



## 'Our Diagnoses, Our Selves': The Rise of the Technoscientific Illness Identity

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### Abstract

Biomedicine situates the definitions, practices, and controls of the medical system within the field of *technoscience*, which relies on new knowledge, high technology, and biomedical health and risk surveillance. Since the middle of the 20th century technoscientific efforts to understand human phenomena at the microbiological level have secured the place of the biomedical model of disease and the technology used to understand and manage human bodies, selves, and socialities. Specifically, high technology has provoked a paradigm shift from controlling disease and finding cures (medicalization) to transforming bodies and managing risk through technoscientific means (biomedicalization). Though there has been a major shift in the role of the medical consumer since the 1970s and a general recognition of patients' rights to meaningful information about their health and illness conditions, biomedicine holds significant authority over peoples' lives to the degree that biomedicalization now involves the production of individual and collective identities that are constructed through technoscientific means. The *technoscientific identity* has even become a type of *illness identity* that involves applying biomedical information and characteristics to a person's sense of self in the face of illness.

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### Technoscientific biomedicine and the (bio)medicalization of society

The foundations of modern medicine have always been grounded in a relationship between the experimental sciences and technology. From the basic thermometer or stethoscope to monitor body heat and sounds to the more complex instruments such as diagnostic x-rays, computerized microscopes, biochemical tests, pharmaceuticals, and laser technologies to visualize, evaluate, and manipulate the body's internal systems – biomedicine increasingly relies on high technology to understand and treat the complex systems of body. Technoscientific interventions include computer and information sciences, molecular biology, genetics, genomics, biotechnology, nanotechnologies, pharmacogenomics, and medical technologies used for the organization of medical care, patient management, visualization, diagnosis, and treatment (Clarke and Shim 2009). The increasing reliance on technoscientific biomedicine thereby extends and reconstitutes medicalization processes, marking *biomedicalization* as one of the primary social forces transforming the 21st century (Clarke et al. 2003, 2010).

In addition to making new kinds of bureaucratic processes and biomedical interventions possible, technoscience alters the definitions, practices, and controls of modern medicine within a biomedical technoscientific framework, one that depends upon highly specialized knowledge, the proliferation of new high-tech modalities, the expansion of biomedical health and risk surveillance, and the transformation of bodies and identities (Clarke and Shim 2009; Clarke et al. 2003, 2010; Rothman 2006). Hence, biomedical technosciences expand medical jurisdiction, resulting in biomedicalization. Biomedicalization

theory argues that biomedicine has magnified the reach of modern medicine beyond the medical profession, the health system, or the provision of medical treatment. Biomedical technoscience makes its way into the life course and into everyday life such that individuals themselves increasingly view their bodies, socialities, and 'selves' through a biomedical lens (Clarke and Shim 2009; Ginsberg and Rapp 1995; Novas and Rose 2000; Rabinow 2008; Sulik 2009).

Clarke et al. (2010) argue that the transformation of bodies and production of new *technoscientific identities* at the individual, collective, and population levels represent a key aspect of biomedicalization. That is, individuals negotiate and produce a sense of self through the framework of technoscience and its practices. These include biomedical classifications and diagnostics (i.e. technoscientific confirmations of particular diagnoses or genetic predispositions) as well as social relations and other structures. Individuals engage with technological choices and options, access technoscientific identities through biopolitical economies of health and illness, engage in discourses and practices of biomedical risk and surveillance, and receive institutional and interactional reinforcement for enacting particular forms of identity. As technoscientific biomedicine shapes our lives to greater degrees, it also holds greater potential to shape the identities that already develop in the face of illness.

Certainly, new forms of sociality may develop around biological categories (Rabinow 1992, 2008) or in terms of risk (Blaxter 2010; Novas and Rose 2000); and, they may also develop through the lens of technoscience but outside of biomedicine, for instance with regard to computerization, mechanization, robotics and cyborgs, and other technological appendages of the 21st century such as using DNA to trace family histories (see Finkler 2000; Furlow 2009; Gottweis and Byoungsoo 2009). However, this review specifically analyzes the capacity of technoscience to shape illness identity, reflecting one of the ways biomedicalization operates in the contemporary context. Thus, the concept of *technoscientific illness identity* unites the concept of *technoscientific identity* defined by Clarke et al. (2003, 2010) and the concept of *illness identity* developed especially by Charmaz (1995).

