HOME CULTURES

VOLUME 4. ISSUE 1 PP 25-44

REPRINTS AVAILABLE DIRECTLY FROM THE PUBLISHERS.

PHOTOCOPYING PERMITTED BY LICENSE ONLY

© BERG 2007 PRINTED IN THE UK

PATRICK LAVIOLETTE and **IULIENNE HANSON** HOME IS WHERE THE HEART STOPPED: PANOPTICISM. **CHRONIC** DISEASE, AND THE DOMESTICATION **OF ASSISTIVE** TECHNOLOGY

ABSTRACT The notions of housing and the home have shifted considerably over the past decades given the significant changes in technological developments, demographics and the constitution of the family nexus. One of the areas in which architecture, design and planning have OF LIFE ISSUES. SHE IS THE COAUTHOR been responding relates to the growing needs of an ageing population with increasing leisure time as well as exposure SYNTAX GROUP AT UCL. to disability or chronic diseases.

PATRICK LAVIOLETTE IS SENIOR LECTURER IN VISUAL AND MATERIAL CULTURE AT MASSEY UNIVERSITY, WELLINGTON, NEW ZEALAND. HE WAS FORMALLY APPOINTED AS A JOINT FELLOW IN THE DEPARTMENT OF ANTHROPOLOGY AND IN ARCHITECTURE AT THE BARTLETT SCHOOL OF GRADUATE STUDIES, UCL, UK, WHERE HE UNDERTOOK THIS RESEARCH AS PART OF AN EPSRC-FUNDED PROJECT ENTITLED "SUPPORTING INDEPENDENCE: NEW PRODUCTS, NEW PRACTICES, NEW COMMUNITIES."

JULIENNE HANSON IS PROFESSOR OF HOUSE FORM AND CULTURE AT THE BARTLETT SCHOOL OF GRADUATE STUDIES, FACULTY OF THE BUILT ENVIRONMENT, UCL, UK. SHE HAS **RECENTLY PROFILED THE UK'S HOUSING** STOCK WITH THE NEEDS OF OLDER PEOPLE IN MIND, HAVING INVESTIGATED THE LAYOUT AND DESIGN OF RESIDENTIAL CARE HOMES IN RELATION TO QUALITY OF THE SOCIAL LOGIC OF SPACE (CUP, 1984) WITH PROFESSOR BILL HILLIER WITH WHOM SHE HAS CO-FOUNDED THE SPACE

Regarding the treatment or rehabilitation from illness, sophisticated medical technologies were once the exclusive domain of hospitals and specialist practices but are becoming increasingly available in the home. The idea behind their recent proliferation is to save money and time for health services as well to allow outpatients a greater participation in their own recovery by avoiding institutional care. Unfortunately, however, studies into the development of assistive technology innovations have largely overlooked the user's changing perceptions about their own needs and towards the ways in which the innovations in question become appropriated into their everyday lives. Additionally, little is known about how they and their extended support network of carers, friends, kin or partners actually perceive the impacts of illness on domestic lifestyles. This paper addresses these issues. It examines the mainstream implementation of telecare in relation to facilitating the independence of older disabled people in their domestic space. From a case study of chronic heart failure sufferers over sixty living in the Barnsley area, we evaluate the expectations, benefits, drawbacks and social meanings concerning a forthcoming pilot installation of such a home-based health monitoring scheme.

INTRODUCTION

What would you say, if by the gradual adoption and diversified application of this single principle, you should see a new scene of things spread itself over the face of civilized society?—morals reformed, health preserved, industry invigorated, instruction diffused, public burdens lightened, economy seated as it were upon a rock, the Gordian knot of the poorlaws not cut but untied—all by a simple idea in architecture? (Jeremy Bentham 1995[1787]).

Panopticon, a term for an all-seeing structure, was designed by Bentham in the late eighteenth century as a twenty-four-hour surveillance edifice. Its architecture ensured that those in residence could never see the inspector who occupied the privileged central location within the radial configuration. Those observed could not know when they were being seen (Fig. 1). In and of itself this mental uncertainty is the crucial instrument for the way that this physical design became a conceptual construction which intended to instill a self imposed means of regulating one's own behavior—an internalized form of self discipline.

Such a metaphor of panopticism has given rise to many variations in our own time. Surveillance is reduced to an idealized and ideological form. Through a series of associations rather than a

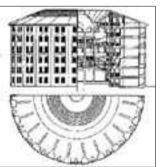


Figure 1 Jeremy Bentham's Panopticon from his Panopticon Letters (1995[1787]).

formal argument as such, this paper indicates the ways in which the telecare system, particularly in the geographical context of Barnsley, exemplifies a contemporary manifestation of panopticism as problematized by Bentham (1995[1787]), Foucault (1963, 1977) and similar discourses in anthropology and architecture (Hanson and Percival forthcoming; Samuelsen and Steffen 2004).

So the idea here is to begin to bridge what has been seen in surveillance studies as a chasm in the social sciences for dealing with the issues related to caring surveillance (Lyon 2001). In these terms, we explore the notion that if domestic healthcare support (in the form of telecare) is to be medically beneficial to the increasing number of older citizens with chronic conditions and to society more generally, then it must possess some of the intimate and emancipatory characteristics of what some scholars have called the synoptical, which stands in opposition to the panoptical (Haggerty and Ericson 2000; Hier 2003). Or what the performance theorist Steve Mann (2004) calls sousveillance versus surveillance. In other words, residential health monitoring technologies need to demonstrate a significant potential for vernacular, grass roots empowerment. And this enabling potential would then have to outstrip the more sinister controlling and liberty removing effects frequently entailed by many institutionally conceived forms of the medical gaze.

