Qualitative Inquiry
18(10) 868–875

DOI: 10.1177/1077800412456963
http://qix.sagepub.com

The Constitutive Nature of Vital Signs: An Examination of the Sociality of Technology in Medicine

Catherine Phillips[1]

Abstract

This article is about two interconnected subjects: the politics of acute illness and the representation of such politics in writing. I present three narratives that were provoked by the witnessing of family member's hospitalization. The narratives focus on the experience of technology and fall within autoethnographic traditions (Denzin, 2003; Ellis & Bochner, 2000; Richardson, 2000), as well as the burgeoning realm of publications that narrate authors' experiences of the illness of a loved one (Dideon, 2005; Oates, 2011; Want, 2010).

In taking seriously the "emergent nature of critical inquiry" (Denzin, 2010), I intentionally move in and out of the narratives inorder to demonstrate how negotiations with "everyday technology" are taken-for-granted. I concern myself with how technology is the primary mode of care and argue that its prolific use calls for a politicization of medicine such that we can see how patients and medical staff alike are configured as mechanistic.

Keywords

medical technology, autoethnography, acute care, granulomatosis with polyangiitis, Wegener's granulamatosis

Introduction and Background

> Is it possible to mine personal experience for its political (de)construction? Can we take what is experienced as intensely personal and private and make it political? Why would we want to? Through displaying our innermost struggles, our counter-voices, can we expose the beads of social regulation, as they are sedimented in our bones, our psyches, and the places of our deepest turmoil and longing (Rockhill, 1991, p. 28)?

As a social scientist trained in, and committed to, the excavation and exploration of stories, experiences, narratives and the knitting of these to interpretations and language, I have learned that my attention does not ever wane or "switch off." This is further entrenched by being a clinical social worker, where I work in narratives unabatedly. This article draws on autoethnographic methods where the writing of the narratives is the method of inquiry (Richardson, 1994; 2000). I am interested in how we come to know and situate ourselves and as Rockhill suggests above, how narratives can help us see, and thus, analyze social regulation.

In this article, I present narrative accounts of my time spent with a family member who experienced several periods of acute care hospitalizations. His hospitalizations occurred more than 18 months at the same acute care facility. This particular hospital was open to family members 24 hours a day, which afforded me an unusual amount of time to spend with him. The narratives are redacted composites of the fragmented notes I took during his hospitalizations. Composing narratives in this way is a common contemporary approach to the exploration of illness experiences. In the past decade, there had been many memoirs and personal journals that have been edited (and subsequently published) that narrate, in the first person, the experiences of family members during an illness (and most often, death) of a loved one. Many of these memoirs gesture to periods of acute care hospitalization, and within them, there is often profound detail about the concept of relationality. For

[1]Lakehead University, Thunder Bay, ON, Canada

Corresponding Author:
Catherine Phillips, Faculty of Health and Behavioural Sciences, School of Social Work, Lakehead University, 500 University Avenue, Orillia, ON L3V 0B9, Canada
Email: cphillips@lakeheadu.ca

example, Barbara Want (2010) in her book *Why not me? A story of love and loss*, describes in precision her interactions with doctors and consultants. And Joyce Oates (2011), in her book *A Widows Story: A memoir*, recounts in vivid detail her last visit with her husband in the hospital and her movement through the hospital space on that day. Bowering (2009) argues that these kinds of writing can be acts of mourning but what these writers also en/act is the idea that such narratives are political in so far as they uncover what is cultural and attempt to represent the human experience using language. In doing so, the authors are asking for care to be better and our relationships to be more humane. For example, as Oates recounts on the day of her husband's death, she asked a nurse to recommend a funeral home. The nurse told her to check the Yellow Pages. Such uncaring aspects of illness are not only material but metaphorical, and reveal the significance of both small moments and the smallness of our lives. As Catherine Bush (2009) writes on the grief of her father, "puny humans, we were nothing in the storm's path" (p. 42).

