Emerging Socialities in 21st Century Healthcare

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Introduction

Some of the constraints imposed by chronic illness prevent people from having what is understood as a 'normal life' that includes working outside the home and maintaining regular social relationships. Some chronically ill people are obliged to spend all day at home, often alone, with few opportunities to meet other people, converse, or express their feelings. They feel isolated and alone. Fortunately, the Internet has changed this situation for many, creating new forms of sociality.

Three decades ago, virtual social relationships in cyberspace would have been inconceivable; today, we take them for granted. As a window to the outside world, the Internet has helped many homebound, chronically ill people overcome social isolation. Participation in patients' online communities, forums, self-help groups, blogs, and other health-related web pages is becoming an important source of moral, emotional, and social support because it enables the sharing of common experiences and interests (Burrows et al., 2000; Josefsson, 2005; Nettleton et al., 2002). Moreover, the Internet has created conditions for the emergence of new forms of care (Atkinson and Ayers, 2010; Burrows et al., 2000)—both caring for and caring about—not only among the chronically ill but also between sick and healthy people.

1 Also referred to as the 'Net'.
2 The notions of virtual relationships, virtual social life, and online relationships are understood here as forms of social interaction in a virtual environment, using computer-mediated practices (also called online practices) that are related to the concept of virtual communities (see Hine, 2004; Miller and Slater, 2000; Rheingold, 1996; Woolgar, 2010). Virtual life should not be understood as opposed to 'real' life, but as part of it, because both are parallel and simultaneous dimensions of people's lives (Wilson and Peterson, 2002; Woolgar, 2002).
3 While this contribution's primary focus is on the social constraints of being homebound, the creation of virtual relationships on the Internet is not exclusive to those who are chronically ill and homebound, or even to those who are ill in any way.
4 Support is given within these three dimensions—moral, emotional and social—and not simply one because they are often closely related. Elsewhere I have explored the significance of this multidimensional support in relation to chronic illness (see Masana, 2010).
Social relations are especially important in times of illness and other adversities. Online forms of sociality among the ill and homebound have received little attention because the ethnographic gaze usually focuses instead on face-to-face relationships. Virtual sociality challenges us to rethink our concepts of ‘data’ and our methodological approaches to ‘the field’ (Hookway, 2008; Hine, 2004, 2005, 2007; Jacobson, 1999; Mann and Stewart, 2000; Murthy, 2012; Turkle, 1995; Wilson and Peterson, 2002; Sixsmith and Murray, 2001). The aim of this contribution is to show how the Internet has partly helped to overcome the isolation and loneliness that accompany some chronic illnesses, and how it enables new types of socialities and new care practices at a distance.

Real people, virtual lives

The data reported here are drawn from my doctoral research on the experience and management of chronic illness in Catalonia, Spain, and focuses on 20 adults between 30 and 50 years old, a subset of my total sample. The narratives quoted in this chapter come from two different sources: in-depth personal interviews conducted between 2009 and 2011 at the homes of chronically ill people, and four months of weekly observation in 2010 in a therapeutic group at the chronic pain unit of a prominent regional hospital in Catalonia in 2010. All participants in the study live in urban areas or in villages close to urban centres, and, with few exceptions, have a computer with an Internet connection, which they use daily for different purposes. Some are now working part-time or full-time, or have some kind of activity outside the home, but had been homebound during certain phases of their illnesses. The others are on long-term sick leave or have some kind of permanent disability pension, and are thus indefinitely homebound. None of the participants are digital natives, but those with computers and the Internet use it for social relations, entertainment, and health-related issues. Those who do not have a computer or use the Internet consider themselves ‘too old for that’, and unable to learn the necessary skills to enter, as one of them put it, this ‘difficult and strange world’.

