The Potential of the Internet for Alternative Caring Practices for Health

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Care and the Internet

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Abstract

The practices of health care in late modernity are informed by competing visions of the ideal human and the nature of care. Western societies typically characterise the ideal human as independent and self-reliant. The resultant welfare systems provide temporary havens away from the everyday, competitive spaces of capitalist societies, termed here the enclave model. Social scientists problematise this model on several grounds: the construction of pathologised and medicalised body forms; the neglect of caring practices that are gendered, invisible and primarily private; the de-politicisation of caring practices. Policy calls reject reference to care and its associations with dependency, make visible and value informal care work or invoke a caring citizenship as a policy goal not just a means.

Into this field of contested notions of care enters a well-documented rise in access to, and consultation through, the internet in everyday lives for a vast range of issues. Health care encountered on-line reflects a similar range in form as that encountered off-line and much that is innovative, whilst clearly of benefit, does nothing to challenge the existing dominance of the enclave model of social care. However, certain groups of sites create spaces through which participants can both express and extract caring relationships that are otherwise unforthcoming. The paper argues that these sites afford potential to develop an alternative model of caring, to reframe questions of how to care about distant others and to demonstrate the centrality of caring relations to human life.

The Potential of the Internet for Alternative Caring Practices for Health

The term 'care' is widely used in everyday parlance across many spheres and spaces of action. Several interrelating strands of research have endeavoured to unpick the meanings and assumptions that inhere to the concept of care and its practice in different spaces. This paper explores whether the relatively new spaces of the internet can enable practices of care that represent alternatives to the conventional structuring of caring relations within contemporary, liberal democracies of Western society.

Problematising Care

The distinction, teased out by Noddings (1984), between caring for and caring about underpins debates of how society might facilitate and express caring relationships. Caring for denotes proximity whereas caring about denotes distance. Social policies reflect the extent that care is positioned as an individual responsibility, caring for, or a societal responsibility, caring about, and as such, structure how a society enables its citizens to care about others. Societal responsibilities are structured through systems to provide health and social care. These formally constituted systems of care acknowledge collective responsibility where the market fails to meet basic needs. As such, caring practices are enacted in specific sites that are set apart from the everyday spaces of a competitive capitalist system for those unable to function therein. This approach, referred to in this paper as the enclave model of care, is premised on a vision of the desirable person as independent and self-reliant; provision of care aims to facilitate functioning in this manner. The increased dominance of neoliberal principles in politics over the last thirty years has further deepened an enclave model of social policy of care for exceptional cases, with everyday care the responsibility of each individual or those emotionally related to them (S. Smith 2005; McLaughlin 2006; Sevenhuijsen 2003; Lawson 2007).

This characterisation of care has provoked three major critiques. First, the disability movement has politicised and rejected the language of care in policy practice arguing that use of the term invokes negative associations through the implicit construction of a normalised body that pathologises other forms, the explicit

inscription of disability as dependency and the framing of assistance as individual, medicalising and marginalizing rather than social, environmental and enabling (McLaughlin 2006). Secondly, social scientists have repeatedly demonstrated the reliance of the enclave model on everyday caring practices that are highly gendered, largely invisible and primarily situated in, and constitutive, of the home, characteristics that further marginalise the place of caring practice in society. The social expectation of performing care contributes to the reproduction of gender inequalities, trapping women into invisible, undervalued and disempowering activities. Feminists have called for the private sphere of informal caring to be visible and valued equally alongside the public domains of economic activity (McKie, Gregory and Bowlby 2002; McKie, Bowlby and Gregory 2004). Finally, this critique is taken further in an argument that the enclave model of social policy does not merely ignore and undervalue the extent of everyday caring practices, but exists exactly because of this exclusion (Young 2000). Caring practices are re-characterised as not just worthy of celebration but central to society and, as such, essentially political (Brown 2003). In this re-characterisation, the desirable social subject as independent is rejected in favour of valuing mutual interdependence. The argument to make central the subjective, emotional and irrational qualities that contribute to caring practices currently marginalised within the private, feminine and non-political spheres resonates with arguments elsewhere to bring emotion to the fore within a policy-relevant social science (Anderson and S. Smith 2001). An ethic of care built into the goals of public institutions and policies and constructions of the market would define equal access to care as the primary right and measure of a successful society (S. Smith 2005; Lawson 2007; Sevenhuijsen 2003). This posits a vision of public policy in which a caring citizenship is an end rather than a means.

