The moral geography of home care

One result of the historical division of labor between nurses and physicians is that nurses became the eyes and ears of the physician, extending their perceptual capabilities across space and time. This "gaze of medicine" has evolved with the rise of technology, hospitals, and the medical profession to a sort of scientific totalitarianism. Protecting and enhancing patient agency, which is part of the moral work of nursing practice, can be difficult under such circumstances. Yet the geography of sickness is changing as patients move from the hospital back to the home. Because home is thought of as private, as the patient's domain, nurses may think that supporting patient agency will be easier with this transformation of health care. But that assumption may not be warranted since the gaze of medicine will follow patients and change the landscape of the home. The challenge for nursing will be to sharpen the "gaze of nursing," which is an antidote to the strictly biomedical understanding of disease.
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At first glance, it would seem that geography has little relevance to nursing practice. Yet the history of nursing is intimately connected to the places of sickness. Early in the development of nursing, people were cared for in their homes; hospitals developed not as meccas of scientific knowledge, but as society's response to the homeless and poor.[1–4] With the rise of technology, therapeutics, and the medical profession, hospitals usurped the home as the preeminent place of sickness and have become, in the words of Van den Berg, "palaces of compulsive healing."[5(p4)] Once again, the geography of sickness is shifting as hospitals are losing their spatial preeminence and

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the home and other structures of the community are becoming central in caring for the sick. Each shift of place has implications for both patients and nurses. Because the intervening century has made profound changes not only in health but also in how we see ourselves, we should not be deceived into thinking that the return to home will be some nostalgic image we hold of the past. Into the homes of the 21st century will go the products of the last 100 years of technology and therapeutics. These are not isolated artifacts but intimate parts of our health care described as an interconnected, institutionalized system of profit, research, patient care, and physician reproduction.[6] The biomedical model that structures the "gaze of medicine"[7] and that has reached its nadir in present-day tertiary hospitals is likely to continue to survey disease in the move from hospital to home. The home, a separate domain from medicine where the inhabitants' agency has been primary, may find itself an extension of hospitals, those "awesome citadels of science and bureaucratic order,"[4(p145)] where it is the agency of the dominant practitioners that is preeminent.

Agency is the capacity to initiate meaningful action. Our acting in and on the world is what constitutes our projects, concerns, and engagements with others—in short, our lives. I deliberately choose the term *agency* over *autonomy* because the latter is currently a very contentious term and has several uses.[8–10] More helpful is the meaning from self-psychology: the self is the center of initiative, and strengths and weaknesses of the self lead to experiences of agency.[11] Although this is a definition of self and not agency per se, it is illuminating in that we can see agency as a mix of motivation and physical action directed toward some end. Agency is concerned with what people do either through their own physical capability or sometimes through another. However, as we shall see, what people can do is frequently constrained by a complexity of factors over which individual agents have little control, even when it affects their bodies and their lives. This is the case with many aspects of life in the late 20th century but is certainly so in health care, where the biomedical model and the technologic imperative have intersected making patient agency, especially regarding the refusal of treatment, a near impossibility.

Yet protecting and fostering patient agency, particularly under conditions of vulnerability, are fundamental features of the moral work of nursing practice.[12] Such protection and enhancement have taken several forms. Some of these include helping the patient through the system, bearing witness to patient lives and speaking to the truth of those lives,[12] and "guerilla nursing."[13] The latter is covert but active resistance to the life-at-any-cost mentality that pervades most of our intensive care units. Nurses practice guerilla nursing when, in the absence of speaking or having their concerns heard, they tinker with machinery on patients who did not want to be so sustained to hasten the trajectory of inevitable death.

The concerns nurses have about the moral work of protecting patient agency will not be eliminated in the new geography of sickness and health care. The reason is, as we shall see, that nurses are a major instrument of the gaze of medicine, and they are likely to figure prominently in the shift from hospital to community. Health care futurists are forecasting a delivery system in which this gaze will penetrate the domains of home, school, the workplace, libraries, and other

community institutions, thereby submerging all other goods from view.[14] Such a situation approaches what Huxley called *scientific totalitarianism*.[15] For patients, the risk of the loss of agency in domains thought of as theirs rather than the expert's is great. Yet while nurses are a major means of implementing the gaze of medicine, there is also a "gaze of nursing." Historically, nursing has had stereoscopic vision, and while this vision may have become less acute under conditions of scientific myopia, we have not lost it.