An *illness identity* is an incorporation of chronic illness or disability into one's sense of self (Charmaz 1995). Illness identities have the potential to reinforce particular personal or social characteristics to help individuals deal with medical uncertainty and changes in their lives, or to reconstruct their personal biographies in ways that accommodate illness (Barker 2002; Charmaz 1995; Clarke and James 2003; Karp 2001; Weitz 1989). Practically speaking, those who integrate an illness into their identities may also gain access to other individuals who are able to share useful biomedical information (Hoffman 2003; Landzelius 2006; Morgen 2002). As people affiliate with others who share similar situations, they may also feel less isolated (Barker 2002). Feeling connected to others, legitimized, and knowledgeable in the language of biomedicine has been useful for helping individuals to challenge medical diagnoses (Borkman and Munn-Giddings 2008) and gain access to non-institutionalized treatments (Epstein 1996; Kroll-Smith and Floyd 1997; Malacrida 2002). As collective identities develop surrounding an illness, individuals may also engage in health social movements to affect not only their own experiences but also the experiences of others (Borkman and Munn-Giddings 2008; Brenner 2000; Klawiter 1999; Spanier 2001). In this conceptualization, therefore, a *technoscientific illness identity* has roots both in the biomedicalization of society and in the ongoing negotiation between individuals and the medical system as they experience illness.

### The push-pull between medicalization and consumer empowerment

To understand biomedicalization as an outcome of the rapid advancements in biomedical technoscience, one must first understand medicalization. *Medicalization* is the process through which the medical system has jurisdiction over common human conditions and experiences, including diseases and health conditions. Conditions that fall within the auspices of a medical framework become subordinated to the definitions, practices, and controls of the medical system (i.e. *medicalization*) (Conrad 1992, 2007; Margolis 1976; Zola 1972). To adopt a medical framework a condition must first be defined in medical terms (as a disease, disorder, deformity, injury, abnormality, pre-condition, or at-risk status). The medicalization of the most basic life processes and events (i.e. aging, birth, and death) extend medical frameworks into bodies and lifestyles such that individuals may seek out medical explanations and interventions to meet social and cultural expectations. Whereas medical interventions have the potential to constrain individuals within biomedical frameworks and practices (Conrad 2007), medicalization also helps to legitimize experiences of ill health thereby providing individuals with resources and support networks they would not have otherwise (Barker 2002; Conrad and Leiter 2004).

Numerous conditions now fall within a medical classification: blood pressure (Kawachi and Conrad 1996); chronic fatigue syndrome (Aronowitz 1998); compulsive buying (Lee and Mysyk 2004); erectile dysfunction (Loe 2006); hyperactivity (Conrad and Potter 2000); menopause (Bell 1990; Fausto-Sterling 1999); motherhood and reproduction (Litt 2000; Mitchinson 2002; Riessman 2003) and short stature (Conrad and Leiter 2004). In addition, medical jurisdiction encompasses an array of social problems (such as psychoses, alcoholism, or drug addiction) that were previously considered spiritual/moral or legal/criminal (Conrad and Schneider 1992; Starr 1982). On the other hand, disease classifications can still be used to stigmatize, marginalize, and exclude (Ilcan 2009). After a condition has been medicalized, it can be de-medicalized if a condition is no longer regarded as medical (i.e. homosexuality) or re-medicalized as new knowledge alters prevailing medical definitions, new interventions are developed, or new diagnostic tools are identified or improved (Conrad 2007; Conrad and Potter 2000). Clearly, the expansion of medical jurisdiction is far more common than its contraction.

Whereas stakeholders within the medical system may collaborate with medicalization processes because of professionalization, market conditions, or economic interests (Conrad 2005), medical frameworks also embed into belief systems and everyday practices.

The concept of *medical consumerism* within health and social services contributed to the elevated status of the individual in medical decision-making and health services (Hardey 2001; Kapp 1999). Typically characterized in terms of informed decision-making that is optimistic, proactive, rational, and responsible – the social role of medical consumer is grounded in market-based logic, responsible citizenship, and demands for the civil rights of patients within the medical system (Sulik and Eich-Krohnm 2008). As individuals engage in *biological citizenship* to lay claim to health entitlements and biomedical resources (Petryna 2002; Rose and Novas 2004), medical consumerism provides a readily available platform. Though there are limitations to the extent to which individuals are able to occupy this idealized category (Fries 2008), medical consumerism may be viewed both as a social response to medicalization and as a form of socio-political empowerment.