The differential value given to rational, universally relevant practices and subjective, contextual, interpersonal practices is given explicit expression and tension within the single sphere of health care. A distinction has been made between care-as-curing, the provision of technical, clinical skills applicable in any setting, and care-as-caring, the provision of context- and person-specific emotional and psychological support (Bauman et al. 2002; Gordon 2003; Howell 2001; Mintzberg 2002). Care-as-curing echoes the enclave model which treats the patient as temporarily dependent due to a condition that can be managed through the application of scientific knowledge,

traditionally determined by the male physician, within a rationalised system for health care provision. Care-as-caring echoes the invisible and informal care work carried out in private spaces on which the enclave model depends and is traditionally part of the routine work of the female nurse. Care-as-caring continues to be relatively invisible within the enclave of the health system, '..the total activities of care contain elements of curing and caring; but almost all existing procedures for appraising "quality of care" today are aimed only at curing' (Feinstein 2001, 201). The lower value accorded to care-as-caring is evident when nurses insist that their primary function is curing not caring (Melia 1987). At the same time, evidence that care-as-caring can be central to a therapeutic process and the prominence in disease profiles of complex, chronic diseases that are not amenable to simple care-as-curing, blur the distinction between the two practices and demands new modes of conceptualisation (Mol 2008).

The sphere of health care is thus complex in that the dual nature of health care as curing and caring involves technical and emotional inputs implicitly defining care as both material and relational, a complexity only deepened by arguments for blurring that distinction. This notwithstanding, use of the term care is infused with an emotional engagement whether in the immediate relations of caring for others or the more distant relations of caring about others. And yet, mainstream approaches to policy-making and system development for health care exclude explicit consideration of these aspects.

Health Care and The Internet
Into this field of contested notions of care enters a well-documented rise in access to and use of the internet in everyday lives for a vast range of health-related issues. Estimates of the population who had ever gone on-line have risen rapidly over the last decade in the US and the UK (Pew Internet 2007; ONS 2008). In the US, 80% of adults with internet access (estimated at over 70% by Pew Internet, 2007) use it, *inter alia*, for health care (Fox 2006). In the UK, 27% of all adults who had accessed the internet in the three months prior to the survey had searched for health-related information. More people go on line for medical advice in any day than visit health professionals (Fox and Rainie 2002). While the majority of health seeking has

always taken place outside the formal spaces of health facilities, this does suggest a shift in the ways and places in which everyday health seeking practices are enacted.

The main health-related activities on the internet involve seeking direct advice on clinical management, information searching, support networking and accessing global health markets through e-commerce (Eysenbach 2003; Hardey 1999; Purcell, Wilson and Delamothe 2002). Most activity is contained within private homes (ONS 2007) and there is concern that the internet deepens existing social and spatial divisions such that those who might most benefit from e-health are least able to access the technology (Blackburn, Read and Hughes 2005; Colle 2000; Forkner-Dunn 2003). Access is not just defined by a connected computer but also by computer literacy, convenience, lack of fear, available time and social filters facilitating use (Colle,2000; Eysenbach 2003; Wyatt et al. 2005).

How, then, do the spaces for health care on the internet intersect with the debates around the nature and practice of care ? In particular, do internet sites merely re-enact or complement existing practices of health care, albeit through a new medium, or is there any sense in which health care sites may represent an alternative space for caring ?

Approaches and Sources
The paper addresses these questions under two headings that reflect the main theme of the paper: complementary and alternative spaces of health care. These 'spaces' examine three of the main health care activities on the internet identified above: clinical management; information searching; support networking. A further type of health care activity, self-diagnosis, is distinguished from information searching and support networking given the importance of this to health care. Health-related e-commerce is not examined, being beyond the scope of the paper.