My purpose in this article is to begin an exploration of the spatial organization of nursing in relation to the moral work of protecting patient agency. The specific focus is the gaze of nursing as the place of sickness moves from the hospital back to the home and community. To show the relevance of geography to nursing practice, I draw on narrative accounts from a research study with home care and psychiatric nurses that sought to understand the ethical concerns experienced in everyday practice.[12] Their accounts revealed a language rich in spatial descriptions, thus showing an awareness of the importance of place to the work and ethical concerns of nursing practice. Without knowing it, they introduced me to the social science of human geography; their narratives add a poignant empiric voice to theoretical work in the discipline. A note on the two groups: while both home care and psychiatric nurses revealed an understanding of place and practice, it was articulated more frequently by the home care nurses, all of whom had the advantage of a comparative perspective. All home care nurses previously worked in hospitals, most often in medical–surgical and intensive care units. They were acutely aware of how the spatial differences between home and hospital changed their practice:

> You're in their territory. You're guests in their home. They're not coming to you in the hospital. Very different, very different. You have to meet them on their own terms. [home care nurse]

> You can come into a home with your ethical or medical–ethical ideals and say, this is what you should do. And if it doesn't fit into their life style, they're not going to do it, you know. If they don't consider what you're telling them is going to help them live their life better, they're not going to do it. If it doesn't work into their routine, they're not going to do it. So you have to make it so, if they don't like it like this, maybe they will like it like this. You have to find out what will work for them. [home care nurse]

SIGNIFICANCE OF PLACE

Place and identity

> It's a very quiet place. It's run by monks for AIDS [acquired immunodeficiency syndrome] patients, and they have round-the-clock care there. But it's very peaceful as you can imagine a Zen center being. Sometimes I would go and there would be very low music on and several of the people, residents there, would have incense burning. And I felt very reverent and peaceful when I was there. Anyway, the room is probably not much larger than the room we're in, and he had all of his entire, this is pretty sad, all of his entire life-long belongings in this one room. His one wall was almost covered with different pictures of different Buddhas. And in the middle of the pictures on this wall where he had not just pictures, but necklaces hanging, different kinds of beads hanging and different buttons that he'd had in his life, Peaceniks and that kind of thing, and right in the middle of the pictures was a picture of his mom and a picture of his sister. It was a very crowded room, but this room was just filled with all of his things in his life that were

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most important to him in the end. It was a very intense moment in time. [psychiatric nurse]

Most of us take our geography for granted, failing to appreciate the influence of place in our everyday lives. But if we reflect a moment, we are likely to recall a place—a landscape, favorite haunts of childhood, the places we met those closest to us, the setting of some painful or joyous event—and such recollections will remind us that places are more than particular arrangements of space. A place is the "center of felt value"[16(p108),17(p138)]; places are symbolic constructions[18] reminding us of our connections to others, to the natural world and animals, and to projects—they give meaning to our lives. Thought of in this way, we can see that place is important in shaping our identities and in fostering (or depleting) our sense of self and agency. This is a knowledge of place with which we are all familiar. Nurses demonstrate this routinely in asking families to bring pictures and personal items of attachment from home for patients in the hospital or themselves personalizing the institutional space patients occupy. By so doing, nurses are helping patients maintain connections to a life across space and time that has been disrupted by disease and illness.

Place, power, and the division of labor

What became hard was to be at the bedside and not be part of the decision making—just be there and have to supply all this physical and emotional care. [home care nurse]

What was hard for me is that there was a disgruntlement among a few of us. We felt like, we're the ones that have to sit and listen to her gasp. Other people can come and go, but we were the people who were directly right next to the bedside of this baby, who had to really see her go through these physical changes of her gasping. [home care nurse]

What may be less evident is that places also organize social space and, therefore, social relations and power, practices, resources, and knowledge.[19] Large-scale social structures intersect with personal agency within a given space, thereby lending authority and legitimation to some agents and constraining others. In other words, some people have social and institutional authority to perform certain actions in a given place, whereas others do not. Ultimately, this is a matter of the social division of labor. How these arrangements are determined are the outcomes of complex social maneuvering or, some might say, power. It has been argued that power is held by those who set the routines,[20] thus dictating the use of space and time. "Struggles, of whatever scale and focus, are always at some level struggles over the use and meaning of space and time."[19(p12)]

