them orality entails the public: it is what enables people to

communicate with each other 'without much effort' (Fernback, 2003: 42), and thus transcend their private existence. Although they recognise the co-existence of oral and literal components in CMC, in fact their accounts imply a preference for the oral. Fernback's account, for instance, celebrates the proliferation of oral culture in online spaces. There is a normative agenda underlying this kind of analysis: online space is depicted as a site of an oral culture, which is geared towards community and sociability. Against common accusations of the Internet as 'devoicing society' (Locke, 1998), analyses such as Fernback's show how CMC revives orality, and thereby sociability. In so doing, however, they seem to understate the persistent significance of the written character of CMC, and its implication for the constitution of both the public and the private in users' lives. That is to say: while there is indeed a great significance for the oral dimension of online communication, by which users easily communicate, exchange information and tell stories about who they are, at the same time, as my analysis has shown, there is a crucial resonance for the written form through which this communication takes place.

Thus, a more complex understanding of the dynamics of the oral and the *written* is required. The following extract from a patient's account of her relationship with her online pal, encapsulates this complexity:

I have a dear friend [...] who lives somewhere in the State of Wisconsin [...] She [We] 'type' at each other frequently and I truly feel a bond between us. (Online narrative 10).

The bonding between the author and her online pal is the corollary of a hybrid communicative mode. On the one hand, the author is aware of the significance of the written character of this communication. She chooses the verb 'type', to highlight the textual component their relationship is based upon. At the same time, she reflexively puts quotation marks on the word 'type', to imply that, in fact, something different is going on here. It is not the regular meaning of 'type' that we might think of from other contexts, signifying the official, technical, impersonal and, by extension, *public*. This is, if you wish, an 'oral typing', that also entails a 'chatty' character: personal, expressive, intimate and, by extension, *private*. It is the convergence of these seemingly dichotomous characteristics that engenders a genuine bonding between the two patients.

Conclusions

Negotiating the public and the private: A dialectical process

The terms 'private' and 'public' often seem to be defined against each other, with normative preference for one term (Warner, 200: 28). Indeed, the tension between the public and the private and its normative load lurk in much of the debate on individuals' use of the Internet. Most significantly, this tension underlies the preoccupation with the concept of 'virtual community' and with the question of whether a genuine community can be sustained through computer-mediated-communication. As Bakardjieva (2003: 306) usefully notes, both pessimists¹⁷ and optimists about this question contributed to the framing of the social meaning of the Internet by elaborating the dichotomy between the private and the public:

Critics like Kumar have seen growing Internet use as contributing to the 'increased privatization and individualization' of existence and the evacuation and diminishing of the public sphere of contemporary western societies' (1995: 163). Enthusiasts, on the other hand, have anticipated invigorated public life and a 'network nation' [citing Hiltz and Turoff, 1978].

The preoccupation with the model of 'virtual community', on both sides of the barricade, implies a normative preference for the public. This normative orientation is framed particularly by the concept of the public sphere.¹⁸ More recently, it seems to have been fuelled by the *Bowling Alone* (Putnam, 2000) debate, influenced by Putnam's account of the increasing tendency towards social privatisation and dissociation, and specifically the claim for the Internet's potential in sustaining as well as challenging this trend.

As this chapter has sought to show, patients' practices and experiences of online communication challenge the private-public dichotomy that has framed the discussion of the social meaning of the Internet. Indeed, as Bakardjieva postulates

The preoccupation with ideologically constructed standards, such as virtual community versus real/genuine community and public participation versus privatization of experience, blinds commentators to the possibility of new, unexpected, unimaginable and yet humanist and empowering variations of technological practice to emerge (Bakardjieva, 2003: 311).

Patients' practices reveal a dialectical process of movement between the public and the private. The intermeshing of the public and the private in patients' experience, enabled processes such as narrating, suggests that the values and meanings of public and private should be carefully contextualised. There is no preset preference for the private or the public; their salience to patients' experience differs according to the patients' respective situations, and according to the specific online environment in which they communicate. Even Bakardjieva, who sensitively recognises the caveat of framing individuals' use of the Internet in terms of the private/public dichotomy, claiming for the enmeshment of the two in users' experience, falls into the normative trap of regarding the public as normatively superior.

The significance of the emerging range of social forms of online communication is thus not unidirectional, 'transcending the narrowly private existence' (Bakardjieva, 2003: 294) of users. Rather, the resonance of the manifold social forms of online communication is in the ways they enable users (in this study, breast cancer patients) to negotiate the boundaries of the public and the private in their lives in both directions, back and forth. Negotiating the public and the private, as shown in this chapter, constitutes a key process in patients' endeavour to construct their social reality in a way that would allow them the capacity to act. Narrating constitutes one communicative process through which those negotiations take place.

A discursive transformative space: Survival as a public testimony

In her account of the narratives of holocaust survivors Rosenblum (2000) suggests regarding the path of writing of one's experience as a third path between complete silence and falsification of the catastrophe. This path, argues Rosenblum, allows an unspeakable truth to erupt onto the social scene, offering a public testimony. The therapeutic effect emerges from the individual's capacity to share his/her suffering. The publication of the story (onto the public realm) enables bearing the unbearable.

The online scene of breast cancer patients offers a significant space for public testimony. Online spaces of breast cancer patients constitute collective scenes of disclosure that enable patients to transcend private meanings. Although the display of private matters in those spaces is often seen (especially by outsiders) as a debased narcissism and as an erosion of any distinction between public and private, in the

actual setting of this communicative space, such displays often have the aim of transformation (Warner, 2002). The visceral intensity of meanings of corporeal pain, shame, guilt, anger and other feeling, and their continual recitation extends them from the private sphere into the public realm (Warner, 2002; Stacey, 1997). Thus,

The stories no longer 'belong to me' but become part of a repertoire of collective narratives of cancer (Stacey, 1997: 242).

And as a consequence 'Publicness itself has a visceral resonance' (Warner, 2002: 63).

Indeed, as I have shown throughout this chapter, by appearing in online interactive forums, a patient's story becomes part of a repertoire of collective narratives of cancer patients. The table displayed earlier, from the 'Shared Experience' 'online cancer knowledge base', demonstrates this idea eloquently.

In light of those observations, and with the inspiration of Warner's account of *Publics and Counterpublics* (2002), patients' production of their private accounts online can be seen as a collective endeavour that forms a counterpublic. A thread that runs through women's accounts of their online participation is that their activity is continuously defined by its relation (and often tension) to the larger public. The stories patients tell online are defined (both by their environments and by themselves) in relation to other available stories in the public discourse of breast cancer. The constitution of online space as private and/or public depends on the wider available meanings of 'private' and 'public' in patients' habitual experience.

Thus, the online space of breast cancer patients can be regarded as a counterpublic. This 'counterpublic' discursive space does more than represent the interests of breast cancer patients in a public sphere. It mediates the most private and intimate meanings of the experience of illness. In so doing, it works to elaborate new social relations in which the identity of breast cancer patients can be lived; developing its particular forms of association, vocabularies, disembodied practices and relations of camaraderie and *communitas*. It can make possible new forms of participation in a social world.

Patients' online 'counterpublic' constitutes a scene of association and identity that transforms the private lives it mediates. This 'counterpublic' is not a natural collection of people, nor is it just 'community', as Internet researchers would commonly describe it. Closely drawing on Warner (2002), breast cancer patients' online participation could be better understood as forming a mediated public rather than a natural community. The online structures and practices, which I discussed throughout this thesis, mediate this public. Like counterpublics of sex and gender, patients' online 'counterpublic', teach us

to recognize in newer and deeper ways how privacy is publicly constructed. They are testing our understanding of how private life can be made publicly relevant. And they are elaborating not only new shared worlds and critical languages but also new privacies, new individuals, new bodies, new intimacies, and new citizenships (Warner, 2002: 62).

Crucially, as Warner (2002) asserts, counterpublics are embedded in larger publics and larger processes of privatisation. In other words, the context of publicness must be available in the wider society and culture, to allow actions of 'going public' to be transformative. I want to focus the remainder of the discussion on two such contexts, in which the counterpublic of breast cancer patients' online communication (particularly narrating) is embedded. The production and display of patients' self-narratives online, through which, among other processes, patients negotiate the public and private, could not have had a transformative effect if it were not ingrained in a wider cultural and social environment. In this environment, I suggest, two contexts are key: the feminist debate and the culture of the enterprising self (Rose, 1992).

The feminist debate

The issue of publicness is intimately interlinked with the feminist debate. The Feminist movement has fought against the effectiveness of silencing techniques by creating forums where survivors can speak: in magazines, journals, television, support groups, demonstrations and now the Internet.

Indeed the dichotomy between the private and the public has been central to feminist writing and political struggle. The Feminist movement sought to reveal the gendering of public and private, in order to explain the subordination of women cross-culturally.

Female was to private, which meant domestic spaces and functions, whereas male was to public, which referred to contexts in which men spoke and made decisions for the community (Warner, 2002: 32, drawing on Rosaldo's infamous essay).¹⁹ What is more, the gendering of the public and the private has particular resonance in the context of the discourses of breast cancer (see Chapter Two), as much as in relation to the debate on women and technology, and the Internet in particular. Recent discussion amongst feminist critics, both in academia and beyond, revolved around the question of whether Computer Mediated Communication reinforces or challenges the traditionally gender-associated distinction of private and public.²⁰

This is a significant background against which breast cancer patients' negotiation of the private and the public, through online narrating and other communicative processes should be understood.²¹ The capacity of online space to furnish a *legitimate* communicative space for the production and display of patients' personal stories is inextricably embedded in a culture where the slogan 'the personal is political' has become a central leitmotif.

The culture of the enterprising self

[...] get over your problems, and get off yourself, and work your life (A, interview 1).

Become whole, become what you want, become yourself: the individual is to become, as it were, an entrepreneur of itself, seeking to maximize its own powers, its own happiness, its own quality of life [...]. On the territory of the therapeutic, the conduct of everyday existence is recast as a series of manageable problems to be understood and resolved by technical adjustments in relation to the norm of the autonomous self aspiring to self-possession and happiness (Rose, 1992: 150-151).