The origins of medical consumerism are closely tied to social movements of the 1960s and 1970s, as various constituencies (including women, people with disabilities, medical subjects, and other reformists and civil activists) began to challenge the authority of

medical experts and the dominance of the medical system (Starr 1982). Coinciding with aims to demystify medicine and take back its jurisdiction over normal body processes such as childbirth and menopause, the women's health movement sought to equalize power relationships between patients and medical providers (Ehrenreich and English 1979; Epstein 1996, 2008). The Boston Women's Health Collective (1973) produced a seminal reference book, *Our Bodies, Ourselves*, which represented a fundamental distrust of medical authority particularly on the part of women who were cast into dependent roles, kept out of medical schools, and dealt with paternalistically. The book inspired the women's health movement to focus on patients' rights to accurate information, personal medical records, informed consent, and respectful health care.

Starr (1982) argues that although distrust of the medical profession was most apparent in the women's movement, the demands for increased regulation of the profession and assurances of patients' rights cut across various mobilizations to fundamentally alter the status of the individual vis-à-vis the medical system. By the 1970s, the high esteem and authority that the medical profession had attained following reforms in professional standards and medical education at the turn of the 20th century had given way to serious doubt (Starr 1982). In addition to garnering other civil liberties individuals wanted to play a role in their health and medical care, and they were willing to organize to do so. Support and education programs sprouted around specific illnesses, health conditions, and healthcare reform issues as the new medical consumers learned the language of medicine and shared this knowledge with others (Barker 2002; Brown 1992; Epstein 1996, 2008; Hoffinan 2003; Landzelius 2006; Morgen 2002).

Access to quality medical information (in addition to products and services) has been a cornerstone for health social movements and medical consumers, and a key pathway to consumer empowerment. There is a symbiotic and at times agonistic relationship between *lay knowledge*, which refers to a wider conception of health and illness in relation to society (Brown 1992; Davison et al. 1991), and *professional knowledge*, which originates from within the scientific and medical establishment (Gabe et al. 2004; Henwood et al. 2003). Consumer health movements sought to understand and use both.

Collective affiliations helped individuals to legitimize their knowledge and experiences (Brown 1992; Clarke and James 2003). Advancements in information and communication technologies made public access to medical information and communications among consumer networks exponentially faster, wider, and deeper (Clarke et al. 2003; Hardey 2001; Radin 2006). The growth of science news and online health information spurred the desire for more information and the expansion of consumers' health choices (Bauer 1998; Hardey 2001). With substantial access to medical information and the tools to comprehend it (often achieved through consumer networks to help translate medical language into lay terms), the boundaries of authority between medical consumers and medical experts weakened.

By the start of the 21st century, the autonomy and dominance of the medical profession had in some ways declined (Starr 1982). In particular, the rise of medical consumerism fostered a more cooperative relationship between doctors and their patients as the *patient-as-consumer* took a more active role in becoming informed, making medical decisions, influencing their care and medical treatment (Haug and Lavin 1983; Jost 2003; Kapp 1999; Kronenfeld 2001; Landzelius 2006; Light 1993; Thomas 2000). From reference books such as *Our Bodies, Ourselves* to personal biographies to on-line communities, collectivities of medical consumers gained leverage through the understanding and production of health knowledge (Barker 2002; Borkman and Munn-Giddings 2009; Kushner 1975). With the rise of technoscience the demystification of modern medicine that was

central to consumer empowerment gave way to increased specialization, perplexity, and biomedical uncertainty.

### **Technoscientization, biomedical uncertainty, and the re-mystification of medicine**

Stakeholders in the medical profession such as health care providers, the health care industry, insurers, the state, and medical consumers, each hold competing interests in medicine that constrain the autonomy of the profession and enable contestation (Light 2000). Insurers and providers struggle to shape health care coverage (Quadagno 2004). Pharmaceutical organizations lobby professional medical societies, government agencies, and consumers through public awareness campaigns to gain buy-in for new drugs (Connell and Hunt 2010). Indeed the most powerful stakeholders within the medical system compete to influence standards and clinical guidelines, create policies and procedures, maintain internal controls, and produce professional knowledge (Clarke and Shim 2009; Fisher 2009; Freidson 1994; Parsons 1951).