Many of these struggles can be seen clearly in our history, where the contemporary division and control of health care labor were forged early. One excellent illustration is offered by O'Brien D'Antonio, who takes us back to the 1830s, several years "before Florence Nightingale brought her vision of nursing reform to the late nineteenth century hospital."[1(p229)] In this study of the domestic roots of our practice, O'Brien D'Antonio shows how the space at the bedside of the

sick person in the home was a contested area for control of the therapeutic relationship. Physicians did not want nurses to render opinions or even respond to patients' questions about anything that might question the physician's claim to therapeutic authority. In attempting to control this situation, a Dr Joseph Warrington proposed that the nurse always refer the patient back to the physician, but that was systematically ignored by nurses, largely midwives. His next step was to argue for a training school for nurses but one organized and controlled by physicians. In this way, nurses would be "trained" by physicians and responsible to them rather than to patients. Such training would ensure that nurses knew and kept their place. Most nurses, however, rejected the control, and since more nurses were needed than were willing to be "trained," the school did not survive.

Things might have turned out quite differently for all parties had the story ended here. Instead, the outcome of this conflict was occasioned by physicians' exploitation of class differences. In the 1830s there was not yet a socially sanctioned, unified view of who was a nurse. Certainly the female relatives of the patient provided care, as did the "professed" nurses[21] who were frequently hired. The result was a division of labor whereby the upper class nursing woman entered "a new relationship with the physician as his eyes and ears and as his superintendent in the sickroom,"[1(p237)] while the lower class nursing woman would do "the physical work of caring for the patient—bathing, turning, cooking, feeding, administering treatments."[1(p237)]

O'Brien D'Antonio's story is a very interesting one on several levels, but the point for this article is the idea of the nurse as extending the perceptual capabilities of the physician through space and time. If this social division of labor was decided in the first half of the last century, Florence Nightingale formalized the centrality of observation to the work of nursing through her writing in the second half of the 19th century. No one could have pressed harder for the idea of observation than did Nightingale; in *Notes on Nursing* she put it this way:

> The most important practical lesson that can be given to nurses is to teach them what to observe–how to observe–what symptoms indicate improvement–what the reverse–which are of importance–which are of none–which are the evidence of neglect–and of what kind of neglect. All this is what ought to make part, and an essential part, of the training of every nurse.[22(p105)]

It was not only the frequency with which she spoke of observing the patient but her tone as well. The necessity of accurate observation of the sick person was critically important, as it formed the linchpin of her argument for nurse education. Nurses could not be good observers if they did not know what they were observing for; this required training in some scientific principles of disease. Nightingale pushed the concept of observation to that approaching surveillance. The differences between them are profound, especially in terms of personal agency. Whereas *observation* is to watch, to attend to, to guard, *surveillance* is to watch with the aim of direction or control.[23] Surveillance absolutely requires a bounded space—and bodies. In other words, many things can be observed, but only people can be under surveillance.

The spatial circumstances of bodies have had a critical role in nursing theory, although we do not think of space but rather

environment. Nightingale maintained that the work of nursing is to put the patient in the best condition for nature to act. This required that nurses attend to cleanliness of surroundings, ventilation, light, visitors, and so forth. However, in making her argument for the necessity of someone to manage or be "in charge" of the sickroom (and person), she was approaching contemporary social science understandings of space, specifically that of locale. The concept of *locale* is that of "a physically bounded area that provides a setting for institutionally embedded social encounters and practices."[19(p22)] In locales, like other conceptualizations of space, personal agency intersects with institutional structures and practices. Nightingale devoted an entire section to "petty management," in which she wrote the following:

> To be "in charge" is certainly not only to carry out the proper measures yourself but to see that every one else does so too; to see that no one either willfully or ignorantly thwarts or prevents such measures. . . . It is often said that there are few good servants now; I say there are few good mistresses now. As the jury seems to have thought the tap was in charge of the ship's safety, so mistresses now seem to think the house is in charge of itself. They neither know how to give orders, nor how to teach their servants to obey orders—ie, to obey intelligently, which is the real meaning of all discipline.[22(pp42–43)]

Within the locale of Nightingale's hospital ward, one could argue that there was surveillance within surveillance; the nurse was granted the right to be at the bedside and the authority to keep patients under her surveillance as long as the genre was that of ever-increasing science. I do not mean to sound too critical of Nightingale: as an extremely well-educated woman who moved within the elite circles of society, she was very much a product of her time—the time was one of surveillance and one offering the dream of the triumph of science.[24] Furthermore, Nightingale provided a powerful qualification to her push for observation. This is critically important, and I will return to it, but first we must see to what effect surveillance and space come together in the present.

INSTITUTIONAL SEEING AND PERSONAL AGENCY

The idea of the nurse as the eye of the physician is still with us.