Patients' negotiation of the boundaries of public and private is interlinked with the wider available discourse of self-governance and the enterprising self. The online space furnishes a space for self-presentation, for confession and introspection. Narrating is one way of providing patients with a framework to reframe suffering and transform it into mastery. Through the provision of a space for narrating and storytelling, online spaces act as therapeutic environments, legitimising the performance of the self. The homepage of the breast cancer 'Young Survivors

Coalition' exemplifies this argument usefully (note the left-hand column of the screen):

Figure 7.3 Home page of 'Young Survivors Coalition' (www.youngsurvivors.org)



It is necessarily in a culture where breast cancer patients celebrate their personal triumph over the disease publicly, on a public train, that online space can flourish as a space for public testimony.²² However, while activities such as the 'Victory Train' are still seen by many (such as A) as violating the boundaries of privacy, the act of disclosing one's personal experience in a disembodied anonymous space appears widely legitimate, if not desirable.

While the discussion on the role of the media in blurring the distinctions between private and public has been around for quite some time (Meyrowitz, 1985; Silverstone and Hirsch, 1992; Silverstone, 1994), what seems particularly interesting about the Internet, and the kind of communication it facilitates, is that it *legitimises* publicness. In furnishing a space that is designed for, and geared towards, the performance of the self, online space facilitates individuals to cross the boundaries of public and private in a seamless, almost 'natural' fashion.²³

Revisiting the dialogue/dissemination dichotomy

The discussion of the negotiation of the public and private invites us to rethink the dichotomy between the dialogic and disseminative models of communication. The dialogic model entails many of the 'private' meanings that have been discussed

throughout the chapter: it represents an intimate interaction, which is selective and restricted to some. It must take place among embodied people, and thus is inevitably oral. Dialogic communication is unique and nonreproducible (Peters, 1999: 35). Although the archetype of the dialogic model is the interaction between a philosopher and his pupil, it conforms to the kind of interaction that would have emerged between two laypersons. The disseminative model, by contrast, whose archetype is Jesus' Gospels, is radically public: it is an exoteric mode of dispersing meanings, democratically open to all. It is highly performative in nature, based on a distribution of discourse by an expert (Jesus) in an inclusive manner. Lastly, the model of dissemination assumes no essential privilege of the body as a carrier of personality (Peters, 1999), and thus arguably, a disseminative interaction can be carried out through writing.

As the discussion of this chapter has demonstrated, those meanings of private and public, and thereby of dialogue and dissemination, are not mutually exclusive, nor are they dichotomous. Rather, they are occupied in a dialectical manner. Breast cancer patients' online participation is thus better understood as a dialectical communicative process, which encompasses the tension between the dialogic and the disseminative. Admittedly, much of what has been described in this chapter in relation to patients' dialectical experience of communicating online is not necessarily specific to narrating. Rather, narrating is one communicative process which, like other processes, is framed by, and at the same time facilitates, the crafting of public/private meanings. In the following chapter, which concludes the thesis, I will critically reflect upon this difficulty, and try to clarify in a summary fashion what aspects of narrating are distinctive and in what aspects it appears difficult to distinguish narrating from other communicative modes.

¹ This message has been significantly led by feminist forces embedded in organisations such as the (American) National Breast Cancer Coalition (NABCO) (Lerner, 2001:245).

² The proposed dimensions are inspired by Warner's account of possible forms that the public and the private can take (2002: 29). However, while the categories suggested in this chapter resonate with broader ideas on the meanings of private and public in social life, they are informed by the particular experience of breast cancer patients' use of the Internet.

³ Zerubavel indeed acknowledges the resemblance of his argument to explanations of space as a marker between private and public.

⁴ These kinds of issue were predominantly tackled from a feminist perspective, and (too) often within a post-modern approach (e.g. Stone, 1995; Terry and Calvert, 1997; Millar, 1998)

⁵ I borrow the concept of a continuum of public and private from Zerubavel (1981: 143-144).

⁶ I purposefully avoid the normatively charged meaning of 'privatisation'. I come back to this point in the conclusions of this chapter.

⁷ The notion of 'preserves' in this context is taken from Zerubavel (1981).

⁸ In order to secure the interviewee's anonymity I do not present the poem.

⁹ See chapter Four.

¹⁰ For instance, at the time of writing this chapter, the 'Shared Experience' website contained 536 breast cancer personal stories, about a quarter of the whole collection of cancer stories (www.sharedexperience.org, data accessed on 7 October, 2003).

¹¹ Crucially, this is a very different argument from the post-modern thesis of disembodiment and the capacity for disconnection from physical 'real' identities. These online narratives have both authors and addressees who are connected by a common experience. The common experience, enhanced by the lack of physical contact, marginalises the significance of differences between the stories and their authors, and emphasises their commonality.

¹² By the same token, there were also a few references to stories patients heard on television or in magazines as 'private' insofar as they were personal, relating a highly subjective experience in an intimate fashion.

¹³ Performance, *à la* Goffman (1969), is 'all the activity of an individual which occurs during a period marked by his [sic.] continuous presence before a particular set of observers and which has some influence on the observers' (ibid.: 32).

¹⁴ As shown by Hodgetts and Chamberlain (1999), this observation is especially sound in the case of television documentaries.

¹⁵ A similar claim about CMC as a hybrid language displaying both oral and written characteristics was made by Ferrara et. al (1991, in Baym, 2002: 65). However, from a linguistic perspective that was quite limited in its capacity to account for the social meanings of this hybridity.

¹⁶ It is striking that Fernback (2003) does not interrogate the centrality of narrativity (which is at the heart of urban legends) in explaining the special character of CMC as containing both oral and written characteristics.

¹⁷ Among this camp are critics such as, for example, Kraut, et. al., 1998 and Locke, 1998.

¹⁸ Throughout this chapter, I have referred to the notion of 'public sphere', however in a very different sense from the Habermassian model of public sphere. I come back to this point in the concluding chapter.

¹⁹ Rosaldo (1974).

²⁰ By no means do I mean that the feminist 'camp' is monolithic in its thinking about the question of public and private. However, it is beyond the scope of this thesis to enquire into the different approaches to this issue. For the purpose of our discussion, my intention is to contextualise the arguments made in this chapter about breast cancer online communication and the negotiation of public and private, within the wider discourse on women, Internet use, and the relation between private and public. For recent studies that examine this relation from feminist perspectives see, for example, Youngs, (in Harcourt, 1999) and Franklin (2001).

²¹ Although none of my interviewees referred to the feminist debate in their accounts, the latter appears a significant backdrop for their active participation in the narrating of their bodily experience of illness online. It will be interesting to consider this issue in future research.

²² There is a crucial US-American context to this culture. I develop this issue in the concluding chapter.

²³ This is, of course, part of the wider media culture, in which televised genres such as reality television blur the distinctions between private and public, and make the publicity of personal lives legitimate and acceptable.

Conclusions

My aim in this chapter is twofold: to reflect upon the key strengths and limitations of the study and to open up some wider issues that the study raises for future research. The first section is a self-reflexive account of the employment of narrating as a conceptual, analytical and methodological tool for the study of breast cancer patients' processes of online communication. I start by considering the usefulness of the shift implied in the concept of narrating from a concern with the textual properties of the communication, to a focus on the process of producing discourse. I follow by evaluating the key argument of the thesis about online narrating as action, that is, as a means for patients' constitution of their agency. Stemming from this is a discussion of the implications of the particular methodological design of the study on its conceptual focus on narrating. This issue is followed by a consideration of narrating as a methodological device for thinking about participants' online communication as a complex and indeterminate social experience. I substantiate this idea by positioning the study in relation to Hine's (2000) distinction between Internet as culture and Internet as artefact. The second section maintains the reflexive approach, exploring the potential contribution and limitations of the study, beyond the aspects of narrating. This part qualifies the scope of the study and reflects on the specificity of the case of CMC and breast cancer. Next, I raise two broader issues that emerge from the study that expand the concern with narrating and breast cancer patients' online communication. The first issue regards the wider claim implied by this study about the therapeutic value of CMC, particularly for patients. Following from this is a consideration of a second issue, namely the application of the Habermasian model of public sphere to the study of CMC. In the remainder of the chapter I introduce a new dimension, which has remained implicit throughout the thesis, namely the culturally specific context in which patients' online narrating takes place. I raise some preliminary possible directions in which we can think about the social action of online narrating as culturally specific. While I point out the US-American dimension of breast cancer patients' CMC, I insist that it still has much to suggest beyond its American context.

Reflections on narrating as an analytical strategy

This study explored the processes of communication and practices involved in the online experience of breast cancer patients. While acknowledging the manifold communicative processes and activities in which these patients participate (information seeking, exchange, lurking, chatting etc.), the thesis focused on a process which has been relatively understudied, namely narrating. Drawing on data from relevant Internet sites and online forums, as well as patients' actual accounts of their Internet use experience, the study suggested that narrating is a particularly useful way of illuminating the specific processes of communication and Internet spaces in which breast cancer patients engage. It highlighted the ways in which patients use and appropriate the new medium to engage in the construction of (or the struggle to construct) their self-narratives; how their online participation is partly an attempt to communicate their experience to others by ordering it in time and gearing it to a closure. The analysis of the ways in which this process take place was theoretically informed by Ricoeur's thesis of narrative and its developments which elucidate narrating as a struggle to produce self-disclosure and achieve closure, and as individuals' endeavour to transform their existing situation and realise their agency. The following section sets out to critically discuss the extent to which narrating has been a useful analytical strategy for thinking about patients' online communication, reflecting upon both its strengths and its limitations.

From text to process

As a conceptual and analytical tool, narrating enabled the move away from a mere concern with, and reliance on, the text as the final product of online communication, to a focus on processes of communication that take place both behind and on the screen. The research agenda on Computer Mediated Communication has given considerable attention to the textual properties of online communication. The latter were commonly seen as the key to explaining online interactions and communicative processes. This approach has been significantly influenced by the preoccupation of Internet literature with the notion of interactivity and conversation, which focused on the responsiveness and the relationships between messages that are being exchanged in a sequence (see Chapter Four). It put the emphasis on the *structural* and somewhat *technical* features of CMC, for instance, the degree of adjacency of messages, or the dynamics of turn-taking. This line of concern was endorsed by the employment of the

Conversation Analysis tradition to study online interactions, the application of traditional discourse analysis to explore various online communication contexts, and the impact that linguistic and literary approaches had on the study of CMC.

Framing participants' processes of online communication as narrating sought to offer a different focus. As exemplified in this study, the concept of narrating suggests that it is not necessarily and merely the actual texts that participants post online that matter, and that can help us understand what is going on. Rather, much can be learnt also by attending to the process of producing or attempting to produce these texts, and the ways in which the texts that participants post are shaped by specific structures of online spaces. Employing narrating as a conceptual and analytical tool in this study has shown that relying only on the observable representational level of online activities, that is, texts, is not sufficient on its own to explain the significance and capture the complexity of these activities. Narrating furnished an analytical strategy which enabled access also to processes behind the screen, and how they translate (or not) into active participation on the screen.