The narrative segments I present are not "pure" or "direct"—language and narrative writing do not work this way. These narratives are methodological, are "performative, pedagogical, and political" (Denzin, 2006, p. 422) and offer the challenge of what Lee (2007) calls a "transitional epistemology" whereby writing is a form of research and knowing. Indeed, I use my experience as I have described elsewhere as "a textual rhetoric of the self" (Phillips, 2007, p. 201) that allows me to interrogate the composition and choreography of different subject positions that I—that we all—occupy, while also gesturing to the complexities and contradictions of understanding our experiences, ourselves, our corporeality. As Rockhill (1993) asks "What are the clues that experience can provide to the regulatory chains that construct our subjectivities" (p. 42)?

In this article, my narratives trace the extent to which the relational aspects of medical care involve technological negotiations and at times, accordance. Within these narratives, it is the life of the patient that I am interested in, less so the technology per say. Or at least that is what I thought. But what I learned is that patients and technology cannot be separated: Medical care is scripted by the technological in every moment. Often the technology is invisible to those who use it the most. In this article I concern myself with drawing our attention to the technology and problematizing how the experience of illness within acute care medical practices incorporates the corporeal occupation of technology for both nurses and patients.

Medical Technology

Theorizations of medical technology have shifted between varying positions: Technology as a "neutral" or passive tool used by experts to a more essentialist position where technology is viewed as deterministic to social relations within medicine. In this latter position, technology is seen as a suppressing or omnipresent force on the body, with the patient viewed as separate to the technology, whereby patients' experiences often contrast with the truth or expert knowledge of machine/technology. In acute care medicine in particular the body is viewed as an unreliable source of information, such that flow diagrams and ventilator settings are used to "re-read" the body (White, 2009), and patient narratives compete with laboratory results (Condrau et al., 2007). In the range of medical practices—examinations, tests and care—patients' experiences of acute illness are reinterpreted for them, on their behalf. In both these studies—White (2009) and Condrau et al. (2010)—there are two interconnected points: One, patients' narratives and experiences are lost as a result of a medicoscientific regime; and two, medical practices as an experience to be felt—by patients, families and medical staff—become reordered and rerepresented within a technological regime. In otherwords, technology does indeed "do something."

Writings within Feminist Science and Technology Studies (STS), have framed the body and technology within the idea of "practices"—whereby medical technologies are neither seen as an entity nor as socially constructed. Rather technology is theorized in terms of how the material and the social are interconnected and mutually constructive (Phillips & Phillips, 2011). Such a perspective infers that technologies are cultural acts and suggestive of a larger contextualized and political conversation. As Coleman (2006) recounts

> Many years ago, Lukács criticized technological determinism and insisted that rather than depicting technology as leading to other changes in society, such developments have to be located in society as a totality and in a historical context. (Coleman, 2008, p. 587)

Using the example of social work, Coleman & Harris (2008) argue that technological developments need to be seen within contemporary political and social forces that surround and affect on social work: ". . . if an area of social work is already proceduralized and existing services are commodified, ICT will reproduce proceduralized and commodified practices" (Regan, cited in Coleman & Harris, 2008, p. 587).

What this suggests is that technology is highly political and the manner in which it is used cannot be simply located as an effect of technology. The boundaries between science and social worlds are porous and "temporary" (Phillips & Phillips, 2011) and the social relations produced, are under constant negotiation, are shifting and moving all the time, indeed negotiated on a daily basis in acute care medicine. Certainly, the social world outside of medicine has changed dramatically in regards to health technologies. As Joyce and Loe (2010) write

> science and technology are central to the lived experiences and normative definitions of health and illness for ageing people. From pharmaceuticals, to walking aids, to cell phones, old people interact with technologies and science on a daily basis. Everyday technologies as well as biomedical interventions can be part of the way older adults pursue, maintain, and negotiate life. In this way, old people are cyborgs in contemporary life, blending machine and biology in both their personal identities and their relations to the external world. (p. 171)