This term is used to identify those born during or after the general introduction of digital technology and to suggest they began using and interacting with digital technology at an early age.
Illness, the Internet, and social life

We can observe two main tendencies in studies of lay use of the Internet in relation to health and illness. First, most studies tend to analyse the e-health phenomenon, that is, use of the Internet as a source of health information for laypersons (Hardey, 1999, 2002; Nettleton et al., 2004, 2005). These practices include acquiring knowledge about one’s disease, symptoms, or treatment; seeking medical and lay advice; formulating a self-diagnosis or looking for a medical diagnosis; and attaining a level of ‘expertise’ in self-medication, among others. These practices focus on the professional–patient relationship and on the medical condition—the disease—and at issue are questions of knowledge, expertise, empowerment, and autonomy.

Second, other studies (Flinkfeldt, 2011; Josefsson, 2005; Loader et al., 2002; Nettleton et al., 2002) have examined the virtual social lives of the chronically ill as new forms of care and social support made possible by the Internet. Personal accounts of illness through blogs, patients’ online communities, self-help groups and forums, Facebook, and Twitter allow us to study relationships between the healthy and the sick and among the sick. These uses of the Internet that pertain to the personal and social experience of illness, not merely the disease, are the focus of this study.

Before the Internet age, receiving visits at home or talking on the phone was the primary way for a homebound chronically ill person to maintain social relationships beyond the domestic unit. While the Internet has opened a window for potential new socialities, it does not, however, exclude previous forms of social interaction (Woolgar, 2002). Despite widespread use of the Internet, some people do not have an Internet connection or a computer, or the skills to use either. Some may have all three, but decide

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6 See also Fainzang in this volume.
7 Content and interactional style in patients’ online communities, self-help groups, and forums vary considerably according to cultural context. For instance, some of my study participants distinguish between the ‘style’ of some Spanish websites versus those in the United States. They valued US sites positively because they contain ‘more disease-related information’, although the volume of information may sometimes be overwhelming. Personal accounts of illness on US sites were also seen as ‘too exaggerated and dramatic’. Similarly, Nettleton et al. (2005), in a UK-based study, found that some British participants avoided ‘American stuff’ because they considered it ‘too dramatic’. Further research attentive to culturally specific Internet ‘styles’ would illuminate the dynamics of the use of these websites by the chronically ill. This chapter focuses not on Catalan-specific uses of the Internet for social relationships, but on common practices among the chronically ill for overcoming isolation and loneliness.
8 Accessibility and ability, among other structural and social context factors, are the main reasons for the use (or not) of the Internet (Woolgar, 2002).
not to use the Internet for health- or illness-related purposes. Using the Internet may therefore be a personal choice for some, while for others it may be their only option. How has the Internet changed or affected the lives of the chronically ill and homebound? How are these new forms of sociality perceived by those who are homebound and chronically ill?

Montse, a woman in her 40s suffering from severely debilitating fibromyalgia, was homebound on long-term sick leave. Despite her illness, she was able to spend hours in front of the computer, and was enthusiastic about her time there:

Oh, the Internet saved my life! I spend a lot of hours every day in front of the computer [smiling enthusiastically]. I read all the posts in the forum, I answer many of them, I chat with friends, we send each other pictures, songs, or whatever. It's my only way not to be alone. When I am there [on the Internet] I feel alive, I almost forget about my pain. Anyway, I can't do other things. What I should do? Lie in bed all day long? That would kill me. And yes, it is painful and tiring to spend so many hours sitting in a chair in front of the screen, but at least there I have a life, I have friends, we talk, I am not alone there. (Emphasis added)

When Montse says that the Internet saved her life, she is not talking about relief for her medical condition; she is talking about feeling alive, being ‘in the world’ and connected to others who support her and help her to manage the effects of the illness on her life, including the possibility of social death, as implied in her reference to a bed-bound life without social interaction.

The Internet offers virtual social life and interaction that provides new forms of moral, emotional, and social support (Nettleton et al., 2002), and alternative caring practices—both caring for and caring about (Atkinson and Ayers, 2010; Burrows et al., 2000)—that ‘save’ not the body but the souls of those who are homebound and chronically ill.