Narrating draws our attention to the activity of the teller, but also to that of the listener, whose role is crucial for the teller to produce her story. The idea of narrating as a central practice in participants' online experience considers not only writing and telling practices, but also activities of reading and listening. As has been shown throughout the analysis, the notion of narrating goes beyond the observable representational level of online activities; it encompasses different ways of engagement, as well as disengagement: from posting a story, through lurking to logging off. The following fragment from an e-mail written by a breast cancer patient to a mailing list of patients, neatly summarises how varied and multi-faceted the unit of 'online experience' is:

[...] if you want to...post as much as you want...even a lot in one day. If you want to, stay silent and get support without posting. If you want to, stay away for a while and come back. We have some members who come and go. AND wow, some of our members "graduate" and feel they are not in need of support ...if those members want to come back...they are always welcome. (An e-mail message posted on a breast cancer mailing list).

Staying in the background reading messages, as the poster cited above describes it, can play a significant role in a patients' project to 'win this game of survival'. Lurking (as discussed in Chapter Six), like other kinds of online activity, can be part of a process in which the participant constructs and tells a certain story about herself to herself and to her environment. Thus, accounting for patients' online communication through the prism of narrating enabled the inclusion of practices and actions that occur *beyond* the discursive representational space on the screen, and that often remain obscured.

So, rather than an analysis of the structural features that characterise the texts that patients post on different Internet sites, this study, informed by a theoretical framework of narrating, presented an analysis of the ways in which CMC enables patients to participate and act in a social space. In so doing, this study challenges the dominant understanding of interactivity which, in foregrounding the technical and the structural, seemed to have underplayed the social meanings of CMC. The following reflection of a breast cancer patient is perhaps the best way to substantiate this claim:

Probably the best part of the internet is that you need to type your question or feeling before you can share it and sometimes just writing it down is a therapy of its own. (Online narrative 21).

If we apply the mainstream definition of interactivity to this patient's experience, we would describe her experience as meaningless. She did not actually exchange messages. Yet her experience of Internet use, of putting her experience into text by typing it – before even interacting – was therapeutic, as she reflects, and thus salient and significant.

Having said that, the move from a concern with the textual properties of online communication to a focus on participants' engagement in the process of narrating runs the risk of ending up with a very broad analysis. Since narrating is not anchored by a clear delimited textual form of 'narrative', but rather refers to the process of production or the struggle to produce this text, it can easily become a vague concept that encompasses too many things. In particular, it seems difficult to draw the boundaries between 'writing' and 'narrating'. If the analysis does not look at specific textual properties, how can we determine that the communicative activity at stake is

narrating, rather than simply writing, as described by the above patient? Indeed, this question emerged in different places throughout the data analysis. By the same token, it is often hard to distinguish narrating from the broader process of sense-making and self-disclosure. On the one hand, narrating is only one particular process by which sense-making and self-disclosure are exercised and performed. The underlying theoretical assertion is that individuals understand themselves and construct their self-identity by working and reworking their interpretation of their own biography in the form of a narrative and a story (Giddens, 1991; Thompson, 1995). On the other hand, since analytically the focus is not the final product of this process (i.e. the discursive form of narrative), but rather the act of construction, interpretation and re-interpretation, it can prove highly tricky to try and demarcate what counts as narrating, and what counts as sense-making that does not involve narrating.

Throughout the thesis I attempted to clarify and qualify the specificity of narrating, particularly by drawing on Ricoeur's theorisation, and emphasising narrating as an attempt to configure events by organising them in temporal order and directing them toward closure. Nevertheless, I admit that there is still a real difficulty of distinguishing this process from other related categories, such as the textual activity of writing on the one hand, or the process of sense-making on the other. I think, however, that this difficulty does not have to do specifically with the attempt to apply this concept to the online context of breast cancer patients. Rather, it is a broader conceptual pitfall of the theory of narrating. Understood as the fundamental process of experiencing time, narrating gains a very central, if not a ubiquitous, status in social life. As such it often appears to be an all-embracing process. Indeed, when reading Ricoeur's seminal volumes on *Time and Narrative* (1984), and later developments of his theory such as the works of Brooks (1994), Gare (2002) and Somers (1994), as well as Giddens' (1991) and Thompson's (1995) accounts of the centrality of narrative in the constitution of agency, it is easy to think of narrating as a key, if not the most fundamental principle of social agency and human sociality.

Hence, the theoretical framework of narrating and its translation into an analytical strategy to examine patients' online communication is very seductive. It sheds new light (as I hoped to show) on the processes of online communication in which those patients are involved, and highlights their significance. In particular, it shows that

patients' online communication does not centre only on information (an aspect on which the 'e-health' literature seemed to focus chiefly), and helps specify the particular aspects and social consequences of what has been hitherto explained mainly in general terms such as 'emotional support', 'esteem support' (Shaw. et. al., 2000), 'social support' and 'personal empowerment' (Sharf, 1997). It invites an exploration of the ways in which specific features of online communication such as the asynchronous nature of online communication or disembodiment shape patients' participation and the specific kinds of discourse that they post. At the same time, framing participants' online experience in terms of narrating overlooks activities which are non-processual in their character, but rather a kind of 'one-off' engagements, such as what B describes:

Some people also wanted just to ask their questions, and they would discuss their subjects again. Get your information, and then they want no connection. (B, interview 2).

Arguably, this kind of immediate, short-term information-oriented participation constitutes a significant part of patients' online activity. Yet it does not necessarily have to do with a complex process of the construction of identity through an attempt to configure experience and direct it toward closure. Rather, it is a practical, even instrumental activity. Clearly, the concept of narrating is limited in its capacity to account for this aspect of participation.

Narrating as action

The question of why what we study is important is probably *the* question every researcher grapples with. The principal argument of this study is that for breast cancer patients the Internet is important because (among other reasons) it constitutes a space and a means to configure their experience into a narrative. Informed by Ricoeur and others' theorisation of narrative, this thesis argued that patients' engagement in narrating online is a way to maintain their capacity to be agents: to have plans and desires, and to hold on to a sense of themselves as agents who have control, however little, over their lives. Through narratives that patients exchange, among other discursive forms, they are able to reach out to each other, help other sufferers and at the same time help themselves, by seeking reassurance and gaining better control over their liminal experience of cancer. Narrating is a means in patients' *rite de passage*,

releasing them from their previous dominant structure (as healthy persons) into a liminal phase with fellow-sufferers online, 'to return to structure revitalized by their experience of *communitas*' (Turner, 1969: 129). In particular, the process of narrating, I suggested, is geared towards the constitution of patients as survivors, directing patients towards the phase of reincorporation into the 'healthy' structure. The ongoing struggle to narrate their experience online plays a crucial role in fashioning patients anew, endowing them 'with additional powers to enable them to cope with their new station in life' (ibid.: 95).

To put it another way, the core argument of this thesis is that patients' participation in online spaces through the act of narrating is significant because it constitutes an action. Unlike the concept of *media effects* which concerns the consequences of the consumption of mediated texts (e.g. watching television) for consumers' behaviour and identity, the view of narrative as action conceives the 'effect' as *embedded* in the act of narrating. The hermeneutic approach, as explored in Chapter One, regards the relation between narrative (text) and agency (action) as interpretative and cyclical: agency is not only the product of the mediated text but also its source. So the potency of the online narrative lies in the actual process of its production and consumption.

Understanding the process of online narrating as the capacity to act (in other words, agency) challenges a moral problem that arises in individuals' engagement in other media, especially television. Bauman (2001: 2) accounts for this moral challenge:

...what form can commitment take when those called upon to act are "thousands of miles away from the persons suffering, comfortably installed in front of the television set in the shelter of their homes [?]"¹

[...] while our hands have not grown any longer, we have acquired "artificial eyes" which enable us to see what our own eyes never would. The challenges to our moral conscience exceed many times over that conscience's ability to cope and stand up to challenge. To restore the lost moral balance, we need "artificial hands" stretching as far as our artificial eyes are able to.

This abysmal gap between the suffering that individuals see and their ability to help the sufferers is encompassed, to a large extent, in the online communication of breast cancer patients. Unlike communicative processes produced by mass media such as

television or newspaper, online narrating is essentially reciprocal. Thus, patients' online narratives, I suggest, provide their narrators with 'artificial hands'. It is in this light that we can fully understand the meaning of the way Susan, a breast cancer survivor, finishes her e-mail to her online protégée, Lara:

...I'm happy to hold your hand until you get the all-clear (Katz Becker, 2000: 13).

The meaning of 'holding one's hand' arises from the specific communicative context in which patients like Lara and Susan participate, where *text* constitutes a social *action*. Online, what one writes or says is what one does. True, this observation can be extended, by a fair degree, to any online activity which involves the aspect of writing. Here too, there is the problem that was discussed earlier, of the difficulty of distinguishing between writing and narrating. Other forms of textual expression online can be equally regarded as actions. The most obvious example in this context is perhaps 'cybersex', that is, the claim that online textuality constitutes sexual action.² At the same time, the notion of narrating, as I have tried to demonstrate throughout the data analysis, emphasises the particular textual 'configurational arrangements', as Ricoeur (1984: 67) put it, that the narrator employs in an attempt to transform the different events of her experience into a meaningful whole, in particular, the attempt to impose a sense of ending. It is in this particular act of configuration and closure, unlike in any other textual activities, that the transformative potency of narrating lies.

Some would argue that there is, however, another limitation to the conception of narrating as action. For them, unlike Ricoeur (1980) or Arendt (1958), action exists beyond the realm of thought and discourse. Thus, the transformative capacity of narrating does not exist in the act of construction and telling the story, but in the extent to which this process translates into action in other realms of everyday life. In the context of this study, this line of argument implies that the significance of patients' engagement in online narrating can only be evaluated in light of patients' 'real' actions. That is, how does the story a patient tells (or struggles to tell) online affect her capacity to act in other spheres of her everyday life? The justification for examining other actions and constructions, beyond those of a patient's online experience, is the claim that there might be a very limited relationship between the online activity and the offline action. To put it in a different way, online narrating can

be disconnected from a patient's offline everyday life, remaining within a fictive realm that does not correspond with her offline agency.³ Even if the online experience of narrating and one's offline actions are connected, this relationship might be problematic insofar as the enabling of action is concerned. That is, online narrating can be also dysfunctional or disempowering. For instance, the process of reading fellow sufferers' postings, and constructing her own story online, can provide a patient with 'a glimpse of alternatives' (Thompson, 1995: 212), however at the same time it may make her realise that those alternatives are not at her disposal or that they are beyond her control. Thus, this reflexive process of narrating can have, in fact, a problematic relationship to action and the realisation of a sense of agency:⁴

Agency refers not to the intentions people have in doing things, but to their capability of doing those things in the first place (Giddens, 1984: 9).