Importantly, the biomedical framework that underlies the system as a whole remains tantamount. The biomedical model relies on unique causality, consistent and recognizable symptoms, and scientifically determined diagnosis and treatment (Weitz 2010), suggesting that unruly body processes can be reduced to specific mechanisms that can be objectively identified, measured, treated, and (hopefully) fixed. Although there has been a shift toward more integrative approaches to treatment and healing, the biomedical model constructs the body rationally and mechanistically (Fries 2008; Hollenberg 2006). In turn, technoscientific biomedicine relies on high technology to reduce the body to smaller and smaller parts at a level far beneath human experience (i.e. cells, molecules, genes, etc.). Technoscientific advancements attempt to pinpoint, and keep track of, biological mechanisms at finer degrees of precision, and with greater accuracy and efficiency (Helman 2001). In the 21st century, technoscientific biomedicine has taken on a life of its own.

*Technoscientization* refers to the ongoing process of understanding, diagnosing, monitoring, and treating biomedical processes through high technology (see Clarke and Shim 2009). The main areas of technoscientization involve molecularization and geneticization, computerization and data banking, and the design, development, and distribution of medical technologies (Clarke and Shim 2009, 215). New technologies, treatment modalities, and pharmaceuticals are constantly being developed, studied, and marketed to the general population (Light 2010; Loe 2006; Moynihan and Cassels 2005; Rosser 2000). Clinical trials require billions of dollars in medical equipment and new technologies to test new drugs and therapies (Fisher 2009; O'Meara 2009). All of these new advancements help to create new medical markets (Conrad and Leiter 2004), in which profit motives and proprietary interests, as opposed to intellectual curiosity, may be driving the research (Moynihan and Cassels 2005; Schafer 2009; Sulik 2010). In the United States, more than 75 percent of drug trials are now conducted in the private sector (Fisher 2009). The pharmaceutical industry, with global sales in the trillions of dollars, relies on high technology to be one of the most powerful and profitable industries in the world (Berkrot 2010). In addition to market incentives, the dependence upon technoscientific advancements in biomedicine creates a widening divide between basic and clinical research and a polarizing effect between those who would direct it (Schafer 2009).

The knowledge and practices produced throughout technoscientific biomedical apparatuses are complex and highly specialized, requiring the expertise of a professional elite (Bryan et al. 2006; Henwood et al. 2003; Hollenberg 2006; Wathen et al. 2008).

Exclusionary language helps to differentiate between specialists and other medical professionals, in particular creating a chasm between biomedical researchers and clinical practitioners. In *The Vanishing Physician-Scientist*, Andrew Schafer MD argues that there is such a 'language barrier' between basic scientists and clinical practitioners that, 'the growing alienation of physicians from serious research careers largely parallels and reflects a widening schism between basic science and clinical medicine' (2009, 7). The physician–scientist who once relied on clinical experience to develop new research and understanding of body processes, referred to as an 'endangered species', has given way to a cadre of non-physician scientists who may have limited, if any, clinical experience.

With the rapid increase in specialized techniques and biomedical language, it is increasingly challenging for specialists to stay current amid the complex and rapidly changing areas of biomedical research and the development of new technologies (Callahan 2009; Hunter and Cohen 2006). According to Hunter and Cohen (2006), the National Library of Medicine's PubMed database is expanding at a compounded annual growth rate of about 4.2 percent, which is contributing to 'literature overload' (589). With over 16 million publications in the system, over 3 million were published in the last 5 years. Running parallel to the production of specialized knowledge, specialist doctors now comprise about 80 percent of total physicians in the United States (Callahan 2009). Unfortunately, the substantial increases in biomedical research, knowledge, technoscientific advancements, and specialists do not necessarily reduce *biomedical uncertainty* – the gap between biomedical knowledge and diagnostic, treatment, and prognostic practices.

