Managing biomedical uncertainty: the technoscientific illness identity

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Abstract

This paper analyses how the biomedical uncertainty of breast cancer contributes to the development of a new type of illness identity that is grounded in biomedical knowledge, advanced technology, and biomedical health and risk surveillance. The technoscientific identity (TSI) develops through the application of sciences and technologies to one’s sense of self. Analysing narrative data from 60 in-depth interviews with women diagnosed with breast cancer, this research demonstrates how women diagnosed with breast cancer develop and maintain TSIs through four processes: (1) immersion in professional biomedical knowledge, (2) locating themselves within a technoscientific framework, (3) receiving support for the emerging TSI from the medical system and support networks, and (4) eventually prioritising their biomedical classifications over their suffering. Developing a TSI enables people to make sense of biomedical information, make decisions, and manage medical processes and relationships in the face of biomedical and personal uncertainty even as it extends the reach of technoscience and biomedicalisation.

Keywords: biomedicalisation, biomedical uncertainty, illness identity, technoscientific identity, breast cancer

Introduction

The medical system occupies a central position throughout the lifecourse and in everyday life. It places common human conditions and experiences (as well as diseases) within a medical framework and subordinates them to the definitions, practices, and controls of the medical system (Margolis 1976, Zola 1972). After a condition has been medicalised, it can be re-medicalised through domain expansion; as new knowledge alters the medical definition, new interventions are developed, or new diagnostic tools are identified or improved (Conrad and Potter 2000). The biomedical model of disease ensures that new definitions, practices, and controls will emerge to strengthen medicalisation. Efforts to understand human differences at the level of the gene secure the place of the biomedical model of disease and the technology used to understand and manage it. Clark and colleagues (2003) argue that dependence on biomedical technoscience in medicine reconstitutes and extends medicalising processes by reconfiguring the logic of medical knowledge and practice. High technology has produced a shift from disease and cure (medicalisation) to choice, enhancement, and risk (biomedicalisation).
A key element to the new era of biomedicalisation involves the production of individual and collective identities constructed through technoscientific means (Clarke et al. 2003). Developing an illness identity is common for those with chronic illnesses or disabilities. Individuals develop and reinforce personal and social characteristics to help them to accommodate aspects of the illness and integrate it into their lives and sense of self (Barker 2002, Charmaz 1995, Karp 2001). Illness identities help people to manage the uncertainty of illness (Clarke and James 2003, Weitz 1989). In managing uncertainty, information (both lay and professional) is paramount. This paper argues that biomedicalisation and biomedical uncertainty together encourage the development of a new kind of illness identity that is based on one’s association with, and knowledge of, science and technology. A technoscientific identity (TSI) transfers 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.

Due to its prevalence and high level of biomedical uncertainty, breast cancer is an important case for analysing the impact of biomedicine on illness identity. Breast cancer is the most commonly diagnosed cancer among women in the US (ACS 2008). There is uncertainty surrounding etiology, diagnosis, treatment, and aftercare. There is no singular, unambiguous cause (Love 2005). Despite attention to genetic causes, only five to ten per cent of diagnosed women inherited a mutation in the breast cancer genes, BRCA1 or BRCA2 (Barlow et al. 2006, Brown et al. 2001, NCI 2006). Known risk factors (such as age, reproductive factors, inherited genetic mutations, postmenopausal obesity, hormone replacement therapy, alcohol consumption, and previous history of endometrial, ovarian, or colon cancer) account for less than 30 per cent of cases (Hulka and Stark 1995, Love 2005, Smith-Warner et al. 1998). Mitigating factors make it difficult to isolate interventions (NBCC 2008). Mammography may not detect fast-growing malignancies early enough to affect cure, leads to aggressive treatment and unnecessary surgeries, and offers only a modest benefit for women between ages 50–70, and a lesser benefit among women aged 40–49 (Institute of Medicine 2001). Finally, those diagnosed face abstract, incomplete, and controversial scientific information about disease treatment and management.