The discussion derives from two sources of information: published literature and user testimonials. Examination of the four types of health care on-line through a lens of care has involved a series of selections from what is already a vast literature. First, health care on-line can clearly produce harm. Whilst not underestimating such risks, this paper purposively focuses on examples that are beneficial in order to

address the potential for alternative caring practices. Secondly, particular health issues have been selected for focus. Clinical management on-line, argued to empower through disease control, is explored through diabetes management because internet use is relatively well established. Information searching, argued to empower through knowledge, is illustrated through a focus on gender. Literature searches were made through major databases – web of knowledge, medline, geobase, google scholar. There is relatively little written about the implications of using the internet for self-diagnosis and for support networking. These uses of the internet find particular relevance for less common conditions of which we selected one, Lyme Disease. The paper draws on formal testimonials posted in publicly accessible spaces on-line (EuroLyme and Lyme disease action, www.lymediseaseaction.org.uk, and the Lyme League of America www.lymeleague.com) or, in one case, e-mailed to the authors with permission to publish. These are not taken from informal or private members' forums and are not posted to initiate exchange and discussion. As such, the data are not obtained through 'lurking' or other covert quasi-participatory techniques that provoke debate about the ethics of on-line research (Madge, 2007).

I. A Complementary Space for Health Care ? Clinical Management and Information Searching

Management of diabetes types 1 and 2 combines diet and exercise with varying levels of medication, particularly of insulin. The management model is for self-care, an explicit policy for patients to 'become experts in the management of their own diabetes' (Pooley et al. 2001, 319). This model is implemented conventionally through routine GP check-ups and specialist referral (Mazzi and Kidd 2002). Operational problems include poor compliance related to discrepant perceptions of needs between patients and practitioners, the lack of reciprocity in the relationship, the perception of negative judgement by the clinician and time constraints in clinical practice to optimise care and self-management plans (Glasgow et al. 2003).

These problems from interpersonal encounters in practitioner-led self-management indicate the potential for an on-line alternative (Grant et al. 2004). Early experiences suggest on-line professional intervention may lower the frequency of hospitalisation

and costs of treatment (Mazzi and Kidd 2002). Evaluations of peer on-line advice for clinical management were positive (MacPherson, Joseph and Sullivan 2004; Zrebiec 2005) with no evidence that users made exclusive use of this source of advice as an alternative to the professional consultation (Kelly et al. 2002). Indeed, 'most of the disagreements in the diabetic group were concerned with arguments over the accuracy of the information' and that, 'Rather than a rejection of evidence-based clinical advice, it offers a secure space where such information can be assimilated and reflexively shaped to inform lifestyle choices – a space where discursive learning about one's condition can be undertaken on a more equal basis' (Loader et al. 2002, 63 and 64).

Web-site developments now enable integrated support whereby the disease can be measured, monitored and managed with tailored care (Mazzi and Kidd 2002). A person with diabetes can read and upload blood glucose measurements across the day to generate tailored advice and help normalise the diabetes into their daily lifestyles. This procedure also addresses important behavioural risks such as activity, diet or smoking, which are dealt with unsystematically in consultations (McKay et al. 2001). The few evaluative studies so far are promising in terms of clinical impacts (McMahon et al. 2005). The use of online dietary coaches has shown significant improvements in dietary behaviour and exercise in the short-term, although this effect may decline with time (Mazzi and Kidd 2002; Glasgow et al. 2003; McKay et al. 2001). The main problem with on-line clinical care is that people with diabetes come disproportionately from age and class categories that have the least internet access (Brodie et al. 2000; Forkner-Dunn 2003; Grant et al. 2004; Mazzi and Kidd 2002).