Biomedical uncertainty is a primary concern of the biomedical age. It affects how knowledge translates to clinical practice and doctor–patient communications as well as patients' functional awareness and decision-making. The three dimensions of biomedical uncertainty explored in medical sociological research are defined as clinical, functional, or existential. *Clinical uncertainty* is related to limitations to what is known about a particular condition, how to deal with it, or to practitioners' mastery of the existing knowledge base (Adamson 1997; Fox 1999; Parsons 1951). *Functional uncertainty* shapes doctor–patient interactions, such as when medical practitioners know and understand the signs of a terminal illness but patients themselves have little to no awareness about the probability or timing of their own death (Glaser and Strauss 1965). When the cause of one's illness is unknown, treatment is indeterminate, or there is a misdiagnosis or incorrect treatment, patients may experience *existential uncertainty* (Adamson 1997; Weitz 1989).

It is likely that all three types of uncertainty operate at once in many medical encounters. The incessant advancement of science and medicine is especially likely to increase uncertainty at the clinical and existential levels. Parson's (1951) argued that as doctors relied more completely on specialized scientific technology to consult with patients and construct diagnostic and treatment protocols. The implications are far ranging, including: not knowing which people with a genetic predisposition will get a particular disease, not knowing which biomedical information will be reliable (e.g. excessive false positives on a mammogram), not knowing how to interpret particular biomedical data (e.g. whether to classify abnormal cells that do not have the capacity to spread as a *carcinoma*), not knowing the shelf life of biomedical information (e.g. high recurrences of certain cancers following a cancer free period), and having difficulty gaining a command of the technological skills and knowledge bases that are continually changing (e.g. implications of the latest clinical trials or accuracy in reading mammograms) (see Fisher and Ronald 2008; Fox 1999; Partridge et al. 2008; Rosser 2000; Rothman 2006; Sulik 2010).

Even in the face of biomedical uncertainty, health practitioners are charged with processing, interpreting, communicating, and acting upon biotechnological information. Biomedical specialists routinely rely on high tech histological representations and biochemical markers to determine etiology, diagnosis, treatment, and aftercare for an increasing number of medicalized conditions and health/body enhancements (Conrad and Potter 2004). Since the language needed to understand biomedical technoscience is complex, esoteric, and virtually incomprehensible for those without scientific backgrounds, this exclusivity grants authority to biomedical knowledge and positions as experts those who produce and communicate it (Kerr et al. 2007). Thus, the rapid expansion of, and reliance upon, biomedical technoscience influences the means through which medical consumers gain access to specialized biomedical information, the kinds of information they obtain, and their capacity to understand and use it (Halfon 2010; Henwood et al. 2003; Wathen et al. 2008).

Highly specialized biomedical language and increased biomedical uncertainty contributes to the re-mystification of modern medicine and erodes to some degree the empowerment potential of medical consumers in more cooperative doctor/patient relationships (Sulik 2009).

### **Technoscience and the language of risk**

A culture of fear is prevalent in western society and in American culture in particular. Anxiety-provoking discourse within mass media and consumer advertising especially warn that danger and risk infuse individuals' everyday lives, from crime to terror to the latest epidemic (Altheide 2002; Best 2001; Glassner 2000). News media and popular culture encourage all manner of consumers to manage pervasive risk by disciplining themselves through the consumption risk management techniques and devices (Halkier 2001). Likewise, biomedical discourse focuses on *risk factors* (i.e. those things that increase a person's probability of developing some disease or medical condition) and *health hazards* (i.e. those things that could cause a health problem for a person or group). These include: natural processes such as aging (which is a risk factor for Alzheimer's and many cancers), the hazards of particular lifestyle choices (such as smoking, diet, and sedentary lifestyle), and hazards beyond one's control such as the potentially toxic and long-term effects of environmental pollution.

The language of risk that dominates considerable medical discourse blends with fear mongering in the broader cultural environment to elevate the supply and demand for biomedical risk surveillance (Clarke and Shim 2009; Clarke et al. 2003, 2010; Lantz and Booth 1998; Rothman 2006). Whereas the onset of symptoms may encourage individuals to seek medical advice or care, the medical community along with mass media routinely advise asymptomatic people to consider their vulnerability to the potential health perils of the day (Brown et al. 2001; Hallowell et al. 2004; Lantz and Booth 1998; Novas and Rose 2000; Scott et al. 2005). To do otherwise would be irresponsible (Clarke and Shim 2009; Fosket et al. 2000; Hallowell 1999; Malacrida 2002; Novas and Rose 2000). In a fearful society that values individual choice and personal responsibility, risk is reason enough to warrant biomedical intervention.