Using qualitative data, this paper analyses how the biomedical uncertainty of breast cancer shapes the development of technoscientific identities. I draw on 60 in-depth interviews and ethnographic data to analyse the experiences of women who are navigating biomedical information and practices to confront their diagnoses. This paper analyses: (1) how the development of technoscientific identity can help people take control of their lives when facing risk and biomedical uncertainty; and (2) how individuals become reliant on biomedicine after science and technology are incorporated into their illness identities. The availability of professional and lay information about medical conditions works in conjunction with cultural ideals about the importance of being an informed medical consumer (Sulik and Eich-Krohm 2008). These social forces encourage the development of TSIs, increasing biomedicalisation.

**Constructing an illness identity within the boundaries of technoscience**

Within the medical model, diseases are defined and treated within a framework that assumes unique causality, consistent and recognisable symptoms, and scientifically determined treatment. Biomedicine situates the definitions, practices, and controls of this system within technoscience, a field that relies on new knowledge, high technology, and biomedical health and risk surveillance (Clarke et al. 2003, Rosser 2000). Biomedicalisation holds potential for empowerment and constraint based on situational and structural factors. The
biomedicalisation of old age reveals how routine medical care overshadows choice, transforms technological imperatives into moral ones, and constructs an ethic of normalcy that relies on routinisation (Kaufman et al. 2004). Mamo’s (2007) research of lesbian reproductive practices suggests that high technology can be used to increase choice and to destabilise moral constraints. For lesbian mothers, assisted reproduction complicates normative definitions of infertility while high cost and lack of insurance for reproductive technologies reinforces patterns of social stratification.

The medical system increasingly emphasises biomedical forms and practices to determine the etiology, diagnosis, treatment, and aftercare for medical conditions. Yet, many conditions do not fit well within this framework, creating uncertainty about how to prevent, diagnose, and treat them. Much literature on biomedical uncertainty focuses on medical definitions, e.g. when conditions are not fully defined in medical terms (see Aronowitz 1998, Barker 2002, Clarke and James 2003, Conrad and Potter 2004, Dumit 2006). Uncertainty also includes indeterminate diagnostics, controversial medical evidence, and ambiguous treatment outcomes. Parsons (1951) argued that the incessant advancement of science and medicine would increase biomedical uncertainty, as doctors rely more fully on scientific advancements and specialised technology to consult with patients and construct diagnostic and treatment protocols. Increased biomedical uncertainty would thereby contribute to increased biomedicalisation.

**Illness identity and biomedical uncertainty**

Biomedical uncertainty necessitates new relationships between the body and the self. While interpreting professional knowledge from doctors and the medical system, patients evaluate the impact an illness will have on their lives, their futures, and their feelings about themselves (Chambre 2006, Charmaz 1991, Karp 1996). As patients assess, redefine, and reinterpret their illness experiences, they make adjustments (sometimes major ones) to their attitudes, beliefs, behaviours, and identities (Charmaz 1995, Karp 2001, Riessman 1990). This can result in self-actualisation and a reformulation of identity (Frank 2002), which can help people to return to a satisfying way of life (Corbin and Strauss 1991). Even 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). Women who were treated for breast or ovarian cancer and underwent genetic testing were more fatalistic about their futures if they perceived themselves to be unwilling or unable to manage the risk (Hallowell et al. 2004).

Whether or not biomedical uncertainty will contribute to a valued identity and hope for the future is related to social context. Broad narratives about what it means to be healthy or sick merge with cultural representations of illnesses, scientific arguments, and group processes. Barker’s (2002) analysis of Fibromyalgia Syndrome (FMS) demonstrates how popularised 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 to transcend their illness.