> So, I'll be like the eyes and ears for the doctor and just report to him. [home care nurse]

> Even still, I mean, we call the physician to get the order; that's the way we do it. We do the assessment. We're the eyes. And we just call them and if we think, gee, this baby looks really yellow, we think it's a good idea [to obtain an order for lab work]. [home care nurse]

The very troubling problem is that the eye is not the eye of individual physicians but the eye of institutionalized medicine, a major embodiment of our contemporary scientific totalitarianism. Under the gaze of scientific totalitarianism, it is increasingly

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difficult to maintain individuality and to resist the intrusion of medical therapeutics into every facet of our lives. In the highly structured place of the hospital, exercising one's agency in keeping with one's beliefs about life, human nature, and the human condition can approach an absolute impossibility. This is because of the languages and sets of practices or codes operating in hospitals. Young[25] identified three: (1) the etiologic code connects the patient's symptoms with a disorder, (2) the therapeutic code submits the patient to the authority of the practitioner, and (3) the institutional code submits both patient and practitioner to the therapeutic regime.

These three languages and practices are not isolated from one another but stand in a dialectic relationship. Nonetheless, it is the institutional code that poses the most serious threat to patient agency. Examples abound of a creeping extension of institutional surveillance of increasingly standardized and universal therapeutic regimens. For example, the requirement by hospitals and the Joint Commission on Accreditation of Healthcare Organizations that every nurse be cardiopulmonary resuscitation (CPR) certified can be understood as a response to "the practical and moral assumption that a medical emergency is an ever-present possibility to which it is imperative to respond."[26(p155)] Other examples are the cooperative oncology groups who determine the "best" and therefore standard treatment of cancers and the practice guidelines being advocated and sold by the Health Care Financing Administration and many nursing leaders. The argument, of course, is that we are ensuring quality by these languages and practices. The question is whose quality of what?

A chilling example dates back to 1977, when a nurse and physician working in burn care published an article suggesting that in cases where patients were burned so badly that survival would be unprecedented, the patient should be allowed to forego treatment.[27] They noted that burn patients usually have about an hour after the burn before serious complications show in earnest. This answered the age-old counter that patients might not "know" what they want. Two years later, a publication followed from a National Institutes of Health conference on the consensus of burn treatment; the accepted stance was that the position taken by the nurse and physician interfered with the progress that could and would be made by research and that patients should always be treated.[28] Scientists and, increasingly, corporations continually produce things that they then convince us we cannot live without. Without any doubt, this is nowhere more true than in medicine. The question of what constitutes medical need is truly infinite.

Before our cultural invention of hospitals as places of sickness—when people were treated in their homes—the power of medicine was not an institutionalized power. The rise of modern hospitals and technological medicine changed that, however, and placed the home outside the loop of the etiologic, therapeutic, and institutional codes. Home is where you go when nothing can be done—to be home is to be beyond the power of modern therapeutics. Yet to be home is also to be the agent of your own life. This is so because of our understanding of the difference between institutions and home. To the extent that our modern sensibility makes us aware of the bureaucratic power of hospitals, it also renders us sensitive to home as a

private space, an idea that began to take shape in the 16th century when the workplace was separated from the home.[29] Home separates inside from outside, private from public. For us, "home is demarcated territory with both physical and symbolic boundaries that ensure that dwellers can control access and behavior within."[30(p36)] The home is a haven from the demands of the outside, public worlds of school and work. In our homes, it is our agency that bestows the spatial and temporal ordering distinguishing our house from our home.[30,31] For Dovey, home is "a sacred place in a profane world. It is a place of autonomy and power in an increasingly heteronomous world where others make the rules."[30(p46)]

Yet as the geography of sickness moves once again, this time from the centralized and centralizing hospital, the home as well as the school and the workplace will no longer be separate domains where the agency of the dwellers predominates. They will, instead, be part of the spatially expansive network of therapeutic possibilities that we have come to believe we must and should have. Highly sophisticated communication systems will link patients and practitioners to the large tertiary facilities.[14] This profound transformation is already under way: we have apnea monitors in the home, and patients with pacemakers transmit their electrocardiograms across telephone lines. In one case, a child in Maine with severe cerebral palsy and other problems was in a public school. The mother asked that no CPR be instituted should the child experience cardiac arrest while in school. The child's physician agreed that CPR would do nothing to alter or improve her condition; the school board was to make a decision. Unfortunately, these will not be isolated and rare instances. Individual agency to make decisions about one's life will be further threatened.