BACKGROUND

This article is a preliminary summary of a period of fieldwork in progress. It is part of a larger four-year research consortium project that operates under the title "Supporting Independence; New Products, New Practices, New Communities." Members of this consortium have been preparing to install assistive technology devices that form a telecare package into the homes of older people with chronic heart failure living in the Barnsley area of South Yorkshire. Though monitoring equipment may be an appropriate medical intervention, it may not be the most effective solution if the home environment is inherently unsuitable for an older person to live in (Lansley et al. 2005). Our role on this project is to address the relationship between people's health, their housing and their ability or otherwise to manage at home. Some of the themes that we are exploring consist of the domestication of technological devices as well as how technology alters the everyday representation of self (Goffman 1956), and how people make, or become susceptible to suggestions to make, adaptations to their home as they get older and as their health conditions change. Ultimately this means we are curious about how the very notion of the home begins to change in an ageing society.

Telecare is health care at a distance. It is achieved within the person's own home through the assistance of information and

communication technologies. It is a way of delivering care not a form of treatment. It operates when monitoring systems made up of various types of sensors are used together to examine specific physical conditions of wellbeing such as vital signs, detection of environmental irregularities (floods, excess heat), regular culinary activity, room occupation and movement. The information gathered is communicated to a remote base or call centre which records medical information for specialists or GPs and monitors for certain alert signals. The breach of any such health warning triggers off automated alarms or arranges for the user, family member, formal carer or emergency services to be contacted, depending on the nature of what is deemed to be occurring (Brownsell *et al.* 2003; Porteus 1999).

Although the decreasing prevalence of lethal or disabling infectious diseases marks the achievement of public health care over the past century, contagious epidemics are being replaced by complexes of longstanding chronic illness. These are associated with extended longevity as well as rather high hygiene and affluence. They fall into a tripartite division (systemic degeneration, biomechanical, psychological). The first category, organic degeneration or systems failure, includes most cardiovascular diseases such as Chronic Heart Failure (CHF). Crucial symptoms of CHF include: night time urination, swelling of ankles, palpitations, fatigue, breathlessness. These rather clear indicators make it a relatively easy condition to monitor and therefore to regulate through medication with sufficient notification (Aldred *et al.* 2005).

Caring for an increasingly elderly population is one of the bigger challenges facing local government and healthcare services over the next decades. People over sixty-five occupy almost twothirds of general and acute hospital beds-in certain instances unnecessarily. About forty percent of NHS (National Health Service) expenditure goes on caring for the over sixty-fives, and although currently a fifth of the UK's population is over sixty, in five years' time this proportion will have risen sharply. The UK presently has the highest proportion of residents over the age of sixty-five in Europe (18.7%). The cost to the taxpayer of supporting a chronically unwell older person at home is estimated at half the cost of a residential home, a quarter of the cost of care in a nursing home and an eighth of providing care in a hospital (Fisk 2003). Consequently, the UK government plans to provide telecare to all who need it by 2010. To this effect, The Department of Health has invested £80 million. At present about 1,700 older and vulnerable people are supported in their own homes with a package of telecare technology. Roughly ten percent of these people have high levels of care or support and would have been considered for a move to institutional care in the absence of a cost-effective alternative. The idea of telecare as a means of helping people stay at home within a risk-managed environment is therefore highly driven by economics as well as the practicalities that the NHS is increasingly facing regarding the changing demographics of gerontology (Tang *et al.* 2000).

The UK is thus at a healthcare crossroads. The form of the NHS' modernization, particularly its use of IT, will be critical in determining the health of the nation. Prioritizing continuous physiological telemonitoring is an interesting opportunity for the future NHS to place equality of self-care in the hands of the public (Shaw 1998). In this sense, the transformations of the NHS could allow it to better situate wellbeing and risk prevention at the core of healthcare, reversing the trend of inequality of care and the increasing disease consequences of the deteriorating lifestyle of the nation—particularly those associated with social disadvantage. The national service frameworks are all based on generic health-promotion standards that are unmet by the current system. Certain medical innovation specialists therefore argue that such standards cannot be easily delivered without recourse to substantial IT-supported change in service provision (Barlow and Venables 2004).

These are compelling reasons for providing long-term care for older people in their homes, whenever possible. This is particularly so since older people usually wish to avoid institutional care (Fig. 2). Indeed, few dispute that older people prefer to remain in their own homes, living independently, for as long as they can (Marcoux 2001). While telecare's potential to reduce health care costs appears straightforward, the perceptions of patients' regarding this new technology have rarely been examined. A study in Scotland by Levy et al. (2002) and a collaboration between Swedish and Californian medical health experts (Agrell et al. 2000) seem to be amongst the few to elicit patients' perceptions regarding home telecare through structured interviews in their own homes. The latter study delivered a survey instrument of thirty-four items to a sample of patients who were currently or had previously been enrolled in the Sonora Health System or UC Davis home telecare pilot projects. Fifteen (56%) of the twenty-seven past or present enrollees agreed to the interviews.