The spaces of the internet therefore can facilitate provision of technical and clinical care. The care draws on scientific, rational knowledge which, although generating tailored management plans, is of universal applicability. This, then, is a variant for chronic conditions of care-as-curing in which, in the absence of cure, care is of management and containment. Moreover, this is care-as-curing to explicitly enable independence through performance of the normal body. As such, there are aspects to monitoring the body which are clearly ambivalent, overlapping with critical discussions of body tyranny, body surveillance and body discipline, particularly in

relation to body size, diet and exercise (Schuurman 2004). Despite the undoubted benefits of such on-line practices in making it easier for people with long-term conditions to function in the world the way it is, it does not fundamentally challenge our social values or political processes; it does not represent a radical or alternative development in caring practices for health.

Searching for health-related information is probably the most common use of the internet for health care and various writers have explored the implications (Baker et al. 2006; Broom 2005a, 2005b; Hardey 1999; Hirji 2004; Pandey, Hart and Tiwary 2003; Radin 2006). It is argued that access directly to information, unmediated by a health professional, has the potential to challenge power relations and democratise caring practices. The in-depth studies of Crooks (2006) and Broom (2005a, 2005b) demonstrate how women and men respectively use information from the internet both to feel in control of their disease and to feel empowered in face-to-face consultations with health professionals. Such studies indicate the potential of the internet to alter caring practices more widely since these have been so highly gendered. The implications are complex. At an individual scale, Kitchin (1998) argued that the docile bodies of women remain docile on-line. Crooks' (2006) examples of how women with fibromyalgia draw on the internet to empower themselves in consultations suggest otherwise. But health and education, traditional female domains, comprise the only on-line categories where women are more active than men (ONS 2007), It seems that at a social scale the gendered nature of caring practice overcomes the gendered nature of internet use.

The internet may provide a space where men can take a more active role in caring activities for themselves and for others (Broom, 2005a, 2005b). Social scientists have long criticised the biomedical model for its depersonalising practices in which the practitioner sees symptoms and organs rather than the whole person (for example Martin, 1987). But it is exactly the depersonalised nature of internet spaces, the physical distance from others that facilitates men overcoming traditional masculine roles and values to seek care and to disclose personal experiences of pain and emotion (Broom, 2005a, 2005b). The depersonalised interface of the internet may provide a strangely caring space in that it is experienced as non-judgemental.

There is, then, evidence that information searching and the impersonal nature of the spaces of care on-line, may impact on patient-professional and gendered relationships of care. However, this does not necessarily signify the radical restructuring of power relations implied. Informed and empowered patients correspond with contemporary, neoliberal discourse in which the user of health care is reconfigured as the client or customer, health services as commodities and care as an economic transaction. Any relocation of care from women to men in this context may only reflect greater market content to care in which men are traditionally more active. And alongside any potential for empowerment, the internet may also bring additional demands on women. Now not only does the caring role involve physical and emotional inputs but also time for information searching, sifting and synthesis. Although on-line information searching may impact on power relations in the micro-politics of interpersonal relations, this does not ultimately challenge the enclave model of health care in society but rather complements changes wrought through contemporary neoliberal policies including deepening individual responsibilities for care with the associated demands on women.

II. An Alternative Space For Health Care ? Self-Diagnosis and Support Networks

Information searching on-line does offer potential for an alternative caring practice when it involves cases where conventional professional health care fails to deliver on what, arguably, is the very area in which the claim for professional expertise most resides, that of the diagnosis.

Lyme disease is one of very many relatively uncommon but potentially debilitating conditions for which the practices of health care on-line may be particularly suitable. It is a tick-borne chronic illness with far-reaching effects on almost all aspects of the body's functioning with time,

> 'I was bitten by a tick in the local woods in 2004. I was playing hide-and-seek with my niece and nephew at the time. I had all the typical symptoms (sickness, shivery chills, bulls-eye rash) but my GP didn't have a clue about it – and still doesn't. By the time I eventually diagnosed myself and demanded to see a specialist, I had excruciating headaches and eye pain, hip pain,

ringing in the ears, blue hands, breathlessness, numb foot, disrupted digestion, depression, high blood pressure, restless legs, unexplained weight loss, extreme fatigue, rib pain, mouth ulcers, heart palpitations and racing heart'

