"ME ON-LINE": NARRATIVE IDENTITIES OF PEOPLE WITH ARTHRITIS

by

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ABSTRACT

Telling stories is a common response to illness, helping people come to terms with the experience. Increasingly, people are telling illness stories online. Existing literature focuses primarily on content analysis of stories, missing an opportunity to explore Internet storytelling in the context of lives.

In this thesis, membership categorization analysis is used to explore *how people with arthritis talk about telling their story online*. People describe using the Internet in various ways and for a variety of reasons, offering a different view from studies of bounded venues such as online support groups, where it is assumed people are there for similar purposes.

Despite differences, emerging in all interviews was the idea of illness as a 'project' and the importance of storytelling to that project. The Internet is seen as a unique tool to facilitate such storytelling, offering unprecedented opportunities to connect with like-minded people worldwide.

ACKNOWLEDGEMENTS

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CHAPTER 1: INTRODUCTION

As a freelance health writer, I have listened to many stories about illness. During the interviews I conduct prior to writing, I am often struck by how important it seems for people to talk with others about their experiences with disease. Stories not only illuminate lives, they connect people, engage them in making sense of seemingly senseless events. It is clear, as Frank (1991) says, that "becoming ill is a call for stories" (p. 95).

Increasingly, illness stories – or illness narratives, as they are known in the literature – are being told on-line, as people turn to discussion groups, support groups, personal websites and weblogs or 'blogs' (on-line diaries) to write about their health concerns.

On-line illness narratives have received little attention in the research literature. This is surprising because many people are using the Internet for various health-related reasons (Rice & Katz, 2001), and there is a large multi-disciplinary literature exploring how people, when they become ill, become story-tellers (O. Sacks, 1992). Some empirical studies explore aspects of on-line storytelling about health, but many of these studies focus on content analysis of posted messages or website material. While such studies do shed light on on-line activities, what is missing, and noted as an important gap by many of the authors of these studies, is an exploration of Internet use in the context of people's everyday lives.

Such is the focus of this thesis, which explores the question: *How do people with arthritis talk about telling their story on-line*? The focus on how people *talk* about it, instead of, for instance, what people *do* or how they *do* it, allowed me to look beyond descriptions of activities and explore the way in which people account for those activities in the context of their lives.

I had several reasons for focusing on arthritis. First of all, I had written about the disease – or more appropriately, collection of diseases – for many years and was interested in the way people managed its ups and downs. Secondly, while research about Internet use and other diseases – most notably cancer – seems to be establishing a foothold, I found only one article about how people with arthritis use the Internet, and it was focused on access to information rather than storytelling. Thirdly, modern medicine is keeping us alive longer, therefore more and more of us will be living with chronic illnesses such as arthritis (Bury, 1991) that biomedicine can not only not *cure*, but often cannot even treat adequately (Delvecchio Good, Brodwin, Good, & Kleinman, 1994). Lastly, when I interviewed people with arthritis for my articles, many of them told me that society is not interested in stories about arthritis. When pressed, people said something like: "Well, it's not cancer," as if that was all the explanation needed: cancer is life threatening, and therefore dramatic and moving; arthritis is just part of getting old, and therefore dull and boring.

Motivated by these reasons and guided by a literature review that helped position my study, I interviewed 19 people with arthritis about how they use the Internet to tell their story. A form of membership categorization analysis (Baker,

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1997), based on ethnomethodology, guided my analysis. This approach treats talk as social action in which both interviewer and respondent draw on shared cultural knowledge to generate categories of people or things. These categories are examined for the ways in which they generate a particular 'version of the world' in which respondents' identities, activities and accounts make sense.

The versions of worlds created in the 19 interviews reported here were as varied as the participants themselves, who represented a number of types of arthritis and differences in the severity of their disease. Interview participants also varied demographically and socio-economically, and there were differences in the extent to which they used – and the reasons for which they used – the Internet. Despite the differences, however, what emerged in all the interviews was the idea of illness as a kind of 'project of the self,' and the importance of storytelling to that project. The Internet is undoubtedly a unique tool to facilitate such storytelling, offering unprecedented opportunities to connect with a huge audience of like-minded and sympathetic people around the world. However, based on the analysis of the interviews, a question is raised about the Internet's role in the experience of illness, and its potential to heighten the pressure on individuals to account for themselves as socially fit individuals in a society increasingly preoccupied with idealistic notions of health. What became clear in the analysis was the centrality of the concept of what Giddens (1991) calls late modernity, which I discuss further in Chapter 5. Late modernity is described as a time of rapid and incessant social change associated with, among other things, globalization, the spread of information via new technologies, a loss of certainty

and traditions, a decline in the legitimacy of systems of authority with a concomitant rise in the reliance on abstract systems of expertise (for example related to technologies which would be impossible to understand without special training), and the emergence of new social movements. Such social changes form the basis of debates about the nature of the self, and have led to theories about how people in late modern societies are constantly 'rewriting the story of the self' in light of new information. This idea becomes particularly relevant in the context of illness, when people strive to regain a sense of a self that may have been disrupted (Bury, 1991). It is within this late modern context – characterized by the paradox of increasing disillusionment with and increasing dependence on medicine, and by the existence of medical practices which seem to deny the fragility and mortality of the human body (Lupton, 2003) – that I explore how people with arthritis use the Internet to help tell the story of the self.

I conclude this introduction by presenting an outline of the thesis and discussing the purpose of my study. Arthritis is defined, and an overview of illness narratives is presented.

1.1 Outline of the thesis

Chapter 2 presents a review of the illness narrative literature, the computer-mediated communication literature, and the e-health literature that is relevant to the study of on-line storytelling, as well as a section about how the review helped me position my study. Chapter 3 presents the design of my study, including the theoretical and analytical approaches that have guided the design. I also provide an overview in that chapter of participant recruitment and of the

participants themselves. Chapter 4 presents an analysis of my data in two parts: part one provides an overview of all 19 interviews; part two provides a more detailed analysis of five interviews. In Chapter 5 the analysis is discussed. It includes sections about the idea of the self as a project, illness as a project, and the Internet as facilitator, as well as a section about theories I expected to see play out in my study, but did not. Chapter 6 concludes with general observations as well as a section about limitations and one about relevance of the study and ideas for further research.

1.2 Purpose of the study

In an increasingly 'wired' world (Eysenbach, 2003), the Internet is an important source of information and support for people with health concerns (Rice & Katz, 2001). As people seek on-line information and support, they are also constructing illness narratives, whether they are 'talking' about themselves in a chat room or discussion group, over e-mail or on a personal website. Regardless of whether the story is static and unchanging (for instance posted on a website) or whether it evolves over time (through a series of correspondences or within a discussion group thread), and regardless of its length, form and structure, McLellan (1997) suggests the "cyberspace equivalent" (p. 88) of a print or verbal narrative is a new form that deserves investigation. Hardey (2002b) agrees, referring to the Internet as a "new and unique space" (p. 31) in which people relate personal accounts of illness. Orgad (2004) suggests the process of the production of a story, and its telling on-line, have meaningful consequences for the ways in which people cope with illness.

Despite being acknowledged as an emerging phenomenon worthy of study – and despite the proliferation of discussion groups, e-mail lists, personal websites and on-line support groups related to a variety of health topics – on-line illness narratives have received little consideration in the research literature to date. My purpose in conducting this work, then, is to focus attention on on-line illness narratives. The study is best described as exploratory, appropriate in cases meant to investigate little-understood phenomena or to identify or discover important categories of meaning (Marshall & Rossman, 1999). I hope to add to already-rich, multi-genre and interdisciplinary theories about illness narratives and computer-mediated communication, and to gain an understanding of the motivations behind the production of on-line illness narratives and of their effects on their authors. Finally, I hope to explore the role of on-line illness narratives in the overall experience of illness.

1.3 Arthritis

My interest in arthritis developed over the period of ten years of writing stories for and about people who live with the disease, for and about the health professionals who study and treat it (including researchers, physicians, nurses and specialists), for the fundraisers who approach potential donors to support research, and for advocacy groups that push for policy changes within government.

Perhaps because I have seen arthritis approached from so many different perspectives, I am aware of how diseases are defined according to context, and

how such definitions in turn inform how we come to understand, experience and talk about diseases. Therefore, I offer several different definitions of arthritis.

As Solomon (2003) points out, medical discourse has predominantly influenced how we talk about illness in society. For example one type of arthritis – rheumatoid arthritis – is discussed below from a medical perspective:

> Rheumatoid arthritis is an autoimmune disease that causes chronic inflammation of the joints. Rheumatoid arthritis can also cause inflammation of the tissue around the joints, as well as other organs in the body. Autoimmune diseases are illnesses which occur when the body tissues are mistakenly attacked by its own immune system. The immune system is a complex organization of cells and antibodies designed normally to "seek and destroy" invaders of the body, particularly infections. Patients with these diseases have antibodies in their blood which target their own body tissues, where they can be associated with inflammation. Because it can affect multiple other organs of the body, rheumatoid arthritis is referred to as a systemic illness and is sometimes called rheumatoid disease. While rheumatoid arthritis is a chronic illness, meaning it can last for years, patients may experience long periods without symptoms. Typically, however, rheumatoid arthritis is a progressive illness that has the potential to cause joint destruction and functional disability. (http://www.medicinenet.com/rheumatoid_arthritis, November 15, 2004)

To ignore other definitions, however, would be to assume the term 'arthritis' has some fixed referent outside of the occasion of its use (Rapley, McCarthy, & McHoul, 2003). What arthritis is – how it is known, interpreted, and treated – depends on who is discussing it, and how. The following is a definition from a health-related website offering information about many different conditions:

> Live long enough and you can pretty much count on developing arthritis: a touch of osteoarthritis, at the very least.

Arthritis ('arth' meaning joint, 'itis' meaning inflammation) isn't a one-note story or even a few variations on a single theme; it actually consists of more than 100 different conditions. These can be anything from relatively mild forms of tendinitis (as in 'tennis elbow') and bursitis to crippling systemic forms, such as rheumatoid arthritis. There are pain syndromes like fibromyalgia and arthritis-related disorders, such as systemic lupus erythematosus, that involve every part of the body. There are forms of the disease, such as gout, that almost nobody connects with arthritis, and there are other conditions - like osteoarthritis, the misnamed 'wear and tear' arthritis - that a good many people think is the only form of the disease.

True, many older people do have arthritis, but it's not just a disease of the old. Some forms of arthritis affect children still in diapers, while thousands of people are stricken in the prime of their lives. The common denominator for all these conditions is joint and musculoskeletal pain, which is why they are grouped together as 'arthritis.' (http://www.be-health-smart.com/arthritis.html, November 15, 2004)

The definition below comes from a self-help manual:

Arthritis. The very word evokes a spectre of fear and pain. People think of getting old, being unable to get around, and of becoming more dependent on others. More so than with any other disease, the term *arthritis* carries with it a sense of hopelessness and futility. But the very opposite should be true. All arthritis can be helped. (Lorig & Fries, 1995, p.3)

People who are advocating for policy changes might describe arthritis in

terms of its more negative effects and its overall effect on society:

One of every six Canadians over age 15 is affected by arthritis...three out of five of these individuals are younger than 65. We also know that people with the condition experience more pain, activity restrictions, and long-term disability than those with other chronic diseases. In fact, of the $4.4 billion arthritis cost Canadians in 1998, long-term disability accounted for 80% or $3.4 billion; 70% of which was incurred by people of working age (35 to 64). (http://www.arthritis.ca/resources%20for%20advocates/arthroscope/introduction/default.asp?s=1, January 10, 2005)

These varied definitions, along with those I heard during my interviews (including arthritis as 'a silly thing,' as 'a train,' as 'a teacher,' and as 'strangely enough, the best thing that's ever happened to me,' to name a few) demonstrate that diseases, rather than being simply a part of nature or biology, are socially shaped (White, 2002) and their meanings are situated in context.

1.4 Illness narratives: a definition

The urge to 'talk about it' is a common response to medical trauma (Hawkins, 1999), as if describing what has happened can "confine the catastrophe" (Broyard, 1992, p.19). Turning illness into a story seems to establish meta-control (Gwyn, 2001) and bring order to chaos, as well as let others into one's suffering, or perhaps satisfy an urge to educate or to spare others a similar lesson (McLellan, 1997).

Such stories are often called illness narratives. There are many types: some verbal (in-depth medical consultations, conversations with friends, or accounts related in support groups), some written (personal diaries, letters, and published books or diaries, which Hawkins [1999] calls 'pathographies'[1]), some created as art (films, documentaries, even photo exhibits) and increasingly, those produced on-line in discussion groups, support groups, personal websites and weblogs, or blogs.

An illness narrative can be understood broadly as a first-person account of experience, relating "not only what has happened, but also how the narrator

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[1] Hawkins (1999) notes the urge to read such stories seems to be as powerful as the urge to tell them: pathographies are hot sellers at the bookstore. She also notes that the genre is a modern one, uncommon before 1950 and rarely found before 1900.

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understands what has happened, and the meaning...created out of it" (King, 2000, p.13). Guided by the foregoing description and the ideas of Garro and Mattingly (2001), an illness narrative is defined as:

> A story that relates an event or events and explores the meaning of those events by linking motive, act and consequence; it shows the audience what it feels like to be in the narrator's world, and it allows narrators to communicate what is significant in their lives.

Throughout this thesis, I use the terms illness narrative and story interchangeably. Although I recognize the Internet is not one thing, but rather is a range of applications (Slevin, 2000), I use the term Internet to refer to the variety of forums through which people are sharing their stories with others via computer, whether in a discussion or support group, a chat room, a blog or a personal website, or over e-mail.

CHAPTER 2: A REVIEW OF THE LITERATURE

This chapter addresses some of the themes in both the illness narrative literature (section 2.1) and the computer-mediated communication literature (section 2.2) that have relevance for this study of on-line storytelling. In a third section I discuss empirical work conducted in the area of e-health that is relevant to on-line narratives, and in the final section I discuss how these literatures helped set a direction for this study.

2.1 Illness narrative literature

The sizeable literature about illness narratives – which is a focus for many different disciplines including anthropology, sociology, psychology, medicine, literature, philosophy, and communications – covers a variety of theories about why people are motivated to tell stories about their illness, what the telling of these stories does for the narrator and the audience, and what those stories might reveal about the individual and as cultural artefacts.

In literary studies, illness stories have been analysed according to mythic or metaphorical typologies such as battle, journey, death and rebirth (e.g. Frank, 1991), or as illustrations of cultural myths, attitudes and assumptions about various aspects of the illness experience (e.g. Hawkins, 1999). In communications studies, individual accounts of illness are often studied as reflecting and constituting wider sociocultural discourses about health (see for

example Gwyn, 2001 and the work of the Health Communication Research Centre at Cardiff University). Analysis of medical benefits associated with illness narratives is explored within clinical disciplines. For instance Kleinman (1988) suggests interpretation of illness narratives can contribute to effective care, and the work that Charon (1993;1994) is doing at Columbia University's Narrative Medicine Program is focused on helping physicians learn how to listen to and interpret patients' stories in a clinical setting.

Illness narratives are a popular topic in sociology. In a review of papers published in the *Sociology of Health & Illness* since its inception in 1979, Armstrong (2003) notes a change in the mid- to late 1990s from celebrating the "validity and integrity of the patient's account (especially in its relationship to the dominant medical paradigm)" (p. 68) as told in the words of the patient, to a greater focus on the motives and contexts that underpin accounts (Bury, 2001). Atkinson (1997), for instance, criticizes the analysis of illness narratives as if they offer "privileged access to personal experience" (p. 325). Although illness narratives are still seen as capable of providing insight into the experience of illness, researchers seem to be paying more attention, for instance, to the influence of history, class and culture (e.g. Reissman, 2002), or to how shared cultural rhetoric is deployed in the crafting of illness stories. The use of such strategies, according to some commentators, affords greater scope for analysis. For instance Hyden (1997) argues that illness narratives can offer a view into the social and cultural foundations of the illness experience.

A particular stance regardless of discipline views illness narratives as emancipatory (Frank, 1991), in which the social act (Mattingly, 1988) of telling illness stories is the focus, rather than their content. Several themes emerge from the literature along these lines. The first is telling stories as a way of constructing identity (Broyard 1992; McLellan, 1997), of 'regaining' experience, of finding a voice in a society that is obsessed by health, but prefers to keep ill people on the sidelines (Frank, 1991). Hawkins (1999) suggests pathography restores the person ignored in the medical setting, where the disease takes precedence. Rimmon-Kenan (2002) discusses the reconstruction of a life story. In a similar vein, Bury (2001) discusses narrative as 'performative,' allowing people to present themselves as morally- and culturally-competent actors. Frank (2000) suggests illness memoirs, in particular, "[create] the self they claim as their origin" (p.1). He also challenges Goffman (1990) about the claim that stigmatized individuals must focus on impression management (often withholding information about their condition) in order to interact successfully with others. Increasingly, Frank finds evidence that people who are ill (or 'different,' such as racial and sexual minorities) are celebrating their otherness, affirming their identities as honourable, and claiming a "privileged state of being" (p.3). Not everyone agrees. Bury (2001), for instance, discusses the phenomenon of normalization through narrative, in which people minimize their differences and their disease. In a study of women with breast cancer, Sturm (2002) noted that the women tended to minimize their differences from well people in their narratives, and suggests that

illness narratives may work to "normalize a condition to the margins of life" (p. 192).

A second theme in the literature suggests stories offer the possibility of escape from societal expectations and normative discourse about illness. As a physician translates the 'illness' into 'disease,' says Kleinman (1988), "something essential to the experience of illness is lost" (p. 6). There is little opportunity to summon what O. Sacks (1992) calls "the metaphorical and poetical powers of illness" (p.xii) in a clinical setting, in which a number of assumptions rule (such as diseases need to be managed, becoming healthy means erasing all signs of disease, *remaining* healthy means subjecting oneself to screening techniques, and avoiding such screening is irresponsible, as is participating in unhealthy activities such as drinking alcohol or sitting on the couch too much). Frank (1991) acknowledges the difficultly of accepting what modern medicine can do without surrendering oneself to its power. Telling illness stories, therefore, may close the gap, as Frank points out, between what one *feels* and what one feels he or she is allowed to say. Broyard (1992), for instance, in his own illness narrative, embraces this possibility wholeheartedly, rewriting the narrative that biomedicine imposes, the "culturally predetermined biomedical story of organ failure and platelet counts" (Morris, 1998, p. 45).