**Chronically ill on the Net: Navigating or participating?**

There are two main forms of engagement with the Internet: *to use it or to be in it*, or, in other words, *navigating or participating*. The first option consists of navigating through web pages searching for disease-related information or reading personal accounts of illness experiences posted on blogs, chat

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9 See Nettleton et al. (2004) for a further description of ‘health e-types’. 
rooms, or forums, without interacting in any way with others. The second implies interaction: responding to others’ posts and participating (more or less actively) in online communities, chats, or forums. Although I am more interested here in participatory and interactive uses of the Internet, in my research I observed that even those who limit themselves to navigating without participating may also feel helped by reading others’ illness accounts. Laura, for example, a 46-year-old woman suffering from four invisible chronic conditions that she has not disclosed to many of her co-workers or friends, and who jealously guards her privacy and anonymity, is reluctant to participate or to ‘show’ herself (as she says) on the Internet, but she does look at it sometimes and read what other chronically ill people write:

I don’t write anything and don’t get in touch with anybody. No. I just read. But by reading, I see others that have a similar situation to mine, and it helps me to understand that I am not the only one. You know, sometimes you feel like you are the only miserable one suffering in the world. And that’s not true. Many others suffer like you. It is good to know, because you feel less alone. (Emphasis added)

While the Internet allows anonymity, many people share a lot of personal and private information about themselves on the Internet. In some cases they create online nicknames in order not to be recognized, but others state clearly who they are, where they live, and other personal data. Although Laura could participate online in an anonymous way, she chose not to do it; for her, ‘just reading’ had already made a positive impact by allowing her to see that she is not alone, and that knowledge helped her bear her own suffering.

Nevertheless, ‘just reading’ can also turn into a depressing, frightening, or anxiety-provoking experience for some of the already vulnerable chronic illness sufferers. When I asked Mariona about her relationship with patients’ online associations for her condition, she answered:

I know that there is one [patients’ association for her condition] on the Internet, but I started to read it once, and I saw people who were even worse off than me, and you know, that got me down. No, it’s too depressing. You read that and it brings you to your knees—and you say ‘I already know all this, and I don’t need to read any more about it.’

Mariona’s account shows us a phenomenon described by Goffman (1995) as a ‘circle of lament’—also present in some self-help groups and patients’
associations offline—that may have a counterproductive effect on those who were initially looking for relief and support, but come away from the encounter with additional burdens and worries. What can be a good, useful, and supportive experience for some may be bad, useless, or even harmful for others, which may lead some chronically ill people to choose not to seek out such sites.

Participating actively on the Internet enables chronically ill people to share their illness experience with others who suffer from the same disease or a similar situation (Atkinson and Ayers, 2010; Hardey, 2002). Through sharing ‘the story of a common problem’ (Canals, 2002, 2003; Silverman, 1980), those who do choose to participate actively are able to develop and maintain social relationships and form part of a community¹⁰ (Hardey, 2002) that keeps them anchored in ‘the world’, as my study participants expressed it, even if they are unable to leave the house. Interacting with one’s peers implies better mutual understanding of the adversity of one another’s situations (Goffman, 1995). Some chronically ill people feel more comfortable sharing their lives with others in similar situations because they know in advance that they will not be judged, mistreated, disbelieved, or delegitimized by others. Participating in such forums, chats, or other types of online communities fosters a sense of belonging, which is in turn essentially linked to moral, emotional, and social support. As Montse says:

We all know what it is. We don’t judge, we support each other. One day I feel bad and another member cheers me up. And maybe another day that other person feels miserable and I can help her to deal with it. At least we share the same thing, we all know what we are talking about. We don’t need to hide, or pretend, or fake anything. We are just [as] we are, ill people.