In this article, I similarly refer to "everyday technology" but within an acute care setting. By "everyday" technology I do not mean big, expensive technologies–computed tomography (CT), magnetic resonance imaging (MRI), biopsies, nor do I mean treatment specific technologies—radiation, dialysis, plasmapheresis. Rather, I am more interested in common everyday applications such as vital signs, monitors and blood work. We increasingly use these technologies to manage ourselves—you no longer have to go the family doctor to have your blood pressure checked, you can go to the pharmacy and test it yourself. Indeed, you can purchase your own blood pressure machines, urinalysis kit, blood sugar kit, and oxygen monitor. Such incorporation of medical technology no longer rests in special moments, but in the everyday we do it to ourselves, we monitor our own bodies from the outside, in. Through technology we have direct access to our own body from the outside. This is both useful and troubling and requires further analysis. I now turn to a series of three autoethnographic accounts in order to pursue this analysis.

Narratives

In the Emergency department we are told it is lung cancer. Kindly, philosophically, considered, the doctor says, "you know how these things are, life happens like this."

By the next evening, he is on a medical ward and the radiologist reports that it is not lung cancer, but benign lung nodules. Various doctors ask questions in repetition and based on the symptomology, begin investigating for a stomach tumor. Two days later, this comes back negative. Internists, gastroenterologist, nephrologists, dieticians, speech language pathologists, and otolaryngologists fill the mornings and early evenings with questions, probing our answers with variation and clarity. It is the kind of precision and knowledge that offers care—although in repetition, I find it exhausting to watch the body examined in parts and piece, exposed and dissected.

Twigg (2006) reminds me that "the body represents the whole subject of medicine, its very ubiquity meaning that no aspect of medicine or health care is untouched by questions of its interpretation and construction" (p. 71). From the mid-18th century onward, medicine increasingly conceptualized the body as a machine—of parts, components, and systems (Stafford, 1991; Twigg, 2006). Such division is reaffirmed in the application of technology where, despite technological capacity to image the biological body holistically (e.g. MRI), the medical order from the doctor is to scan one area at a time. Such use of technology, despite its capabilities, reflects the body as a machine. A machine looking at a machine. Strangely, disconcertingly, the fact that the body is not whole does not bother me. Something is desperately wrong with him, he is dreadfully sick, maybe even dying, I am not sure and I angst for them to figure out what is happening.

An understanding, analysis and critique of the biomedical approach to life and illness, has been fully theorized in multiple disciplines such as sociology and social work. As Twigg (2006) summarizes,

> the biomedicine account is far removed from our everyday experiences of ourselves and others. Medicine rests on the objectification of the patient and his/her body, and largely ignores subjective and embodied experience. Under its gaze, the person becomes a body, an object, a site of physical and causal processes, of health care interventions. Doctors are taught to lay aside or sift the patient's narrative in such a way as to see below what is often presented as a subjective and mistaken account, seeking the signs of an underlying condition. (p. 83)

Like other authors who have critiqued biomedical approaches, I know Twigg means this as a critique of medicine and yet, I find myself grateful for the doctors' seeking of causal relations and signs. I certainly experience the confusion and mechanics of technological application but not correlationally in a difficult way. The gaze of doctors, specialists/consultants is not inherently problematic. I repeat the narrative of his developing illness as I having been witnessing it—over and over again and on each piece of his body. I am acutely aware they are looking for clues. I often ask, what are you looking for and through their varied replies, I can see that care gets done in a multiplicity of ways and questions. I ask him if he minds the repetitious questions and he says he does not mind, because all it will take is one question to find out what is wrong. This does not erase the exhaustion but helps me feel less worried about the objectifying effect on him.

Every weekday morning, a team of doctors move from room to room, standing outside the door, often around a mobile laptop. As a teaching hospital, these medical rounds are significant moments for senior residents and medical students. They discuss the test results and reports, determining which parts of his body warrant closer examination, and in what order. Often they come into the room to examine him, and ask questions, sharing their puzzlement with one another at the lack of a diagnosis and sometimes sharing their decision-making processes by explaining the value, secondary complications and risks of various tests and medications. Sometimes they flip through their handheld electronic devices, citing statistics, percentages, and contraindications. On each occasion, they remind me of the risks of their decisions, their reliance on technological certainty, their frustration with corporeal uncertainty, and the research and experiences that define their choices. For the fourth time, on the 6th day, the chief internist thinks he palpates a mass in the lower left quadrant and more tests are ordered.