In a third theme, Kleinman (1988) has suggested that the health of society as well as of individuals is improved when people tell and listen to stories about illness. Positive social changes and group empowerment and inspiration have been noted as the cumulative effects of illness narratives (Frank, 2000). This

view takes illness narratives beyond the personal, suggesting they can create new cultural knowledge and awareness and potentially change social narratives about illness. Solomon (2003) picks up on this theme, suggesting that:

> Stories of illness carry powerful messages about how a person *does* their illness and what meanings society, in general, attributes to the idea of illness. Embedded in the personal stories that people tell about illness are larger cultural ways of talking about illness and numerous other narrative discourses that are drawn upon to story our identity. Personal stories about illness serve as resources or examples that counter or support the development of cultural illness narratives. In other words, larger cultural ideas about illness are incorporated into the ways people talk about their own personal experience of illness. And as people construct and share new and different stories about their personal experiences of illness the established cultural narratives may be challenged or reified. (p. 6)

The illness narrative literature has to date addressed on-line storytelling to a very limited degree – perhaps because on-line illness narratives are relatively new phenomena – although the gap has been noted. Frank (2000), for instance, suggests on-line illness narratives extend the parameters of autobiographical work, allowing others' comments to be incorporated into – and to change – one's story. McLellan (1997) claims that an on-line illness narrative is a unique form, not merely the print equivalent writ large on the screen, but rather a product undeniably shaped by the medium on which it is produced. Hardey (2002b) agrees, saying the interactive and dynamic nature of the Internet makes it possible to produce much more than what he calls 'conventional' illness narratives.

In summary, existing theories within the illness narrative literature, which suggest storytelling can be a way to construct identity, to reconstruct a disrupted

life story, and to present oneself as a competent individual, have much to offer the exploration of on-line storytelling. I now turn to some of the literature about on-line environments with relevance to this study.

2.2 Computer-mediated communication literature

New technologies have always inspired utopian visions (Burnett & Marshall, 2003), perhaps none more so than the Internet. Ever since the Internet became available through personal computers that starting entering homes and offices throughout the developed world in the 1990s (Mosco, 2004), it has been uncritically embraced as a force for democracy and social change (Barney, 2000). Although the utopian rhetoric seems to have settled somewhat as the Internet becomes an everyday tool for many people in Western societies, Burnett and Marshall remind us that quite different from technologies that are "use-specific like a toaster or a dishwasher…the Web, in contrast, is the channel through which greater and greater portions of our lives are carried out through its various Internet manifestations" (p. 21-22). Therefore, debates about the extent of its influence continue.

A strong theme in many of those debates is the "constructability of one's identity" (Kraus, 2000, p.1) in late modern times as opposed to earlier times when identity was more or less set. Burnett and Marshall (2003) map the course of this theme in what they call cyberculture theory, including arguments about the 'virtual self' in opposition to the 'real self' (which arguments they point out were often made in relation to small subcultures that exemplify the extremes of Internet use) as opposed to arguments from those who question the capacity of

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the Internet to allow one to "abandon the confines of a limiting self" (p.63). Those in the latter camp suggest theories of computer-mediated environments rely overly on the idea of emancipation from our physical selves, pointing instead to empirical research that reveals selves to be "anchored in the unitary physical body" (Jensen Schau & Gilly, 2003 p. 400). Hardey (2002a) also argues against the idea of disembodiment, pointing out that "embodied lives, identities and material circumstances of users are themselves significant in affecting patterns of access to and use of the Internet" (p. 581).

Burnett and Marshall (2003) suggest that new communications technologies cannot help but partially reconstruct the self, "creating new opportunities for reflection, perception and social experience" (p. 60). Others agree, drawing often on Bauman (1999), Giddens (1991) and Goffman (1990), among others, to theorize about the role of the Internet in the construction of self in late modernity.

Many of these theories centre on personal websites or home pages, and blogs. Among the more modest claims is that the creation of a home page "fosters self-integration and self-effectiveness" (Doring, 2002, p. 7); a more extreme claim is that creators can transform the way they think of themselves and even change who they are (Chandler, 1998). The personal home page indeed seems well suited for presenting the self as an ongoing project. An on-line identity can be a person's imaginative view of him or herself "as he [sic] likes to think of himself [sic] being and acting" (Walker, 2000, p. 102). Electronically speaking, there is probably no closer identity statement, given the possibilities for

presenting oneself using digital rather than physical referents (Jensen Schau &

Gilly, 2003). The creator of a home page is free to mull over the identity

statement, recreate it and perfect it – and then change it again. The emotional

benefits of on-line storytelling are referred to frequently in empirical research

about personal websites. For example, one interview participant commented that

"Before I start to look at/write about something I'm often not sure what my

feelings are, but after having done so, I can at least have more of an idea"

(Chandler, 1998, p. 9). Another described his home page as an outlet for him to

sort out and validate his own feelings: "I was the intended audience, strange as it

might sound" (p. 10).

> Blogging is described as:

> A personal diary. A daily pulpit. A collaborative space. A political
> soapbox. A breaking-news outlet. A collection of links. Your own
> private thoughts. Memos to the world. (http://www.blogger.com,
> July 30, 2004)

Blogging is part of what McNeill (2003) calls "the unparalleled explosion of

public life writing by private citizens" (p. 25). Indeed an increasing number of

private citizens seem to be involved: there were 4.2 million blogs worldwide as of

October 2004, reportedly up one million from just a year earlier (Rosenbloom,

2004). Although blogs resemble the print version of a diary, they are obviously

quite different from their print counterpart, incorporating feedback from readers,

allowing group blogging, and offering possibilities such as 'audio posting.'[2] Even

the term 'blog,' suggests McNeill, invites interpretation of these sites as a new art

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[2] Audio posting involves leaving a message on the website host's phone which is then posted to
one's blog as an audio file.

form. Like personal websites, they seem to provide unprecedented opportunities, using Frank's (2000) words once again, to "create the self they claim as their origin" (p. 1). Nardi, Schiano, Gumbrecht, and Swartz (2004), in a study that revealed great diversity in blog content, motivations, and characteristics of the bloggers themselves, suggest blogging will soon become a mainstream activity.

Another theme in computer-mediated communications literature revolves around community and the new mechanisms of human association that are shaped by – and also shape – the Internet. In this debate, Slevin (2000) rejects the ideas in Rheingold's (2000) work about virtual communities and similar studies that he says lack a critical approach to the concept of community in the context of current day society. The problem, says Slevin, in a criticism similar to that voiced by critics of the idea of a disembodied self, is that such studies "consistently cordon off these studies from the real world" (p. 107), thus failing to grasp the broader implications of the Internet in community life. Burrows, Nettleton, and Pleace (2000) also address this issue, rejecting anecdotal evidence about the benefits of on-line community groups and calling for empirical research that explores how participants experience the Internet and what impact it has on their lives and their selves.

In summary, much of the computer-mediated communications literature echoes the illness narrative literature, suggesting communications technologies can be facilitators in the construction of the 'self.'

2.3 E-health literature

E-health is the use of emerging technologies, especially the Internet, to improve or enable health and healthcare. The literature about e-health is growing rapidly, much of it concerned with access to health information over the Internet by lay people (e.g. Eysenbach & Kohler, 2002; Hardey, 1999; Hardey, 2001; Jadad & Gagliardi, 1998) and, to a lesser extent, the support people receive on-line for various health conditions (e.g. Burrows et al., 2000; Davison & Pennebaker, 1997; Finn, 1999; Turner, Grube, & Meyers, 2001). Although on-line storytelling about illness is reflected in only a little of the literature, some authors have drawn on the ideas mentioned in the previous section to study this phenomenon.

Gillett (2003), for instance, examines websites created by people who have HIV/AIDs as a strategy for self-representation. Using what he calls an ethnographic approach to Internet research, he reviewed websites and conducted an e-mail survey with 21 authors of health websites, using grounded theory to guide data coding. Gillett found four organizing themes – autobiography, expertise, self-promotion and dissent – and argues that the Internet has potential to "raise the private troubles of people with health problems as public issues through a revitalization of the public sphere" (p. 608). Gillett finds website producers "contest the meanings generated by the mass media, [thereby challenging and transforming] the representation of what it means to be a person with HIV/AIDS" (p. 621).

Pitts (2004) is not quite as optimistic as Gillett. She explores the question of whether or not the Internet might encourage the telling of a wider range of stories and experiences about breast cancer than are tolerated in the mass media. She examines websites of women with breast cancer for their potential to create new knowledge, awareness and agency in relation to illness. Although she finds some cause for optimism, she also suggests the Internet can be a medium for circulating conventional messages and "affirming norms of femininity, consumerism, individualism and other powerful social messages" (p. 33).

Hardey (2002b) draws on theories of lay versus expert knowledge in an examination of personal websites and e-mail surveys to their authors. He proposes a four-fold typology (my story and explanation, my story and advice, my story and solution, my story and products and services), each type slightly different but all uniquely defined by personal narrative. Hardey argues that home pages allow a mapping of the transformation of people from *consumers* of information and care to *producers* of information and care, and that home pages are part of a reconfiguration of the relationship between lay and medical expertise. Ziebland (2004) and Ziebland, Chapple, Dumelow, Evans, Prinjha, and Rozma (2004), who interview people with cancer about their Internet use, also raise the theme of expertise. They argue that the existence of the Internet allows people to gain knowledge of their condition but also might pressure them to feel they must become expert patients.

Reeves (2001) interviewed people who are HIV-positive to investigate the

Internet's effect on their coping ability. Using a constant comparative method,[3]

she revealed three themes related to Internet use and coping: empowerment,

social support, and helping others. Like Ziebland, Reeves notes that it seems to

be important for people to be able to speak with authority about their condition,

and that using the Internet allows them to do that.

Another group of empirical studies, while not explicitly mentioning illness

narratives, clearly deals with storytelling as a means by which people are

engaging on-line. For the most part, the authors of these articles report about

content analyses they have conducted of messages posted to on-line discussion

support or self-help groups. Sharf (1997) concludes that a breast cancer support

group fulfils the function of a community and has the potential to enhance

patient-provider communication. In a study of a diabetes newsgroup, Loader,

Muncer, Burrows, Pleace, and Nettleton, (2002) discuss the possibility of a

renegotiated relationship between medical knowledge and lay experience, along

similar lines as Hardey (2002b). Davis and Pennebaker (1997) suggest the

Internet offers a unique opportunity for insight into how people develop illness

meanings. Rumsey (2001) concludes that involvement in an on-line support

group helps people with cancer come to terms with their illness.

Many of these articles refer to the need to end polarized, extremist

debates about the Internet's being either the answer to all ills or the end of

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[3] Charmaz (2000) explains the constant comparative method as a) comparing different people
(their views, actions etc.); b) comparing data from the same individuals with themselves at
different points in time; c) comparing incident with incident; d) comparing data with category; and
e) comparing a category with other categories.

civilization as we know it. Despite that acknowledgement, there is an overwhelming trend in the articles towards exploring the potential of the Internet for health-related matters, which seems to orient the authors' analyses that way *a priori*. For instance Houlihan, Drainoni, Warner, Nesathurai, Wierbicky, and Wiilliams (2003) start out by discussing the potential of the Internet to promote the health and welfare of people with major disabilities, and then study people's use of the Internet from that position, finding that the importance of the Internet to such populations cannot be trivialized. Mendelson (2003) suggests Internet listservs and other forms of virtual communities can be an important source of support and information for people with lupus, and sets out to find out what types of support are available and what benefits they offer participants.

Despite their contribution towards the understanding of on-line health-related activities, many of the above articles do not venture further than offering descriptive lists of things people do on-line, such as sharing personal perspectives, gaining social support, developing personal empowerment and using storytelling as common grounding. However, most authors acknowledge that in order to gain more insight into people's on-line activities related to health, it is necessary to move beyond content analysis (e.g. Burrows et al., 2000; Finn, 1999; Pitts, 2004).

2.4 Limitations of past research

Literature about illness narratives, computer-mediated communication and e-health confirms that people are indeed telling stories about their health on-line – in what has been suggested as a new genre (Hardey, 2002b). The literature

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also reveals some fairly substantial claims are being made about the importance of storytelling about health and illness.

The first limitation is that only a few articles that addressed people's use of the Internet for health-related storytelling offered insights into this activity from the perspective of the storyteller. It seemed an important gap in the literature, and a way in which to complement the perspective offered by content analysis. As discussed, such an approach was mentioned as important by authors of some of the above studies. Others who wrote about illness narratives (Frank, personal communication, September 30, 2004) and computer-mediated communication (Orgad, personal communication, March 9, 2004) have also mentioned contact with on-line narrative authors as being crucial to understanding the conditions and effects of Internet use.

Secondly, some interesting questions arise about context, both within and outside of Internet environments. Only a few studies explored Internet use in general for health purposes: most dealt with specific venues such as on-line discussion or support groups or websites. Since many people are involved in several different types of on-line activities, broadening the scope of the exploration may allow for a different perspective about Internet use. Studies about on-line activities also largely neglect how Internet use for health-related concerns fits into people's everyday lives. This observation is related not only to health-related research: Hardey (2002a) notes that "the majority of research *about* the Internet has been research *in* the Internet" (p. 571). Studying Internet use in the context of lives would allow a fuller exploration of the motivations

people have for using the Internet in various ways, as well as why they may *not* use the Internet for certain activities. It would also allow for a number of other questions to be addressed: are the motivations for on-line storytelling different from the 'off-line' motivations?[4] In other words, are people who tell their stories on-line looking for something they cannot find in a face-to-face or paper-to-pen situation – and are they finding it? Do they speak in dichotomous terms of lay versus expert opinion – or is it only researchers who do that? Does the Internet offer a unique opportunity to 'keep a particular narrative going' which Giddens (1991) suggests is fundamental to one's identity? Does storytelling on the Internet have the potential to change perceptions about illness or normative discourses about health?

Lastly, I wanted to move beyond exploring the potential of the Internet from the outset, which I believed would "confirm the technocratic vision of the centrality and normativity of technology" (Wyatt, Thomas, & Terranova, 2002, p.25). Although I could not escape the fact that the interviews were *about* the Internet – and indeed, the participants were there because they *used* the Internet – I wanted to leave what Nettleton, Pleace, Burrows, Muncer, and Loader (2002) call 'analytic space' in which to view a social technology about which people may be ambivalent at a number of different levels.

In summary, I was interested in hearing about how people talk about using the Internet to tell their story. Since most of the empirical studies I read employed

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[4] Exploration of this question may in turn shed further light on the 'on-line/offline' discussion. Some authors (e.g. Orgad, 2004; Slater, 2002) suggest we should move beyond the distinction, although many researchers still refer to cyberspace as separate from 'real life.'

a similar analytical technique to generate themes from data (the method was sometimes referred to as grounded theory, but often not named as a specific analytic method), I felt a different type of analysis could offer a new perspective on on-line storytelling related to health. The approach I took in addressing the gaps in previous research outlined above, and the rationale for that approach, are addressed in the next chapter.

CHAPTER 3: RESEARCH DESIGN

My review of the literature about e-health suggested the phenomenon of on-line storytelling could be approached effectively from a new perspective (Wolcott, 2001) by exploring how people with arthritis talk about going on-line to tell stories about their illness. Although in-depth interviews seemed the obvious strategy, I was aware of the importance of overall method – which Morse (2002) describes as "a collection of research strategies and techniques based on theoretical assumptions that combine to form a particular approach to data and mode of analysis" (p. 2). Choice of a model was the first step.

Silverman (2000) proposes three different models relevant to interview data: positivism, in which interview data are seen to offer facts about the world; emotionalism, in which the data are seen to give insight into people's authentic experiences; and constructionism, in which interviewers and interviewees are seen as actively engaged in constructing meaning and generating data. My approach is in the latter camp, as I view interviews as socially situated occasions in which "Speakers negotiate identities, display knowledge of a cultural world in common, and [work] jointly to build a corpus of 'research knowledge'" (Roulston, 1999, p. 747).

Within this framework, I could have chosen a number of analytic approaches. A social constructivist grounded theory, for instance, would have allowed me to study how action and meaning are constructed in the interview by

generating conceptual codes and applying them across all interviews, using what is called a constant comparative method (see footnote 3 on page 21). A narrative analysis, used by Ziebland (2004) in her analysis of two interviews with people who have cancer, offered another possibility. Narrative takes a chronologically told story and focuses on how elements are sequenced, why some elements are evaluated differently from others, how the past shapes perceptions of the present, how the present shapes perceptions of the past, and how both shape perceptions of the future. However, although the *topic* of my interviews was illness narratives, I was not sure the data would emerge in a form appropriate for narrative analysis. In addition, much work has been done with both grounded theory and narrative analysis about the experience of illness, and using an ethnomethodological approach – which I had found referred to in only one study about illness – presented an exciting challenge.

Under the umbrella of ethnomethodology, I chose a form of membership categorization analysis outlined by Baker (1997, 2002) based on H. Sacks' (1992) work. An overview of ethnomethodology and membership categorization is presented below.

3.1 Ethnomethodology

Attributed to the work of Harold Garfinkel and colleagues in the early 1960s, ethnomethodology – literally 'the study of people's methods' – is concerned with the everyday ways in which people act and reason. Rather than taking `social facts' and `social structures' as givens, ethnomethodologists study the details of how participants in social settings use common sense to manage

their 'membership' in a group or social setting. Although there is an emphasis on proceeding inductively (Silverman, 1998), ethnomethodology has a strong theoretical perspective in its view that members of society are involved in an ongoing "production of social order" (Livingston, 1987, p. 18).

Ethnomethodology has been described variously as "revolutionary, misguided, radically innovative, and trivial" (Flynn, 1991, p. 1). Some commentators describe it as a movement within sociology, others as a separate discipline altogether, with sociology and ethnomethodology offering "completely incompatible technologies for the investigation of social order" (Livingson, 1987, p. 138). These types of disagreement are not surprising: as Flynn points out, ethnomethodology itself, by virtue of its perspective, is "situationally constructed each time anyone 'references' the movement in practical situations of inquiry, discourse, or professional presentations of self" (p.4).