Figure 2 Barnsley Care Home for the Elderly, 2005. Photo by P. Laviolette.

Most had neutral (9 of 15, 60%) or positive (5 of 15, 33%) feelings about home telecare before their participation. Subsequently all were either considerably satisfied (10 of 15, 67%) or fairly satisfied (5 of 15, 33%) with the services provided. Fourteen of fifteen (93%) agreed to receiving future home telecare services and all fifteen would recommend the system to family or friends.

Even though they were informed to the contrary, patients imagined that the presence of telecare equipment in the home implied round the clock access to care or a nurse. The disclosure of intimate information during tele-visits was obviously a source of concern for many while others lamented the reduced amount of time nurses spent "socializing" as compared to in-person visits. Despite anxieties regarding its confidentiality and ability to approximate the social stimulation of in-person nursing visits, patients in these pilot trials seemed satisfied with home telecare and appeared ready to accept its widespread use. The outcomes of such studies to date suggest that reductions in hospital delayed discharges would possibly occur and quality of life for service users should improve (Sinha 2000).

METHODOLOGY

Participants for our study are being chosen at random from a list of several hundred cardiac patients at the Barnsley District Hospital by our research partners there. For their purposes of providing a quantitative study of the telecare package, they are attempting to gather at least fifty-five people who fall into a telecare intervention group and a non-telecare control group. We have recruited a sub-set of about thirty-two participants from them, mostly from the intervention group. The basis for our selection is the type of housing in which they live—e.g. Victorian terraced house, council house/flat, purpose-built or converted dwelling, detached or semi-detached bungalow. This means that we have at least five participants for five different housing types, a number of types that is roughly representative for the average socioeconomic conditions expected in this area of South Yorkshire.

Of the thirty-two interviews, twenty-eight have been men and four have been women, with five from the control group. The gender bias is indicative of this medical condition, which disproportionately afflicts men. The interviews have occurred in three batches over the course of October/November 2005 and early March 2006. The research nurse who solicits their participation has been leaving a brochure with them that explains the desire to recruit certain people concerning how they feel about the system. These people are being invited to participate in a housing audit coupled to an in-depth, qualitative interview about the relationship between their housing, health, and activities of daily living. We are then given a list of names from those that express an interest and left with the stipulation that the interviews need to be completed within about a week so that the telecare kit can be installed quickly.

Seventeen participants have accepted the Lifestyle Monitoring sensors which means that their homes will be kitted out with various types of sensors for movement, occupancy (chair, bed) and utility (kettle, fridge, microwave, cupboards). Except for the five controls, all will have the Docobot health monitoring computer. Nearly half, however, have refused the sensors and are simply accepting to use the computer. Follow up interviews will involve questions about living with the system. Also tours of the home, a furniture inventory, photos and amendments to map plans consisting of locating the sensors (if installed) will be requested at this stage.

The first semi-structured interviews have been rather informal. Most lasted about an hour and a guarter. A couple took over three hours. They have taken place before the installation of the telecare in order to get a preliminary sense of what the tenants expect of the project, their views of modern technology (particularly health technology) and the reasons they have volunteered to participate. The idea is to get a before and after picture by visiting them again after nine months of living with the telecare system. After a series of questions about their homes, and their perceptions of the benefits and drawbacks of telecare, we have been getting the informants to talk us through their daily routines and the uses they make of the various places in their homes and beyond (Highmore 2002). Not only is this to assist in the understanding of everyday lifestyles but also to correlate with whether the sensor data gathered by our Dundee consortium partners will bear any resemblance to what people say they are doing.

The interviews finished up with making a sketch plan of the room in which the encounter took place and an approximate plan of the entire home, more detailed if the participants offered to provide a tour. The idea here was to get them to speak about where they had been told or imagined the sensors would be installed. Only three people offered a tour of their flat or house and the success rate in obtaining a cup of tea was only fifty percent. Finally, a few people have offered to sketch the place out themselves, which is of course ideal ethnographically.

MATERIALIZING MEDICAL DISCOURSES

In our sample over half the participants have had a triple heart bypass. A few have pace makers. Many spoke about having had one or several heart attacks in their home. But they nearly all still want to live where they are, the exceptions related to their growing difficulty with negotiating stairs. So overall, there is a strong positive potential for developing remote medical technologies that allow people to stay at home. And at the surface, many of our participant responses have been related to encouraging such development. Most of them are proud of the family support networks that they have and feel that the telecare is either going to be an interesting backup system for them, or there to alleviate some of the strain upon this support network. Indeed, they hope it will be a good safeguard mechanism or something that is around to double check their health. But they are generally ambivalent about telecare if it were to begin replacing the full professional nurse care. Perhaps surprisingly, however, hardly any mentioned, without some prompting, that they were concerned about alienation or possible reduction in human care contact.

Many felt the most useful thing to come out of any telecare treatment was that it would save travel time for them and NHS staff. They supported strongly the idea that if it helped make the NHS more efficient and save time and money for health care professionals it would be a good thing. Amusingly, a couple of people felt that they themselves were the equivalent to community alarms for their neighbors who relied on them for help. Several thought the sensors for detecting movement would be rather useless but were happy "to give it a go." A couple of others added that this was going too far and did not feel comfortable with them so they have declined to have them. A few people even felt that the telecare would help with learning about their own condition (below we describe the example of one of them in relation to weight monitoring).