Rereading Giddens' notion of agency (presented in Chapter One) in the context of this study might actually suggest that, while patients' online narrating represents their intentions and desires, it does not necessarily correspond with their actual capacity to fulfil these desires, i.e. with their capability to act beyond the realm of the story they tell. This interpretation argues that the claims made in this study about the centrality of online narrating in constituting patients' agency are limited. As much as I attempted to avoid a celebratory tone, and eschew uncritically buying into patients' accounts of their online experience, I felt that there still emerged from the data a strong utopian sense of empowerment and, at times, even omnipotence. This aspect is coupled by the triumphalist and cheerful aspect of breast cancer discourses: breast cancer and narrating appear to be about the capacity to act, rather than about the failure to do so.

Narrating and methodological aspects

Recognising this limitation also leads us to acknowledge that the specific methodological design of the study has shaped in significant ways the study's conceptual focus on narrating. If the research had been designed differently, other communicative processes could have emerged as significant, and perhaps narrating would have appeared differently in terms of its centrality in patients' communication. For example, if I recruited participants from offline sites such as face-to-face support

groups, I could have probably accessed informants whose practices of online participation are substantially different, and for whom narrating either did not play a role, or had a limited or problematic relationship to the constitution of their agency in their everyday life. It is only with ethnographic evidence from people's everyday lives outside the realm of storytelling, scholars like Slater argue, that we can make claims about the connections and disconnections between participants' online and offline lives, and in the case of this study, between the narratives they produce online and their agency.

Elsewhere in the thesis⁵ I explained why ethnography was rejected as a methodological strategy for the purpose of this study. Notwithstanding the limitations involved in not doing ethnography, narrating has been developed throughout the thesis as a *methodological* tool that seeks to capture not only what happens on the screen, but also behind it. More particularly, narrating was suggested as a tool to encompass two different settings of Internet culture: 'on the screen' (observable online texts, in the form of narratives) and 'behind the screen' (processes and practices of Internet use in which users engage, that take the form of narrating).

To exhaust this point, I wish to position the study in relation to Hine's distinction (2000) between Internet as culture and Internet as cultural artefact. Hine's distinction usefully encapsulates the existing common thinking in CMC literature, by which the Internet is perceived *either* as 'culture' *or* as 'cultural artefact'. The first view of *Internet as culture* regards the Internet as a place, a social space in its own right, where culture is formed and reformed. The second perspective, of the *Internet as a cultural artefact*, perceives the Internet as a medium. It asks how the Internet is used as a means of communication within users' offline social world. While each of these categories has considerable explanatory power in its own right, as Hine admits, the distinction as such does not necessarily exist in users' actual experience, nor does it represent a straightforward reflection of online/offline boundary (39). At the same time, the problem is, as Slater (2002) acknowledges, that this kind of distinction has coloured to a great extent the thinking about CMC, and the offline/online distinction has significantly shaped the way users' experience of the Internet has been perceived and studied.

Framing patients' online communication as a process of narrating, enabled, I suggest, a way to encompass this dichotomous distinction conceptually, analytically and methodologically. It showed that the distinction between Internet as culture and Internet as cultural artefact (and thereby between online and offline) does not necessarily exist in breast cancer patients' actual experience. For users, the Internet constitutes both a *place* and a *medium*.

Internet as culture

It is evident throughout the analysis that many patients conceive of the Internet as a kind of a place to be. Some described the online context explicitly in terms of a 'place', for instance:

...interpersonal relationships are a vital factor for healing in the /body/mind/spirit connection during the entire process. Doctors who treat a patient like an intelligent fellow human, nurses who are careful and considerate of a weakened body and spirit, medical techs who are empathetic to a patient's fear and frayed nerves, and a support system of close friends and loving family make up the mix that's guaranteed to facilitate healing and peace of mind, provided the patient is herself/himself open to healing. **The internet was the only place**, in the beginning of my bc [breast cancer] journey, where those vital elements were present. [...] My sanity and peace of mind are a testament to the effectiveness of internet support groups. (Online narrative 24, my emphasis).

The Internet emerges as a place where patients, among other activities, evaluate their personal stories in relation to those of their peers, consider alternative versions of these stories, refigure their lives in accordance with their chosen version of the stories of which they are part, and consequently take responsibility for their lives. In enabling these processes (which I encompassed under the concept of 'narrating'), for breast cancer patients the Internet serves as a place for agency, where they can potentially become creative agents of their experience and identity.⁶

In this sense, the Internet is a social space in its own right (what Hine relates as 'Internet as culture'). The notion of online space as 'counterpublic', as proposed in Chapter Seven, captures precisely this perspective. Breast cancer patients' online space constitutes a discursive place that mediates the meanings of the experience of patients' illness, elaborating new social relations in which their identity can be lived, developing its particular forms of association, vocabularies, disembodied practices and relations of camaraderie and *communitas*, making possible new forms of

participation in a social world. The metaphor of a family, often used by patients to describe their belonging to the communicative online space in which they participate (see Chapter Six), encapsulates their view of the Internet as a self-contained culture within which forms of communication, sociality and identity are produced.

This view of the Internet as a family implies that its members – the agents who participate online – are being socialised and formed within the process of communicating in this space. To put it differently, the view of the Internet as a place or a culture is closely tied in with its transformative dimension. As a self-contained culture, the Internet constitutes a place in which processes of transformation are central. Narrating is one such process. As I have shown throughout the analysis, narrating is a playful and creative practice, through which individuals may come to reflect on their life conditions, and think about how they can transform it. The narrative they construct is transformative insofar as it can allow them to control the uncontrollable, to establish themselves as active heroines, and claim authority through authorship.

Internet as cultural artefact

The idea of the Internet as a transformative place has been commonly explored from a post-modern view, with a focus on identity-play as the key idea to account for the transformative processes that occur online. This line of thinking endorsed the view of the Internet as a separate place, a self-contained and self-sustained social space. For the latter view, the source of the transformation through which the participant goes, is in the separation between her online and her offline experience:

Like the anthropologist returning home from a foreign culture, the voyager in virtuality can return to a real world better equipped to understand its artifices (Turkle, 1996: 263).

By contrast, in stressing the link between narrating and agency on the basis of Ricoeur and others, my account suggested that the source of transformation lies in the interweaving of participants' online and offline experiences. For breast cancer patients, the Internet is not only a place, but also a 'cultural artefact': it is a means of communication, embedded in their everyday lives. It is a *medium* patients employ within their existing social world, particularly in order to communicate their

experience in story form. As I have already mentioned, some would argue that without ethnographic evidence of patients' activities in everyday offline realms that are beyond online narrating, the claim for the centrality of their online activity in the constitution of their agency remains unconvincing. This is a fundamentally thorny issue that stretches far beyond the methodological aspect. It raises the critical question of whether one accepts the ontological assertions upon which this thesis is predicated. In particular, the view that discourse and thought (and thereby the act of narrating and storytelling) are an integral part of the everyday realm, and that they constitute action.

To summarise, by elucidating the processes of communication in the online experience of breast cancer patients as narrating and storytelling, this study sought to bridge the two apparently dichotomous and mutually exclusive views of Internet as culture and Internet as cultural artefact. Indeed, as Hine asserts, this distinction should serve merely as a heuristic device for thinking about the indeterminacy of the Internet. The framework of narrating enabled a complex understanding of the Internet: as a creative and playful place but also as a functional and practical medium, a space in its own right, often perceived by users as magical and fantastic, but at the same time deeply connected with other spaces and contexts in users' lives; the generator of processes, practices and forms of communication (for example, of what I suggested calling 'online communitas'), but also the product of existing cultures, norms and discourses. However, far from advancing narrating as an exclusive or primary model of communication that can encompass the two perspectives, this study aimed to employ narrating as a specifically helpful way of examining breast cancer online communication, which combines a view of 'Internet as culture' and 'Internet as cultural artefact'. More generally, such a combined approach enabled a more complex understanding of CMC, identifying its unique and varied qualities, while at the same time recognising CMC in continuity with other social practices, and within the wider cultural and social context of users' lives.

Reflexive remarks on the study's context

The study examined a specific health context in which CMC takes place, namely breast cancer. As such, it lays claim to being a contribution to understanding the ways in which meanings of health (and breast cancer in particular) are constructed and negotiated via patients' use of the Internet. Notwithstanding recent growing

recognition of the Internet as a potent tool in the exercise of patients' endeavours, the processes of communication among patients are as yet little understood. This study has sought to illuminate this crucial area of practice, particularly by exploring the centrality of narrating and storytelling in patients' experience.⁷

At the same time, the scope of this study extends the boundaries of the discussion on health and the Internet. The exploration of breast cancer patients' CMC is, more generally, a study of the social uses individuals make of the Internet to realise their agency. It connects to the broader concern with CMC and its role in people's lives, particularly its potential significance for processes of self-formation and for individuals' elaboration of their self-understanding (not necessarily in situations of crisis such as chronic illness).

Why then the decision to focus on the online experience of breast cancer patients? As I sought to show throughout the thesis, the communicative context of breast cancer online furnishes an extremely fruitful scene for the examination of the broader concern with the relation between individuals' Internet use and processes of agency. The CMC of breast cancer patients constitutes a kind of a 'magnifying glass' that reveals complex connections between participants' online communication and the management of their everyday offline experiences. Such connections exist also in other contexts of online communication, however they often remain unexplored because (among other reasons) their manifestations are more latent or subtle than in the experience of breast cancer patients. The case of breast cancer patients' online experience reveals the online space as a site where individuals' exercise of self-formation is amplified. It illuminates CMC as a key discursive context for the communication of personal experience (particularly given the cultural meanings of breast cancer, which emphasise the significance of patients' communication of the disease). Furthermore, given the highly embodied nature of breast cancer, patients' online communication manifests an apparent tension between the disembodied nature of CMC and the embodied character of the illness. I have thus used the case of the use of the Internet by breast cancer patients to engage with the broader quandary of CMC and disembodiment, and to discuss how participants appropriate this disembodied medium as a way to transform their life circumstances, however limited the transformation may be.