The first intervention comes in the form of *risk surveillance* – an abundant supply of biomedical technologies used to assess, evaluate, and manage risk (Crawford 2004). Risk surveillance encourages empowered medical consumers to work with biomedical experts to evaluate their risk for a particular condition or set of conditions. Health evaluations, genetic tests, aspects of family medical history, assessment tools, and cancer

screenings, for example, help medical professionals to create risk profiles for individuals who have no symptoms of disease and no cancer diagnosis. Experts use the risk profile to assess the person's overall risk and make recommendations about the next biomedical intervention (Fosket 2004). The next intervention may involve more surveillance. It may require interventions to ascertain the level of risk with greater precision, such as biopsying a suspicious area to look for cancer. Or, it may warrant prophylactic surgery, pharmaceuticals, or perhaps lifestyle modification. With each of the latter interventions, ongoing surveillance continues as well (see Donovan and Tucker 2000).

In each of the above scenarios, it is the risk itself that receives the biomedical intervention, not the condition or disease for which the person is *at risk*. Rose writes:

Susceptibility indexes move from genetic determinism to a new world of genomic probabilism... The idea of susceptibility brings potential futures into the present, makes them subject to calculation and the object of remedial intervention (Rose 2007, 9).

A culture of medical consumerism already elevates the individual responsibility to take action proactively and methodically in regard to health and/or illness. As individuals synthesize lay and professional knowledge about health and illness conditions, they may seek expert knowledge to better understand their susceptibility to diseases and medical conditions (Davison et al. 1991). Captured in the familiar phrase, 'Talk to your doctor about whether [X] is right for you', biomedical surveillance and intervention encourage empowered medical consumers to seek out biomedicine as a means for managing probability and risk.

Proactive engagement in risk surveillance constructs individuals as autonomous, rational, and entrepreneurial (Robertson 2000, 2001), but it also comes with moral obligation (Howson 1998). Women who were treated for breast or ovarian cancer and underwent genetic testing, for example, were more fatalistic about their futures if they perceived themselves to be unwilling or unable to manage the risk (Hallowell et al. 2004). In addition, those who cannot or choose not to conform to sanctioned biomedical recommendations to avoid risk may blame themselves or face social stigma (Fosket et al. 2000; Sulik 2010).

Extending medical jurisdiction beyond a disease or medicalized condition to the state of risk or pre-disease also increases medicalization. However, Clarke and Shim (2009) emphasize that whereas medicalization focuses on *control over* medical phenomena, biomedicalization emphasizes *transformation of* these phenomena through technoscientific means. Not only does high tech biomedicine hold authority over a widening array of medical conditions and diseases, it now holds sway over asymptomatic individuals and their risk profiles.

In a high-risk society where health is a commodity, the pre-diseased are an ever-expanding market of consumers, and the body (after it has been biomedically re-engineered) is a prized possession (Clarke and Shim 2009, 214). Optimal health then is also a moral imperative and source of identity (Kaufman et al. 2004; Rose 2006; Stepnisky 2007). Rose (2007) argues that biomedicine has produced a shift in identity toward a new molecular ontology of life, or a somatic sense of self. In other words, biomedicine enables individuals to think of themselves and their lives in terms of their most minute parts, at biochemical, genetic, cellular, and molecular levels. Awareness of genetic risk can encourage people to develop new relations with themselves and their futures (Finkler 2000; Hallowell et al. 2004; Novas and Rose 2000). Likewise, as individuals with an

illness synthesize biomedical information about risk, they might also develop a new form of identity that is based on technoscientific biomedicine.

### **The technoscientific identity as an illness identity**

The biomedicalization of risk and the explosion of biomedical knowledge and technoscience, have provoked a shift in the frameworks people use to develop a sense of self (Atkinson et al. 2007). The avoidance of health hazards and risks through technoscientific means works in conjunction with the uses of biomedicine for health enhancement to create an idealized vision of health optimization and the maximization of life itself (Conrad and Potter 2004; Lafontaine 2009; O'Meara 2009; Rose 2006). It is the stuff that dreams – and sci-fi movies – are made of. The advancements in technoscience are indeed so astounding that these superhuman imaginings breathe life into the biological realities of regular human beings, those who get hungry, tired, sick, old, and sometimes chronically or terminally ill. Yet, in the face of chronic illness and disability individuals typically develop ways of incorporating the new condition into their identities to manage the illness, deal with biomedical uncertainty, and accommodate risk. When facing chronic illness especially, thinking of the self within a biomedical technoscientific framework may help to create order where the body has gone out of control and new hope in the wake of uncertainty and risk (Sulik 2009).