(emailed testimonial, diagnosed early 2007)

Testimonials published and posted by sufferers of Lyme disease on internet sites from both UK and US share a series of common experiences:

- being told the health professionals cannot find anything wrong
- in the absence of anything else, being given a psycho-somatic diagnosis such as depression or stress and questioned about their domestic life
- being ridiculed, treated as a malingerer or as imagining an illness – one sufferer was asked in hospital, 'have you got any more symptoms today?'
- having their self-diagnosis, other person's diagnosis and even another physician's diagnosis ignored
- not being given more advanced tests when the basic test returned negative
- receiving inadequate treatment that did not follow up-to-date protocols
- experiencing serious delays in treatment so that the condition of the disease was vastly worse when finally diagnosed
- more positively, gaining treatment even though the diagnosis was not confirmed

The testimonials emphasise the power of medical practice as the gatekeeper of access to treatment. Professional ignorance of uncommon conditions is understandable; indeed physicians themselves increasingly turn to the internet under such circumstances (Greenwald 2005; Tang and Ng 2006). What is striking is the lack of a caring about the patient, ridiculing them, making them feel in the way or reducing the patient to an object for study. The experience of a physician who himself contracted Lyme and went undiagnosed is instructive,

'In the end it was easier to live with the symptoms rather than be ridiculed by those from whom I might seek advice…..' (Wilson 1999, 649).

Another testimonial highlights the emotional vulnerability of the undiagnosed case,

'.. it was full of students waiting to see the great doctor at work and learn all they could from the master. After he inspected me and let all the students inspect me he gave his diagnosis….. I went from feeling fairly good to feeling depressed within seconds.'

http://www.lymediseaseaction.org.uk links, patient stories. Accessed 21st May, 2009

These examples of professional ignorance, inability to diagnose or treat and the lack of caring practice question whether an ill-informed use of internet spaces will always risk greater harm to health than expert consultation. The role of the internet in these cases is not just to empower patients to become their own health care managers but to empower patients to demand and extract caring practice in circumstances where it is otherwise unforthcoming. This may involve challenging existing power relations and in particular those power relations based on the authority of expertise. This can pose many challenges,

'We live in our bodies, we know what is happening to our lives. We need to educate these doctors to LISTEN to their patients. Do not be afraid to mail information to these so-called educated physicians when they deny lyme exists or refuse to treat you… And most importantly… don't give up. YOU ARE NOT CRAZY. Yes you have Lyme, but you also have lots of support. Visit the lyme sites on this website and as many as you can find on the internet. Get a lyme-literate doctor, get educated about your illness and most importantly, GET BETTER' [*emphases in the original*]
www.sewill.org/story1.htm (accessed 2nd June, 2009)

'We are still struggling to get treatment after 14 years while Doctors in our state claim Lyme disease is "not in our area", that chronic Lyme "doesn't exist" or that they won't treat longer than 30 days because of the medical boards and insurance problems. This is unacceptable!'
www.lymeleague/com (patient stories, Wisconsin, accessed 21st May, 2009)

These testimonials and other studies of information searching are based on sites that also provide support networking through user and disease-specific on-line groups,

> 'It's been a long haul but I'm making good progress. The Eurolyme support
> group has been a great way of judging how well I'm doing. If it hadn't been for
> that I'm sure I would be very despondent by now at the length of time it has
> taken. However, others are very encouraging when it's needed and it's such a
> relief to converse with others who know how awful it is'
> (emailed testimonial)

There has been no research on the roles in society of those who not only go on-line
and support one another, which might be seen as reciprocal and therefore explained
through individual interest, but who voluntarily set up such sites. Testimonials on
support sites demonstrate the effort involved,