As new illness identities emerge, individuals sometimes begin to affiliate with those in similar situations to establish a collective identity based on key attributes, e.g. disease classification or survivorship. Collective affiliations make it possible to legitimise knowledge and experiences (Brown 1992, Clarke and James 2003), reduce alienation (Barker 2002), challenge medical diagnoses (Borkman and Munn-Giddings 2008), access non-institutionalised treatments (Epstein 1996, Kroll-Smith 1997, Malacrida 2002), or participate in social movements (Brenner 2000, Borkman and Munn-Giddings 2008, Klawiter 1999). Such efforts
have been crucial for women’s health activism, increased funding for research, participation in clinical trials, and agency in medical encounters (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.

Biomedical information plays a key role in identity development as individuals synthesise lay and professional knowledge (Brown 1992, Davison et al. 1991, Gabe et al. 2004). Although some patients at times try to avoid information about their conditions (Henwood et al. 2003, Weitz 1989), this is increasingly difficult, given the proliferation of health information in print and electronic media. The explosion of biomedical knowledge and technologies has enabled a shift in the frameworks people use to develop an embodied sense of self (Stepnisky 2007). Furthermore, a culture of medical consumerism elevates the social responsibility of the individual to proactively and methodically take action in regard to health and illness (Sulik and Eich-Krohm 2008). Even prior to diagnosis, the medical community routinely advises people to determine the extent to which they are ‘at risk’ for particular conditions (Scott et al. 2005). With genetic risk comes ‘genetic responsibility’ (Novas and Rose 2000: 1). The individual assessment of health and health risk has been integrated into a cooperative model of care, in which individuals are obliged to work with doctors in medical decision making (Kronenfeld 2001, Landzelius 2006).

In this context many patients seek expert knowledge the better to understand their susceptibility to diseases and medical conditions. Rose (2007) argues that biopolitics and biotechnology have produced a shift in identity toward a new molecular ontology of life, a somatic sense of self. The premise is that biomedicalisation based on risk and susceptibility has colonised identity. ‘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). As people synthesise information about risk, they develop new self-awareness that fosters a somatic sense of self, a type of illness identity that may, or may not, be related to actual disease conditions.

The research reviewed suggests three premises: first, biomedical uncertainty is an inevitable component of the medical model of illness that requires strategic negotiations on the part of doctors and patients. Secondly, advancements in science and medicine intensify biomedical uncertainty even as they increase the medical system’s reliance on them. Thirdly, patients develop ways of incorporating illness into their existing identities or forming new illness identities to manage illness, deal with biomedical uncertainty, and accommodate risk. Building upon these premises, I argue that people do not develop an illness identity only to cope with illness, they do so in response to technoscience, increased biomedical uncertainty, and biomedicalisation itself.

**Technoscientific Illness Identities**

A technoscientific identity (TSI) is a type of illness identity that involves applying biomedical information and characteristics to a person’s sense of self (Clarke et al. 2003, Dumit 1997). Rather than simply possessing a particular biomedical marker or classification, the person identifies so strongly with it that he or she integrates the classification into his or her identity. A person may unexpectedly learn (or even seek out the knowledge) that she is predisposed to a particular medical condition, or 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 the person has received a diagnosis and is embedded within the medical system for treatment and aftercare, biomedical classifications hold greater social force. In these scenarios, biomedical knowledge is incorporated into one’s
sense of self, mandates specific behaviours, shifts self-perception from ‘healthy’ to ‘sick’, increases self-knowledge (perhaps anxiety or fatalism) about individual susceptibilities and potential pathologies (Clarke et al. 2003), and enables the identification and interaction with others who share the technoscientific classification. The TSI functions as a means to manage biomedical uncertainty and increase a sense of control over the experience of illness, uncertainty, and risk.