The movement has been criticized for concentrating on the micro-process of social interaction and failing to account for larger social and cultural processes that may affect interpretive activity at a local level (Tucker, 1998). However, as Schneider (2002) explains, from the perspective of ethnomethodology:

> The structure-agency binary is a false dichotomy. Neither affirming nor denying the existence of social structure, ethnomethodologists are interested instead in the question of how social order is produced as a local accomplishment of social actors. Structure is realized through the actions of agents, and therefore the two cannot be studied as independent domains that interact in particular ways (p. 173).

However, while ethnomethodologists do not see social interactions as being solely the *effects* of social structure, this does not mean that the local

character of interactions cannot be related at all to larger social contexts. As Boden and Zimmerman (1991) put it: "The socially structured character of...any enterprise undertaken by members is...not exterior or extrinsic to their everyday workings, but interior and intrinsic, residing in the local and particular detail of practical actions undertaken by members uniquely competent to do so" (p. 7). In other words, interactions are seen as "constituted in part through the participants' orientation to the social-structural context of their interaction" (Wilson, 1991, p. 24), and interactions can be see as involving "a recognisable appeal to wider social process, concerns and factors" (Housley & Fitzgerald, 2002, p. 78). In this way, suggests Fitzgerald (personal communication, March 14, 2005), through examining how people construct accounts, it is possible to see how politics is done, how social sanctioning happens, how knowledge is perpetuated, and how versions of the world come to be accepted.

Ethnomethodologists have not historically paid much attention to interview data, focussing instead on what they describe as naturally occurring settings. H. Sacks (1992) in particular tended to reject interview data because of his belief that they are generated in pre-set categories and do not encourage exploration without pre-existing ideas of what one might find. Recently, however, researchers have been taking an ethomethodological approach to analyzing interview data, arguing that the interview is as 'real' as any other situation (Fitzgerald, personal communication, March 9, 2005) and rejecting neat distinctions between the natural and the cultural (Miller & Glassner, 1997). Baker (1997) agrees, suggesting the key is to see an interview as a form of social action in which both

interviewee and researcher draw on cultural knowledge to actively construct meaning in talk.

Baker (1997) suggests three considerations for approaching data ethnomethodologically. First, interviewing is understood as an interactional event in which participant and researcher work to produce meaning. Second, questions and comments from the researcher shape participants' responses. Third, data are treated as accounts – "the work of accounting by a member of a category for activities attached to that category" (p. 131). This view is similar to that espoused by proponents of an 'active' style of interviewing, (e.g. Holstein & Gubrium, 1995; Mishler, 1986) in which participants in effect become researchers themselves, "consulting repertoires of experience and orientations, linking fragments into patterns, and offering 'theoretically' coherent descriptions, accounts and explanations" (Holstein & Gubrium, 1995, p. 13).[5]

Such a focus on *how* interview data are generated does not mean the topic of the interview – or *what* people say – becomes irrelevant or that knowledge of the social world beyond the interaction cannot be obtained (Miller & Glassner, 1997). Although the focus is on observing locally produced 'accounting practices,' such practices can subsequently be interpreted in terms of more general ideologies relating to the social order (ten Have, 2004). In fact, the analysis can enhance the way the topic is approached (Baker, 2002; Silverman,

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5 These ideas also link with George Kelly's (1955) model of man-the-scientist, in which people theorize and create their own ways of seeing the world rather than the world creating those ways of seeing. As with many ethnomethodologists, Kelly does not dispute that social structure places constraints on how people see that world. Kelly's ideas have recently gained ground in the sociological disciplines.

2001) as has been shown in several interview studies. For instance Paoletti

(2001) uses an ethnomethodological approach to explore in detail the topics that

arise in interviews with caregivers of relatives. By attending to the finer processes

of conversational interaction, Paloetti suggests she is able to see how topics and

facts related to caregiving are constructed, and therefore how they are

perpetuated as social knowledge. Roulston (1999) suggests an

ethnomethodological approach complements the content of talk in her interviews

with music teachers by forcing her to look at the co-production (by interviewer

and interviewee) of data. In this way, Roulston says, she is able to generate a

more complete picture of what it is like to be a music teacher than if she had

simply looked at themes emerging through the topic of the interview talk.

3.2 Membership categorization analysis

H. Sacks (1992) described how in conversation, members (of a social

group or setting) generate categories (e.g. mother, father, son, nurse, doctor),

which then roll up into collections of categories (family, occupation) to

communicate with each other in ways that make sense. These categories and

collections are associated with category-bound activities (feeding and clothing

children, giving inoculations), which further explicate the categories. Since people

can be part of more than one category, and categories can be part of more than

one collection, members must work to resolve ambiguities. Thus they can be

seen to be using 'membership categorization devices,' which Roulston (1999)

defines, following Baker and Freebody (1987), as:

A method that speakers and hearers use to decide the occasioned meaning of ambiguous terms, to select referents in order to invoke particular contexts of meanings, and to account for actions and events...Uses of these devices include attaching particular activities or attributes to categories within a set or collection of categories. (Roulston, 1999, p. 2)

Such resources are part of the "commonsensical framework of members' methods and recognisable capacities of practical sense-making" (Housley & Fitzgerald, 2002, p.62), allowing them to build and challenge particular versions of reality and construct particular identities that can be associated with the activities they describe (Silverman, 2001). Analysis, therefore, involves hearing how people generate and use categories as ways of describing and making sense out of events and situations. An emphasis is placed not on the content of the categories, but the ways in which they are invoked (Silverman, 1998).

Hester and Francis (1994) suggest H. Sacks' original ideas negate the potential reading of the membership category analytic framework as one that pays attention to the local use of categories by members in context. H. Sacks' work, they suggest, seems to reference a determinate structure of knowledge that members are seen to possess (e.g. police arrest people, students study, babies cry). Thus they propose an 'occasioned' model in which the specific meaning of categories is created within interactions. A 'reconsidered model' of membership categorization analysis by Housley and Fitzgerald (2002) takes into account this occasioned model and addresses attempts to overcome the dualism of micro versus macro perspectives. Such a model, they say:

Preserves a focus on the radical ethnomethodological conceptualisation of social action, organization and context and

sets an agenda for empirical enquiry that will be of interest to wider sociological audiences in an era where the relationship between interactional processes and structure is of increasing foundational importance. (p. 80)

In sum, I believed the study of Internet storytelling would benefit from this ethnomethodological approach because it is a method that to my knowledge has not been applied to the study of Internet use. Most of the studies of Internet use I have read use a method to generate themes from data. It could be said that the categories used in membership categorization analysis are a type of theme. However, an ethnomethodological approach differs from most theme generation methods in that the researcher's participation in the creation of data is taken into account. Many methods that use theme generation are also concerned primarily with analysis of topic (*what* is being said) rather than also paying attention to context (*how* it is being said). I believed that an ethnomethodological approach would allow me to go beyond a discussion of Internet use in isolation, attending to the ways in which people present their version of the world such that storytelling about arthritis on the Internet makes sense. Below I discuss the analytic process.

3.3 Analytic process

Baker (1997) outlines the steps involved in analysis in membership categorization analysis. They are: 1) taking as established the original category membership (in this case, *person with arthritis who tells his/her story on the Internet*); 2) looking for other, related or oppositional categories of people or things that are generated in and that underpin the talk; 3) working through the

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activities associated with each of the categories in order to fill out the attributions that are made to each of them; 4) looking for the production of identities and the assembling of a social world that is "familiar, orderly and moral" (p. 143).

I began transcribing tapes and analysing data as soon as I had done the first interview, so as not to have to play 'catch-up' (Silverman, 2000) afterwards. I transcribed the tapes verbatim, including my own contributions, and noted emphasis, tone, hesitation and so on. I preferred to analyze the transcripts on paper using pencil rather than use a computer program. This was simply a personal preference, as the transcripts could also have been coded using a program such as NVivo

I began by reading each transcript through several times to recapture a sense of the interview setting. As I began analysis, I resisted the temptation to start at the first line and work my way through the interview making notes as I went. As Silverman (2000) explains, the danger of such an approach is that "observations tend to be *ad hoc* and commonsensical" (p. 131). Silverman suggests formulating a 'puzzle' to help kick-start the analysis, after which one can work backwards and forwards through the transcript to find out how the puzzle is resolved. Baker's (1997) instructions as above provided me with the puzzle: what categories of people or things are generated in and underpin the interview talk, what activities are associated with each of the categories, and how do both interviewer and interviewee discuss the categories and their attributions such that a world in which Internet storytelling makes sense is described? I worked through each of the interview transcripts in this way, ultimately

developing the three major categories (health professionals, other people, and active people) I discuss in the next chapter. I discuss in that chapter the differences and similarities of the categories between interviews.

3.4 Participant recruitment

I was interested in talking to people with arthritis who use the Internet to tell their story, regardless of the type of arthritis they had, the extent to which they used the Internet, or any of their particular demographic or socio-economic factors. I did not want to pose limits to participation both because I wanted to ensure I had the maximum number of people possible, and because I was interested in how people in different situations would provide different – or the same – perspectives. I did, however, limit the study to people in British Columbia due to constraints on time and budget.

After receiving ethics clearance from Simon Fraser University, I sent a recruitment poster (Appendix A) to an advocacy group (Arthritis Consumer Experts) and a not-for-profit society (The Arthritis Society, BC & Yukon Division) and asked them to distribute or post it as appropriate. Although I had plans to distribute the poster further – through treatment centres across the province – I started to get responses immediately, and so I put further recruitment on hold.

In total, 19 people responded to my poster – 17 women and two men, which reflects approximately the gender breakdown of people with arthritis. The participant group was very diverse, affording me contact with people who had very different types of arthritis, as well as different levels of severity and length of

time they had had the disease. Participants were demographically and socio-economically varied, and differed in the extent to which and the ways in which they used the Internet (see Appendix B for a table of participant demographics).

All the interviews were tape-recorded; all except two took place in participants' homes (two people preferred to come to my house). I travelled out of B.C.'s Lower Mainland, where I am based, for five of the interviews. At the beginning of each interview, I talked about the purpose of the study and my desire to cover three broad topics: their story, storytelling about illness in general, and storytelling on the Internet. Participants were invited to ask any questions (most people did not) and asked to fill out a consent form (Appendix C) before we started. They were also given a demographic form, which I asked them to fill out later and send back to me in a self-addressed, stamped envelope. Two people did not return the form. I e-mailed them a reminder and they said they would get around to it, but did not. Although these two participants could not be included in the demographic table, I discuss them in the next section along with other participants.

The interviews were open-ended and averaged an hour in length. Although all the conversations started on a light note, several participants became quite emotional as they recounted their experiences. I believe that because I have a history with arthritis, having written about it for so long, and because by virtue of my research I was seen as being interested in what people have to say about the disease, participants felt comfortable talking about their experiences.

My choice of method was further confirmed during the interviews, when it became obvious I was not so much collecting data that were ready to be gathered as helping to generate them in the context of the interview. As Silverman (2001) points out, respondents are not so much repositories of knowledge as they are constructors of knowledge in collaboration with the interviewer. Whereas the standardized interview would try to limit informational spillage from one interview to another, active interviewing (Holstein & Gubrium, 1995) "takes advantage of the growing stockpile of background knowledge that the interviewer collects in prior interviews to pose concrete questions and explore facets of respondents' circumstances that would not otherwise be probed" (p. 46). Guided by such ideas, I would, depending on the situation, sometimes mention something I had read about illness narratives, or relate what another participant had said, which in turn engaged participants on that level. It was clear, as I suspected, that most people had not thought of their on-line activity as storytelling before they had read my poster, but it made sense to them when they thought about it, and they were interested in exploring the concept.

Membership categorization analysis is very detailed, and my work on the 19 conducted interviews is too lengthy to present in its entirety in a thesis. Instead, I have chosen to present a two-part analysis: in the first part, I discuss the major categories that arose in all interviews (health professionals, other people and active people); in the second part, I present a more detailed analysis of five of the interviews. I chose these five interviews from five different groups based on stage of arthritis in which people seemed to self-identify. Those groups

were: 1) those whose onset of arthritis was gradual (seven people); 2) those who developed arthritis suddenly and were profoundly affected (four people); 3) those who have had arthritis from a very young age (two people); 4) those who developed it more or less suddenly but considered themselves healed (two people); and 5) those who developed arthritis more or less suddenly and still had it but were coping (four people). The way I chose the five from within those groups for presentation in my thesis was to ensure I could show the range of characteristics and activities that existed among participants. That said, it is important to note that it is not my intention to compare data across these groups or other across other defining characteristics (for example age, gender, type of arthritis). Rather, I am looking at the data both individually and collectively across all participants. I will now introduce those participants and discuss how they use the Internet to tell their story.

3.5 Participants and their Internet use

This section presents an overview of the people who took part in my study and discusses their activities related to on-line illness narratives. A demographic table is presented in Appendix B. As mentioned above, two participants – Martina and Helena – are not included in the demographic table but their participation in interviews is discussed below. Pseudonyms are used for all participants.

3.5.1 Arthritis: a gradual onset

Seven participants described their arthritis as developing gradually over the years. Susan is a single 60-year-old woman whose osteoarthritis first started

to affect her ten years ago. She has gradually had to give up more and more activities (she was once quite physically active) and eventually her work as a movement therapist. She has tried many alternative therapies with not much success, and had a hip surgery also with little success. She says she is gradually coming to accept that she can no longer do the things she once did, and is trying not to dwell on those things. Susan's Internet storytelling takes place primarily on a discussion group related to a particular kind of surgery. She says telling and listening to stories on the Internet gives her access to information and ideas that do not arise in medical encounters. Although she participated in on-line storytelling for some years, she says she is going on-line less and less because the treatment that is being discussed in the chat room she belongs to was not successful for her, and it is painful to read about people talking about their successes. However, Susan appreciates the opportunity to tell stories on-line to people who understand what she is going through, rather than burdening her friends with her troubles.

Peter is a retired farmer who lives in the Interior region of British Columbia with his wife. He has had osteoarthritis for about 35 years, and says that it seemed to come on in one area of his body at a time, starting with his shoulders. Over the years, he says, he has been on many medications, most of which have helped for only short periods of time. He has had the most relief from acupuncture and exercise, and still visits the local pool several days a week to exercise in the water. Storytelling on the Internet for Peter means connecting via e-mail with friends and family. He does not visit chat rooms or discussion groups,

and he is reluctant to spend time looking for health information as he thinks it is 'a waste of time' and that it is possible to 'get lost' very easily. However, he is intrigued by the idea of on-line illness narratives because he sees them as a way for people to get across the message about the seriousness of arthritis, which he feels is not understood.

Terry is a full-time nurse in her 50s who had rheumatic fever as a young girl and then developed rheumatoid arthritis in her 30s which has been with her ever since and has varied in its severity over time. She is divorced and lives with a grown son (her daughter is married and lives nearby). Although Terry says there is no way to describe the pain of an acute flare of arthritis, she prefers not to dwell on the pain and says she 'won't give in.' She attributes her on-line storytelling to a desire to help other people deal with arthritis, which she does by participating in an on-line forum on an arthritis group website. Terry does not like the idea of chat groups because she says she does not trust who is on them. Anonymity and privacy are very important to her.

Hannah is in her late 40s, unemployed, and living with her daughter and a male roommate in a low-income apartment. She attributes her osteoarthritis, which primarily affects one knee, to an incident with an abusive partner some years before. She was very keen to tell me her story, and to talk about how she is trying to put a troubled past behind her. She does not use the Internet much at all (which I found a little confusing at first given her response to my recruitment notice), but she wanted to *talk* about using the Internet. She was interested in finding out about groups she could join and what kind of support she could

receive both on the Internet and off. Hannah had received a poster about my

study via e-mail as part of an arthritis mailing list, but she says she rarely goes

on-line because she does not know enough about how to do so, although she is

learning. She said she was interested in my study because she feels there are

not enough opportunities for people with arthritis to tell their story.

Bonnie is a retired private-school teacher who lives alone. She has had

osteoarthritis since she was about 45, which was exacerbated, she feels, by a

bad car accident ten years ago. She volunteers as a leader of an arthritis self-

management course and as a call-taker on an arthritis telephone help line, and

says in both settings she hears a lot of stories. Like Hannah, Bonnie is not a

great user of the Internet, although for different reasons from Hannah's. Bonnie

has a good technical understanding of computers, and does her banking and

pays bills on-line. But she is nervous of chat rooms and discussion groups

because she is afraid of who is on them, and what they could do to her if they

found out her identity. Her on-line storytelling is limited to e-mails to people she

knows. However, she is very interested in the potential of chat rooms and

discussion groups, and would like to overcome her nervousness. She feels there

is far too little understanding in society of what it means to be ill, and sees

storytelling as a way to make things happen – to get policies changed in favour of

people with disabilities, and to raise awareness of what it is like to live with a

disease.

Paula is a full time student who moved to the Lower Mainland several

years ago from the Middle East with her husband and three children, who are

grown but live at home. She has had osteoarthritis for about 20 years, but says in her home country the doctors did not know what it was, so she didn't receive proper treatment. Since she has moved to Canada, she feels she has received much better care as well as education about her condition and what she can do to maintain her mobility (for example exercising). Like many of the people I interviewed, Paula had to try several medications before she found one that worked, and the side effects often outweigh the benefits even of those medications that offer some relief. She says she is dealing well with arthritis, though, and with the help of friends and family, is able to enjoy life. Paula expressed shock at the difference between the medical knowledge about arthritis in her home country and the medical knowledge in Canada. She feels she would not have had to suffer so much if her original doctors had known more about arthritis. The Internet, she feels, is part of a wonderful trend towards making health information available to almost anyone who wants it. Her on-line storytelling takes place in e-mails to friends and family, where she appreciates the opportunity to share how she is feeling without telling everyone separately and in person.

The last participant in the group of people who said their arthritis came on gradually is Anne, a single woman in her early 70s whose osteoarthritis started to develop when she was about 45. Anne is an avid Internet user and regular participant on an on-line discussion group, which she says gives her an outlet to talk about how she feels without being accused of complaining. Anne is discussed in detail in part two of the next chapter.