At the same time, although I have used the case of the online communication of breast cancer to understand broader aspects of CMC, I acknowledge that this is yet quite a specific, and to some extent even idiosyncratic, context. It is important to bear in mind that the practices, relations, and processes described in this study, and particularly the act of narrating and storytelling, emerge in a particular setting, namely the online communication of breast cancer. The latter has specific characteristics that shape in, significant ways, the experience of its users, and which consequently inform the inquiry of this context: First, the experience of breast cancer is an integral part of a patient's everyday life, her identity and self-narrative. As such, its communication – whether online or offline – is inextricably interrelated with the offline experience of the illness. Furthermore, the experience of breast cancer is highly embodied, and thus evokes a continuous challenge to the disembodied character of CMC. It might be that in online contexts that are, for instance, more abstract, and whose meanings are less bodily than breast cancer, the offline-online connections are less evident. Still, I would argue, CMC is never an experience that is isolated from social life.

In the light of this recognition, issues discussed in this thesis should be understood as significantly grounded in the specific context of the experience of breast cancer and its communication. First, the phenomenon of self-disclosure and the centrality of narrating are closely embedded within the culture of breast cancer, which emphasises these practices (see Chapter Two). Arguably, these practices would take quite a different shape, volume, and style in other contexts communicated online. (The latter point, reinforces, of course, the inseparability of online and offline, in examining CMC). Second, the exchange-based relations that develop and are maintained online between breast cancer patients, are also significantly set in a specific social and cultural context of breast cancer, a context which allows and perpetuates this kind of relationship. A look at health-related public interactive forums, where patients exchange experiences, reveals the prominence of breast cancer over other health-contexts, including other types of chronic illness.

Another possible argument, which remained implicit throughout the thesis but which might shed light on the specificity of breast cancer online communication, has to do with the feminine bias of this communication. Breast cancer CMC is a communicative context on a women's issue, by women and for women. Some might argue (among

whom are two of my interviewees) that the fact it is such a women-based communication determines its features and dynamics in significant ways; that the centrality of practices and relations of exchange, bonding and self-disclosure has to do to a large extent with the femininity of this communication. For reasons I discussed earlier (Introduction, footnote 2) this aspect was not developed in this study, however it would be highly interesting to account for it in the future. Lastly, although the private/public issue, as discussed in Chapter Seven, has much to suggest beyond the specific context of breast cancer CMC, nevertheless it has a clear idiosyncratic component, which stems from the particular nature of the experience of breast cancer and its social construction. Arguably, more than many other experiences being communicated online, even if those are health-related, breast cancer evokes an inescapable tension between the private and the public, regardless of CMC. As discussed in Chapter Two, breast cancer is a highly intimate experience, whose social construction is imbued with meanings of publicity, publicness and, by extension, 'publishing the self'. So whereas similar tensions probably arise in other CMC contexts, I think that the centrality of these tensions in this study is greatly influenced by the actual content and context of the communication under scrutiny.

Now that I have discussed the scope of the study and its limits, I wish to move on to explore three wider issues that derive from the study but which, however, open up questions and issues that extend beyond the specific concern of this study with narrating i.e. CMC and breast cancer. The first issue explores the claim for CMC as a therapeutic context. The second aspect evaluates, on the basis of this study, the appropriateness of the Habermasian notion of the public sphere to the study of CMC. Lastly, I open up questions about the cultural specificity of online communication.

The therapeutic value of CMC

The exploration of narrating as a process in patients' online experience depicted the online space as a communicative therapeutic space. That is, a space for individuals' self-interrogation of their experience and its configuration into a coherent framework that they can make sense of and plan actions around. Significantly, however, there is nothing *inherent* to the Internet as a reflexive and therapeutic medium. Nor is there a necessary connection between narrating and the online space; patients engage in a variety of other communicative processes, and they can engage in narrating in various

sites outside the online spaces in which they participate. It is the constellation of the specific uses individuals such as breast cancer patients make of it, and the particular social and cultural context in which these uses are embedded, that make the Internet a significant therapeutic space, and that make narrating specifically enabling in this context. The particular social and cultural meanings of the illness, especially the stress on patients' communication of their experience, furnished a vital context for the Internet to develop as a key communicative site for breast cancer patients. Equally, the socio-technical properties of the Internet provided a fruitful context for the proliferation of breast-cancer related online colloquy, and particularly for patients' appropriation of the new medium for the narration of their experience.

The therapeutic, however, is not unique to the online culture. It is a central component of wider contemporary culture: communicative spaces where therapeutic practices and processes of self-understanding and self-interrogation are exercised are increasingly expanding. What is significant specifically about the Internet as a therapeutic space? What are the consequences of the observation that the Internet constitutes a therapeutic space, for a consideration of the role of the Internet in everyday life?

One of the important things Computer Mediated Communication seems to do is to *legitimise* self-reflection and the performance of the self. By enabling individuals to disclose their experience in a joint-action with other peers, therapeutic practices are being externalised and expropriated from delineated professional spaces of therapy (such as the analyst's couch) into the new discursive space of the Internet. In so doing, the therapeutic becomes an accessible popular 'product', rather than something restricted to professional interaction. In this sense, the Internet should be seen as part of a wider contemporary media culture, in which therapy and psychoanalysis are being increasingly popularised. This trend is most associated with audience discussion television programmes such as 'Jerry Springer' or 'Oprah'. Indeed, patients often referred to their Internet use as related to other mediated therapeutic forms, such as reading self-help books, or watching a talk show about breast cancer experience.

At the same time, CMC seems to embody also a different kind of therapeutic practices and relations from those presented by television audience discussion programmes or

self-help books. Particularly salient is the different role and power of *expertise* in the therapeutic space of CMC. Mediated therapeutic forms such as audience discussion television programmes are based on the traditional contrast between 'lay' and 'expert'; they are embedded in a culture that binds us to the power of expertise. (Rose, 1992; Livingstone and Lunt, 1994). CMC, as I have shown in the case of breast cancer patients, seems to offer a far more hybrid space, where the boundaries between expert and lay are essentially blurred. This hybrid character of CMC offers a kind of release from the dependence on expertise. First, breast cancer online communicative spaces are designated in a way that excludes experts and intends to include only patients. Second, even if a kind of hierarchy is created among patients, by which some patients take on the role of experts who mentor newcomers, the formers' expertise is contained; they are still, at the end of the day, lay persons. In all the interviews I conducted it was clear, that notwithstanding patients' appreciation of the significance of their online interactions with fellow-suffers, they regard this communication in very different terms from their communication with their doctors. While there is a clear sense of *dependence* on the medical experts in their lives, patients seem to be released of this reliance on expertise in their online communication. Users may appropriate the new opportunities for communication offered by CMC, however when it comes to their views of expertise, and their trust in experts, they seem to maintain conventional norms. Notwithstanding the hybrid lay/expert character of CMC, for most of the users I interviewed, *expertise* remains the territory of medical professionals, and is usually associated with offline times and spaces of their medical encounters. Online, on the other hand, is primarily the terrain of 'the people genre' (as one of my interviewees called it), that is, a space oriented for the communication of personal *experience*. Narrating, as I argued in this thesis, is one of the processes through which personal experience is communicated. The therapeutic is thus promoted and mediated mainly through experiential communication between laypersons, rather than through expert-lay relations. This observation limits, I suggest, the moral panic about the danger of patients being misled by information they get from other laypersons online. It also challenges research such as Stone's infamous study of the *Cross-dressing Psychiatrist* (1995) which stresses the seductiveness of disembodiment and anonymity, and the way users can be deceived by it. This study argues that online participants are not 'dopes' who follow whatever they read online,

enchanted by the new opportunities of disembodiment and anonymity; nor do they subscribe that easily and quickly to new forms of knowledge and relationship.

CMC and the model of public sphere

The idea that the online space is not as strongly bound to the power of expertise as other mediated therapeutic spaces, goes hand in hand with Habermas' conception of the 'ideal communication community' which aims at the dissolution of asymmetrical structures of power, authority and expertise (Gardiner, 2000: 217). Indeed, as I have shown, there is a strong egalitarian dimension in patients' CMC, which resembles in some ways the idea of 'public sphere'. In particular, patients' CMC forms an open public discussion, where private persons communicate their intimate lives in a disembodied and un-authoritative fashion. In the narratives they construct and publish online, patients sometime exercise critical or rational language, as indeed some of my interviewees did, regarding matters such as the treatment they receive or the medical doctrines they are exposed to. At the same time, patients' online communication suggests a significantly different model of public participation from the Habermasian bourgeois public sphere. Fundamentally, the basis for patients' engagement in the online public sphere is predominantly reflexive and expressive rather than critical and rational. It is a therapeutic public sphere, based on an experiential and affective rather than argumentative dialogue, which transforms fundamental styles of discourse and social relations. This is perhaps what partly makes narrating a useful and appealing mode of discourse for patients: it allows experiential and affective expression, transcending medical discourses that patients engage with in other sites of their lives, but also transforming affective styles of discourse in which they engage in other spaces in their lives, for instance, by generating disembodied communal storytelling. In short, the character of participation and discourse online is far more varied than that suggested by the public sphere.

This observation has another crucial aspect. The bourgeois public sphere consists of private persons whose identity is formed in the privacy of their conjugal domestic family, and who enter into rational-critical debate on issues common to all by bracketing their embodiment and status (Warner, 2002: 57). On the other hand, the online counterpublic of patients, as I suggested in Chapter Seven, is a scene of association that transforms the private lives it mediates. This online counterpublic

necessarily entails realms of subjectivity which are open to affective and expressive dimensions of discourse (based on Warner, 2002). Rather than acting out a clear-cut separation between 'private' and 'public', users continuously negotiate between the two.

On the other hand, the separation between 'private' and 'public' which is maintained by the bourgeois model of the public sphere, has had a strong imprint on the ways CMC has been studied, both in an ontological sense (i.e. the claims made about the essence of CMC), but also regarding methodological and ethical consideration of CMC. The ontological claim (voiced by scholars such as Amy Bruckman) has been that online space is private and discursive, separate from clear 'public' spaces. Participants, so the argument goes, perceive what they do and post online as private and restricted to a specific audience. Therefore, the ethical implication is that researchers should not use any online personal material without participants' consent.

In light of the study of breast cancer patients' CMC, the separation between the public and the private appears unsustainable, neither on ontological nor on ethical grounds. Patients who participated in online discussion of an extremely intimate and private experience (chronic illness) often had a very ambivalent perception of the extent to which their online communication is indeed 'private'. We cannot necessarily simply assume that 'online=private'. Ethically, therefore, while we need to make every effort to maintain participants' confidentiality and anonymity, rigid guidelines that do not allow any use of individuals' online communication without participants' consent, appear unreasonably restrictive of research and are thus unhelpful.