Thinking of the self in technoscientific terms allows the diagnosed to develop lay understandings that correspond with expert/medical knowledge. Correspondence contributes to the legitimacy of medical consumers’ claims to biomedical and technoscientific expertise, which can influence interactions with doctors. In a study of women’s experiences with hormone replacement therapy, Henwood and colleagues (2003) found that doctors rejected or dismissed women’s opinions when they did not correspond with those of the medical profession. This was true even for women who had informed themselves about treatment. Academic elites develop technoscientific discourse within a medical-industrial complex that supports it. Therefore, lay knowledge that is incomplete, insufficient, or does not correspond with the expert/medical knowledge is likely to hold diminished power when negotiating medical encounters. On the contrary, lay knowledge that is consistent with professional knowledge may enjoy greater institutional acceptance and a higher degree of negotiating power (Kerr et al. 2007).

This paper will demonstrate that situating oneself within technoscientific discourses is an attempt to manage biomedical risk and uncertainty. Developing a technoscientific identity grants authority to biomedicine and the technoscientific apparatuses that support and explain it, thereby limiting the full range of discourses available to patients while increasing their reliance on medical authority and technoscience. 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 breast cancer), the TSI supplies the belief that medical science eventually will progress enough to produce unequivocal answers.

Method

This article is part of a larger study on US women’s experiences as breast cancer survivors (Sulik 2005). I conducted interviews over a three-year period (2001–2004) with 60 breast cancer survivors, using a grounded theory approach to qualitative analysis (Glaser and Strauss 1967). I used informal interviews and other observational techniques (Gubrium and Holstein 2002, Lofland and Lofland 1995), and worked for six months as an administrative assistant and volunteer with a community-based organisation before and during data collection. In addition to interacting with volunteers and researching breast cancer issues, this allowed me to participate in business meetings, regional and national conferences, community events, and educational programmes. I read books written for survivors, examined websites and informational materials typically given to newly diagnosed women, and read accounts of women’s experiences (e.g. newspapers, magazines, promotional materials). My goal was to understand participants’ holistic worldview by eliciting illness narratives, to understand the social context, and generate theory using a comparative method (Glaser and Strauss 1967).

After gathering data from a sample of 18 women from the organisation I observed, I recruited participants from five support groups, two treatment centres, two breast-cancer-related community events, public bulletin boards, and through snowball sampling. Participation was voluntary and unpaid. I conducted 60 intensive interviews in total with women in New York and Pennsylvania, aged 31–79 years (mean = 53.6), who were diagnosed with...
breast cancer. The years of survivorship ranged from one year (22 per cent) to 10 or more years (13 per cent), with the greatest percentage of women in the two- to four-year range (42 per cent). This suggests that the experience of breast cancer remains vivid for many women years after diagnosis and treatment. The majority of participants were white, married, and highly educated. Sample characteristics are illustrated in Table 1.

Sample composition suggests that the data predominantly reflect white, heterosexual, middle-class norms. Research has found group differences in the knowledge women have about breast cancer and therapies based on educational level and racial/ethnic background (Donovan and Tucker 2000, Lee et al. 2000). Since the development of a TSI is based on one’s knowledge of biomedical information, educational level would probably impact the extent to which women seek out and understand it. Half of the women in the study used information to become ‘lay experts’, but only 27 per cent of these women developed a TSI. While this is not a large percentage, it is a noteworthy pattern. Those who developed TSIs had two additional years of education on average (17.5 years, and 15.5 years respectively). The role of race/ethnicity is less clear. Eighty-nine per cent of women with TSIs were white, compared to 82 per cent of the lay experts. Women who developed TSIs were also younger (age 50, compared to age 56), possibly reflecting the increased use of technology-based information among younger people.

**Interview schedule and data analysis**
In-depth interviews ranged from one to four hours and were held in a location of the participant’s choice, usually homes or offices. The interview schedule had a loose chronological order, open-ended questions, and clustered themes (Reinharz 1992). The participant played a key role in determining what was most relevant and the order of the questioning. The line of questioning involved the diagnosis story and the impact of breast cancer on daily life, relationships, and perspectives. I inquired about reactions from family, friends, co-workers, medical professionals and others to gain insight into experiences of support or stigma.