3.5.2 Arthritis: sudden and profound

Four people I interviewed said their arthritis came on very suddenly and their lives remain profoundly affected. One of those participants was Charlotte, who is in her early 20s and lives with her mother and father and a brother. Charlotte was just about to enrol in a teacher's training certificate program when she was diagnosed with arthritis. Unlike most participants, Charlotte's on-line storytelling activities (keeping a blog and participating in an on-line gaming community) do not involve an arthritis community. Charlotte is discussed in detail in part two of the next chapter.

Georgia is another young woman in her early 20s who was struck suddenly with arthritis several years ago. She lives with her mother (her father died about eight years ago) and a brother and sister. Despite the sudden onset – overnight, she says, she was bedridden – it took several months to get a diagnosis of rheumatoid arthritis. After trying several different drugs, she has managed to find one that eases the pain and allows her to walk and move around, although she has had to give up activities like skiing, hiking and swimming. Georgia is dismayed at the lack of understanding in society of arthritis as a disease that can affect young people. She says she often feels guilty because she does not have a lot of energy to participate in social activities. She wonders if friends think that she is making excuses. Georgia participates in several Internet chat rooms for people with rheumatoid arthritis, which she describes as 'amazing' in terms of the opportunities they present to tell stories, give advice, receive advice, and listen to others' stories.

Natasha is a divorced mother of two grown sons who lives alone in an apartment she has just moved to which has been modified to allow her to move around easily. Until a few years ago, she says, she was a healthy woman with a full time job as the front desk clerk at a hotel. She says one morning she woke up with rheumatoid arthritis, and it has changed her whole life. She needs a walker to get around, and has trouble moving her wrists and arms and even other joints such as her jaw. What surprised Natasha most was that friends and family did not know how to deal with the fact that she had arthritis, and she has lost touch with many people. In an act of desperation, she says, she took her sons to the rheumatologist so he could explain the disease to them and talk about how it affected their mother. She says her relationship with her sons has been good since then, and believes it was very hard for them to come to terms with having to take care of her after she had cared for them most of their lives. Although arthritis has been physically devastating for her, Natasha says in many ways she has never been happier in her life. Her storytelling on the Internet consists of chatting over e-mail. Since she is not able to get out easily, e-mail allows her to stay connected with people and let them know what is going on in her life.

The last participant in this group is Kyla, an elementary school teacher who lives in a small town in the Interior of British Columbia with her husband and 12-year-old daughter, without whose support, she says, she would be lost. Kyla's story is much like Charlotte, Georgia and Natasha's in that she went from being healthy one day to 'a physical wreck' the next, with 48 joints affected. She spent six weeks in hospital and describes it as the scariest time of her life. Kyla says

her Internet storytelling – which takes place mostly over e-mail – is a way for her to talk about her arthritis without getting the reaction she says she gets when she is talking to people face-to-face. It is inevitable, she says, that well-meaning people will advise her about what medications to take, what foods to avoid, or what exercises to do. She does not feel the need to join a chat group with other people who have arthritis, as she says she does not like the idea of 'trying to feel good by hearing about how bad everyone else is.'

3.5.3 Arthritis from a young age

Two young women I interviewed have had arthritis since they were very young. One of them is Linda, an Indo-Canadian woman in her late 20s who lives with her mother and her two brothers and their wives. Linda uses the Internet to meet potential partners on dating sites. Similar to Charlotte, then, Linda's on-line activities do not involve a community of people who have arthritis, although those activities are relevant to her identity as someone with the disease. I discuss Linda in detail in part two of the next chapter.

The other participant in this group is Martina, a 32-year-old Mexican woman who recently married a Canadian and has settled down in Vancouver. She works full time as a travel consultant for a development company. Like Bonnie and Hannah, Martina does not use the Internet much, but was interested in talking about the possibilities of on-line storytelling. She has had juvenile rheumatoid arthritis since she was about four, so it is very much a part of who she is – she has never known anything different. Like Natasha, Martina seemed relentlessly positive. For instance she talked about taking it in her stride when

people ask her if she 'slept wrong,' which apparently they do often because she has a stiff neck and holds it at an angle. Martina's on-line storytelling is limited to e-mail. Although she is interested in chat rooms, she does not trust an environment where she does not know who everyone is. Sharing her story is very important to Martina, but she wants to share it only with people whom she believes are well-intentioned.

3.5.4 Arthritis: here and gone

Two people I interviewed were struck fairly suddenly with arthritis but after successful operations, they consider it healed. One of those people is David, a married university professor in his mid-50s with grown children. David was diagnosed several years ago with arthritis in one of his hips. His Internet storytelling connected him with a group of people who were discussing a particular kind of surgery. David is discussed in detail in part two of the next section.

The other participant in this group is Nancy, a former athlete in her early 40s who says she thought nothing of running 20 miles every few days before she developed arthritis in both hips. Nancy says her identity was very strongly linked to her athleticism, and it took her a long time to come to terms with being ill. She says she had often thought, before she had arthritis, that becoming disabled would be the worst thing that could ever happen to her. Before she developed arthritis, she had never been part of a chat group, but in her search for information about her condition, she stumbled across a Yahoo group for people who had hip problems and were pursuing a new type of surgery. She credits the

group and their stories with helping her through a difficult time in her life, and says without the Internet's ability to connect people across geographic boundaries, she would have had a very different experience. Now that Nancy has had two successful hip surgeries, she visits the chat room only occasionally, but she says there is no other environment in which it is so easy to 'bare your soul' without worrying about how other people will react.

3.5.5 Arthritis: sudden but manageable

Four people I interviewed described their arthritis as coming on quite suddenly, but said they are managing quite well. Helena is an active senior who lives in an apartment in a suburb of Vancouver with her granddaughter, who is attending college nearby. She developed rheumatoid arthritis as a young mother, but kept working full time. Helena talked about how much she loves the Internet, and how nice it is for seniors to be able to connect with family members they might not otherwise keep in touch with. Although it frustrates her that so many people do not understand what it is like to have arthritis and how debilitating it can be, she says she tries not to let it bother her. Her Internet storytelling consists of e-mailing friends, family and members of the volunteer groups she belongs to. Telling and listening to stories on the Internet, she says, makes her realize she is not alone.

Jody is a retired hairdresser (she had to stop work early because of her arthritis) who developed rheumatoid arthritis fairly suddenly about five years ago. She is delighted to be as healthy as she is: physicians initially told her she may be in a wheelchair very soon, but she is still quite mobile. She and her husband

live in the Interior of British Columbia and travel to the southern United States

every winter in their motor home. The Internet is quite new to Jody. She laughs

about her first experiences in a poker game website when another participant

'got a bit too friendly' so she turned the computer off, almost as if she thought he

had been able to see her. Since then, she has become more used to the

computer (although she says her grown children laugh at her lack of typing

ability) and appreciates that she can tell stories on it anonymously. The

anonymity is important to her not because she is nervous, but because she looks

extremely healthy, and she says people tend not to believe she is ill.

Holly is a divorced mother of a grown daughter who lives alone. She is on

disability leave from her job, which she says is the best situation for her even

though she loved working full time at the various jobs she has had. Although

Holly is managing quite well – in fact she says this is the first time in her life she

has spent time relaxing – she mentioned several times how guilty she feels being

on disability. She says she cannot get rid of the feeling that other people feel she

should be trying hard to get better and go back to work. She also feels there is a

lack of understanding in the medical community about arthritis – not only about

what it is like to live with it, but about the actual medical processes involved.

Despite being struck fairly suddenly, Holly went from doctor to doctor and had

conflicting diagnoses before it was determined she has rheumatoid arthritis. Holly

is familiar with computers through her work, and her storytelling takes place over

e-mail, although she says she doesn't do that much. Like a few other

participants, she asked me for advice about what on-line groups I knew about so she could check them out.

The last participant in this group is Karen, a divorced realtor in her 50s who was diagnosed quickly and put on drugs that relieved her symptoms effectively. Karen developed an e-mail relationship with a woman who has arthritis with whom she shared stories for several months. Karen is discussed in detail in part two of the next chapter.

3.5.6 Participant summary

The 19 participants I have introduced above represented a number of types of arthritis and differences in the severity of their disease. Interview participants also varied demographically and socio-economically, and there were differences in the extent to which they used – and the reasons for which they used – the Internet. However, there were interesting similarities in the ways in which they talked about the experience of illness and the role that Internet storytelling played in that experience. The next chapter discusses my analysis of the interviews.

CHAPTER 4: ANALYSIS

Part one of my analysis discusses the three major categories that arose in my conversations with participants. Participants identified the categories of *health professionals*, *other people*, and *active people* as central to the activity of on-line storytelling. Because meanings of categories are constituted in specific contexts, however (Hester & Francis, 1994), I show in part two of my analysis – through more detailed excerpts from five interviews – how participants and I interacted to construct situated versions of these categories, and how those and other categories interweave to produce an account of using the Internet to tell one's story.

Pseudonyms have been used for participants. Transcriptions have not been edited, in order to show the interaction in its entirety. Underlined text indicates emphasized words, square brackets enclose notes of explanation to the reader, and '...' indicates a pause. Participants' initials precede their comments, and 'B:' precedes my comments.

4.1 Part one: membership categories across the interviews

In accounting for membership in the category *person with arthritis who uses the Internet to tell one's story*, one calls on and interweaves a host of other categories and their attendant activities, knowledge, duties, obligations, rights and identity attributions (Paoletti, 2001). Three major collections of categories

surfaced repeatedly in the 19 accounts: *health professionals*; a category I have

called *other people*, which was variously referred to as healthy people, people

who don't have arthritis, and people who don't understand what it's like to live

with disease; and *active people*, which was a little different from the other two

categories in that people not only invoked and discussed it as separate from

themselves, but attached themselves to it and claimed it as an identity in a

variety of ways.

4.1.1 Health professionals

Not surprisingly in a discussion about illness, *health professionals*

constitute a major category. In this case, the category – or more appropriately,

collection of categories – includes doctors, nurses, specialists, and an

unspecified 'they' with unquestioned authority. Activities commonsensically

connected to this group – prescribing drugs and diagnosing disease – are

glossed over in participants' discussions of their interactions with medical staff,

assumed to be what we all know about health professionals (who else would

prescribe drugs, diagnose disease?). The understanding of various other

attributes attached to the category – not listening, being impatient, not caring

about quality of life, not taking people seriously, or on the other hand, welcoming

second opinions or accepting a patient's theory about a certain symptom – has to

be worked at by participants, since not everyone may share this view of health

professionals. To this end, participants explicate their version of the category by

telling stories in which particular attributes are apparent, illustrated in the

following extract:

There was a period in 19...8...3, when I gained 20 pounds. And I went to the doctor, I was still working, doing an office job, sitting at a desk, and very busy with some night school stuff and caring for my mom each night, I would go to the residence she was living in and spend a couple of hours with her. And...I couldn't get the doctor to understand that the <u>reason</u> I had gained weight was that because my hands were so bad the only food I could prepare for myself was sandwiches! And I was eating sandwiches three times a day. Uh...because at that point my thumbs were just starting to become involved. And that is so painful when you try to pick anything up. I could for a little while use a soup spoon so I could eat soup. But...not...not well. I began to use my left hand a lot. But...I couldn't make the doctor understand that the weight gain, he says "well you've got to cut back" and I said "but what will I eat then?" and he said "well eat salads like everyone else does" and I said "well how am I going to prepare them?" And finally got him...after maybe two or three visits, to look at my hands...you know we were talking about...about telling your stories to the doctors. And I thought that was just so important at the time...that no one was listening to why my weight gain was there. They were testing my thyroid and all sorts and I said no, no it's the food I'm eating. Because you know it [arthritis] just changed the way I was living. (Anne, personal communication, September 24, 2004)

In this extract the doctor is positioned as doing what doctors do (administering tests, advising about weight loss) but ignoring her unique situation (assuming she could just eat salads like everybody else). His not listening is underscored by Anne's rejection of the identity – both to the doctor and to me – of someone who would gain 20 pounds simply by lazing around. On the contrary, she worked hard, went to school, cared for her mother every evening *and* ate soup instead of sandwiches until it was no longer possible. Her diligence is also evident in her persistence with the doctor, which paid off after two or three visits when he finally looked at her hands. This extract calls on my understanding of the medical profession as necessary for ordering tests and looking at hands but

unconcerned with mundane aspects of daily life such as preparing meals or caring for a sick parent.

Another participant evokes this category and its attributes by contrasting it with a different category:

> 'Cos I just…if there is one take away message for me it's just…you know, the doctors…I just…I just would never have got the help that I truly needed, you know, I really…and I think just the whole concept of losing control with the medical system, you know and then finding a group, and it was through the Internet then the control came back and with it the power and the self-empowerment. (Nancy, personal communication, September 30, 2004)

The fact that there is 'one take away message' in the whole interview underscores the importance of this category to Nancy. She stops short of actually saying what the doctors do or don't do (the doctors…I just…) but calls on a shared cultural knowledge of what they are like (you know) before and after she attaches them to a 'system' in which it should be understood as easy to lose control. Control is then regained through another category (a group on the Internet) that is the opposite of the health professional category she describes.

Although this category is invoked in all the interviews, it is not always with frustration. In one or two cases health professionals are discussed as partners or allies, and Internet use, rather than positioned as an escape from an unsympathetic medical community, is positioned as a vehicle for information gathering to enhance that partnership. Even in those cases, however, the attribute of 'not understanding' is still evident in the transcripts (see for instance David, in part two of the analysis). Throughout the interviews, then, the category

of the health professional as someone who plays a vital role, but can't meet all needs, is constructed to account for storytelling on the Internet.

4.1.2 Other people

This collection is variously referred to as people who don't have arthritis, people who don't understand, and healthy people. Depending on the situation, it includes colleagues, friends, family, society, and even health professionals (although the latter usually have additional attributes attached to them, which warrants putting them in a separate collection). In evoking this category, participants create a version of the world in which they are not understood or not taken seriously, and in which storytelling on the Internet allows them to escape such misunderstandings, or connect with people who *do* understand.

Stories of other people offering unwanted advice are common in the interviews, for instance:

> Without the prednisone [a drug used to treat rheumatoid arthritis] you're without life. It's that bad. So when people say [mimics speech] "Oh you should never have taken prednisone" I think no, I should have just curled up in a corner and died! (Helena, personal communication, September 24, 2004)

The category of people who don't understand is invoked here in the mocking tone a participant uses to show me what kind of advice someone from this category might offer. I am called upon to recognize the ridiculous nature of the advice, not only through the mocking tone, but through an explanation of how bad arthritis can be if one doesn't take strong medications (you are without life; and may as well curl up in a corner and die). A number of people told me they

had given up trying to educate people about such matters, which may account for why Helena didn't *say* anything back to people who say things to her, but only *thought* her response. Another strategy used to invoke this category is to contrast it with a different one:

> You're either well or sick. You're either gung ho and healthy or we aren't. And I think you can put a lot of the overweight people in that...there's a whole bunch of people that are...that...don't fit the norm and that...that's where it...uh...I see the division. If you don't fit the norm, like I find a lot more acceptance in the people that are disabled...because they have a disability too. So we have that in common. (Helena, personal communication, September 24, 2004)

In this excerpt, Helena has divided the world into two: those who are well and don't understand, and those who are not well or 'don't fit the norm' and *do* understand. The former category is called into being through an explanation of what they are *not* and what the latter category *is*: accepting.

The last excerpt shows how the category is invoked slightly differently – with understanding:

> I work with nurses and <u>they</u> don't really know what rheumatoid arthritis is. Why would they? We don't...we don't see them in hospital much any more because we're able to function and stay home. Sort of. And those that don't function quit work. So you don't see them in the workplace. And you don't necessarily see them on the streets 'cos they may not be able to walk, may be in wheelchairs, so you may not see them in your everyday life. So...it's...it's not a very visible disease? (Terry, personal communication, September 29, 2004)

Even nurses, who are in contact with ill people through their work, might not understand what it's like to have arthritis, says Terry. But she also points out that we shouldn't expect everyone to know what arthritis is (why would they?) and then goes on to offer an explanation of why they might not. As part of her

explanation, Terry uses the category of *people with arthritis* to account for why others might not understand: people with arthritis are either functioning and hiding it, or staying at home and hiding it.

Regardless of exactly how the category is described – with frustration or with some understanding – it accounts in most of the interviews for people using the Internet to tell their story.

4.1.3 Active people

Most participants brought a category of *active people* into their accounts. The category was different from *health professionals* and *other people* in that as well as invoking it as a category apart from themselves, participants also claimed it as their own identity. 'Being active' seems to have several meanings: involving oneself in physical pastimes, being a productive member of society, being motivated to seek treatments and get well, or helping other people to get well. In all cases, the category seems to be used as a moral claim (Schneider, 2003), drawing on a shared cultural understanding of activity and productivity as desirable and expected ways to behave.

Some accounts revolve around how physically active people were before they had arthritis:

> As a kid, you know right, just every...team sports, you know, field hockey, a lot of field hockey from...grade five 'til...after high school...any sport imaginable. A lotta track, during school, and... soccer and...and you know once I graduated just...always in sports...never ever had a pain in my life. And then when I hit...about the age of 35, and I was...I'd already run a couple of marathons, and you know, I was a high level squash player, so I mean I could just...do it all. And then one day I was golfing, and I

just got a sharp pain in my left hip. At the front of my hip. And I thought that's a weird place to pull a muscle! And...you know...I just kinda...kept golfing, and ...you know ...as I'd go for my runs the pain got worse and worse, and...and...just couldn't...I kept thinking I'd pulled a muscle. So anyway finally I went to the doctor and said god, I hate to be here for a pulled muscle but...this darn thing won't heal. (Nancy, personal communication, September 30, 2004)

Nancy claims a place in this category by listing the great number of sports in which she was once involved, explaining the lengths to which she went to keep physically active even after she started to feel pain, and revealing her reluctance to bother her doctor (I hate to be here for a pulled muscle). The intention seems to be to demonstrate she is not the type of person who would easily submit to a disease unless it was very serious. When the diagnosis was rheumatoid arthritis, she could no longer be physically active but as she explains it, she instantly jumped into researching about it.