So thinking about online communication in terms of a communicative context that has therapeutic potential suggests a different concept of communicative sphere. It is not the Habermasian kind of public sphere, nor is it a 'community', a concept so often used to describe CMC. In fact, I deliberately avoided using the word 'community' throughout the thesis, with all its attendant baggage, and its inevitable trap of the 'real' versus 'virtual' community debate. The alternative model suggests that CMC is a practice-based communicative context: breast cancer patients' CMC constitutes a social context that is centred on therapeutic situations, narrating being one of them. The boundaries of this social context, the nature of participation in it, its discourse,

and the way it evolves and is maintained, are determined by the *practice* and its *effect*, rather than by given definitions of the kind of discourse that should be exercised (e.g. critical-rational) or by structural definitions of what constitutes 'community'. Recent works such as Miller and Slater's (2000) or Bakardjieva's (2003) have taken research in a direction that this study attempted to follow while developing its specific implications and emphases for the study of CMC.

The cultural specificity of CMC

Throughout the thesis I have argued that patients' online narrating constitutes a significant action in the constitution of their agency, and as a consequence, it has a therapeutic effect. I now wish to introduce another dimension to this argument: online narrating is a social action that takes place *within a specific cultural context*, and it is within that context that it has a therapeutic effect. The claim for the cultural specificity of CMC re-qualifies the argument made so far: the therapeutic effect does not occur in a vacuum but is culturally bound. In the remainder of the chapter my concern is to substantiate my claim for the cultural specificity of breast cancer patients' CMC, by throwing light on the cultural structures that underlie this communication. These structures, I suggest, provide specific forms of language, clichés, motifs, references and other symbolic repertoires that allow and constrain what is said (and what is not), and how it is expressed.

In so doing, I am, in fact, revisiting my own presupposition about the global character of breast cancer patients' CMC. When I started the investigation of the online communication of breast cancer patients, I thought about the Internet in terms of a universal, non-specific communicative space that is undifferentiated by cultural or national boundaries. Clearly, I was influenced by the view promoted in academia and beyond, of the Internet as a global space. The discussion of health-related CMC seemed to particularly enhance this view, regarding users' experience as essentially boundless in terms of its cultural context (e.g. Hardey, 2002). At face value, the online communication of breast cancer seemed to constitute a 'global' site: a universal disease being communicated between patients across the globe, beyond geographical, cultural or national boundaries. Indeed, if one types in 'breast cancer' as key words, the leading search engines return hundreds of online resources. The majority of these resources have top-level global domain names (.com., org and .net). The concept of *narrating* as a central communicative mode endorsed the idea of the global nature of this CMC. Narrating itself is

a universal communicative process, which arguably enables patients to develop communication that occurs beyond cultural borders. Furthermore, participants themselves seemed to subscribe to this 'global' view. In their interviews, patients often stressed the global and 'placeless' character of their communication. They particularly stressed how by posting their message online they reached out to patients who are remote from their locale (geographically and/or culturally). Reaching readers on a 'global scale' was often seen by the poster as a sign that her message has 'global' value, beyond her personal realm.

However, the empirical experience of this study, and the consequent data it generated, challenges the idea of patients' CMC as 'global and borderless' very early on. While I posted the message to invite women to participate in my study on what were arguably 'global' websites (particularly avoiding national websites such as that of the American Cancer Society), the majority of respondents were from the United States. Recruiting non-American respondents proved very difficult.⁸ I realised that this methodological issue is in itself a significant finding: the American bias of my sample is not accidental. It alludes to the idea that this communication of breast cancer patients online occurs within a certain cultural setting (however invisible the latter might be). It invites a deeper interrogation of what Halavais (2000: 24) has usefully described as the cultural borders of the Internet:

We must recognize that 'social borders have their own cartographies' and go about mapping these structures (citing Harvey, 1996).

I suggest that the evaluation of online narrating as a therapeutic process can be adequately done only when considering the cultural 'cartographies' that underlie breast cancer patients' CMC. Certainly, a thorough mapping of those structures is desirable in the future. At this stage and within the space available here, I wish to discuss possible preliminary directions for exploring those 'cartographies'.

We cannot imagine America without its self-help groups. And, we cannot imagine an America that is not in love with technology. Cyberspace and the recovery movement were meant for each other (Denzin, 1999: 113).

Following Denzin's observation, which usefully identifies the link between self-help movements, CMC and US culture, the proposition I am making is that the online communication of breast cancer patients takes place within cultural settings that have significant North American resonance. In particular, the process of meaning production through narrating relies on the tacit knowledge of the audience to be able to infer that meaning. It relies upon a shared *cultural inheritance*, which is significantly American. By no means do I imply that 'US culture' is a homogenous monolithic entity. I do, however, suggest that there are certain values, symbols, discourses and beliefs that are characteristic of what a person in the US is socialised by and acculturated to, that underpin the communicative context of breast cancer online. In identifying these 'structures', which I relate to US culture, I especially draw on the account of my non-US interviewee, who reflected on much of what she encountered online as 'American' (and as such, as something she found difficult to relate to). Her reflections seem to coincide quite neatly with other observations about the kind of beliefs and values US culture consists of, and I incorporate them into my account.

It is a difficult task: it is impossible to 'prove' or 'disprove' the claim that the communication under scrutiny is 'American'. Even if it were possible, it is not my intention. My aim is to throw light on the cultural component and the role it plays in shaping the online context we examine. I wish to highlight the potential connection between the proliferation of patients' personal narratives of survivorship online and the overwhelmingly American context, within which these stories are constructed and told.

I have already mentioned the fact that it was mainly American women who replied to my message online, and consequently participated in the study. Beyond the reasonably possible explanation that more American breast cancer patients are connected than other patients in the world, I suggest that the willingness to disclose one's personal experience has to do with the American context 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 link I suggested in this thesis between narrating and the therapeutic is not culturally naked. Rather, this link gains meaning

only within a very specific cultural framework that is underpinned by the idea that it is possible to understand anything and explain it, especially through narrative (Becker, 1994). This framework, I propose, has a significant American imprint.

Responding to my online message (and by the same token, exchanging messages with fellow-sufferers) is a way to assert oneself as a survivor. Tellingly, one of my interviewees started her e-mail, saying:

I am still alive and well in Northern California. (Online narrative 15).

Not responding, or not communicating online, is often considered as 'losing the battle' against cancer:

The ones who stick around 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 narrative 15).

This view of the 'fighter' who communicates and 'sticks around' online, is closely underpinned by 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 stage of the world (Polanyi, 1985). This cultural myth is one way in which the online and the offline interweave in users' experience: giving up online is an admittance of giving up offline and vice versa.

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 (Frank, 1995: 63).

Indeed, a reluctance to admit failure and loss seems to be continuously endorsed and perpetuated in the CMC of breast cancer patients. Key motifs of patients' online discussion are the notable absence of death and the ways in which expressions of despair and hopelessness are being excluded or contained in the postings. The titles of the messages 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. The online colloquy of breast cancer is about enablement and hope, as Sharf (1997) bears out; participants make the online discussion about *living* with the illness, rather than *dying* from it (ibid.).

While the motifs of self-responsibility, triumphalism and cheerfulness are emblematic of the wider culture of breast cancer (as discussed in Chapter Two), there is still a significant US historical context to the discourse of breast cancer. It is interesting to note that the only interviewee who was critical of this kind of cheerful discourse was my non-American interviewee. The promotion of reconstructive surgery of the breast in online forums, seems to her part of the message that 'one can help oneself', a message which has significant American context:

...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, it just seemed to be really normative, and I was surprised by that. I suppose it might depend on women's ages, but **I think it is also a cultural thing.** I was really surprised by that, I was surprised how pervasive it is. (K, interview 11, my emphases).

On a more general note, it seems to me that the online space constitutes a stage for the performance of survivorhood. This performance is produced by a narrator, and accepted by its audience according to specific 'hidden rules', as my non-American interviewee put it. Whether the participants (both narrator and audience) are Americans or not, the actual communication in which they are engaged has American underpinnings. They therefore have to work within this setting, which determines what is said and what is not:

There were certain things that went on; people made supportive comments to each other and you're allowed to raise questions...[...] 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!

(K, interview 11)

This observation suggests that the participant should not only be competent in the use of CMC in the technical sense, but should also have social and cultural competency, that is, knowledge of the discursive frameworks and the 'hidden rules' of the communicative context. The non-American breast cancer patient whom I interviewed (K, interview 11) is perhaps the most *computer* literate of all my interviewees. However, she was not sufficiently *culturally* competent to participate actively in any of the online discussions. A more complex concept of media literacy is thus desirable, one that involves 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 Internet literacy.

The point about the cultural specificity of breast cancer patients' CMC also urges an expansion of the research agenda in relation to processes of exclusion and inclusion in CMC. To date, the only literature that has probably engaged with this issue from a cultural perspective is the debate around the digital divide. It questioned the extent to which the online space is indeed inclusive and egalitarian, focusing on the disparities between the 'haves' and 'have nots'. It accounted for the socio-demographic (and chiefly economic) reasons underlying dynamics of inclusion and exclusion in online communication. This study calls for the need to include also a critical consideration of the cultural specificity that frames online communicative contexts, and works to exclude and to include certain meanings.

We must also recognise that the methodology we employ in our research has social and cultural borders. It would be naïve to think that doing Internet research means doing global research. In this 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 experience, is largely due to their US cultural context. A valid question remains: Would I have been able to pursue the same methodology in a different culture with the same degree of success? The answer is 'no', at least not in the UK, if the words of my only British interviewee are anything to go by. 'You would have never found *me* online' she told me.

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

The recognition of the cultural specificity of breast cancer online communication does not disqualify the study's contribution to, and implications for, the wider conceptualisation of CMC. As I tried to argue in this chapter, and hoped to have convincingly shown throughout the thesis, despite its American orientation and its other distinctive aspects, the case of the online communication of breast cancer raises several key issues and broader questions that invite further research.

¹ Bauman cites Alfred Weber.

² For a discussion of a related point, see Slater (2002: 541).

³ There are various examples in 'cyber literature' but also in recent ethnographies that demonstrate how people construct fictive identities online, which they distinguish from their offline identity and sense of agency (e.g. Stone, 1995; Turkle, 1996; Miller and Slater, 2000). I thank Don Slater for this important observation.

⁴ I thank Don Slater for this useful insight.

⁵ See chapters One and Three

⁶ In making this observation I draw loosely on Gare's discussion of the connection between narrative and agency (2002: 97).

⁷ I intend to develop the implications of this study for the debate on Internet and health in a separate article or paper.

⁸ I later tried to recruit women from the UK by posting messages on specific UK websites. Remarkably, however, I hardly received any replies whereas messages I posted on '.com' or '.org' sites had generated several.