*Illness identity* is a concept that bridges the relationship between the body and the self in the face of chronic illness or disability. As patients assess, redefine, and reinterpret their experiences of illness, they make adjustments (sometimes major ones) to their attitudes, beliefs, behaviors, and identities (Charmaz 1995; Karp 2001; Riessman 1990). This can result in self-actualization and a reformulation of identity (Frank 2002), which can help people to return to a satisfying way of life (Corbin and Strauss 1991). Barker's (2002) analysis of Fibromyalgia Syndrome demonstrates how popularized illness narratives encourage the construction of a unified, though fluid illness identity. As people translated their lived experiences into public narratives and simultaneously used these narratives to understand themselves, they retained and/or gained valued self attributes. These attributes incorporated the illness into their sense of self, enabling people in a way to transcend their illness.

Illness identities also develop as individuals affiliate with those in similar health situations and identify with key attributes surrounding their illnesses, e.g. disease classification or survivor status. People use illness identities to develop and reinforce personal and social characteristics that help them to accommodate aspects of the illness or disability into their lives, manage uncertainty, and integrate the illness into their sense of self (Barker 2002; Charmaz 1995; Clarke and James 2003; Karp 2001; Weitz 1989). Illness identities help people to reduce alienation (Barker 2002), learn the language of biomedicine (Hoffman 2003; Landzelius 2006; Morgen 2002), challenge medical diagnoses (Borkman and Munn-Giddings 2008), gain access to non-institutionalized treatments (Epstein 1996; Kroll-Smith and Floyd 1997; Malacrida 2002), and participate more fully in health social movements (Borkman and Munn-Giddings 2008; Brenner 2000; Klawiter 1999; Spanier 2001). Although affiliation may strengthen emerging illness identities, individuals *continually interpret* their illness experiences as they adjust to biomedical uncertainty, treatment, and disease outcomes.

Similar to the aspects of illness identity above, a *technoscientific* illness identity functions as a means for increasing a sense of control over the experience of illness while managing risk and biomedical uncertainty (Clarke and Shim 2009; Hallowell et al. 2004; Sulik

2009). In addition, a *technoscientific illness identity* involves applying biomedical information and characteristics to a person's sense of self in the face of illness, transferring biomedical information and characteristics directly to the person. Instead of acknowledging that one *has* a particular biomedical classification, the TSI encourages the person to *become* – think of oneself in terms of – the classification. For instance, a person may unexpectedly learn (or even seek out the knowledge) that she is a genetic carrier of a disease. Instead of simply acknowledging the biomedical marker as a piece of information, the person begins to think of herself as pre-diseased. If, however, the person has already received a diagnosis and is embedded within the medical system for treatment and aftercare, a biomedical classification such as this may hold even greater social force.

The development of a technoscientific illness identity is neither automatic nor fully established even in people with technoscientific leanings. In fact, my own research, which involved women diagnosed with breast cancer, reveals a complex and multi-stage process (Sulik 2009). To develop an illness identity that was technoscientific, the diagnosed first had to seek knowledge and immerse themselves in biomedical information. Second, they had to use this information to locate themselves within a technoscientific framework. Then, they needed institutional support from within and beyond the medical system, which included reinforcement from medical authorities and/or rationalized biomedical discourse. Finally, the diagnosed had to consider their biomedical classifications, rather than their suffering, to be determinant factors for synthesizing knowledge and making decisions.