We wait for another biopsy, another report. It too is negative. Bowel cancer, then an upper GI mass, intestinal cancer, then oesophageal cancer. Scopes, biopsies, scans, echoes, enhanced scans, daily bloods, x-rays, swallows. With each test, the doctors sometimes forget to tell us the results. They seem, what I find shockingly, but unassumingly, unaware that we have been anxiously waiting. I learn two things: One, that a casual walk, hands in their pockets, signals a negative test result; and two, if the test is negative and there is no abnormality, then there is nothing to tell.

Time is interposed by other lives and other corporeal moments, which unfold around us continuously. Two men in his room spend the evenings discussing their regrets in life, their bowel functions and the tests they have had. These seem important conversations that would not happen in many other spaces, except that the corporeal vulnerability of waiting for a diagnosis or just receiving one in a communal space can carve out such moments. Days are replete with misunderstandings. Behind curtains drift stories, questions, corrections, and serious misunderstandings. To me these conversations/interactions feel full of life—finding out about life. There are so many choices of how questions are asked, and so many choices of how they are answered—by both patients and doctors.

Waiting for results and consultations, the days turn into a series of vital signs. The taking of vital signs is often the only time we see a nurse in stretches of hours. Oxygen saturation, temperature, blood pressure, pulse and now blood sugar. 128/75 . . . 150/90 . . . 180/70 . . . another night goes by. His body starts to balloon. Staring at his hands, he remarks that they must belong to someone else. He is too weak to sit up, take off his glasses, hold his beloved newspapers, and swallow a pill. I watch him waste, my heart in my throat, my stomach in my mouth, and my hands in his hands. Hands that are someone else's. The internist stops me in the hallway to tell me that he is sorry that he does not know what is wrong with him. This stroke of reflection, of humanity, stays with me as I watch the details of vulnerability draw out in bodily moments.

As his oxygen level drops, his vital signs unstable, we see the nurses more often. They do not offer anything, just take more vital signs. I quickly learn the range of vital signs and their significance to them, to him and to me.

One day, I ask myself the question I have been avoiding resting my thoughts on, is he living or dying? Since his admission, I have been struggling to understand which it is. One morning I arrive and ask him, what did the doctor say this morning? Oh, I do not remember what she said. He pauses. Did she say what the results of the test were, I ask? No, I do not remember. He pauses again and says, I appreciated whatever she did. He continues, she didn't do or say anything that upset me. In this felt moment, when he inserts himself into our conversation, he reminds me of what is important and I realize that I have been watching him both living and dying.

Another weekend arrives and he seems to becoming desperately fragile. I write down the vital signs and study them for any sign of stability. Some mornings bring a new problem. More problems. Blood in his urine, nausea, arrhythmia, on and on. My exhaustion is not just physical but also composed of weariness in trying to understand new words and possible complications. The days feel long as the doctors continue to discuss more tests. Ultimately, he decides for them as his organs start to fail and he cannot tolerate the technological demands made upon him. He can no longer give consent and I find myself making decisions I have no knowledge or right to make. But I do it, and they keep asking me, are you sure he can swallow? Are you sure he has not been experiencing any pain? Are you sure his voice has always sounded like that?

On the third week they send in a rheumatologist. First arrives a student who in response to each of our answers to her questions says: "cool". Later in the day, the staff rheumatologist comes by and tells me that they call him when the internists do not have an answer, or do not have a diagnosis. In essence, when they do not know what else to do. He says they are "the service of last resort." I find this strangely comforting, and wonder why it is not the service of first resort. Like the division of the body into examinable areas, medicine is similarly divided—internists, cardiologists, neurologists, and so on. This territorial or disciplinary division carries into functional and epistemological activities, specifically the care of patients and how their bodies are understood. In other words, each body part/system belongs to the attention of a different and distinct service/discipline. The rheumatologist asks questions that are clearly outside such a division and proceeds to examine his hearing, breathing, and skin.