But there was some dissent. One chap, Mr Green (aged sixtyeight), who withdrew from the project the day after his preliminary interview, said as soon as he was approached that he was not keen. He greeted the interviewer from the top of the stairs with the music blaring from the lounge downstairs after he had been rung on the phone because it was apparent that he could not hear the doorbell. While climbing down the stairs hesitantly, he indicated to go into the lounge. He sat down in his favorite chair without turning the music down and proceeded to say that he was already housebound and did not want this "tele thing" to make matters worse. When arranging the first interview, he agreed only once it was clarified that he need not displace himself and would be visited at home. He was obviously not prepared to go out of his way. His first comments were to say that after sixteen years of having it, he canceled his subscription to Sky last month. He went on to explain that he recently got rid of his blood pressure gauge because it was too complicated and would soon be ridding himself of his mobile phone which he felt was only for show offs, perhaps a subtle reference to the fact that he had just been called from a mobile to answer the door. He then complained at length about the number of tablets he has to take, saying he could keep a chemist in business. Interestingly on this point, the location for storing medication was usually haphazard by most informants. People kept their tablets in bags by the TV in the lounge. The kitchen was also a main place for keeping them and sometimes the bathroom and bedroom.

It came out that Mr Green had only agreed to participate in the project to get his money's worth from the NHS—that he had paid his taxes all his life and that the government would not get anything further off him. Rather he wanted whatever benefits he was entitled to as long as it implied minimal input on his part. The inference here is that the telecare project was beginning to be more trouble than it was worth.

Most people stated that they were not sure what to expect from the project or how it could help them. They were nonetheless keen to participate because the information collected might help others in the future. Willing "Guinea Pigs" was a recurring term. A typical reason was because they felt they owed the NHS their lives; that each time they had been hospitalized, the staff had been brilliant so they were willing to play their part. One person even claimed, "if I could dedicate an hour a week to helping the NHS I would with no quibbles."

On the whole most respondents have been exceptionally supportive of the care they have got from Barnsley Hospital, hence their main desire to participate in the research. A few, however, were quite unfavorable about this hospital in particular. What is interesting is that they believe most others feel the same way. Here is one example by one of the younger gentlemen (aged sixty-two) who was in the minority in not having his wife present during the interview even though she was in the house:

We used to hear stories about the family doctor visit. I've only had one doctor in my life who on his own bat came to visit me when I were in hospital many, many years ago. The only one who showed any interest and I don't think they do today, oh no. I think most people will talk that way, they're all disappointed. We've got to go to Rotherham at the weekend because she can't go to Barnsley, she's got an eye problem, especially because she gets iritis for many years and now you've got to go to Rotherham, if it's Friday or Saturday, you've got to go twenty miles, it's rubbish.

Another example of grievances comes from Mr and Mrs Lister who actually live in a caravan by the coast for nearly half the year and whose actual potential to contribute meaningfully to the telecare project is therefore questionable. They described how the Barnsley doctors sent Mrs Lister home to die in 1968 when she was deemed terminally ill (she is not the CHF sufferer). "I remember telling the doctors at the time, I'm not coming back to Barnsley Hospital because you bury mistakes here." They go on to explain that Barnsley used to have a lot of power cuts so living near the old hospital was convenient to avoid that. "But when they moved up Pogmoor, new hospital got a bad name early on. They seem to spend more time and money developing waiting areas. And referrals seem to be something they're good at. Must get paid by number of visits and referrals. They like you to come back." Another point that they raised is that patients are seen by junior people and the "top dog" sits and observes but does not give any contact time. They suggest that this is necessary for training "but the more and bigger hospitals get, the more people fall through the cracks and you end up with many incompetent specialists ... these days you don't actually get cured." Their grievance is effectively about how people are kept in a self-perpetuating system of nurturance where they are shuffled around—where one is never seriously ill but never altogether not ill either.

This view is supported by Mr Littlewood (aged sixty-seven) who says "hospitals would make you into an invalid if they could." He is very active and wants to die in a manner that is guick and dignified "like that Yorkshire gardener Percy Thrower. Y'know, second heart attack, bam! Gone." In other words, Mr Littlewood is not keen in a protracted, drawn out death. He also comments antagonistically about how some people "live in their illness ... they won't stop talking about it to the point where you'd think it was something that they cherished, y'know that was valuable in their life." The idea of living in illness not as a hypochondriac but as someone with genuine problems which they nurture is interesting. Mr Littlewood was speaking of someone like Mr Churn (aged seventy-five) who was particularly concerned about why he was chosen for the study. Most probably, he was anxious that it was a poor health criterion and that we were interested in him while he was still around because we must know something about his condition. Several times during the conversation he commented guite mournfully about the few things he still had left, like his family and home.

Few participants felt they would be competent enough to use the technology involved adequately. They expressed that they needed the system to be "idiot proof" because they were useless with new technological innovations. They added of course that they were not of the right generation to understand many modern gadgets. "There's only one concern I've got. I'm as thick as two planks normally. I'm not sure I'll be able to follow if it's too complicated. She'll [the district nurse] have to leave me a clear and simple list of what to do step by step, otherwise it'll be no use y'know."