> 'Having found I was suffering from Lyme disease in 1997 I spent several
> hours trawling the web for as much information as I could find on the disease.
> At the time there was little UK specific data. I thought it might be useful to put
> a site together that linked all the most useful information that I had found. I
> also provided a pack of information to help give a more detailed view for the
> medical profession and anyone interested.'
> http://www.lymediseaseaction.org.uk   links - patient stories, accessed 21st
> May, 2009

Sufferers post their own story on-line for others, strangers, to read. The intentions
are two-fold: enabling individuals to get help and redressing systemic inadequacies
in formal care practices,

> 'I hope you can do something with this: it's not everything but it's a start. If we
> help one person then some good will come of all this. I have been asked what
> I want from all this ? Well I want my country to love me as I love it. I want the
> NHS to give people the help they have paid for over the years. I want my
> family to grow up loving life and not fearing it'

http://www.lymediseaseaction.org.uk links - patient stories, accessed 21st May, 2009

Such support work may be interpreted as fulfilling individual interests in that through
such action, people make sense of lives that have been otherwise blighted by ill-
health and thus reclaim value, meaning and purpose to their lives. Whilst this may be
so, what is interesting is that this reclaiming is not, or not only, through a return to

the work-force and the everyday spaces of capitalist society, but through caring about others, distant strangers, who may face the same experiences in the future. The previous quotation by a British male uses the word 'love' three times, not an everyday practice in public spaces amongst strangers in the UK. It is this ability of the internet to bring distant others into the same space to form more intimate interactions that represents its potential to challenge and rework the practices of how society cares about others. In particular, these sites of health represent spaces that are constructed on non-market, non-individualistic principles and as such are mutually constituted and constitutive of caring relationships enacted in part at a distance but also in part on a one-on-one basis.

Last Reflections

The internet inevitably reflects and reproduces relations, values and processes of wider society. Cautionary tales relate to the potential of the internet to exacerbate existing inequalities through the digital divide or to fulfil the fantasy of the global market-place where you can buy anything regardless of whether you should. Similarly, celebrations of the internet in health care concern its enhancement of strategies for people to maintain socially acceptable identities and functions, its support of the neoliberal construction of health user as customer and personal health manager through ease of access to information and empowered engagement with health professionals. As such, the internet affords spaces of health care that complement existing off-line options. But part of what is valued about on-line care-as-caring is an impersonal quality, complicating accepted critiques of clinical training in 'detached concern' (Fox 2006; Halpern 2001) and offering new spaces in which to explore human subjectivities in health-related encounters.

Further renegotiations of the practices of care are evident through sites that support uncommon conditions such as Lyme disease. This space does several things. The individual empowerment of self-diagnosis goes beyond that depicted by those using information to enter a more equal dialogue with professionals. The sufferers of Lyme are extracting various forms of care from a formal system from which the necessary care is not forthcoming. The further investment that some individuals or groups are prepared to make into creating and maintaining support sites brings to the fore the importance of caring relationships in giving meaning to human lives. Self-help

support sites on the internet can be interpreted as a bid to secure a more caring citizenship in what at times seems a care-less landscape. Whilst self-help and support groups existed long before the internet, the potential ease of access from any place at any time makes this a particularly important emerging form of caring practice.

These potentially alternative spaces of health care on the internet contribute in reframing to some extent a question of how to express caring about distant others (Silk 2004; D. Smith 1998). The internet spaces of health care argued here to offer an alternative practice of care do so by tackling the question of how to express caring about distant others in two ways. First and most obviously, the internet creates spaces which brings distant others together into a virtual proximity, effectively eroding some aspects of distance. It cannot erode the real physical distance or enable the intimacy of touch, a distinctive aspect of caring. But as already indicated, this new capacity for virtual proximity without physical intimacy has its own benefits in caring practices. Secondly, in a capitalist system, emotions and moralities of care about others have to find translation through a financial medium. The internet spaces explored here have the capacity to enable a caring practice that transcends the need for financial mediation. The opportunities to expand this kind of internet social engagement that may be afforded through the next generation of technology, most immediately web 2.0, beg for in-depth on-line ethnographies to further explore the nature of caring practices on-line.

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