Another night and I sit outside his room. I crouch down and close my eyes. I can see that he is dying. Riddled with grief, my heart beats hard. Slow and hard. I feel afraid for what is happening to him, to me in this moment and wonder what else I can possibly hold onto. On this occasion, the doctors have decided in the late evening hours to insert a femoral line in order to give him urgent treatment. I walk deliberately, methodically around the ward, passing his room, feeling my heart beat in the back of my throat. Slow, hard. I think of him lying there, the doctors digging for the vein, threading in the line. I hope they talk to him, explain what they are doing. I hope he is not just a pile of flesh on the bed, but understood as a person who is loved and loves.

I sit day after day watching each breath. 87% on room air. 78%. 94% on 1.5 liters, 96% on 2 liters. I watch his chest go up and down, up and down. The pauses of human breath last forever, finding and fuelling my worry, clutching a hold of me, not letting go. Such pauses cause me to hold and then catch my own breath. I watch his body waste, his muscles atrophy, and his breathing requiring assistance. The nurse is administering a drug that requires her constant presence for 15 min in case of a negative reaction. She speaks in punctured sentences; rote, routine but effective, responsible. I close my eyes and feel my stomach rocks a horrible rhythm. Up and down. Sideways.

I become even more vigilant. Each move a nurse makes and each look between doctors I watch with piercing care, deconstruction, and worry. Many of my questions are drawn from these looks. The vigilance is a kind of exhaustion that I have never known and as I wander through the hospital and see other families, I know that they are caring with such vigilance in concert.

One night he is feverish, mildly incoherent, and his oxygen level is dropping even on a few liters—the nurse has been given a medical order to check his vital signs every hour. The respiratory therapist has come and made some preparations with the oxygen equipment. I know from my work as a medical social worker, that this is a bad sign. I know it means he is on their list in the instance that his breathing becomes more labored and he needs to be intubated and sent to the intensive care unit. An hour seems like a long time. At 1:20 a.m. the nurse comes in and leaves the portable oxygen saturation monitor attached to his finger. She reminds me what numbers are good numbers. I do not know if she was worried, or not—she did not show it or let me know. I wonder if I am being complicit with technology, though the comfort of the monitor was immense and left me to consider that there are other ways to think about the production of my subjectivity as a family member in such technologically imbued moment. Acts of caring can encompass technology and corollary, technology can be used in unexpected ways that are not solely passive in relation to the body.

. . .

Seven months later, he is back in the hospital. On this admission, there are worrying signs about his "nutritional status." The disease has stolen his appetite and he is emaciated. Because of my constant presence and the protracted nature of his eating, I have been assigned to write down his "intake"—he has been placed on a three day calorie count. For each meal I must assign a percentage to how much he has consumed of particular categories—0, 10, 25, 50, 75 or 100%. The categories are broken into hospital food groups—soup, milk/juice, vegetables, potato/rice, meat/fish, dessert. A perfectly cut 1/8th of a pie, one pile of peas, a scoop of potatoes, 2 similarly matching slices of meat. Even food can become quantified, technofied, and can be produced in shapes that aid calculations. Please I say, have another bite. Hours pass. After 8 trips to the microwave, I retire and count the peas. 5? 10? 25? I resent that somehow his care counts on my ability to count peas even though it would seem obvious from looking at him that he is not eating sufficient calories. The fact that I am counting feels like it should be indicative of concern. The need for evidence or proof seems excessive, almost comical.

As the 3-day calorie count ends, I am despising and despairing that he needs to eat to sustain himself, there is both the indignity of my desperation as well as him having to listen to me say 20 times, eat another bit. On the fourth day, the nutritionist comes by to discuss the results. The nutritionist says she did not realize he was losing weight (though I recall telling her that at least twice) and the team has decided to put in a feeding tube. She bends down to talk to him. I dread every carefully worded phrase. He looks so small. She says that his nutritional status is poor. She looks at me, repeating this conclusion emphatically as if I have not been counting peas and kernels of corn all weekend. I feel fraught by her wish for a more aggressive intervention, but know it will save his life.