**Table 1 Sample Characteristics**

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Years of survivorship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>76.7% (n = 46)</td>
</tr>
<tr>
<td></td>
<td>1 year</td>
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<tr>
<td>Divorced</td>
<td>11.7% (n = 7)</td>
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<td></td>
<td>2–4 years</td>
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<tr>
<td>Widowed</td>
<td>5.0% (n = 3)</td>
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<tr>
<td></td>
<td>5 years</td>
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<tr>
<td>Never Married</td>
<td>6.7% (n = 4)</td>
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<tr>
<td></td>
<td>6–9 years</td>
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<tr>
<td></td>
<td>10 or more years</td>
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<tr>
<td></td>
<td>21.7% (n = 13)</td>
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<tr>
<td></td>
<td>41.7% (n = 25)</td>
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<tr>
<td></td>
<td>3.3% (n = 2)</td>
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<tr>
<td></td>
<td>20.0% (n = 12)</td>
</tr>
<tr>
<td></td>
<td>13.3% (n = 8)</td>
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</table>

<table>
<thead>
<tr>
<th>Race/ethnicity</th>
<th># Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>90.0% (n = 54)</td>
</tr>
<tr>
<td></td>
<td>3 or more Children</td>
</tr>
<tr>
<td>African American</td>
<td>5.0% (n = 3)</td>
</tr>
<tr>
<td></td>
<td>1–2 Children</td>
</tr>
<tr>
<td>Other</td>
<td>5.0% (n = 3)</td>
</tr>
<tr>
<td></td>
<td>0 Children</td>
</tr>
<tr>
<td></td>
<td>15.0% (n = 9)</td>
</tr>
<tr>
<td></td>
<td>56.7% (n = 34)</td>
</tr>
<tr>
<td></td>
<td>35.0% (n = 17)</td>
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</table>

<table>
<thead>
<tr>
<th>Educational attainment</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school degree</td>
<td>Service</td>
</tr>
<tr>
<td>16.6% (n = 10)</td>
<td>11.7% (n = 7)</td>
</tr>
<tr>
<td>Some college</td>
<td>Administrative</td>
</tr>
<tr>
<td>15.0% (n = 9)</td>
<td>35.0% (n = 21)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>Education</td>
</tr>
<tr>
<td>31.7% (n = 19)</td>
<td>35.0% (n = 17)</td>
</tr>
<tr>
<td>Beyond Bachelor’s</td>
<td>Professional</td>
</tr>
<tr>
<td>36.7% (n = 22)</td>
<td>25.0% (n = 15)</td>
</tr>
</tbody>
</table>

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When I asked what kept them going during the most difficult times, I learned of strategies to deal with role strain and feelings of personal responsibility. Dealing with breast cancer can change people in profound ways, and these women wanted to share their experiences. I simultaneously collected data and developed analyses, including coding data, formulating concepts, and constructing theoretical models. As conceptual categories and properties emerged, I developed a model of the processes that influence experiences and coping. The concept of TSI largely emerged from the diagnosis story and as women explained their attempts to understand and gain control. Developing a TSI was one way women asserted control and incorporated breast cancer into their lives. By defining the properties of the TSI as a core category and understanding its relationship to other categories (such as doctor-patient relationships, decision making, lay versus professional information, coping, and support systems), I developed an understanding about how some diagnosed women dealt with biomedical uncertainty and developed illness identities that were technoscientific in nature.

The development of a technoscientific identity

Participants incorporated technoscientific identities into their sense of self to different degrees, some not at all. Being diagnosed with breast cancer was not enough to develop a TSI. The development involved four major processes. First, women sought knowledge and immersed themselves in biomedical information. Secondly, they used this information to locate themselves within a technoscientific framework. Thirdly, they had institutional support from within and beyond the medical system, which included reinforcement from medical authorities and/or rationalised biomedical discourse. Finally, they considered their biomedical classifications, rather than their suffering, to be determinant factors in knowledge synthesis and decision making. As women developed ways to manage their illness, the technoscientific classification sometimes became the frame of reference for some to develop an illness identity. Assimilating expert knowledge into lay understandings of the illness led these women to incorporate technoscientific classifications into their sense of self as a form of embodied self-awareness.