Not everyone I interviewed had such an athletic background, but all accounts displayed people's 'social fitness' as productive members of society – or their desire to regain that fitness. For instance:

But I think I'm not gonna get my full self back until I can get my arthritis under control and be able to have a job and feel like I'm part of society. 'Cos I think that's the biggest problem is that I'm not really part of what society seems...calls normal. (Georgia, personal communication, September 16, 2004)

Above, we see *other people* (society) apparently not understanding what it is like to have arthritis, but they are also implicated in defining norms – productivity and activity – with which Georgia wants to identity. Getting arthritis

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under control is discussed as something Georgia takes responsibility for and is capable of acting on, which will enable her to be part of society.

Accounts of activity also revolve around people's reluctance to give in to their disease, for example:

> Like when I go to the doctor they ask you to fill out these forms like do you need help dressing, do you need help brushing your teeth, do you need help eating, do you need help with this do you need help with that…and even at my absolute worst, I answer no to all those questions. Because I refuse to let people help me. Because if I do it means I've given in. I mean I'll ask for help for certain things, like I can't clean sometimes or…I can't mow the lawn, which I have to do sometimes because of…it's too long and I can't find the dog poo [both laugh]. You know? It's…I mean sometimes I get forced to do them but…I mean for the most part there's certain things I just can't do. I won't go and wash a whole counterful of dishes, I'll just go and throw them in the dishwasher 'cos I <u>can</u> <u>not</u> wash them. It hurts too much. (Georgia, personal communication, September 16, 2004)

Even at her absolute worst, says Georgia, she refuses help because it means giving in. She contradicts herself in the second half of the excerpt by admitting she will ask for help for certain things – things she cannot do (because it hurts too much). The excerpt can be seen as a moral claim: she will refuse to give in to the extent possible, but because she is ill, she shouldn't be expected to do everything and in fact should be credited for understanding that she cannot do everything.

Another strategy involves distancing oneself from people who are not active:

> I think…I think people with chronic disease, from the various meetings and forums that I've been to can be literally divided in half. There's those that can't deal with it and they become whiners

and they are those who get sick and get worse. And there's those who say ok I'm going to live with this, I'm going to deal with it, and I'm going to get on with my life, and they're going to do better. (Terry, personal communication, September 29, 2004)

Terry places herself in the latter category and explains that such people have made an active decision (ok I'm going to live with this) while the former category simply become whiners.

Active people are thus invoked in accounting for oneself as a person who uses the Internet to tell stories, whether it is to demonstrate responsibility for one's health, to connect with others who can share health-giving advice, or to play a role in helping other people deal with arthritis. In all cases, activity is used as a moral claim to social fitness.

4.1.4 Summary

The above three categories are invoked in the interviews repeatedly in order to account for storytelling on the Internet. However, it is the subtleties of categorization, the interweaving of them with other categories, and their invocation as part of an interaction between researcher and participant, that brings out the finer points of the analysis, as I show in part two.

4.2 Part two: an analysis of five stories

The following five analyses show how the above categories and others are connected in individual stories. As discussed, there is one story from each of five interviews analysed in-depth: Anne defined her arthritis as coming on gradually over many years; Charlotte says she was suddenly struck and profoundly

affected; the onset of David's arthritis was sudden but after surgery he considers himself healthy once again; Linda has had arthritis since she was very young; and Karen says her arthritis came on very suddenly but she is coping. Each section contains several extracts from a detailed analysis of the whole interview, which was framed by the topic of telling your story on-line as a person with arthritis. In each section, I also include excerpts from other interviews to further illustrate various points.

4.2.1 Anne

Anne is a single woman in her early 70s whose osteoarthritis started to develop when she was about 45 and which has become worse over the years. She reports being very desperate at times because of the restriction arthritis has caused her and the 'full blast' nature of it, as she calls it, in many of her joints. Most of Anne's storytelling on the Internet takes place in an on-line discussion group, which she says connects her with like-minded people who understand what she deals with on a daily basis.

Through the extracts below I show how Anne and I interweave some of the categories discussed above to account for her on-line activities. Just before the following extract, I had asked her if she sees storytelling as important.

> A: Oh, I do, totally! I mean...wh...when you get to a certain age and you have a chronic condition...you're still the same person who got up and went to work at your job. You've got your working personality. When you're...when you have someone who has a chronic condition, and you've had to retire, or you're, it's time to retire, um...who are you? Are you umm...you're still a daughter, a mother, um, a friend, but...if you go to a ...go to a party anyway, and people say "Oh, nice to meet you, how do you do?" um and

and what do you do? Well, when you're retired what do you say? Particularly when you had to take an early retirement. What do you say to them? "Well I um...I get through my day." And...immediately it sounds as if you're asking for sympathy. And most people with a chronic condition don't want sympathy. That's the <u>last</u> thing they want. They want understanding. They don't...sympathy is...forget that, you know everybody breaks down and cries when it's sympathy time. You want good practical ideas of what you can do...I I'm off on a tangent there.

B: No, no, it's perfect, because it's really clicking with something that someone else [another participant] said to me...about understanding. She felt guilty because she felt like she was lying.

A: Oh yes, big time! Mm hmm! [pause].

B: They wouldn't believe she was tired... "How can you be tired, you're in your 20s?"

A: How can you have fatigue when you're 20, mm. People, oh, that is so important, a lot of the chronic conditions have fatigue and people say well, I just can't do it I was trying to explain at um...to a group at the church the other day why I can't go to a meeting at two o'clock in the afternoon. And I said "I'm sorry but that's my nap time." And they said "Your nap time! Have your nap at night! What are you doing napping?" And I said "I have to because if I'm going to breathe and if I'm going to be able to swallow my dinner, I need to have ...be horizontal for three quarters of an hour in the afternoon! If I'm not, I have to build my day around making sure there's somebody there if I suddenly start choking. Because that's what'll happen." "But you look so fine! Oh, it'll be good, come on anyways, you know. "

What emerges in the above excerpt is the distinction between those who have arthritis and those who do not. Anne not only belongs to the former category, but she speaks on behalf of them and positions them as responsible and productive (they want understanding and practical ideas). The latter category is set up in opposition as just 'not getting it' – not only not getting it, but being particularly harsh, as evidenced in Anne's repeating their dialogue ("Have your

nap at night! What are you doing napping?"). Although Anne appears to have no

patience with their insensitivity, she seems to need to justify her behaviour, both

to them and to me, which she does through an explanation of the dire

consequences of not napping (I won't be able to breathe). According to her

account, they even ignore that ("Oh, it'll be good, come on anyways") – they have

the last word in this explanation.

Although I belong to the category of *other people* and therefore may not

understand either, my membership in the category of researcher – presumably

someone who *wants* to understand – seems to take precedence. Anne

acknowledges my place in this category by being concerned about how she

plays the role of interviewee (I'm off on a tangent here). In return, I give her

account credibility by not only telling her that her response is perfect, but by

telling her another participant has made a similar comment, and prompting her to

elaborate (They wouldn't believe she was tired...)

In the following excerpt about storytelling in an on-line discussion group,

Anne is again setting up the categories of those who are ill and get it, and those

who are not, in opposition. The importance of connecting with people who are

like you is literally underscored:

> A: When you're telling it on-line you're not expecting to get back
> that awful 's' word, the sympathy, whether it's fake or real. You're
> not ex...expecting to get that when you're on-line. You <u>know</u> you're
> not going to get it, you know that you're talking to people who are
> <u>like</u> you. This is the advantage of being on-line.

In the context of the full interview Anne's identity comes to be understood

as a responsible, hardworking, adaptable, helpful and caring person who has

arthritis, who has an expertise different from but complementary to that of the medical profession and an interest in 'good practical ideas' that will help keep her healthy. We have created a version of the world in which there is not much appreciation of or acceptance for what it is like to have arthritis – even sometimes among friends and colleagues – and therefore one in which it makes sense to engage in on-line storytelling with people who understand what you are going through and who will confirm your status as a fit participant in the activities of the social world.

A similar picture of the world is evoked in most of the interviews. Kyla, for example, spoke of the insensitivity of friends who make 'lifestyle' recommendations:

> People say to me oh you should do the health route, you should get off all those drugs...I'm lucky I can tie my bloody shoes! I'm not messing with anything! (Personal communication, October 16, 2004)

Peter spoke of the frustration of having an "invisible disease" and the fact that with arthritis there is "no blood on the floor":

> Nobody can understand what it is to have arthritis that hasn't had it. They may think they can but they can't...uh...unless you've got something that hurts, and nobody's gonna apparently do anything about it. And it hurts and hurts and hurts, and some days hurts worse than the others, and it's hard to tell somebody that hasn't got any of that. It's desperately hard. And...and you just can't convince them. (Personal communication, October 16, 2004)

4.2.2 Charlotte

Charlotte is in her early 20s and lives with her mother and father and a brother. She had just finished a Bachelor's degree and was about to enrol in a teacher's training certificate program when she was diagnosed with arthritis, which she describes as striking suddenly and profoundly affecting her. Charlotte explains her life over the last few years as one setback after another, involving not only the symptoms associated with arthritis, but the ongoing health problems she suffers as a result of a bad car accident after she got arthritis.

Charlotte's account is different from Anne's in a significant way: she doesn't want to connect with people who have arthritis – or at least she says she doesn't want arthritis to be the *reason* she connects with people. Her on-line activities – participating in an on-line gaming community and keeping a blog – do not involve an arthritis community, although she does consider herself to be telling her story on-line.

The collection of categories I have called *health professionals* takes the lead in our discussion. It is invoked through references to typically-expected activities such as diagnosing disease and providing treatment, but it is also constructed as a category that doesn't take people seriously. The strategy Charlotte uses is to cast herself, through dramatic storytelling, as someone who is obviously so ill, it is absurd *not* to take her seriously. This extract relates a scene that took place after she had been to the doctor several times and been told nothing was wrong:

C: I was...21...and I went to the univers...I was still going to university, so it was kind of hard to do, take notes and whatnot, but my professors were pretty understanding I could photocopy some things. And um...I was just on a basic anti-inflammatory. But in...later on? In the spring? My symptoms started to get worse, and all of a sudden within the space of three days maybe or so? Um, my feet started to swell up and everything else followed in rapid succession, and before I knew it all my joints were swollen and...within a month I was like basically stuck...in bed. And I couldn't even...because my jaw was so swollen, I couldn't even fit a grape in my mouth it wouldn't open at all. I was stuck on a liquid diet for a couple months because of that. I coul...I couldn't do anything, like if I was in bed and I wanted to lift my knee up I'd have to get my mum to lift my knee up. If I wanted to ...do anything at all...like I couldn't do anything. 'Cos of my shoulders and my legs and everything was just so bad. And um...yeah... I basically lay in bed and listened to books on tape and radio because I couldn't do anything else. And um...then my rheumatologist was so... scared because it just flared so fast that she referred me to [another specialist].

To invoke the category of health professionals as those who do not take people seriously, Charlotte has positioned herself as someone who is responsible (at university trying to 'take notes and whatnot' even though it was difficult) and seriously ill – clearly someone who should be taken seriously. Her account calls up 'serious illness' by shifting suddenly from uncertain, questioning comments (later on? In the spring?) to a rapid-fire commentary on how the disease swooped down on her and rendered her immobile to the extent that despite her being a grown woman, her mother had to lift her knee for her. Even the rheumatologist – a specialist herself – became scared and referred her to a new specialist.

Charlotte relates several other incidents that serve to construct this category, including being dismissed by a doctor as not needing a CT scan, when ultimately a scan revealed a ruptured spleen from which she nearly died, and

being refused admission to a live-in treatment facility until they finally realized how ill she was.

A similar view of health professionals was presented by Susan as she described her relationship with a surgeon who did not want to engage in any discussion about various options, preferring to adopt an 'expert knows best' attitude with her. Intimidated, and feeling she did not have enough information to make a decision, she withdrew her name from the surgical wait list. Here she describes the surgeon's reaction:

> Like he was really mad and he...he was...he was...it was very unpleasant. I got out of there like really like shaking and...um...because he said...uh, you know he...accused me of putting him in a ...a bad situation towards the hospital and I was telling him like it was a month before, so it's not like I was telling him you know a few days before surgery I don't want to do it, it was plenty of time...and there's tons of people...(Personal communication, October 14, 2004)

Although Hannah describes her doctor, as 'a good doctor,' she says:

> You just know they don't really understand. They don't... I don't think they understand the pain people go through. With the arthritis. (Personal communication, September 20, 2004)

In all interviews, including Charlotte's, the medical expertise of health professionals – once they take people seriously – is never in question. Charlotte, however, unlike most participants, does not turn to the Internet or to other people to get what the medical profession cannot give her (for instance practical advice and understanding). Her account reveals a desire to forget her arthritis altogether, because other people do not understand, do not seem to *want* to

understand, and ultimately cannot help her. This exchange took place when I asked if it would help if people listened to her story:

> C: They could listen, but...physically, they can't do a whole lot about it, so that's part of why I think they don't want to talk so much about it. If there's something they can do to help? Well sure, tell me what the problem is and I'll try to fix it, but if it's not fixable...
>
> B: Yeah, people like to fix problems.
>
> C: Yeah, they like to fix problems. And if they're not fixable, then people don't...like to know that they exist.

In this extract, 'just listening' is not going to do much – as far as she is concerned, as far as *other people* are concerned, and even, as shown by my agreement, as far as I am concerned.

Unlike Anne, for instance, Charlotte distances herself from people who have arthritis by insisting she is the same person she was before she got the disease, even though other people may not realize it. Her on-line activities connect her to a community of people (on-line gaming) that have nothing to do with arthritis (although they know she has it) and give her an outlet (her blog) to write about the ups and downs of living with the disease:

> C: I write uh...yeah I write in there...and um...just ah...people on-line can read it, and they can make comments if they want, but that way you don't have to tell everybody in your daily life you know, what I... struggle with, I can get it out of my head and onto the computer and just kind of like, people can see it if they want to but if they don't wanna listen to me they don't have to. So only people who wanna listen will be the ones who'll use it if they want to.

By distancing herself from the category and 'getting arthritis out of her head,' Charlotte rejects identities that she feels physicians, her family and *other*

people might have of her as a person with arthritis, including demanding patient, dependent daughter and 'a different Charlotte since she got arthritis.' In the context of this interview, Charlotte's identity is constructed as a responsible, independent young woman who wants to become a teacher but whose independence and career path have – temporarily, she hopes – been diverted by a series of setbacks. By constructing in this interview a version of the world that seems to exhaust her with its various demands and expectations, Charlotte and I account for her storytelling on the Internet as an escape, albeit one that allows her to stay connected to herself through writing about her feelings, and to others who read her story if they want to.

4.2.3 David

David is a married university professor in his mid-50s with grown children. He was diagnosed several years ago with arthritis in one of his hips. He describes himself as an active person prior to getting arthritis, and after having a new type of surgery that seems to have fixed his hip, is active once again. In some ways, David resists speaking as a member of the category of *person with arthritis who uses the Internet to tell his story*, positioning himself as someone who *did* do that, but doesn't now because he has recovered. At the same time, he makes it clear that if he has more trouble – in his other hip, for instance – he would not hesitate to do the same. For David, storytelling on the Internet helped him deal with a situation at hand – in this case by connecting him with a group of people who were discussing a particular kind of surgery.

David's identity in this account is closely tied to the category of *active people* who are involved in sports, busy in the world, and in control of their lives, including being responsible – with the guidance of health professionals – for their own well-being. His activeness is invoked in the story he tells and through the way he tells it: a straightforward, chronological account of a quick diagnosis, an intense search for the best treatment option, a surgery, a fairly rapid recovery, and an account of how he has 'moved on.' This control is evident from the beginning of our interview as David talks about his conversation with a surgeon:

> D: And I said "Well what's my options?" And he said if you go on that doesn't mean if you your time uh…you know when you come up to the top of the list if you're not quite ready yet you don't go to the back…to the bottom of the list so there's really no disincentive for not actually going on the list and I'm just really pleased that I did because then basically it enabled me to have the operation exactly when I wanted it. Um…
>
> B: And that was the hip replacement?
>
> D: I'll get to that.
>
> B: Oh sorry, ok.
>
> D: It's all right, not…it's just this is kinda the full story.

The above extract positions David as an active person, both in health care decision-making (asking the physician for his options, making his own decisions about going on a list and deciding when he is ready, finally getting an operation when he wanted) and in the interview itself (making it clear – when I interrupted, thinking he had finished talking – that he is in control of his story). I support his identity by acknowledging his activeness in and control of the interview (oh, sorry, ok).

David is also active in his search for information to complement his physician's knowledge of the surgery he was considering – information that he obtained through telling and listening to stories on a discussion group:

> D: But in a sense what you've got here and that's what interested me about your project ah you've got an incredible resource of people who've actually experienced this...these phenomena. And most doctors don't...I mean most doctors haven't had hip operations themselves. They've never really had the kind of actual experience of going through these things. And so they have to do everything vicariously. Either through their own patients or through the literature. And when...in a procedure like this the literature just isn't that large yet. Uh which is why a lot of doctors are um...have the kind of response that you mentioned earlier that...of suspicion, concern...[I had mentioned a participant's experience with a doctor who did not appreciate being told about treatment options by patients].
>
> B: He seemed almost offended.
>
> D: Yeah, well that's the whole doctor thing. That...that...doctors have to appear infallible.

In the above excerpt, David makes clear how important it is to talk to and hear stories about people who have similar experiences to one's own. By not having that experience, health professionals are invoked, as in the other interviews, as people with unquestioned expertise (doing surgery) but who cannot meet all of one's needs. The casual way in which we discuss what he calls 'the whole doctor thing' makes common sense of the fact that physicians can be touchy, suspicious and capable of being offended at the same time as being medical experts, especially when David presents an excuse for them in this case (the literature is not that large).

Finally, as an academic, David knows how research interviews are conducted and has an understanding of the computer-mediated communication literature. It is from that perspective as well as one based on his own experiences that he offers a closing comment about storytelling on the Internet:

> I think it gives people access...to stories and information...in ways that you just would never have had access to in the past. And so in that sense I think the Internet is beginning, you know it's not a bad example of what some of the initial theorists and advocates of the Internet 15, 20 years ago as it was coming on-line were arguing that it would be a liberating, democratic ah forum. And ah, and I think this is...not a bad example of ...that appearing.