DOMESTICATING HEALTH CARE

The telescreen received and transmitted simultaneously. Any sound that Winston made, above the level of a very low whisper, would be picked up by it; moreover, so long as he remained

within the field of vision which the metal plaque commanded, he could be seen as well as heard. There was of course no way of knowing whether you were being watched at any given moment. How often, or on what system, the Thought Police plugged in on any individual wire was guesswork. It was even conceivable that they watched everybody all the time. But at any rate they could plug in your wire whenever they wanted to. You had to live - did live, from habit that became instinct - in the assumption that every sound you made was overheard, and except in darkness, every movement scrutinized (Orwell 1949: 4–5).

We have taken longer than the social critic George Orwell thought to get to the stage of a *Nineteen Eighty-Four* scenario, but elements of it are on their way. Before embarking on the telecare installation in Barnsley, focus group work was undertaken there with older members of the general public, their informal carers, and local health care professionals, to introduce the possible uses of telecare through discussion of specially designed case scenarios that explored whether telecare could be a potentially valuable service. All our focus group discussions with older people, professionals, and carers spontaneously mentioned the phrase Big Brother at some point.

According to many of these participants, we live within a culture of creeping surveillance (Fig. 3). Surveillance is already an issue for some older people living in supported housing settings and a number of participants commented on how existing community alarm systems can feel intrusive. One carer recalled how a friend, living in sheltered housing, routinely whispers when communicating with visitors, thinking that the presence of the piper alarm enables people to overhear general conversations. Professionals mentioned tenants who have a "sense of being watched" and resist this perceived passive surveillance by refusing to have monitoring calls from wardens and insisting that they will "pull the cord" if they



Figure 3 Barnsley District Hospital from New Lodge, 2005. Photo by P. Laviolette.

want help. Participants questioned the use of lifestyle monitoring devices, where private routines are open to public scrutiny without good reason, summed up by the comment "I don't want anyone to know how many times I pull the bloody flush, it's personal."

Such fears emerge in other research. Magnusson and Hanson (2003) describe how a number of frail older people and their carers felt worried that ICT equipment could enable other people to see into their home. Brownsell *et al.* (2003) found that respondents needed reassurance that their warden could not see them via the lifestyle monitoring systems. Fisk (2003) makes a fundamental point in regard to this ethical aspect of telecare when he says that if there is to be surveillance that gathers personal information about domestic routines, the consent of the service user is vital. Such consent appears not to have been requested in the study evaluated by Bowes and McColgan (2003: 16), with staff objecting to the use of video "to view a person in their house without their knowledge."

Older people who are becoming frail but want to remain in their own home may have strong reasons why they wish to keep their daily routines and behavior private. Of particular importance is the reluctance to publicize difficulties, or as one professional put it, "this whole issue of who finds out about your deteriorated state." Relevant studies have noted that older people do not always want falls within the home to be known or responded to, for fear of negative consequences such as pressure to relinquish the home and move into institutional care (Brownsell and Hawley 2004). It is also important to note in the context of falls that an older person's psychological priorities may differ from those of carers or service providers.

For example, in their empirical study of the ways in which risk of falls was "constructed" by older people, Ballinger and Payne (2002: 305) argue that while service providers are "oriented to the management of physical risk," older people themselves are more concerned with the risk to their "personal and social identities" as well as to the challenges posed to their "self-image." This emphasis on the self-perception of the older person is crucial. Some authors even consider self-esteem as "one of the most valuable indicators of adjustment in old age" (Jensen *et al.* 1998: 255). Self-esteem is also a hallmark of older people's sense of independence, alongside "continuity of the self" (Secker *et al.* 2003: 375). Many participants echoed this point in our discussion groups, which one person summed up with the reflection, "I'm a nuisance, so they'll take me out."

One of the more interesting things to arise from the interviews is the exceptional longevity of residence of the participants. They simply have not moved much in their lifetime and do not plan to. Twenty-five of thirty-two have been in the same house for over thirty-five years. Of the four that have moved more recently, three had remained local so that only one of them was from outside South Yorkshire. This is potentially a trait of the region. As a borough, Barnsley seems to have a reputation for resident stability. An internet reference to a study in 2003 reveals that over the past several years the average number of people moving out of the area was 115 per year for a population of over 225,000 (www.reference. com/browse/wiki/Barnsley). The website suggests therefore that this is related to a high satisfaction with Barnsley as a residence and hence that it could be seen as one of the best places to live in Britain—a direct opposition to the way it is often represented in the media. To this effect, Ken Loach's film *Kes* (1969) and Mark Herman's *Brassed Off* (1996) are particularly telling in exposing the working-class, coal mining heritage of the region.

An interesting paradox therefore exists between independence and mobility, or the lack of it. The people in this region are not geographically mobile as a society nor are the tenants in question particularly mobile as a group. The idea of telecare at home for their increased independence means remaining in place is what is encouraged by the service. Independence means the ability to remain static, which seems to be what they want. This is far from objectionable but the idea of independence here should not be conflated with greater mobility as far as moving house is concerned. Such an emphasis is crucial in the way that it is in conceptual contrast to the idea of being *At Home in the World* (Jackson 1995) or how migration becomes a form of identity creation (Rapport and Dawson 1998).