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Breast Cancer Action Nova Scotia. www.bcans.org

Breast Cancer Group. www.breastcancergroup.org

Breast Cancer.org: A Nonprofit Organization for Breast Cancer Education.

www.breastcancer.org

Delaware Breast Cancer Coalition www.youngsurvivors.org

Internet Breast Cancer Support Group hosted on Yahoo Clubs. www.breastguide.com

National Cancer Institute. http://cis.nci.nih.gov/fact/5_6.htm

OncoChat: Online Peer Support for Cancer Survivors, Families, and friends

www.oncochat.org

Shared Experience Cancer Support. www.sharedexperience.org

Susan Love MD.org: The Website for Women. www.susanlovemd.com

The Breast Cancer Site. www.thebreastcancersite.com

Appendix 1

A Selective List of Breast Cancer Related Online Sources¹


| Website / Forum | URL address |
|--|--|
| Cancer organisations | |
| American Cancer Society | www.cancer.org |
| Breast Cancer Society of Canada | www.bcsc.ca |
| Breast Cancer Answers – University of Wisconsin Cancer Center | www.medsch.wisc.edu/bca |
| National Alliance of Breast Cancer Organisations | www.nabco.org |
| OncoLink : University of Pennsylvania Cancer Center | http://oncolink.upenn.edu/disease/breast |
| Online health information suppliers | |
| WedMD | www.webmd.com (search for 'breast cancer') |
| Medscape | www.medscape.com (search for 'breast cancer') |
| Breast cancer patients and survivors' forums | |
| Breast cancer Action Nova Scotia | www.bcans.org |
| 'Friends In Need' Forum for Breast Cancer Patients | www.friendsinneed.com |
| Breast Cancer Support Group hosted on Yahoo! Clubs | www.breastguide.com |
| Susan Love's website/ Community | www.susanlovedmd.org/community_frames.html |
| The Susan G. Komen Breast Cancer Foundation / 'Talk Back' | www.komen.org/talk |
| American Cancer Society's Cancer Survivors Network | www.acscsn.org/CSN_Home_Page |
| Breast Cancer Wall of Courage | http://www.dramy.net/wall |
| Between Us - breast cancer survivors | www.betweenus.org |
| www.youngsurvival.org | www.youngsurvival.org |
| New Brunswick Breast Cancer Network | www.brunnet.net/cancer |
| Breast Cancer Survivor Network | http://bcsn.org |
| Fundraising and advocacy groups | |
| Sew for the cure | www.sewforthecure.org |
| Avon Breast Cancer | www.breastcancer3day.org |
| Race for the cure@ | www.raceforthecure.com |
| Breast Cancer Legislation USA | http://members.aol.com/BCLEGIS/index.htm |

¹ All online sources were last accessed at 29 October 2003.


Appendix 2

Examples of Breast Cancer Online Interactive Forums

A. Breast Cancer Action Nova Scotia's Discussion Forum (<http://forum.bcans.net>)*


Address  <http://forum.bcans.net/index.cgi?>

Links

- **NEW** [TIRED OF WAITING AND NO TIME TO SPARE](#)
7 messages (7 new)
- **NEW** [Very Encouraging News - Breast Cancer Vaccine](#) 
14 messages (0 new)
- [OVARIAN CYSTS](#)
1 message
- **NEW** [thanks! felt all of you with me](#)
14 messages (4 new)
- **NEW** [Dr. Day](#)
7 messages (4 new)
- [SandyL - Favor please](#)
2 messages
- **NEW** [update on sister](#)
4 messages (1 new)

* The names, dates and times of the postings have been omitted.

B. 'Friends In Need' Forum for Breast Cancer Patients (www.friendsinneed.com)


Address  <http://www.friendsinneed.com/>  

Links

Pink Ribbon Sock
A beautiful cotton sock with subtle "pink ribbon" woven on ankles

Breast Cancer Pins
Unique gifts for breast cancer patients and cancer survivors.

Ads by Google



Friends in Need

(A Support and Chat Forum for Breast Cancer)



Have you had your Mammogram?

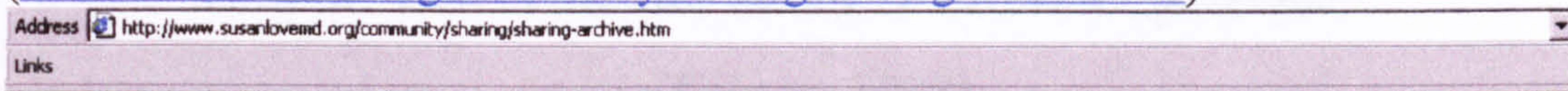
[Friends in Need Mall.....Click Here!](#)

[Breast Cancer Chat Rooms](#)

~ Newsflash ~

[Indy Face to Face 2002 - Breast Cancer Meeting](#)

C. Susan Love's Website, 'Sharing My Story' Forum
 (www.susanlovemd.org/community/sharing/sharing-archive.htm)*



SusanLoveMD.org
 The Website for Women

search this site:

| | | | | | |
|------------------------|---------------------------------|-----------------------------|-----------------------------|---------------------------|-----------------------------------|
| home | decision making | living with | take charge | community | personal guidance |
| events | links | marketplace | about us | search | site map |

Sharing My Story

Past Stories

When I received the news that I had breast cancer it felt like I had received a death sentence, and I felt as though I was going to fall apart. Then, in moments, I decided NO the cancer is not going to control me, I am going to control the cancer.

[click here...](#)

I'm a 32-year-old woman with no family history of breast cancer. I actually have a family history that is remarkably cancer-free.

[click here...](#)

We never think we will hear the words, "I am 95% certain you have breast cancer."

[click here...](#)

At 45 life was grand. My husband and I had adopted a little girl from Ukraine and we couldn't have been happier. Alexandra (Aii) was one when we brought her home from a dreary orphanage in Ukraine. When she was about to turn three, I was diagnosed with breast cancer.

[click here...](#)

* The names, dates and times of the postings have been omitted.

D. Online Diary of a Breast Cancer Patient



Good Morning. Welcome to my site!

Wake-Up Call:

My journey with breast cancer and what I am learning from the experience.

As early as the age of 12, I had discovered a tumour in my right breast. A biopsy confirmed the tumour was benign. I heaved a sigh of relief.

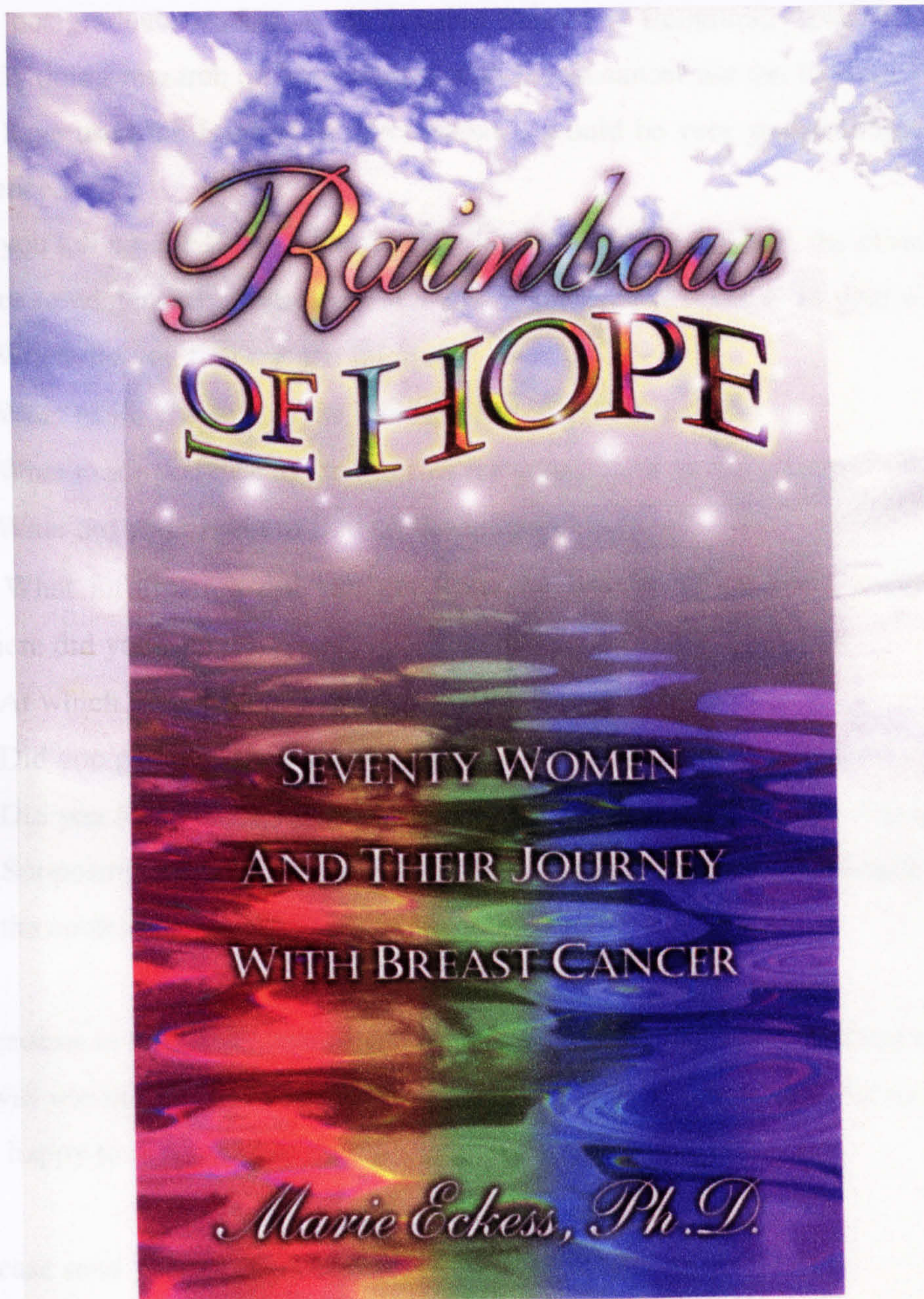
Twenty years later, I again detected a tumour in my right breast. This time round, I was psychologically prepared and told myself that I could have contracted breast cancer. However, the medical report still said the tumour was benign. Two years later, the same thing happened; but this time, the tumour was in my left breast.