Virtual social relationships develop not only among the ill, but between the sick and the healthy as well. Mariona, who is now 36, made new healthy friends through the Internet. She was born with a congenital cardiopathy and has suffered from pulmonary hypertension since the age of 28, when her condition forced her to stop working outside the home. In the beginning

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¹⁰ For a discussion of the concept of community in mutual support groups, see Canals (1998). On virtual communities, see Burrows et al. (2002); Castells (2001); Josefsson (2005); Rheingold (1996).
she lost some friends because she was unable to take part in their regular social activities, and this made her even less inclined to leave the house. When I asked about her social life, she explained how she managed to rebuild it after three years of homebound isolation, ending nearly in tears:

We created a group of friends on the Internet, through the chat. It was a very good [experience] for me, because I could escape from being shut in here [at home]. We have lunch and do other things together, and now I can enjoy life again like other [healthy young] people. This did me a lot of good, because I had spent three years very closed in [on] myself, because, you know, I spent all my time worrying about my illness, and when you talk to other people you don’t know what else to talk about, it’s just the illness and, you know, I was so closed off.

**Online rules for virtual relationships: Unexpected consequences, negative outcomes**

While the Internet has a positive impact on the lives of many chronically ill people, others have had negative experiences. As in everyday face-to-face interaction, online communities and virtual relationships operate according to rules that are both explicit and implicit. Disrespectful and offensive language is explicitly prohibited, and other implicit rules, grounded in reciprocity (Mauss, 1971) as a central value, are demanded. This involves regular communication: posting often, responding to others’ posts, asking and answering questions, and sharing intimate details of one’s personal experience—all in all, the quid pro quo rule. Clara once tried to get involved in an online forum of people suffering from fibromyalgia and chronic fatigue syndrome recommended by some members of a biweekly therapy group she was attending. She could not, however, keep up with all the news, posts, and chats because she often felt too unwell to spend the necessary time sitting in front of the screen reading and responding to others’ posts and writing her own. Surprisingly for her, these peers whom she assumed would be more understanding and supportive complained about her online behaviour:

Every time I went to the therapy group, if I hadn’t been very active and didn’t participate enough [online], they complained and said, ‘Ah, you

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11 Losing friends can be one of the unpleasant negative outcomes of living with a chronic illness (see Frank, 1991; Kleinman, 1988).
don’t show up’, ‘Oh, you aren’t answering any messages’, ‘Oh, you never write anything about yourself’, ‘You’re always off’, ‘You don’t care’, and so on. They made me feel so bad with their complaints! I couldn’t do otherwise; I can’t spend as many hours at the computer as they do, reading and reading and reading, and answering, answering, answering. No, I couldn’t and I can’t. THEY should understand, but some don’t. So I quit. (Capital letters added to emphasize the tone and intensity of the oral account)

One of the main characteristics of virtual interaction is its temporal structure: it allows for asynchronous as well as synchronous communication, which is an important feature for the chronically ill, because it allows them to participate whenever they feel well enough to do so, at their convenience. Some people may not be able to stay on top of things all the time—if at all—and one might expect other people with chronic illnesses to be more accepting of this. Complaints such as those Clara received from her peers are related to the perception that she had broken the implicit rules of reciprocity. Because she did not write, respond, participate, or communicate with the expected frequency or in expected ways, she disappointed the others. In Clara’s own words, she had broken the unspoken rule: ‘Don’t expect me to share my life with you if you are not willing to share yours with me, or if you are not going to say anything in return.’ Clara’s unpleasant experience was not unusual; other study participants recounted similar experiences. Negative responses from peers can lead some chronically ill to withdraw from engaging in these online communities.

Sharing and caring

Sharing information about ‘the story of my illness’ (Hardey, 2002) is generally intended to ‘help others’ in a similar difficult situation: to learn more about the disease; to show people how others manage the situation; to express support; to give advice; to cheer people up; and, of utmost importance, to let others know that ‘you are not alone’. The latter is a key and often-repeated message, since those who are aware of the social constraints of illness know firsthand that social isolation and loneliness are among the biggest fears of the homebound chronically ill. Sharing one’s life with others in an empathic way—‘I know what you’ve been through’—generates a sense of belonging and shows that others care about you. As Montse says, ‘We do care, we care about the others. And we take care of each other. Feeling
supported allows us to deal with it [the illness] better, because not feeling alone is very important.’