Mr and Mrs Skate (aged seventy-three and sixty-five) are amongst the slim minority of "middle-class" informants recruited so far. They live in a large four-bedroom house which they purchased themselves privately (twenty-seven of the thirty-two participants have obtained their houses or flats through the council). Further, they have recently moved into Barnsley, although Mrs Skate is from the area originally. The interview with them lasted for several hours. They explained that they refused the installation of sensors in the kitchen because they felt that their alternative lifestyle was of a particularly sub-hygienic standard, particularly because of their dogs. They did not hesitate, however, in offering a guided tour of their house, something again that many participants did not volunteer. Upon entering the kitchen/dining area it became apparent that it was not just the dogs but the pets more generally that could have been referred to. Several fish bowls were present in this area of their home. A smallish one was completely greened over in a cover of algae. Floating at the top of another much larger tank is a rather big (four-inch) goldfish. The flesh was noticeably decomposing around its blackening body. It had been dead for at least a couple of weeks.

What is interesting in this case is that the sensors in question would have no way of picking up this kind of eccentric behavior about hygiene or lifestyle and this couple is perfectly aware of that. And yet they were the ones who suggested a tour around their house where such things could be observed. To an extent then, their rationale must be related to the difference between human versus mechanical monitoring. It is the technology here, no matter how intimately related to healthcare, that cannot be allowed to see the human flaws of "everyday lifestyles," to use a term that Henri Lefebvre was partial to (1991). This technology is thus rearticulating boundaries between private and public spaces, distance and proximity (Weber 1964). No longer can we assume that privacy is either spatially or temporally stable. Objects are less permeable than subjects, conjuring not an embodied virtuality or a virtual embodiment, but simply a reality that exists in opposition to the technological (Arnold 2003).

The questions remain, however, how does telecare's panoptic structure become democratic? How is it supervised by society as a whole? The answer is obvious, the NHS. Barnsley District General Hospital was founded in the 1970s by joining St Helen's Hospital and the Barnsley Beckett Hospital. It was built on the top of the hill at the site of St Helen's, which was mainly a large Victorian maternity ward. The Beckett Hospital, situated further down the hill in the city center opposite where the Technical College is now found, was the home so to speak, of the maimed and injured workers of the dangerous South Yorkshire occupation of mining. The amalgamation became possible with the assistance of the foundation of the NHS's Hospital Trust scheme.

The panoptical aspects of this newer Barnsley General District Hospital are numerous. The most obvious is its geographical positioning as a central reference point on the top of a hill around which the city extends (Fig. 4). It can be seen for miles around from nearly all directions and has an ominous presence in daily life. It is also one of the main employers in the regions and the NHS Foundation Trust for Barnsley Hospital has 12,500 members. Nearly everyone knows about it and it is next to impossible to ignore because there is little else of contemporary socioeconomic significance. Furthermore, there seems to be a disproportionate number of ambulances and mobility scooters that roam the streets.

This geographical setting parallels the idea of telecare as a classic case of medical surveillance technology where the hospital practices themselves reach into the home. For Foucault (1977), panopticism is a disciplinary mechanism that improves the exercise of power by making it lighter, faster, and more effective. It is a design of subtle internalized coercion for a future society. It de-individualizes power and surveillance so that it becomes difficult to determine who exercises them. Most proponents argue that

HOME IS WHERE THE HEART STOPPED



Figure 4 Barnsley District Hospital from Monk Bretton, 2005. Photo by P. Laviolette.

telecare applications act as the democratization of this ubiquitous power so that it comes into the grasp of the outpatient/tenant (Mair and Whitten 2000). It is thus empowering since he or she becomes aware of and responsible for their own condition. For instance, Chalfen (2002) shows how video intervention assessment (VIA) can sometimes allow patients to use video in representing their own illnesses to professionals, thus becoming more empowered along the way. Additionally, it is argued that telecare clients are surveyed anonymously through machines rather than by individual nurses or carers, hence it is potentially less invasive rather than more (Norris 2001; Porteus and Brownsell 2000).

So Foucault's model is valid in its assertion that the panopticon produces homogeneous effects of power, which is indeed turned in on those who are aware of its presence. We become the principle of our own subjection. There is equally an economic geometry of efficiency here, what Bentham called the "House of Certainty" (1995[1787]). Thus we can talk of an "Internalised Insight"—a pure architectural and optical system of political technology that exists in everyday life (de Certeau *et al.* 1998).

The centrally controlled database of telecare is again a parallel. Panopticism makes it possible to classify, provide typologies, draw up differences and similarities amongst patients. So much for observation, but what about the potentiality of panopticism as a laboratory, an arena to alter behavior? An perfect example here is Mr Hannoy (aged sixty-three) who lives with his wife some miles from Barnsley in a little country village. He mentions in relation to his awareness of his weight problem that the telecare system will hopefully allow him to become more diligent about his diet. "Knowing that someone on the other end is keeping an eye on my weight might provide enough of an outside incentive to help me regulate what and how I eat, kinda like peer pressure or something."