. . .

A year later we are back in the emergency department. I arrive a day after he has been admitted to a medical bed—a bed which is assigned to the service of internal medicine. He waits in the Emergency department for this bed to become available—either through discharge or death. The room he is placed in has two doors opposite each other. One door, the one we both came through, leads to a long public hallway of only patient rooms, the other is presumably for staff. This two door design is one that I have seen other hospitals in urban centers adopt. There is a monitor in the room that he is connected to, and an intravenous (IV) pump that he is also connected to. The pump is running at 10 ml per hour. I assume that this is just to keep the line open. The monitor registers vital signs, which I also assume are his—heart rate, pulse, diastolic and systolic blood pressure, and oxygen level. After two hours, I understand that the monitor is providing the primary care task. Having worked as a medical social worker I know that this machine supposedly reports to another machine outside the door. In essence a machine watching another machine, watching you.

After four hours, the only person I have seen is a cleaner who comes in the staff door, talking on her portable phone. She does not look at us and exits through the public door, as though the patient room were a hallway. After 2 more hours, I tentatively open the staff door which reveals a large area squared by low desks. I am careful not to cross the threshold of the door. I feel interruptive and intrusive so I just look around casually and see no one. It is clearly not meant to be an area that families or patients enter, and so even in my peeking, I feel an inconvenience. Far at the one end, I can see a few people hovering at a counter. I know there must be a considerable number of staff around because it is a regional trauma hospital. I see a scattering of monitors at various places on the counters and wonder if anyone would hear them alarm. This kind of medical care requires a lot of trust in technology and an understanding of a "patient" that does not include nursing care; the human × nurse interaction has been replaced by a machine × nurse interaction. The machine constructs its objects as a machine, patient and nurse alike. He is a group of vital signs—stable or dead. And the nurse a mere reader of machines. The machine reads the patient's body and the nurse reads the machine, in effect the nurse and the patient do not meet. The patient is the abject mirror of the technological applications that medicine has embraced and that the medical culture putatively requires in the confrontation of illness. I calculate that at 10ml per hour, it will be 100 hours before anyone finds us. I realize that, like us, there are many patients and their families in this situation. The issue of patients waiting for long periods in emergency departments is a chronic issue in many countries (Bond et. al, 2007; Braitberg, 2007; Schiff, 2011).

Over the course of 3 days, waiting for a bed on a ward, blood is taken twice a day by a phlebotomist, several x-rays are taken, the specialists come by and we see a nurse when we go out and find one, if the doctor changes the order or if it is shift change. At shift change, they write the numbers off the monitor and bring in medication. It seems that if they did not have to chart, they would forget the patient. Although our time is embedded in technology, the strangeness I experience is not the technology but the lack of a nurse who seems to be managing the technology, who could hear the monitor alarm, or explode for that matter. And yet the nurse's interaction was still significant, noteworthy by its punctuality and efficiency. The sociality of technology in this setting is such that the everyday politics of care seem to be about our respective relationship with technology, rather than one another.

After three days of the machine watching him in the Emergency Department he is sent to a series of "off service" beds—a burn unit, an orthopaedic unit and then a medical teaching unit. I spend much of my time on the former two units searching for a nurse that might have a different relationship with technology. By the time he is discharged three weeks later from four experiences of "care" on different units—emergency, burns, orthopaedics, and medicine—I feel sure that the constituted character of a "patient" is indeed the precondition of their agency, such that patients are rendered intelligible through technological practices—which at times, are not treated as practices, but rather as essential tools. Being seen through this sociality of technology within the current political context of acute care medicine in Canada, and perhaps other welfare states as well, means being distinctly seen and known as a series of vital signs. I was surprised to the extent this was the case on every single floor, regardless of the nursing skill set.