Another characteristic of online social interactions is its expressiveness. Along with comforting words, jokes, and other forms of humour intended to lift people’s spirits, participants also share ‘emoticons’: virtual smiles, winks, hugs, kisses, flowers, suns, and so on. All these displays of affection, which I understand as caring practices that provide moral, emotional, and social support, bring people together and create a sense of closeness, belonging, friendship, and companionship. The Internet removes physical boundaries and enables caring at a distance from one’s home: being there [online] enables being in the world, having a social presence, caring for others and being cared for, which is important for those who are homebound and physically isolated.

As I have argued elsewhere (Masana, 2010), we tend to understand care practices as limited to functional activities or tasks. My data show that the sharing of information and experience on the Internet also constitutes a form of caring both for and about others, even when this is not the explicit intention. Human understanding in itself is a form of support (Josefsson, 2005).

Final considerations

Virtual social relationships create new forms of socialities that allow home-bound chronically ill people to partly overcome isolation and loneliness. People engaged in these online illness communities play an active and reciprocal role in caring practices: they care for/about others just as others care for/about them. Proof of this is the fact that most illness-related web pages, blogs, and forums are initiated and promoted by people with those illnesses, because they want to help, inform, advise, and support others facing similarly adverse conditions (Atkinson and Ayers, 2010; Burrows et al., 2000; Flinkfeldt, 2011; Hardey, 2002; Josefsson, 2005; Loader et al., 2002).

This does not, however, mean that chronically ill people spend all day in virtual contact only with others like themselves. They may also have active virtual social lives through Facebook, Twitter, and other social networks not specifically related to health and illness. The Internet allows homebound chronically ill people to build relationships not only with other chronically ill people, but also with healthy ones, and in this way it makes it possible for them to remain connected to others.

The virtual and the ‘real’ are not mutually exclusive dimensions of social life (Wilson and Peterson, 2002; Woolgar, 2002). People can ‘play’ in both at
the same time. Moreover, all people (healthy or sick) can combine face-to-face relationships with virtual ones, and in some cases they may meet in person those whom they get to know through the Internet. The difference, however, is that for people whose lives are constrained by chronic illnesses severe enough to keep them from leaving their homes or even receiving visits, virtual social life may be the only option available. For these people, the Internet becomes an important window to the outside world that overcomes physical boundaries, evidenced in statements like these: ‘It’s like going out [from home] and meeting other people [chronically ill or healthy]’, and ‘It’s like a meeting place for us [other people with chronic illness]’.

Although still underrepresented in the literature, virtual relationships and communities constitute a new ethnographic field (Armstrong et al., 2012; Capogrossi et al., 2015; Kozinets, 2010; Mudry and Strong, 2013; O’Brien and Clark, 2012; Paechter, 2013; Rodríguez, 2013). The analysis of narratives from the Internet—so-called virtual ethnography or netnography—still encounters some resistance because it challenges our well-established ethnographic methods: face-to-face interviews and direct observation (Hine, 2004; Turkle, 1995), raises new ethical concerns (Hookway, 2008; Jacobson, 1999; Paechter, 2013; Sixsmith and Murray, 2001; Wilson and Peterson, 2002), and exposes the limitations of the traditional concept of ‘the field’ that contrasts with ‘home’ and is predicated on the ‘naturalization of cultural difference as inhering in different geographical locales’ (Gupta and Ferguson, 1997, p. 8). Nevertheless, this field cannot be ignored and further research—for example, on culture-specific or gendered uses of the Internet—is needed to build up ethnographic data that will allow us to gain insight into this relatively new form of social interaction among the chronically ill.

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12 Severe cases of multiple chemical sensitivities would be an example of this, as described in the blog created by a young Spanish woman, Eva Caballé, who must live completely isolated from the outside world (see http://nofun-eva.blogspot.com/p/sobre-mi.html, last accessed 22 May 2012).

13 Please note that this chapter was written in early 2012, and that while a few more publications have appeared since, more are needed.
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