GAZE OF NURSING

The language and practice of nursing afford nurses the possibility of stereoscopic vision and therefore different kinds of knowledge. On one hand, nurses share the gaze of medicine in surveying and probing the body for physiologic and behavioral transgressions extending beyond the normal. On the other hand, our concept of and commitment to the person supports a view of the patient as living a particular life in a particular place, and this is an entirely different domain of knowledge. But the possibility of stereoscopic vision is only that—a possibility—because what we can see is determined by where we are placed. The social construction of space structures what we can see and therefore have to confront.[32] Contemporary hospitals tear patients from the context of their day-to-day lives, thus making it easier for nurses to focus exclusively on the biomedical parameters of disease. The following home care nurse gives voice to the homogenizing practices of our hospitals and how they obscure a patient's world and need:

> I never knew where anybody lived. Everybody is so much more alike in the hospital because they're all in their patient gowns and you don't see what's in their luggage. You don't see the bags that they bring in. So there's a lot of stuff that you just really don't see in the hospital that, when you get to see them at home, you see a whole different person. At home you see the other things that they're dealing with, besides whatever made them go into the hospital. [home care nurse]

In this next narrative, another home care nurse poignantly illustrates how the space of the hospital structures what it is possible to see. This in turn constrains the language that is used and therefore how problems are defined.

When possible, we're in contact with the [diabetic] clinical nurse specialists in the hospital regarding certain patients. And in this particular lady's case, she was fairly well known to the CNS [clinical nurse specialist] who didn't understand why this kept happening to this woman who is an intelligent, articulate woman. If you're not around her a lot, you don't see the lapses in her memory and her confusion that arises. So, I got the impression from this CNS that she just thought this woman was being difficult and noncompliant. She would say, well, what is the problem here? I don't understand. It's a very simple thing. She just has to check her insulin, check her blood sugar, take her insulin. It's like, why does she keep coming in here? And then I explained to her, this is where she lives. She doesn't even have a refrigerator to put juice in if she does have hypoglycemia. Then she forgets to even buy canned juice. I've tried to teach her certain foods that aren't perishable. She had no idea. Now, of course, they're told, insulin has to be refrigerated. Well, that would be the refrigerator in the kitchen, which is closed, except for cafeteria hours, and it's on the bottom floor, and it's totally impractical, you know. So there's real limitations. [When I told the CNS], she said, "Oh!" I don't think it even occurred to her. [home care nurse]

This was part of a lengthy narrative in which the home care nurse spoke at length about how she worked with this woman to help her achieve some sense of mastery in living with her diabetes. The woman's agency was enhanced because the home care nurse saw and had knowledge of the woman's world as she actually lived in it. This story leaves me hopeful that this CNS learned a very valuable lesson, a lesson that moves her from the understandable but too easily found place of diagnosing to the more difficult place of seeing face to face the demanding realities of life for many patients.

Earlier, I said that Nightingale qualified her insistence on observation. Toward the end of *Notes on Nursing* she wrote the following in a tone as passionate as was her demand for observation of signs and symptoms:

In dwelling upon the vital importance of *sound* observation, it must never be lost sight of what observation is for. It is not for the sake of piling up miscellaneous information or curious facts, but for the sake of saving life and increasing health and comfort. The caution may seem useless, but it is quite surprising how many men (some women do it too) practically behave as if the scientific end were the only one in view, or as if the sick body were but a reservoir for stowing medicines into, and the surgical disease only a curious case the sufferer has made for the attendant's special information. This is really no exaggeration.[22(p125)] [Emphasis is Nightingale's]

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It would seem that after 134 years, the scientific end has indeed usurped every other moral good; science has become an end in itself. What is the end or goal of nursing care? For Nightingale, it was saving lives, health, and comfort, although given what the first two have come to mean, she might choose different concepts if she were writing today. One answer is not merely in helping patients stay alive or even healthy but in helping them to have a life.[12] To have a life is to have a sense of agency, to occupy social and political space, to live a temporally structured existence, and to die. Protecting

and fostering patient agency only are part of this, but they are central to all the others. Helping patients direct their lives will not necessarily be easier as we move out of hospitals. The challenge for nurses will be to sharpen the gaze of nursing, which looks not to the biomedical model of disease but to what it means to have a life; to articulate it more forcefully; to continue to develop nurse-run facilities; to continue to insist on a seat at the table of power where the control of space and time are set, particularly in terms of reimbursement; and to have the courage to act in accordance with our gaze.

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