At times, the attentiveness I gave to vital signs, medical examinations, tests and technology felt as though it was the only caring available to me, and felt as significant as other modes of care that in conditions of consent, wellness and good health, would have otherwise been possible. In my autoethnographic accounts it is clear that the embodied experience of illness rests so distinctly within a sociality of everyday acute care technologies. The constituted character of a "patient" in acute care is often viewed as someone who is a passive recipient of technology, rendered intelligible as a "patient" through the technology. And yet, what I learned was that there were still many moments to contend with and technology and our relationship to it, is indeed constitutive. Technology does not reduce life to a biological entity, rather life and our experiences are fluid and highly social and political. The use of technology implicates us all but theorizing technologically imbued cultures does not mean reconstituting our experiences as outside of, or oppositional to, technology. Rather, it requires a renegotiating of what constitutes care and relationships within this culture.

Coda

In 1897, Scottish otolaryngologist Peter McBride (b.1854—d.1946) described a patient with the same symptoms that my family member experienced. However, it was not until 1936, when the German pathologist Frederich Wegener (b.1907—d.1990) published findings on the distinct results of a series of patients, that this disease was categorized. Wegener's work led to the eponymous name of the disease: Wegener`s Granulamatosis (Woywodt & Matteson, 2006). This disease came to me to be known to me and my family as Wegener's.

Wegener's is a form of vasculitis (an inflammation of the blood vessels), and an autoimmune disease in which the body's immune system attacks its own tissues. Untreated, the body in essence, kills itself. In medical terms, Wegener's is characterized by inflammation of the body's small and medium sized blood vessels affecting the respiratory tract—sinuses, nose and ears, trachea, lungs and kidneys. The systemic inflammation ultimately damages lungs and kidneys by limiting the blood flow, thus destroying the body's normal tissue. In everyday life it can be experienced as the loss of hearing, nose bleeds, changes in the sound of one's voice, a persistent cough and fever, skin lesions, nasal ulceration, joint pain, fatigue and loss of appetite. My family member repeatedly told the doctors that his illness seemed to be moving from his head down his body; that is how he experienced it, hearing loss to a cough, to the inability to eat and drink. And yet because of the range of symptoms in different parts of the body and perhaps the disciplinary divisions within the practice of medicine as I discuss in this article, the process of differential diagnosis can be protracted.

Wegener's is not contagious and its etiology is unknown. It occurs most often in those between the age of 40 and 65 (American College of Rheumatology, 2011). He was 83. It is estimated to affect 3 out of every 100,000 people (Ibid.), and indeed most of the doctors we met, had never known a patient with Wegener's. Furthermore, approximately 10% of patients with Wegener's have been found to have another disease concomitantly, called anti-glomerular basement membrane (anti-GBM) (Gmurczyk et al., 2010). Anti-GBM disease is also known as Goodpasture's Syndrome if it involves the lungs. It is very rare for patients to be "double positive" (Levy, Hammad, Coulthart, Dougan, & Pusey, 2004; VCRC, 2012) and according to the Levy et al. study (2004), one person in a million will have both Wegener's and anti-GBM. He was one in a million. Anti-GBM disease is the result of injury to the capillaries (small blood vessels) in the kidney or lung specifically. The capillaries are attacked, ultimately reducing—and frequently destroying—kidney or lung function.

There is a sociopolitical element to this disease that unfolded during the time of his acute illness. There was evidence that Dr. Wegener was a member of the Nazi party during World War II. As such, the American College of Rheumatology, European League Against Rheumatism, and American Society of Nephrology recently recommended a shift from the eponym, Wegener's granulomatosis, to granulomatosis with polyangiitis (Falk et al., 2011; Smith, 2011). It is perhaps unfortunate the name has been changed, as its capacity to destroy the small vessels that carry life, makes its association with a genocide metaphorical and appropriate. I will always know it as Wegener's for its destructive capabilities.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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Bio

Catherine Phillips, PhD, is a professor in the School of Social Work at Lakehead University. Prior to joining Lakehead University, she was a lecturer at the University of Plymouth, UK. Her research and teaching interests are focused on two areas: One, the development of approaches to critical inquiries, in particular alternative forms of writing and knowledge dissemination and two, the body in social work practice.