Here David is offering his experience as a person who has told his story on the Internet, and providing a perspective on the Internet phenomenon based on his knowledge of relevant theories. In the context of this interview, then, David and I have attributed to him the identity of active, capable, knowledgeable and busy professional who is as much aligned with me – perhaps as a mentor who has done many years of research compared with my couple of years – as with people who have arthritis. Having experienced arthritis as a bit of a blow to his self image as an athletic person, David's goal was to get back to a reasonably active lifestyle again. The Internet is positioned as a tool to help him reach this goal, and storytelling as a way to gain expertise on his condition and the options for treating it.

Most participants displayed a level of similar 'activity' – especially related to health seeking behaviour and 'social fitness' – during the course of the interview. Martina, for instance, downplayed the effect of arthritis on her life and distanced herself from people who use arthritis as an excuse to 'do nothing':

I always support the positive ways. You know, right? There's always positive and negative. I'm part of a young group here and I find generally speaking, I cannot say everybody, right? But most of the young people take it like for not doing anything. I know [someone who] thinks 'I'm young, I'm like 19, 20, and I'm disabled. And I'm disabled and I don't wanna go to university, it's too painful for me. I don't wanna do this, it's too painful for me.' Ahhh! And in my eyes, she is absolutely healthy. Like just for the little thing like our joints. Well for me it's nothing, right? So she took somehow saying I have arthritis and poor me. Right? The world has to give me everything because I cannot do anything. (Personal communication, September 17, 2004)

Even when people are talking about being *in*active, they make it very clear that they know activity that is praised by society. This excerpt from Holly's interview is an example:

I inwardly feel sick but I don't feel...because I don't show it, who else cares, you know? Like there are days when I just wanna stay in my housecoat and do nothing all day. And I feel guilty? 'Cos I feel I should be opening the drapes and saying hello to the world and sometimes I don't want to (laugh). (Personal communication, October 29, 2004)

4.2.4 Linda

Linda is an Indo-Canadian woman in her late 20s who lives with her mother and her two brothers and their wives. Linda has had arthritis since she was two. Her condition seems to be very serious, judging from the more-than-a-dozen operations she talks about having had over the last 20 years.

Linda identifies very strongly with her culture, and would like to marry into an Indian family. Since her parents did not arrange a marriage for her due to her arthritis, she uses the Internet to meet potential partners on dating sites. Similar to Charlotte, then, Linda's on-line activities do not involve a community of people

who have arthritis, although those activities are relevant to her identity as someone with the disease.

Although Linda's story turns on all the categories described in part one, *health professionals* seem to be less relevant, with their strengths (saving her life) and weaknesses (taking forever to make a diagnosis) simply accounted for as common sense activities related to that category. The collection of categories she draws on most is *people who don't understand what it's like to live with arthritis*, which includes employers, society, and guys – especially East Indian guys – and even her family and its culture, despite how strongly she identifies with them.

Because Linda's account of storytelling on the Internet relates so strongly to her cultural background, and because I do not know that culture, Linda's strategy is to educate me, as shown in this long excerpt:

> L: In my culture you're not supposed to sleep with a guy...'til you're married? Um...that is looked upon like...giving your family a bad reputation or giving yourself...like a bad name, to your family, to yourself. Um...you're embarrassing them, you're putting the family down. Um...and even like the whole marriage thing it's like, we still have introduced marriage, introduced marriages like I might tell my, like I may have a guy friend and he's looking for a girl to get married to and my friend might be looking for a guy to get married to so you kinda introduce them? And then they might talk for like a week or two weeks and...or a week and then meet, and...talk and see each other two or three times and be like ok we wanna get married to each other? Then it becomes official between the two families? Like the families then meet?
>
> B: So... it's not really an arranged marriage, it's ah...
>
> L: Kind of like a introduced marriage. You know? Like...and then the family will give the guy money, and the guy's family will give the girl money? But at that point it's basically like...a settlement has

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been made, an arrangement, right? And then you start planning your wedding but at the same time you're getting to know each other?

B: So part of your interest in meeting someone has to do...

L: With that, yeah.

B: With the expectations of your culture, your fam....

L: Yeah. And...because everybody is like, there's so many weddings, it's like unbelievable, like it's like ok so and so's getting married, so and so's getting married, when am I gonna get married? When am I gonna find somebody to like me for me, you know? What's happening for me? But sometimes I think I'm not capable of being loved. That...ah...someone's not gonna accept me for me? And I've also been brought up with the parenting that...because you have a disability, no Indian guy's gonna marry you.

B: Is that what you've heard, or is that the feeling you get?

L: Yeah that's what I ...my parents used to say.

B: They did?

L: That no guy's gonna marry you after we pass on ...like we, we'll take care of you, and after we pass on your brothers will take care of you?

In this extract, Linda and I work over several conversational turns to develop an understanding of what happens within her culture related to marriage. I ask for clarification (so...it's not really an arranged marriage...), she makes sure I'm following (you know?), I show what might be perceived as disbelief or shock that her parents would tell her that no Indian guy will marry her (they did?) and she repeats that no guy will marry her. The understanding is further developed on the basis of a shared commonsense notion that people should not put their

families down or give them a bad name, regardless of culture. In this extract, although Linda identifies very strongly with her parents and her culture, they are still positioned as not understanding that she is capable of being loved and could be happily married despite having arthritis.

Also in the collection of categories of *people who don't understand* is mainstream society in the city in which she lives:

> L: I don't like society here so much. I find society here to be…I don't know if this is like hypocritical like I'm not saying everybody is like this but mainstream? I find it here like everybody's too…fake? Too um…nobody cares about each other, it's all about you and the way you dress and…um…your body shape and…you have to be tall and thin and pretty. Um…you have to have the right cars the right…stuff to be accepted, almost?

Linda's hesitation in introducing the words 'mainstream' and 'fake' – as well as her assurance that probably not everyone is like this – indicate a desire to secure my understanding further, perhaps because I am part of this mainstream culture. In the above extract, a category of people with arthritis is evoked as *not* being what mainstream society values (tall, thin, pretty and in possession of the right cars) and accepts.

People with arthritis – in fact ill people in general – are discussed similarly by many other participants. Ursula describes how there seems to be very little patience in society for people who can't move quickly:

> I think that it's not just arthritis, I think it's for…people tend to turn a blind eye to anybody who has difficulties. Yeah, I mean even travelling on the bus sometimes, most of the bus drivers are good but there's a few of them that are really, you know, hurry up and get on the bus! You know? And they…they can be very cruel to people

that you can see are...having a great deal of trouble. (Personal communication, September 22, 2004)

The idea of one's 'lack of value to society' as an ill person surfaces in my interview with Natasha, as she speaks about her former co-workers:

I'd worked with them for...well two [of them], 15 years. And when I got sick, they totally dropped out of my life. And I would call, and I could feel this coldness, and those...there was two or three and I haven't seen them for...and I couldn't figure that out. That hurt. But I think it's the same as...my boys [her sons]. They didn't know how to deal with it, they didn't know what to say, and the easiest thing was, you know...that's it. (Personal communication, October 6, 2004)

Returning to Linda, although she does not attach herself to a category of physically active people, her claim to social fitness is evident in the stories she tells about stoically weathering the ups and downs of a serious illness and making decisions about treatments and timing of surgeries. Her identity in the context of the full interview is therefore constructed as someone who has overcome many obstacles and achieved much, and who has definite ideas about how she wants her life to be, yet who still lives in a world in which she is measured on what she *cannot* do (make chapattis for an Indian husband, take care of children). Storytelling on the Internet is therefore accounted for as allowing her to pursue the life that she wants and that other people are preventing her from having.

4.2.5 Karen

Karen is in her 50s with grown children, lives alone, and works as a realtor. Like David, she describes herself as an active person who, before she

got arthritis, was 'always moving at a hundred miles an hour.' She says her arthritis came on suddenly: from a few aches and pains to 'Oh my god, what's happening?' Fortunately, she says, she was diagnosed quickly and put on drugs that relieved her symptoms effectively. As such, she describes herself as being hit suddenly but coping well.

Not a frequent Internet user normally, Karen developed an e-mail relationship with a woman who has arthritis whom her acupuncturist put her in touch with, and with whom she shared stories for several months over e-mail. Since she has come to terms with having arthritis, Karen does not tell her story on-line any more. As such, like David, she seems to distance herself from the category of *people with arthritis* and associate herself more strongly with *active people*. In an interesting difference from most of the other interviews, she also attaches herself to the category of people who do not understand, even as she dealt with having arthritis. In the following excerpt Karen talks about finally coming to accept she has the disease:

> K: 'Cos what I realized was...this is a headspace as much as anything. I'm quite stoic in that regard. Um...it is what it is, right? It sucks, um...I can't stand areas where I've had to lose some independence 'cos I'm very independent, but hey it's not...it's not world peace. So I had to get my head around it. And once I started feeling better physically i.e. the drugs kicked in, once I started allowing myself to relax and have a sleep if I needed it, once I bought a raised toilet seat, changed all the handles on the doors, bought a fat toothbrush, all that stuff, um...I got my head around it, and ah...basically I dove right in. I got, for the first five months I had acupuncture twice a week, massage twice a week, um, which was fantastic symptomatically, um...I felt the first three or four months I felt I was kind of identified by this silly thing. It was consuming everything. 'Cos I had to make all these alterations and I had to accept the fact that I...there were things that I couldn't – or shouldn't – do. And I remember going to an occupational therapist

proudly and saying "Guess what? I opened a can of coffee!" I was so proud, and she said "No, no, no, no, no. This isn't bite your lip and climb the hill. Go get an electric opener!" That was the stuff I had trouble with right? Like 'cos I grew up where …if it was tough you get on with it….and…and…now I've gotta get the boy across the street to mow the lawn because raking hurts…my….my wrists and that kinda thing. So I had to get my head around that.

Karen attaches herself to a category of *active people* in two different ways: first by trying to remain active physically and mentally (being stoic, opening coffee, getting on with it) and second, by actively accepting that she was ill (having acupuncture and massage, buying a raised toilet seat and a fat toothbrush). She also places herself in the category of people who do not understand by talking about how she proudly told the occupational therapist that she opened a can of coffee, when it turned out that was something that could be detrimental to her health. In Karen's account, the two categories are sometimes interwoven: because she is such an active person, she cannot understand how something like arthritis (which she diminishes by calling a 'silly thing') could affect her.

Karen talks about on-line storytelling with her e-mail companion as enabling her to accept she had arthritis. She did not want face-to-face contact with someone who was sympathetic:

> K: Because for me normally, growing up, or ever since I can remember, if I'm not feeling well, I tend to withdraw. I've never liked to be pampered or fussed about. And my mum used to always say she could tell when I wasn't feeling well 'cos I'd just go off and have a sleep or read a book or lie down or whatever. So…it was interesting for me and I liked the fact that it was Internet in this case. Because it still was private, not that I didn't want anyone to know I had it, but I wasn't being fussed over, physically. And yet I was being fussed over in a support way. Somebody was there to

say "oh god I totally understand," and "I remember this," and "you'll find this." It was great.

Even as a child, says Karen, she was stoic, refusing comfort from her mum and disliking being what she calls 'pampered.' She positions needing help as unusual (it was interesting for me) and makes sure I understand that the Internet is not her first choice for connecting with people (I liked the fact that it was the Internet in this case). For Karen, there seems to be a big difference between being fussed over physically and fussed over in a supportive way, on her terms.

Nancy displays a similar stoicism in her account. Like Karen, she appreciates using the Internet because it allows her to maintain a distance:

> I think the anonymity just allows you to just...I mean I'm like this with just my own friends, I mean I just like I don't really wanna pick up the phone some nights, cos it's just, you know I might have ten minutes but I don't wanna spend 45 minutes on the phone and the friend might, and how do I control that, but on the email I just control it, and I can really give...I mean I might give you some really deep thought and feeling and story but I can just click send and shut it down. (Personal communication, September 30, 2004)

Like Nancy and David, now that she considers herself to be coping with her arthritis, Karen tends to distance herself in her account from the category of people with arthritis who use the Internet. In this excerpt, she is responding to my question about whether she belongs to any discussion groups:

> K: Who would I...why would I do that? What I mean is I have no reason, I'm not hunting for a man, I'm not...freshly out of the closet, like I'm try...I don't know why I would...do it I think there are probably great...things, I'm not being critical of it. But I'm not sure...I assumed maybe incorrectly that they were, singles over 50, or, um...canoeists of the world unite or something...

> B: Or Scrabble players! [we had been talking about Scrabble earlier].

> K: Yeah, like I...I haven't felt a need to go there for...a group activity. I think it would be fascinating, I don't quite know how you do it. I think it would be great fun but I've never done that.

Although Karen is careful to position herself in the above as not critical of people who join discussion groups, she distances herself from them by attributing neediness (looking for a man, coming out of the closet) or strange activities (canoeists of the world unite) to the category, which I support by adding to the list of unusual things people do on-line. Even though she backs down by admitting it might be fascinating or fun to join a group, she insists she doesn't quite know how to do it and has indeed never done it, thus identifying herself once again as active, stoic, and independent. For Karen, as for David, Internet storytelling was an activity that served a specific purpose at a specific time:

> C: It's about somebody...it's like a voice crying out...somebody tell me...listen to what's happening to me, or can I tell you how much I hurt and oh my god, is this what it's...what it's about?

Once she found out what it was all about, however, that was all the support she needed. In this interview, Karen's version of the world is one where bad things sometimes happen, but they are not usually 'world peace,' and it is best to deal with them – in this particular case, and in part, by telling and listening to stories on the Internet – and move on.

4.3 Summary

In this chapter, I introduced three categories – *health professionals, other people,* and *active people* – and through analysis of five representative

interviews, I showed how these categories are invoked by people with arthritis and how they account – albeit in different ways – for participants' use of the Internet to tell their story. Health professionals, while having unquestioned expertise in treating arthritis, are positioned as not understanding what it is like to live with the disease. For some people, this is very frustrating, for others it is to be expected. People tell Internet stories as an escape from unsympathetic health professionals as well as to connect with people who can share information to enhance a relationship with a health professional.

Other people are also positioned as not understanding what it is like to have arthritis – even though they may be well-meaning and loving. Participants spoke of telling stories on the Internet as a way to both escape a world in which people don't understand what it is like to have arthritis, as well as to connect with people who do understand.

Active people are invoked by participants as they make a moral claim to social fitness. By talking about how they connect on-line with others who can share health-giving advice, or how they help other people deal with arthritis, participants create a version of the world in which they feel compelled to demonstrate health seeking behaviour.

In the next chapter, I discuss how the categorization work described above reflects many of the ideas discussed in the literature review of Chapter 2, particularly those concerned with the construction of self or identity – both on the Internet and elsewhere. I present sections on the self as a 'project,' illness as a

project, and the Internet as facilitator to those projects. Finally, I discuss ideas

from other theories which I expected to play out in my data, but which did not.

CHAPTER 5: DISCUSSION

As the preceding analysis shows, interviews are settings for displaying cultural knowledge that can be used to account for oneself and one's activities (Baker, 2002). These cultural knowledges turn on references to categories – whose specific meaning is determined through the interaction – that play a central role in participants' social words.

A number of similar collections of categories are invoked in the interviews, including *health professionals, other people* and *active people*. As actors in the social world, we understand there could be several 'correct' descriptions for each of these categories, but the point is that particularly selected and developed descriptions do explanatory work (Rapley et al., 2003) in context. The explanatory work we observe in the preceding five stories is unique in each case, with people talking in very different ways about how they use the Internet, why they use the Internet, and the extent to which they use the Internet. Such talk leads to the construction of a variety of identities and versions of worlds in which Internet storytelling takes place and makes good sense. In her interview, Anne creates a world in which other people, including physicians, do not give her credit for being a responsible, sensible and practical person who has arthritis, and the Internet allows her to tell stories with people who *do* understand, therefore allowing her to claim identity as a person who practically deals with her arthritis. Charlotte's world is one in which her identity as the same person before she got

arthritis, with the same hopes and dreams, is not recognized by others. The Internet allows an escape from expectations and perceptions she feels different people have of her – her family, her friends and even various physicians – and provides a venue for her to sort out her feelings and share them with people who are interested. David's world is one in which activity takes centre stage, and knowledge is the key to regaining and maintaining that activity, in partnership with health professionals. Storytelling on the Internet[6]– for David, a sporadic activity – allows him to hear from other people who have ideas and information to share.

Linda's use of the Internet is only indirectly related to arthritis. Her world as evoked in our interview is one in which she is being blocked from having the life she would like – by her family, mainstream society, potential employers and guys – and she is active in trying to create that life through use of the Internet. Storytelling on the Internet allows her to present herself as a person who has arthritis but is also still worthy of love and capable of making a happy marriage. Lastly, Karen – whose Internet storytelling, like David's, was time-limited – presents a self that likes to deal with issues and move on. Although she was shocked by the diagnosis of arthritis – and spoke of the situation as unique in that it was impossible to ignore and simply move on from – she says she is

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[6] David's Internet use may be seen as information seeking rather than producing illness narratives. However, he identified strongly with the idea of on-line storytelling, as writing about his experiences – and reading about others' experiences – was part of information gathering. Preece (1998) points out that much of what could be called information seeking on the Internet turns into much more. She found only 17.4 percent of the messages she analysed from an on-line discussion group were "purely factual questions or answers and showed no empathy or reference to personal experience" (p. 36). She also found that when seemingly seeking empathy, men – more than women – did not ask for support directly, but tended to tell stories, which "often has the effect of eliciting empathic responses" (p. 41).

pleased with having accepted it, even though it meant adapting her life. Storytelling through e-mail with a woman who has arthritis played a big role in her acceptance.

Even though the 19 study participants were recruited into the role of *person with arthritis who tells stories on the Internet*, the analysis demonstrates how people present a range of identities to account for themselves and their activities – even, in the case of David and Karen, rejecting to some extent the identity from which they are presumably speaking.[7] The analysis presents a much different picture from one we might see in a study of one Internet venue such as an on-line support group, where people may be tempted to list pros and cons of on-line activities without putting them in the context of Internet users' lives. Much more than straightforward, uncritical reports about the benefits of using the Internet, these are rich accounts that allude to versions of worlds in which on-line storytelling – in a number of different ways and for a number of different reasons – makes sense.