It was in October 1996 that I found a tumour in my right breast for the fourth time. A Mammogram did not show anything wrong. But after removal of the tumour, it determined it to be malignant, a 1.8cm. Infiltrating carcinoma (Bloom- Richardson Grade 2 /3) with negative estrogen receptor status. The tumour was small, so the cosmetic result of a lumpectomy would be good. To my understanding, cutting more does nothing to improve survival chances. So I had a lumpectomy with lymph node dissection, which showed no lymph node involved. I underwent 6 cycles of chemotherapy (Cytosan, Methotrexate and 5-fluorouracil-CMF) and 3 weeks of radiation therapy. During my treatment, I like eating spicy and flavorful foods. I enjoy and crave for foods. I have a well-balanced

Appendix 3

The Cover of the Book '*Rainbow of Hope*'

(Eckess, 1998)



Appendix 4

The recruitment message that was posted online

Hello all

I am a postgraduate student at the London School of Economics and Political Sciences, currently doing research on how women with breast cancer use the Internet as a resource.

If you have used the Internet in this context, I would be very grateful to hear about your experience.

Could you tell me the story of the relationship between the Internet, the disease and you.

Here are some general questions which you might want to relate to in your writing:

1. When did you first use the Internet?
2. What made you turn to the Internet in the first place?
3. What made you turn to the Internet for your health problem?
4. What did you expect to find on the Internet?
5. What information did you get from the Internet about your health problem and where did you find it?
6. At which points / stages did you use the Internet and for how long?
7. Did you get any information from the web that you did not get from your doctor?
8. Did you feel that the information that you got from the web was trustworthy?
9. Supposing there was no Internet, what are the things that you would miss the most in the context of your medical problem?

Needless to say, the information received will be treated in the strictest confidentiality. I will use the information merely for my research. If you would like to see it, I would be happy to send you the report once it is completed.

Please send your story to the following e-mail:

Many thanks for your collaboration.

Yours sincerely

Shani Orgad

London School of Economics and Political Science

Appendix 5

Socio-demographic table of participants*

| Face-to-face interview | | Online narrative | Age | Place of residence | Socio-economic group | Education | Marital status | Children |
|------------------------|-----------|------------------|------|-----------------------------|--------------------------------|------------------------------------|-----------------------|-------------|
| Name | interview | | | | A= high B= middle C= low | | | |
| A | 1 | 1 | 32 | suburb, NY, US | A-B | high school | married | none |
| B | 2 | 2 | 52 | suburb, NY, US | B | BA | married | 3 |
| C | 3 | - | 76 | suburb, NY, US | B | high school | married | 2 |
| D | 4 | 4 | 50 | suburb, NY, US | A-B | MS | married | 1 |
| E (man) | 5 | 5 | 50s | city, NY, US | B | BA | married | none |
| F | 6 | - | 58 | rural area, Connecticut, US | A-B | high school and secretarial school | married (second time) | 2 |
| G** | 7 | - | 43 | small town, NY, US | B | MS | married | 2 |
| H | 8 | - | 65 | suburb, New Jersey, US | A-B | BA | married | 2 (adopted) |
| I | 9 | - | 69 | suburb, New Jersey, US | A-B | BA | married | 2 |
| J | 10 | - | 44 | town, New Jersey, US | B | BA | married | 2 |
| K | 11 | - | 49 | city, UK | B | PhD in progress | married | 3 |
| L | 12 | - | 53 | town, Israel | A-B | high school | widow | 2 |
| (Letter narrative) | | 3 | 40 | city, Israel | B | BA | married | 2 |
| - | | 6 | 56 | city, Texas, US | B | BA, MS in progress | divorced | 5 |
| - | | 7 | 43 | town, NY, US | B | high school | married | none |
| - | | 8*** | 39 | town, NY, US | A-B | BA | married | 2 |
| - | | 9 | **** | city, UK | B | **** | **** | **** |
| - | | 10 | 58 | town, Michigan, US | B | high school and religion studies | married | 2 |
| - | | 11 | **** | town, NY, US | **** | **** | married | 1 |
| - | | 12 | **** | city, Minnesota, US | B | BA | **** | **** |
| - | | 13 | 40s | city, Texas, US | B | 1 year of college | married | none |
| - | | 14 | 52 | city, Nevada, US | A | BA | divorced | 1 |

| Face-to-face interview | Online narrative | Age | Place of residence | Socio-economic status | Education | Marital status | Children |
|------------------------|------------------|------|---------------------------|-----------------------|-------------|----------------|--------------------------------|
| - | 15 | 49 | city, California, US | **** | **** | married | 5 |
| - | 16 | **** | city, Washington, US | B | **** | **** | **** |
| - | 17 | 42 | city, Greece | B | university | married | none |
| - | 18 | 48 | city, Florida, US | B | high school | married | 2 |
| - | 19 | 40s | town, Pennsylvania, US | B | high school | married | 2 |
| - | 20 | 50s | city, Missouri, US | B | **** | married | 5 |
| - | 21 | **** | town, North Dakota, US | **** | **** | married | **** |
| - | 22 | **** | rural area, Oregon, US | **** | **** | married | none |
| - | 23 | **** | small town, Georgia, US | **** | **** | married | number of children unspecified |
| - | 24 | 50s | town, Virginia, US | B | university | married twice | 2 |
| - | 25 | 50s | rural area, Michigan, US | B | high school | married | 3 |
| - | 26 | 48 | small town, Louisiana, US | B | high school | married | 2 |
| - | 27 | 40s | city, Florida, US | B | **** | **** | **** |
| - | 28 | 42 | small city, Arkansas, US | B | **** | **** | **** |
| - | 29 | 42 | city, NY, US | B | **** | married | number of children unspecified |

- * The details were correct at the time when the participants took part in the study (face-to-face interviews: time of interview; online narratives: time of writing the account).
- ** Telephone interview
- *** The patient in narrative 8 was supposed to meet me for a face-to-face interview, however the interview was cancelled at the last moment following deterioration in her health.
- **** Data missing.

Appendix 6

Interview Topic Guide (face-to-face interviews)

1. Introduction to the interview:

- ❖ Informal introduction, thanking for agreeing to meet me;
- ❖ Stating my interest: the purpose of the research, the goal of the interview and the significance of her account;
- ❖ Explaining the way the interview will be conducted, emphasising it is intended to be an open conversation.

I want to ask you to tell me about your experience of using the Internet in relation to your health condition. Your experience is highly valuable and will contribute to a research on the ways women with breast cancer use the Internet. It is part of a doctoral research I am doing at the London School of Economics and Political Science in the programme of Media and Communications .

During the interview, I will ask a few general questions, but most of the time I will be silent and listen to you. Please take your time and also give details, because for me everything is of interest that is important for you.

- ❖ Explaining technical aspects (taping, taking notes while she speaks, estimated length of interview);
- ❖ Stressing that the interview is confidential.

2. Interview questions:

1. *When did you start using the Internet? On which occasion? / For what purposes?*
2. *What made you turn to the Internet for your health condition? What did you expect to find when you first started using the Internet in relation to breast cancer / the diagnosis?*
3. *What were the main things you use/d to do when you went online? Are there particular websites you used to visit?*
Could you recall the websites you visited, what kinds of communication you prefer? (message boards? chats? discussion groups? just downloading information? etc.).

How did you become proficient in communicating on the Internet?

4. *Can you recall at which points did you use the Internet and for how long? (Before/after the diagnosis? Between meetings with the doctor? Before/after mastectomy?) When did you typically used to go online and why? (daytime/evening/night etc.)*
5. *Is there anything special in communicating in the Internet?*
6. *Did you exchange your experiences with other fellow-sufferers? (or: in the story you wrote you told me you used / still use to exchange e-mails with other fellow-sufferers). Please tell me more about these e-mails. How did it begin? How did it emerge? What are the main issues you talk about? Did your correspondence continue on a regular basis? How often? When? Were there particular periods you used to write? Have you communicated via other media as well? Did you meet?*
7. *What have you found that you can talk about on screen which you cannot do off screen?*
8. *Could you tell me more about your experience of writing your personal experience on the website and reading others' stories? Did you write about your experience elsewhere other than this website (on other websites or in other media / forms)? Can you recall when did you write it?
How did it feel like? Were you excited?
(Was it a 'spontaneous' decision to submit your story to that website or did you hesitate before doing that? Why did you feel like telling your story? Did you get any responses / replies after publishing your story on that website? From whom? Did you contact the people who responded to your story? How often did you use to check that message board to read others' stories? How do you use to read it – are you going through the full list of stories or do you do a specific search to get only particular stories you're interested in?)*
9. *How was the information you got on the Internet used in your interaction with your doctor? Did you get any information from the web that you did not get from your doctor? Did you feel that the information that you got from the Internet was trustworthy?*

10. *Did you have experiences which were not necessarily positive in using the Internet?*

Any kind of problems (technical, making communication, expressing yourself, others?)

11. *In what ways do you feel the Internet has changed your life? your relationships (family, friends). Do you feel that using the Internet was / is in place of other things you used to do before?*

12. *Supposing there was no Internet, what are the things that you would miss the most in the context of your illness?*

3. End of interview:

Clarifications and elaborations:

- ❖ Is there a particular reason why you haven't talked about....
- ❖ Is there anything else you would like to add?

Appendix 7

Follow-up E-mail – Request for a Face-to-Face Interview

I hope this message finds you well.

Last year you kindly sent me your story about your experience of breast cancer and the use you made of the Internet in relation to your health condition. I remember you thought your story would not be of much help to me, however your input was extremely valuable and contributed a great deal to my research on the role of the Internet in helping people to cope with cancer.

This research has been further developed as part of my doctoral study on the communication on the Internet of women with breast cancer. The experience of people like yourself, who use the Internet to obtain and disseminate information about their health is invaluable. It is only by attending to what people actually have to say about their health and the ways they use the Internet that this research could have real impact.

It will particularly influence health care policy and patients' communication through the web. Patients nowadays develop innovative ways to empower themselves, exploiting the potential offered by the Internet for accumulating health care information and delivering emotional support. There is wide interest among health organisations and patients in developing this area.

I have currently completed the first year of my PhD research at the London School of Economics and Political Science and I am now about to start my actual empirical work which involves, among others, carrying out face-to-face interviews with women like yourself.

In September 2001 I am coming to the US specifically to meet women who are willing to be interviewed. Would you agree to meet to tell me more about your use of the Internet and breast cancer? I would use the interview to follow up the story you've already told me by e-mail in greater depth. Needless to say, I will suit myself to your convenience in terms of time, place etc.

Your input would be of great value to this research, and I would be extremely grateful if you agreed to take part in this significant project. Please let me know soonest whether, in principle, you agree to the interview. We could then set up the meeting at a mutually convenient time and place.

Many thanks in advance, and my best wishes,

Shani