CONCLUSIONS

This article has implicitly raised the question as to what extent older people feel included in modern society in the first place (Porter 2004). During a conversation on gerontology and the shifting demographics of many European countries, an anthropologist colleague recently commented "older people are becoming the new 'Other' in contemporary western societies." If there is some truth in this claim, then the notion about the sensitivity towards the exploitation of the Other must be taken seriously. This leads us to question how biomedicine is embodied in local contexts and therefore to situate the importance of cross-cultural as well as interdisciplinary ethnographic approaches in studying the cultures of the home (Duncan 1988). Care of the poor is often given by low-cost solutions, most often with disastrous consequences. The relevant point here is to consider the NHS's high investment in poor areas for understanding whether telecare is financially viable as the lowest cost solution. As the medical anthropologist Veena Das (1999) reminds us, illness is indeed a testing ground of social relations. In a similar way, so too would it be the case for ageing or financial hardship—and incrementally so when the three meet.

And so like Bentham, the NHS's rhetoric for implementing telecare on a wide scale is a utilitarian one concerned with the greater good. It offers telecare as a potentially light, cheap, and efficient means of supporting the independence of older people. A system that allows them to become more aware of their health and participate in their own treatment. On principle, few can object to such ideals. Nevertheless, one does need to point out the more cynical Foucauldian perspective about pervasive surveillance and power dynamics when it comes to medical research (1963). As an aside, however, even Foucault's position on all this is not all that cynical. He acknowledged the benefits of the panoptical system as a metaphor for a disciplined self-regulating society. Indeed, he supported Bentham's desire to remove God from the surveillance equation.

But his deliberations are important in revealing that the idea of the greater good is riddled with the complexities of sacrifice. This is where it is crucial to analyze at whose expense the greater good is being sought. In this case, it is important to ask why it is that these people in particular are being used in the trial runs. We must highlight that the people on whom this technology is being tested are potentially at risk in certain respects. Not only are they an ageing population that suffer from a chronic disease but they are also from regions that suffer from significant socioeconomic hardship. Is it no coincidence that Doncaster, Barnsley, Plymouth, and West Lothian are principal UK sites for telecare research? With the exception of West Lothian perhaps, these are generally guite impoverished areas with a substantial working-class, ageing population. Being cynical of the utilitarian perspective is healthy here since it indicates that the greater good might directly be tapping into docile populations that are meant to be supported by the health service industry. That is, that these test runs are taking as their guinea pigs or lab rats the most easily coerced segments of society.

So in Gaston Bachelard's (1957) terms of spatial intimacy, this article has itself explored the ideas implicated within both intimate and intimidating home-based technologies. It has further suggested that it also becomes pertinent to question the reasons why, on a relatively national scale, overtly panoptical models of technological health surveillance are being tried and tested in the places that they are being at present. This is at the heart of an issue that will increasingly affect the homes of all ageing populations.

ACKNOWLEDGMENTS

An earlier draft of this article was presented at the symposium "Interior Insight: Design, Ethnography and the Home," Royal College of Art, November 24–25 2005. Thanks to the organizers Inge Daniels and Alison Clark for the invitation to contribute as well as the participants and discussants for their intellectual generosity in offering many constructive suggestions. The telecare consortium "Supporting Independence: New Product, New Practices; New Communities" comprises Barnsley District Hospital, Dundee University, Imperial College, The Pocklington Trust, Tunstall Group Limited, and University College London. In particular, the authors wish to thank Hazel Aldred, Simon Brownsell, and Mark Hawley of Barnsley District Hospital. The consortium gratefully acknowledges the assistance of the Engineering and Physical Sciences Research Council and the EQUAL European Social Fund Community Initiative for providing funding.

REFERENCES

- Agrell, H., S. Dahlberg and A. F. Jerant. 2000. "Patients' Perceptions Regarding Home Telecare." <u>Telemedicine Journal and e-Health</u> 6(4): 409–15.
- Aldred, H., M. Gott and S. Gariballa. 2005. "Advanced Heart Failure: Impact on Older Patients and Informal Carers." *Journal* of Advanced Nursing 49(2): 116–24.
- Arnold, M. 2003. "On the Phenomenology of Technology: The 'Janus-Faces' of Mobile Phones." *Information and Organization* 13(4): 231–313.
- Bachelard, G. 1957. La Poétique de l'Espace. Paris: P.U.F.
- Ballinger, C. and S. Payne. 2002. "The Construction of the Risk of Falling among and by Older People." <u>Ageing and Society</u> 22: 305–24.
- Barlow, J. and T. Venables. 2004. "Will Technological Innovation Create the True Lifetime Home?" *Housing Studies* <u>19: 795–</u> 810.
- Bentham, J. 1995[1787]. "The Panopticon Letters." In M. Bozovic (ed.) The Panopticon Writings, pp. 29–95. London: Verso.
- Bowes, A. and McColgan, G. 2003. Evaluation of Home Comforts Smart Home Technologies Initiative—Final Report to South

Ayrshire Council. Stirling: Department of Applied Social Science, University of Stirling, UK.