Despite the differences in the accounts, it is possible to comment on the interviews collectively, a world outside the interviews, and the phenomenon of on-line storytelling. As discussed in Chapter 3, accounting practices can be interpreted in terms of more general ideologies because they draw on and perpetuate shared cultural knowledge about how the world works. As such, the categorization work done in the interviews reflects many of the ideas discussed

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[7] It is no doubt the case that different types of arthritis, the differing extents to which it affects people's lives, and different demographic and socio-economic factors are responsible for variations in people's accounts. However, as discussed, it is not the intention of this study to explore the way in which such factors account for differences in how people use the Internet.

in the literature review of Chapter 2, particularly those concerned with the construction of self or identity – both on the Internet and elsewhere. Construction is an apt word here, given the category of *active person* was invoked in all interviews and claimed in some way as an identity by all participants. Common to all the interviews was a version of the world in which activity – including physical pastimes, pursuit of wellness and social fitness – is a moral imperative. Because this version of the world is such a strong feature of these interviews, it raises questions about whether storytelling on the Internet will heighten the pressure on individuals to present themselves as socially fit, or provide them with a forum to rewrite the cultural narrative (Solomon, 2003) of social fitness, challenging its ideology. I discuss this further below.

The self-with-illness, then, is positioned within an ongoing project of the self (Giddens, 1991), which storytelling on the Internet can be seen to facilitate by helping to "keep a particular narrative going" (p. 54). Below, I turn to each of these ideas – the self as a project, the self-with-illness as a project, and the Internet as a facilitator – and discuss how they are reflected and perpetuated in interaction. In a last section in this chapter, I discuss ideas about theories I expected to see play out in my interviews, but did not.

5.1 The self as a project

Many of the distinctive features of the self today, writes Slevin (2000), drawing on Beck and Giddens, are:

> The outcome of a set of fundamental transformations that began in the early modern period. With the advent of modern society, and

parallel to the institutional contexts in which it exists, the self has to be reflexively made. (Slevin, 2000, p.157)

Faced with unprecedented levels of choice in daily life, in part because of a loss of traditional guidelines and former systems of authority on which to rely (Tucker, 1998), people in Western societies must "produce, stage, and cobble together their biographies" (Beck et al., 1994, p. 13), making sense of overwhelming amounts of information from a variety of sources, none of which can be considered ultimately authoritative. This period of what Beck et al. (1994) refer to as reflexive modernization affects how we 'do' life, including how we feel about ourselves and how we interact with others. It can also be seen as accounting for the self as a project (Giddens, 1991; Holstein & Gubrium, 1999; Slevin, 2000; Tucker, 1998), which engages people in the continuous construction of identity. Rather than being transformed by forces that operate behind the backs of individuals, our selves are seen as "actively and intelligently involved" (Slevin, 2000, p. 157) in this project. However, selves are not autonomous, and self-construction cannot help but be conditioned by a sense of what we should be in particular circumstances, as well as by social arrangements within which selves are produced (Holstein & Gubrium, 1999). Such involvement and conditioning are highlighted through an ethnomethodological analysis of interview data, in which the meaning of the categories we use to make sense of the world are constructed based on shared senses of how to 'do' social life, and in this case, how to 'do' illness in social life.

A significant way in which people engage in the self as project, establishing and re-establishing identity, is through narrative (Schneider, 2003).

Keeping a narrative going through an engagement in relationships and activities that enhance it is fundamental to one's identity, suggests Giddens (1991). Holstein and Gubrium (1999) draw on these ideas in their discussions about the self and its journey, sociologically speaking, through history. It was only several centuries ago, for instance, that the subject as an individual was constituted as separate from the church and state, with never-before social, legal and moral dimensions. Today, Holstein and Gubrium refer to a postmodern[8] self that is "filled to capacity...by the ever-increasing demands of life in a consumption-oriented, media-driven world" (p. 9). Rather than submitting to ideas of the postmodern-self-at-mercy-of-the-social, however, the authors suggest the self is more actively formulated than some commentators would have us believe: "The self, in other words, is not only something we are, but an object we *actively* construct and live by" (p. 10). Holstein and Gubrium suggest that 'restorying' the self, by drawing on resources provided by life circumstances and cultural knowledges and discourses, constitutes this active construction. This observation plays out in my 19 interviews, as participants draw on shared cultural understandings to invoke categories in accounting for themselves. Illness itself, as presented in the interviews, is one of the resources used in the ongoing construction of the self, with the Internet used as a tool for this construction as well. I discuss these areas next.

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[8] Holstein and Gubrium's use of the term postmodern aligns with Gidden's term of 'late modern': it is the latter I have used throughout this thesis except with specific reference to Holstein and Gubrium's work.

5.2 Illness as a project

Approaching the self as a narrative project corresponds with discussions of late modern illness, described by Morris (1998) as the ways in which we "[reconstruct] illness through the distinctive stories we tell at a time when the major cultural narratives of illness are seriously in conflict"[9] (p. 277). Under the conditions of late modernity, the experience of illness has been considerably reshaped. (e.g. Bury, 2001; Gwyn, 2001; Morris, 1998). Where once the patient's subjective experience provided the evidence on which the physician would act, with the rise of scientific biomedicine and the advent of ever more sophisticated technology, the importance of the patient's experience diminished. Increasingly, the physician was able to 'see' – and ostensibly understand – the disease without the patient's help. Disease slowly became separated from the individual, in no way linked to his or her circumstances, lifestyle, beliefs or values. The effect was to render the patient – an apt word, in this case – passive and silent. Perhaps in reaction to the medical model – which still has both feet planted, if not completely firmly, in much earlier times – there is evidence that people are challenging the passivity of the sick role (McKay, 2001), shifting the experience of illness in late modernity (e.g. Bury, 2001; Hardey, 2002b; Hawkins, 1999; Morris, 1998).

It is one thing to challenge the passivity of the sick role, however, and quite another to take full responsibility for both *being* sick and for becoming – or

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[9] Bury (1991) cites the following reasons for such conflict: the increasing impact of degenerative and chronic illnesses which can be only managed, not cured; a renewed emphasis on primary care, as high-tech biomedical care becomes more and more expensive; a recent reduction in hierarchical relationships; and an unprecedented expansion of information about disease through various media.

at least appearing – well. Aspects of this responsibility surfaced in my interviews

as people talked about protecting their credibility as ill people with other people –

including health professionals. Pitts' (2004) research about websites constructed

by women with breast cancer reminds us that empowerment can be a double-

edged sword, on the one hand freeing people to redefine their experiences on

their own terms, but on the other leading to new burdens related to preventing

and managing disease. The conditions of late modernity I have been discussing

in this chapter raise a question about the role of the Internet in the emergence of

a felt need (Ziebland, 2004) to present oneself as a socially fit person-with-

illness.

There are many different ideas about why people might take on such

responsibility for their health and feel pressure to demonstrate this social fitness.

Gwyn (2001), for instance, discusses "the quest for total health" (p.7) as a recent

phenomenon fuelled by "advertisements, television programmes and films

[discharging] constant streams of images and models upon which we style our

bodies and appearance" (p. 6). Even in public health, suggests Gwyn:

> Much is made of the "responsibility" of the individual for his or her
> health, but what does this actually mean? According to
> Lupton…disciplinary power is maintained through a range of
> screening procedures, fitness tests and through health education
> campaigns which set out to invoke guilt and anxiety in those who
> do not follow a prescribed behaviour. The rhetoric of public health
> obscures its disciplinary agenda since health is presented as a
> universal right and a fundamental good. (p. 8)

Although I am somewhat sympathetic to this view, I think it makes too

much of the power of public health and its disciplinary agenda as outside of and

in opposition to individuals, a power that sets out to invoke guilt and anxiety. There seems to be a similar kind of passivity attributed to people here as that discussed above in relation to playing the sick role. This time, however, it is the passivity with which people unquestioningly accept the disciplinary agenda of public health and its rhetoric. My interview transcripts do indeed reveal self-disciplinary activities – such as keeping one's weight down, exercising, avoiding certain foods – invoked as common sense. However, it seems more accurate – and helpful – to observe talk of such activities as situationally-produced and constitutive of as well as reflective of wider social processes, rather than as evidence of social institutions imposing power on unsuspecting individuals. In this way, analytic space (Nettleton et al, 2002) is opened up to see the ways in which individuals are involved in reproducing ideologies in social action.

Another accounting for the self-with-illness as a project comes from Goffman (1990), whose influential *Stigma* focuses on the attempts of the stigmatized to project a credible self. Individuals who are ill downplay their disease and symptoms in order to successfully interact with others, suggests Goffman, thereby playing by the rules of proper conduct. Although Goffman presents individuals as skilled agents, they seem to be seen as acting in isolation, leaving little or no room for an exploration of larger societal processes in interaction (Barnhart, 1994). Goffman has thus been criticized for ignoring structure and power in his discussion of how social actors – including those stigmatised by illness – perform their selves (e.g. Denzin, 2002; Giddens, in Tucker, 1998).

Another way of looking at illness as a project of the self is provided by

Radley and Billig (1999), who seem to strike a middle ground between structure

and agency (or perhaps ignore the dichotomy altogether) in their discussion of

how individuals claim identities as "fit participants in the activities of the social

world" (p. 19). This view encompasses more than the search for physical

wellness (seen as imposed, for instance, by a powerful public health agenda) into

other areas of life that are affected by one's health, for instance work and

relationships. We also move beyond observing how people manage their

performances in isolation into observing how people, in interaction, articulate a

world in which ideas about health and illness seem commonsense. In this way, it

is possible to see how health beliefs "simultaneously reflect general themes

within a culture and specific experiences, feelings and intentions of the individual"

(p. 18). Solomon (2003), in a study of an on-line support group for people with

multiple sclerosis, sees this simultaneous construction:

> When we talk about illness we do not simply mirror the cultural
> narratives that seem most applicable to our situation. More often
> general meanings of the available narratives are considered in the
> context of our experience and are then actively storied into
> personal accounts on our own terms. In this way personal illness
> narratives are dynamic, fluid, influential and continuous. They
> change over time and in different situations, ever-influencing larger
> cultural narratives by reducing difference, resisting stereotypes, and
> even creating new narrative resources. (p. 27)

Radley and Billig's ideas provide a useful lens through which to view my

interview data. As discussed, the transcripts reflect a variety of individual

experiences, feelings, and intentions; however cultural ideas about social fitness

and the right way to 'do illness' were very present in the versions of the worlds

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created. Because these ideas were so present, I am reminded of what Slevin (2000) calls "the ambivalent potential of the Internet" (p. 5), and wonder about the extent to which storytelling on the Internet will heighten the pressure to demonstrate one's social fitness, or to which it will allow one to challenge ideas of social fitness. Regardless, the Internet is undoubtedly a powerful tool with which to articulate the illness experience and potentially reconfigure social identity. I turn to this discussion in the next section.

5.3 Internet as facilitator

In my interviews with people about how they tell stories on-line, the Internet is positioned for the most part as a useful tool rather than a unique and life-changing vehicle. People described how as part of their everyday lives they used the Internet to share experiences with people who understand them, to air their thoughts and feelings, to connect with people who have information to share, to get time-limited support in dealing with a situation, to escape people who seem to have unrealistic expectations, and even to undertake activities that may on the surface appear to have nothing to do with their health (for example Linda, who used the Internet to chat with potential partners) but which are inextricably bound up in who they are in the world. The longer the Internet has been around, perhaps, the less people are inclined to engage in polarized debates about its benefits versus its harmful qualities. There was very little discussion, for instance about privacy concerns or the desire for anonymity. The everyday nature of the Internet may be especially relevant for the younger

participants in my study, whose lives from a fairly young age have always involved the Internet.

Participants, then, put the Internet in its place, appreciating it in their lives but not according it a status above all else – even, in some cases, admitting to not using it for long periods of time. Rather than simply the passive recipients of technology, then, people are seen to be "active and important actors in shaping and negotiating [the Internet's] meanings" (Wyatt et al., 2002, p. 25) – as well as in constructing those meanings in research interviews.

However, as Hardey (2002a) points out, it would be a mistake to underestimate the changes in social life facilitated by the Internet. Cyberspace may not be a total departure from all previous history (Poster, 2002), but there are considerable differences between it and other modes of communication. The Internet "extracts us from territorial spaces and phenomenological time, repositioning us in strange ways" (Poster, 2002, p. 483). Before the Internet, there would not have been a way for people to link with hundreds of others across the world in a discussion about, for instance, a rare disease they had in common. These connections often go far beyond storytelling-in-the-moment. Several of my participants, for instance, had found a discussion group about a new kind of hip surgery, less invasive than total hip replacement, but done in only a few countries. They told me – separately – that the stories they shared with people who had had this surgery, and their commitment to raising awareness of it, had brought it to the attention of physicians and surgeons in Canada, resulting in some becoming trained to do it, and others apparently determined to expose

its dangers. Even storytelling that is not aimed at such explicit action can affect

social life. Illness narratives are socially generated – people develop attitudes

and expectations by talking with others, hearing stories and comparing them with

their own experience. As people engage with others in interactions, they reflect,

share ideas, develop new opinions and outlooks. Frank (2000) and McLellan

(1997) have both discussed the 'dialogical' possibilities of on-line illness stories,

in which comments from others – often strangers – disrupt, enhance, and

become incorporated into the story of the self.

The Internet, then, fits nicely into discussions about selves as projects,

and selves-with-illness as projects. As Slevin (2000) says, it is no accident that

the Internet has emerged in late modernity, a time of important developments

such as the intensification of globalization, the detraditionalizing of society and

the expansion and intensification of social reflexivity (Giddens, in Slevin, 2000).

Nettleton et al. (2002) agree: "There seems to be developing a profound elective

affinity between processes of reflexive modernization, on the one hand, and

developments in information and communications technologies (ICTs) – the

Internet in particular – on the other" (p. 177). Burnett and Marshall (2003) say the

Internet's influence over the cultural stories that shape our sense of who we are

cannot be denied: it has "partially reconstructed the self and its world, creating

new opportunities for reflection, perception and social experience" (61).

The Internet, then, can be seen as a late modern medium for the

construction of the self and self-with-illness through storytelling. Reflecting on the

question of whether or not people may be looking for something on-line that they

cannot find elsewhere, this does seem to be the case for many people. Participants discuss finding empathy on-line that other people do not seem to have, finding escape from expectations that seem ever-present in daily life, and finding a way to demonstrate social fitness on-line that health professionals do not seem to appreciate. Frank (1991) noted society's reluctance to acknowledge illness: "To talk about illness you must go elsewhere" (p.15). From my interviews, the Internet does seem to be elsewhere, offering a new place to exchange stories about illness and help rewrite the narrative of the self (Schneider, 2003).

That said, a caution is raised about considering the Internet a "separate place to dwell" (Slater, 2002, p. 533). Although mythologized as cyberspace, the Internet, rather than a unified on-line culture, has always been "a highly diverse amalgam of cultural conjectures, not all of which originated in the new media" (p.537). New media have tended to be studied as though they constitute a new social space that requires new theories and methods of analysis rather than as phenomena that complement existing social relations and practices (Slater, 2002; Slevin, 2000). In this study, people talk about the Internet in the context of their daily lives, and about their use of the Internet as one of the many activities they undertake as social actors, thereby suggesting there is no need for blatant distinctions between the on-line and the offline.

A question is raised, however, about the extent to which use of the Internet may heighten the pressure on individuals to display themselves as socially fit actors – seeking wellness or the appearance of wellness, encouraging wellness in others – or to which it may facilitate a challenging of ideas on what

constitutes 'doing illness' or being socially fit. In a study of how people with

schizophrenia position their identities, Schneider (2003) finds they use a variety

of strategies to resist negative meanings attached to the disease, thus helping to

"reinforce or reshape cultural knowledge about schizophrenia" (p. 185).

Schneider's article is not about the Internet, but it does provide a view on how

people resist – rather than simply recirculate – cultural narratives about health

and illness, in turn offering the opportunity to reshape cultural knowledge.

Opinion seems to be divided about the extent to which the Internet could reshape

such knowledge, or may simply perpetuate it. As discussed in Chapter 2, Gillett

(2003) sees websites constructed by people with HIV/AIDS as challenging

assumptions about health and illness, offering the possibility of social change

and new ideas about what it means to live with the disease. In his view, the

Internet, by offering a medium for self-representation, is capable of revitalizing

the "public sphere" (p. 608).

Pitts' (2004) study about the websites of women with breast cancer,

however, suggests the Internet is *not* an inherently empowering technology.

Although she describes women with breast cancer as developing their sites to

generate new forms of knowledge, awareness and agency in relation to illness,

she points to studies that "affirm social norms rather than deviate from them" (p.

35). The idea that people might display "social responsibility to consider our

selves and our bodies as projects that must be continually reworked, improved

and upgraded" (p. 36) is especially relevant in the study of women with breast

cancer, who may feel pressure to erase signs of illness. On the other hand, Pitts

does not completely discount the idea that the Internet may provide space for "women to narrate their experiences and generate new definitions of self and identity" (p. 38). Ziebland (2004) draws on Radley and Billig in a narrative analysis of interviews with people who have cancer, observing that their use of the Internet may allow – but also increase the pressure on – people to present themselves as "more than a patient" (p. 1792). Ziebland's study relates more to the phenomenon of accessing on-line information than storytelling on-line (the narrative part of her study relates to the stories people tell in their interviews), but the role of Internet use in invoking a "felt imperative" (p. 1786) to display social fitness is still a relevant question. Although such questions cannot be resolved easily, I agree with Gillett (2003) that research about the media practices of people with health problems is an important area of study, and one that can shed light on how meanings of health and illness are perpetuated in society. From an ethnomethodological point of view, the Internet will be an important place to observe how people's activities are simultaneously embedded in and constitutive of the ways in which people 'do' illness.