As the diagnosed develop an illness identity and ways to manage their illness, a technoscientific classification may, for some, become the primary frame of reference. Rather than simply possessing a particular biomedical marker or classification, a diagnosed person may identify so strongly with it that he or she integrates the classification into his or her developing illness identity. Throughout this process biomedical knowledge is incorporated into one's sense of self, mandates specific behaviors, shifts self-perception from 'healthy' to 'sick' or 'sicker', increases self-knowledge (perhaps anxiety or fatalism) about individual susceptibilities and potential pathologies (Clarke et al. 2003), and enables the identification and, if desired, interaction with others who share the technoscientific classification (Atkinson et al. 2007; Gibbon and Novas 2008; Rabinow 1992, 2008). When technoscientific techniques do not resolve the uncertainty or risk associated with a diagnosis or medical condition (e.g. genetic tests that do not reveal a genetic cause of one's diagnosed cancer), the technoscientific identity then supplies the belief that medical science eventually will progress enough to produce unequivocal answers (O'Meara 2009; Sulik 2009).

As these processes suggest, biomedical knowledge is a critical factor in the development of a technoscientific identity because thinking of the self in technoscientific terms allows the diagnosed to negotiate biomedical expertise (Halfon 2010; Mamo 2007; Sulik 2009). In the current historical moment, the ability to understand and use biomedical knowledge in medical encounters is crucial. In fact, Shim (2010) argues that consumerism, patient initiative, self-knowledge, self-surveillance, and self-management represent a set of skills and resources (i.e. *cultural health capital*) that are critical to the ability to effectively engage and communicate with clinical providers. Similarly, in a study of women's experiences with hormone replacement therapy, individual doctors rejected or dismissed women's opinions when they did not correspond with their own (Henwood et al. 2003). This was true even for women who had informed themselves about treatment. When developing lay understandings of expert/medical knowledge, those that correspond with it are likely to contribute to the legitimacy of medical consumers' claims to biomedical and technoscientific expertise, which can influence communications and interactions with

doctors (Henwood et al. 2003; Kerr et al. 2007; Shim 2010; Sulik 2009). The extent to which a person is able to use biomedical knowledge to understand their condition(s), communicate with their doctors, and get the kind of care they want, also contributes to the development of a technoscientific illness identity.

### Conclusion

Biomedical technoscience and biomedicalization hold potential for empowerment and constraint. The title of this article, *Our Diagnoses, Our Selves* pays homage to the health social movements that sought to claim their embodied experiences and demystify modern medicine for the sake of empowerment and respectful relations within medical encounters. Certainly, an illness identity centered on biomedical, technoscientific information encourages people to take ownership for understanding information, assessing their risk, and making medical decisions. Some are also empowered to seek greater scientific knowledge, make medical decisions, and produce new knowledge. Others have elevated hope for the future and are therefore better able to manage their illnesses in their everyday lives. Those who believe in technoscience may have a greater sense of control when using the language of biomedicine, illuminating the cooperative potential of doctor–patient interactions. For these individuals, technoscience may answer the call for empowered and healthful living.

However, biomedicine can also function as a means of surveillance and social control. If professional knowledge is synthesized into lay understandings of illness through the development of a technoscientific illness identity, then reliance on medical science and high technology also contributes to the professional colonization of lay knowledge, shaping its discursive boundaries. Medical practitioners and patients may be susceptible to the power of biomedicine, and likely to accept its terms and outcomes without questioning underlying assumptions, systemic effects, or long-term implications. Additionally, biomedicalization processes involve corporatized and privatized biomedical techno-services that serve the interests of genetics laboratories, pharmaceutical companies, scientists, researchers, and corporations more than they do individuals (Rothman 2006). Finally, technoscientific illness identities promote behaviors that fortify the position of the technoscientific medical advances (e.g. genetic testing and screening technologies) that system agents promote. Susceptibility and potential pathology encourage these identities even when people are asymptomatic or post-symptomatic, and reliance on biomedical frameworks and technologies reinforce them, drawing attention away from social and cultural factors that contribute to health and illness and prioritizing biomedicine over other healing practices and ideologies.

### Short Biography

Gayle Sulik, PhD, is a medical sociologist and independent scholar. She received her MA in women's studies in 2001 and her PhD in sociology in 2004 from the University at Albany (SUNY), where she currently holds an appointment as a research associate. Sulik has also held prior faculty appointments at Vassar College and Texas Woman's University. Her research emphasizes women's health, interdisciplinary community research, comparative health contexts, and health policy. She has published scholarly papers on illness identity, technoscience, gender, and care work in *Sociology of Health and Illness*, *Gender and Society*, and *Qualitative Sociology*. Her recent book, *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health* was released this year from Oxford University Press.

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