- Brownsell, S., D. Bradley and J. Porteus (eds). 2003. Assistive Technology and Telecare: Forging Solutions for Independent Living. Bristol: The Policy Press.
- Brownsell, S. and M. Hawley 2004. "Fall Detectors: Do They Work or Reduce the Fear of Falling?" *Housing, Care and Support* 7: 18–24.
- de Certeau, M., L. Giard and P. Mayol. 1998. The *Practice of Everyday Life (Volume 2: Living and Cooking)*. Minneapolis, MN: University of Minnesota Press.
- Chalfen, R. 2002. "Snapshots "R" Us: The Evidentiary Problematic of Home Media." *Visual Studies* 17(2): 141–9.
- Das, V. 1999. "Public Good, Ethics and Everyday Life: Beyond the Boundaries of Bioethics." *Dadealus Online Journal* Fall Issue: 1–10.
- Duncan, J. (ed.). 1988. Housing and Identity: Cross-Cultural Perspectives. New York: Homes & Meier.
- Fisk, M. 2003. Social Alarms to Telecare: Older People's Services in Transition. Bristol: The Policy Press.
- Foucault, M. 1963. Naissance de la Clinique: l'Archéologie du Regard Médicale. Paris: P.U.F.
- Foucault, M. 1977. *Discipline and Punish: The Birth of the Prison*, pp. 195–228. Trans. Alan Sheridan. New York: Vintage Books.
- Goffman, E. 1956. *The Presentation of Self in Everyday Life.* Edinburgh: Edinburgh University Press.
- Haggerty, Kevin and Richard Ericson. 2000. "The Surveillant Assemblage." *British Journal of Sociology* 51(4): 605–22.
- Hanson, E. J. and J. Percival. Forthcoming. "'I'm Like a Tree a Million Miles from the Water's Edge'. Social Care and Inclusion of Older People with Visual Impairment." *British Journal of Social Work* (in press).
- Hier, Sean. 2003. "Probing the Surveillant Assemblage: On the Dialectics of Surveillance Practices as Processes of Social Control. Surveillance and Society 1(3): 399–411.
- Highmore, B. 2002. Everyday Life and Cultural Theory: An Introduction. London: Routledge.
- Jackson, M. 1995. At Home in the World. Durham, NC: Duke University Press.
- Jensen, J., J. Mace, Z. Meghani-Wise, B. Parkes and J. Porteus. 1998. "Specific Areas of Work, Research or Investigation." In R. Bull (ed.) *Housing Options for Disabled People*, pp. 236–67. London: Jessica Kingsley.
- Lansley, P., S. Flanagan, K. Goodacre, A. Turner-Smith and D. Cowan. 2005. "Assessing the Adaptability of the Existing Homes of Older People." *Building and Environment* 40: 949–63.

Lefebvre, H. 1991. Critique of Everyday Life. Vol. 1 (1947/58). London: Verso.

Levy, S., D. A. Bradley, M. J. Morison, M. T. Swanston and S. Harvey. 2002. "Future Patient Care: Tele-empowerment." *Journal of Telemedecine and Telecare* 8(2): 52–4.

- Lyon, D. 2001. Surveillance Society: Monitoring Everyday Life. Buckingham: Open University Press.
- Mair, F. and P. Whitten. 2000. "Systematic Review of Studies of Patient Satisfaction with Telemedicine. *British Medical Journal* 320(7248): 1517–20.
- Magnusson, L. and E.J. Hanson. 2003. "Ethical Issues Arising from a Research, Technology and Development Project to Support Frail Older People and their Family and Carers at Home." *Housing and Social Care in the Community* 11: 431–9.
- Mann, S. 2004. "'Sousveillance:' Inverse Surveillance in Multimedia Imaging." ACM Multimedia Annual Conference Proceedings, pp. 620–7.
- Marcoux, J.-S. 2001. "The 'Casser-Maison' Ritual: Constructing the Self by Emptying the Home." *Journal of Material Culture* 6(2): 213–36.
- Norris, A. C. 2001. Essentials of Telemedicine and Telecare. London: John Wiley & Sons.
- Orwell, G. 1949. *Nineteen Eighty-Four*. London: Secker and Warburg.
- Porter, R. 2004. Flesh in the Age of Reason: The Modern Foundations of Body and Soul. New York: W.W. Norton & Co.
- Porteus, J. 1999. Telecare Brief. Bradford: Anchor Housing Trust.
- Porteus J. and S. Brownsell. 2000. Using Telecare: Exploring Technologies for Independent Living for Older People. Bradford: Anchor Housing Trust.
- Rapport, N. and A. Dawson. 1998. *Migrants of Identity: Perceptions* of Home in a World of Movement. Oxford: Berg.
- Samuelsen, H. and V. Steffen. 2004. "The Relevance of Foucault and Bourdieu for Medical Anthropology: Exploring New Sites." *Anthropology and Medicine* 11(1): 3–10.
- Secker, J., R. Hill, L. Villeneau and S. Parkman. 2003. "Promoting Independence: But Promoting What and How? <u>Ageing and Society</u> 23: 375–91.
- Shaw, B. 1998. "Innovation and New Product Development in the UK Medical Equipment Industry." *International Journal of Technology Management* 15(3–5): 433–45.
- Sinha, A. 2000. "An Overview of Telemedicine: The Virtual Gaze of Health Care in the Next Century." <u>Medical Anthropology Quarterly</u> 14(3): 291–309.
- Tang, P., R. Curry and D. Gann (eds). 2000. *Telecare: New Ideas for Care and Support at Home*. Bristol: The Policy Press.

- Weber, M.M. 1964. "The Urban Place and the Nonplace Urban Realm." In M. M. Weber (ed). *Expositions into Urban Structure*, pp. 19–41. Philadelphia, PA: University of Pennsylvania Press.
- $\frac{www.reference.com/browse/wiki/Barnsley}{11\ 2005},\ accessed\ on\ October$