5.4 Other theories

There is much discussion in the e-health literature about the rise of the expert patient. Hardey (2001) discusses the "reconfiguration of expertise" (p. 388) in his study of how people are not just consumers of health information but are also producers. In Ziebland et al.'s (2004) studies of people with cancer, one of the distinct ways in which the authors see them using the Internet to "transform roles and change involvement in health care" (p. 565) is to question

their doctors' advice. They report searching for the possible meaning of symptoms, seeking reassurance that the doctor is conducting the right tests, and generally gathering information about cancer and its treatments. Ziebland points out how the Internet allows people to "gain, maintain, and display familiarity" (p. 566) with a remarkable body of medical, as well as experiential, knowledge about their illness. Reeves (2001) notes the importance that people who are HIV-positive seem to attach to being able to speak with authority about their condition, and discusses the role of the Internet in allowing them to do so. The participants in her study associate information with empowerment; one goes so far as to equate expertise about the condition with strength, and lack of information with weakness or being a victim.

The notion of the expert patient was not prominent in my interviews, except perhaps in the case of David, who worked hard to inform himself about his hip condition as well as the options for treating it. My study confirms, then, the extent to which the Internet is used for health reasons unrelated to health information seeking and unrelated to becoming an expert, a phenomenon that is the focus of much of the literature about Internet health. Even as participants spoke in terms of expertise, it was not medical expertise they sought, but expertise related to practical strategies that would make everyday activities easier. These strategies were usually shared over the Internet through the telling of stories about difficulties and frustrations, to which other people would respond with proposed solutions. I am not suggesting that the notion of the expert patient is misplaced, only that it was not apparent in my interviews. I suspect one of the

reasons it did not surface is that arthritis is not usually considered life-threatening, while cancer may be. A diagnosis of a cancer, therefore, may send people to the Internet to gather information and connect with people about matters that will allow them to make immediate decisions about treatment. My study suggests that regardless of disease, however, not everyone is interested in become an expert about his or her condition. As shown, the Internet may be seen as allowing people to escape dealing with the medical details of the disease.

Closely related to the notion of the expert patient is what I will call the lay versus medical dichotomy, which seems to position patients' experiences of illness in opposition to physicians' notions of disease. Davison and Pennebaker (1997), for instance, write about the physician's office as opposed to the "natural world of the person suffering from chronic disease" (p. 482). Narratives about the Internet are positioned as capable of shedding light on the latter, thereby having the potential to improve communication processes in the former. Burrows et al. (2000) discuss the "privileging of lay knowledge and experience over the 'expert' knowledge of health and welfare professionals" (p. 116) and point out the extent of debate about the issue in the social sciences.

Participants in my study did not distinguish finely between lay and expert explanations of and approaches towards disease – in fact many of their accounts exhibited what could be seen as expert discourse and explanations. To be sure, many people expressed frustration with health professionals, for instance questioning the length of time it took them to make a diagnosis, accusing them of

overlooking people's efforts to keep well, or discouraging them from pursuing

certain treatment options. These frustrations, however, were not placed in the

context of how experts approach illness as opposed to how people who are not

considered experts approach illness, and I did not see evidence of a conflict, as

Kleinman (1988) describes, between two explanatory models of illness. As Gwyn

(2001) points out:

> There is something at once suspect about the modifier 'lay' in the
> description of anything. The word presupposes the existence of
> another 'official' or 'expert' version. Along with the knowledge that
> one's version of reality is not 'official' comes the implication that it is
> necessarily deficient. (p. 33)

Rapley et al. (2003) also point out the tendency of such distinctions to

implicitly or explicitly judge lay accounts as inferior to scientific or expert

accounts, when in fact, in their study of media coverage of a mass shooting and

the motivations for the responsible individual's actions, what are considered lay

accounts (for example from the man's neighbours and family) and expert

accounts (for example by psychiatrists) are "remarkably congruent" (p. 427). The

point here is that all members of society, regardless of their occupation, privilege

certain explanations over others in situated accounts. In my interviews, people

were much more likely to talk about the physician's office as *part of* their natural

world, rather than separate from it. As far as privileging lay knowledge over

expert knowledge, it would be impossible to tell where one domain ends and the

other begins. That view seems to see the definitions of lay and expert as having

a life of their own in the social world apart from how they are invoked in accounts.

In the next section, I summarize the above discussion and refer to limitations of the study and ideas for further research.

CHAPTER 6: CONCLUSION

I began this thesis by claiming that equally as interesting as surfing the Internet for health information – which activity is the focus of much academic research and discussion – is the extent to which people are producing illness narratives on-line. As an increasingly important source of information and support for people with health concerns (Rice & Katz, 2001), the Internet – while facilitating the search for such information and support – encourages people to construct illness narratives as they participate in on-line support groups, discussion groups, chat rooms or blogs, or on personal websites.

My intent in this study was to explore the phenomenon of illness narratives from a new perspective using a different theoretical and analytic approach from other studies I had found that examine on-line storytelling. I chose an approach related to ethnomethodology, specifically a form of membership categorization analysis proposed by Baker (1997, 2002) based on the work of H. Sacks (1992), which allowed an exploration of *how people talk about using the Internet to tell their story*. The approach suggests that in their interactions, members of groups or social settings cannot *help* but produce categories of people or things to create meaning in interaction. Members constantly use categories to attribute rights and obligations, assess, judge, describe and understand each other (Paoletti, 2001) and the world in which they live.

The analysis revealed that through the interaction of participant and researcher, the categories of *health professional*, *other people* and *active people* – whose specific meanings were negotiated in context – were invoked and connected to create identities and social worlds and to account for activities.

The interviews revealed a number of very different ways in which people use the Internet, as well as a number of different motivations for using it, which allows a view of Internet use beyond other studies of bounded on-line venues such as support groups or discussions groups, in which people are often assumed to be there for similar reasons related to fixed identities they hold in the social world.

Despite the differences in the versions of the worlds that people created, unique to all accounts were the notions of the self as a project, the self-with-illness as a project, the importance of storytelling to that project, and the Internet as facilitating such storytelling. I conclude, then, that the Internet is a unique tool offering unprecedented opportunities to connect with a huge audience of like-minded and sympathetic people across the world. However, a question is raised about how Internet use may affect the experience of illness in late modernity, and the extent to which it may heighten the pressure on individuals to account for themselves as socially fit individuals in a society increasingly preoccupied with idealistic notions of health, or on the other hand, allow them to challenge ideas of what it means to be socially fit.

There is a need to end polarized debates about the Internet; it is neither inherently bad nor good, but context-dependent. The reference to on-line versus

off-line lives or behaviours perpetuates a distinction that is not made by people

who use the Internet, at least when such use is studied in the context of their

lives. Finally, I have always been sympathetic to Poster's (2002) concern about

how much research approaches the Internet "as a tool for determining the fate of

groups *as they are currently constituted*" (p. 480, italics in original). Poster

encourages research that explores how the Internet might change individuals

and groups in unforeseeable ways:

> If such questions are foreclosed, one cannot examine critically the
> political culture of new media…one can merely put forward existing
> cultural figures of the self – race, class and gender, or citizen,
> manager or worker – to test the role of the new media in furthering
> their positions as they see themselves and as they are. Such a
> framework overlooks the constitutive character of media as a space
> which encourages practices and which in turn serves to construct
> new types of subjects. (p.480)

By approaching the study of Internet use from an ethnomethodological

perspective, I have undertaken research that exposes this constitutive character

by exploring the ways in which people talk about using the Internet to tell their

story.

6.1 Limitations

I conducted 19 interviews in this study. Although I was surprised by the

differences in participants – from type of arthritis and severity of the disease, to

age, to the extent to which and reasons for which they used the Internet, and

more – I cannot claim these findings represent the majority of people with

arthritis. For one thing, my study attracted people who were interested in and

comfortable with telling their story to a researcher – and no doubt there are types

of stories and versions of worlds that exist that I did not hear about. For another

thing, I interviewed people who use the Internet – they are physically capable of

doing so, are comfortable with it, and can afford it. As Wasko and Mosco (1988)

point out, in many discussions of the Internet, we "[lose] sight of a growing class

of people who cannot afford the price of admission to the information age" (p.10).

Writing and reading on-line are still privileged activities (McLellan, 1997), and it is

important to remember that there are still many voices, many points of view, and

many stories that will not be heard in this environment. Indeed, my study was

about people who use the Internet, but I must be aware that when discussing

something as sweeping as the experience of illness in late modernity, I am

talking about that experience from the point of view of certain people only. (On

the other hand, I am not suggesting that everyone *should* be connected to the

Internet. As Wyatt et al. [2002] point out, there are a variety of reasons people do

not use the Internet, and not all of them have to do with inequality and

disadvantage. In this study it has not been my intention to uncritically accept the

promises of technology, only to explore what people say about it in interviews.)

Lastly, despite my defense of the interview as a natural setting, I am

sensitive to the huge reliance in social science on interview data. Although my

interactions with participants were more like conversations than like strict

interviews in which the researcher asks the questions and the respondent

answers them, it is important to accept the limitations that may be imposed by

the setting. Both researcher and participant come to the interview with an

understanding of the roles they will play, and strive to fulfil their expectations of

those roles as they discuss the topic at hand. My choice of an ethnomethodological approach – including an analysis of the researcher-participant interaction – was an acknowledgement that the study must be about how people play their roles in interviews as well as about the subject of on-line illness narratives.

6.2 Relevance of the study and suggestions for further research

The research grows daily about how people use the Internet for a variety of health-related reasons – to search for information, to connect with others, to share advice and so on – but only a small portion of that research even touches on on-line illness narratives. When it does, it is usually for analytical purposes, rather than an examination of the phenomenon itself.

I have suggested throughout this thesis that the phenomenon of on-line illness narratives constitutes an important area of study for several reasons: to ensure this new genre is incorporated into the already-rich, multi-genre and interdisciplinary theory related to illness narratives; to gain an understanding of how the production of electronic illness narratives affects authors; and to explore the effect of the Internet on the experience of illness. In this study, I have attempted to touch on all these aspects with a cohort of people who have arthritis and who use the Internet to tell their story, by using an ethnomethodological approach to interview data.

I believe, however, that this study only scratches the surface of a potentially large and exciting area of research about health-related Internet use in

the context of people's lives, and the role of the Internet in the experience of health and illness. Future study could place more emphasis on the personal and cultural factors that drive Internet use as well as the impact of Internet use, following Hardey's (2002a) suggestion that "the casing of the offline world in [studying Internet use] remains important because it shapes whether, how and why people turn to the Internet" (p. 582). Such studies could build on and align with sociological and communications-related research on the experience of illness. Both ethnomethodological approaches and narrative approaches (recent developments in which, says Reissman [2002], suggest the benefits of longer-term collaborative relationships with research participants) offer great potential to reveal important issues about identity and experience in late modern cultures (Bury, 2001). Critical or ethnographic discourse (both micro and macro) analyses could broaden the scope of such explorations by taking into account a range of other media – as well as other social settings such as clinical appointments, self-help groups etc. – and their role in perpetuating ideologies of health and illness.

In sum, as significant numbers of people turn to the Internet as a medium for stories of their lives (Zuern, 2003), I believe that on-line illness narratives offer an important view on the changing nature of the health and illness experience. It is through further study of Internet use in the context of people's lives, and through the study of those lives in the context of culture, that the potential for such insight will be realized.

APPENDIX A: RECRUITMENT POSTER

Wanted to interview: People with arthritis who use the Internet

The project:
This research project, ***"Me on-line": Narrative identities of people with arthritis,*** explores the stories people with arthritis tell about themselves as they communicate on-line or electronically.

These stories may take any number of forms:
- a series of e-mail updates;
- postings in a chat room;
- an on-line diary or journal (a blog);
- a personal Web site;
- chatting through Instant messaging with friends and family

The length of the story and the audience do not matter – only that you are telling your story. Telling your story may help you come to terms with your situation, reduce stress, allow you to rediscover the person behind the diagnosis, or empower you to act on behalf of yourself or others.

There is a lot of research on the benefits of "illness narratives," as they are called. However, not much research has been done on the on-line versions of these stories (as opposed to "offline" ones such as personal diaries, published books, or conversations with friends and family.).

The goals of this study include:
- Learning more about how people manage chronic disease;
- Providing insight for medical practice (the benefits of listening to people's stories); and
- Social advocacy (how people with chronic illness might find a "voice," and how such activities may contribute to changing societal perceptions of chronic illness).

The request:
If you are interested in finding out more, I would love to hear from you. The requirements for participation are:

- You have arthritis and you use the Internet to "tell your story";
- You live in British Columbia.

The research involves an in-person interview of approximately one hour. As an expert on the subject matter, you will be asked to comment on the findings and provide input into the final report. All materials collected will remain anonymous, and you are welcome to have a copy of the final document. This project, which is approved by the Simon Fraser University Research Ethics Board, is part of my thesis towards a Master's degree.

For more information:
Please e-mail Beverley Holmes at Beverleykev@telus.net or call me at 604 873 1353. I hope to conduct interviews during the fall of 2004. Thanks in advance for your consideration.

APPENDIX B: PARTICIPANT DEMOGRAPHICS

Participant/sex (order of I'view)	Primary arthritis/years	Age (at interview)	First language	Work status	Education	Income	Computer use
Georgia, F	Rheumatoid, six years	24	English	Unemployed due to health	Post sec.	$60-79,000	Once or more daily
Martina, F	NO FORM						
Hannah, F	Osteoarthritis, ten years	48	English	Unemployed due to health	Secondary	Under $20,000	Once every 2 or 3
Bonnie, F	Osteoarathritis (24 years)	67	English	Retired	Post sec.	$20-39,999	Once every 2 or 3 days
Linda, F	Juvenile rheumatoid, since age of one	28	Punjabi	Working part time	Post sec.	Under $20,000	Once or more daily
Helena, F	NO FORM						
Anne, F	Osteoarthritis, 30 years	77	English	Retired	Post sec.	$20-39,999	Once or more daily
Charlotte, F	Rheumatoid, two years	23	English	Sick leave/disability	Post sec.	Under $20,000	Once or more daily
Paula, F	Osteoarthritis, 19 years	56	Arabic	Student	Post sec.	$20-39,999	Once or more daily
Terry, F	Rheumatoid, 46 years	62	English	Working full time	Post sec.	$40-59,999	Once or more daily
Nancy, F	Osteoarthritis, seven years	44	English	Working full time	Post sec.	$60-79,999	Once or more daily

Participant demographics, cont'd

Natasha, F	Rheumatoid, four years	56	English	Sick leave/disability	Post sec.	Under $20,000	Once every 2 or 3 days
Susan, F	Osteoarthritis, ten years	61	French	Unemployed due to health	Post sec.	Under $20,000	Once or more daily
Karen, F	Rheumatoid	57	English	Working full time	Post sec.	Over $80,000	Once or more daily
Kyla, F	Rheumatoid, eight years	40	English	Working part time	Post sec.	Over $80,000	Once every 2 or 3 days
Jody, F	Rheumatoid, ten years	60	Dutch	Unemployed due to health	Post sec.	Under $20,000	Once or more daily
Peter, M	Osteoarthritis, 35 years	82	English	Retired	Secondary	$40-59,999	Once or more daily
David, M	Osteoarthritis, five years	56	English	Working full time	Post sec.	Over $80,000	Once or more daily
Holly, F	Rheumatoid, three years	56	English	Sick leave/disability	Post sec.	Under $20,000	Once or more daily

APPENDIX C: CONSENT FORM

"Me on-line": Narrative identities of people with arthritis

Informed Consent By Participants In a Research Study

The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. This research is being conducted under permission of the Simon Fraser Research Ethics Board. The chief concern of the Board is for the health, safety and psychological well-being of research participants.

Should you wish to obtain information about your rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact the Director, Office of Research Ethics by e-mail at hweinber@sfu.ca or phone at 604-268-6593.

Your signature on this form will signify that you have received a document which describes the procedures, possible risks, and benefits of this research study, that you have received an adequate opportunity to consider the information in the documents describing the study, and that you voluntarily agree to participate in the study.

Any information that is obtained during this study will be kept confidential to the full extent permitted by the law. Knowledge of your identity is not required. You will not be required to write your name or any other identifying information on research materials. Materials will be maintained in a secure location.

Title: **"Me on-line": Narrative identities of people with arthritis**
Investigator Name: **Beverley Holmes**
Investigator Department: **School of Communication**

Having been asked to participate in the research study named above, I certify that I have read the procedures specified in the Study Information Document describing the study. I understand the procedures to be used in this study and the personal risks to me in taking part in the study as described below:

(Consent form continued)

Risks to the participant, third parties or society:
None

Benefits of study to the development of new knowledge:
Illness narratives -- the stories people tell about being ill -- help people make sense of their experiences, as well as come to terms with and even cope better with their situation.

Although much research has been conducted on illness narratives in general, most of it has focused on the verbal telling of stories or written accounts in diaries or published books. Almost no research has been conducted on the illness narratives people tell on-line, either through an electronic discussion group, in an Internet chat room or even on a personal Web site.

This research study focuses on the phenomenon of on-line illness narratives, exploring how such narratives may benefit people with chronic disease -- in this case arthritis.

This study will also reveal further questions for study into health care practice (e.g. the way in which health professionals might listen to patients' "stories") and social action (e.g. helping people with chronic illness find a "voice").

Procedures:
Participate in an interview and comment on the research findings.

I understand that I may withdraw my participation at any time. I also understand that I may register any complaint with the Director of the Office of Research Ethics or the researcher named above or with the Chair, Director or Dean of the Department, School or Faculty as shown below.

Department, School or Faculty:　Chair, Director or Dean:
School of Communication　　Martin Laba

8888 University Way,
Simon Fraser University,
Burnaby, British Columbia, V5A 1S6, Canada

I may obtain copies of the results of this study, upon its completion by contacting:
Beverley Holmes (investigator)
885 East 30th Avenue
Vancouver, V5V 2W2
604 873 1353
bholmesa@sfu.ca

(Consent form continued)

I have been informed that the research will be confidential.

I understand that my supervisor or employer may require me to obtain his or her permission prior to my participation in a study of this kind.

I understand the risks and contributions of my participation in this study and agree to participate:

The participant and witness shall fill in this area. Please print legibly

Participant Last Name: Participant First Name:

Participant Contact Information:

Participant Signature: Witness (if required by the Office of Research Ethics):

Date (use format MM/DD/YYYY):

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