The process of developing a TSI begins with the search for knowledge, and all women were primed to develop TSIs as they became informed about breast cancer. Through a variety of channels, including books, medical journals, Internet sites, questions to medical staff, support groups, personal contacts, and educational meetings, women tried to discern who they were in relation to their medical classifications. Am I estrogen positive? Am I in remission? Am I at increased risk for a soon-to-be-discovered BRCA2 genetic mutation? Situating themselves within a technoscientific framework was an effort to understand diagnosis and risk, make decisions about treatment, and exert agency in doctor-patient interactions. During this process some women immersed themselves in information to such a degree that they developed a level of expertise that became a regular part of their lives, and sometimes their sense of self.

Information immersion and self location in the biomedical framework

Samantha is a secretary who explained that she ‘didn’t know anything about anything’ when she was diagnosed at age 45. Following a routine mammogram, the doctor asked Samantha to schedule a biopsy and an appointment to review the results:

I went into his office and in one full breath, without even any explanation, he just kept pointing to the report. He said, ‘This report reads that you have LCIS and DCIS.}
which are lobular carcinomas in situ, and I am very concerned. I have taken this report to a board...of 15 members...we have agreed that what you need to do is have a bilateral mastectomy.' I just sat there completely aghast, not understanding what he said to me. I understood bilateral mastectomy... It didn't make sense why I needed to have one, but I knew that term...so I asked for additional explanation. He said, 'I just told you what you have...with what you have, this is what you need to do. I want you to schedule an appointment to see an oncologist...I want that appointment to be done in two weeks. Within a three week time period I want you to schedule to have a mastectomy.' I just sat there...dumbfounded. I left his office, went to the ladies room, broke into tears, pulled myself together, came back out, made the appointment via his nurse.

Although Samantha had a bachelor’s degree, she had no background in medicine or medical terminology. She did not know what the lab report meant, or that an oncologist was a cancer specialist. No one accompanied her to the doctor’s office that day, and she had no idea she was about to be diagnosed with breast cancer.

Poor doctor-patient communication can encourage people to seek medical expertise on their own. Likewise, Samantha urgently began the process of becoming a lay-expert:

I immediately called a Cancer Resource Center...they gave me...Dr. Susan Love’s Breast Book. I read through the entire book, went back...the next day and said, ‘There’s one chapter...that talks about what I’ve been diagnosed with. I can’t make a decision on one chapter. What else do you have?’ They said, ‘Nothing.’ I said, ‘I need more research. I need other books. I need research papers. I need to know what I’m going to be dealing with. I can’t make a decision without it....’

Medical knowledge felt compulsory for Samantha, and she immersed herself in medical terminology, research reports, and scientific journals. Through her research she developed a working knowledge about breast cancer and biomedicine that empowered her decision making:

I read 56 articles out of radiology, oncology, and surgery magazines, specifically ones that would target breast cancer surgery. You can learn a totally new language if you are forced to...over the period of three months I did the research. As I went through the research, I realised DCIS was stage zero...so I had the time to...completely understand what it was I was dealing with and make a good, logical decision about what was right for me...I am constantly online now...to stay up with the research...[emphasis added]

In the process of gathering and assessing information, Samantha situated herself and her diagnosis within a body of expert knowledge. Her goal to comprehend the science of breast cancer enabled her to think of herself as proactive, informed, and empowered.

During our interview, Samantha looked back at the journal she kept during this time. She said, ‘it amazes me that I was able to do what I did, knowing absolutely nothing about breast cancer...to truly understand it as well as I did and to stand up for myself against the doctors.’ Samantha thinks of herself as ‘DCIS Stage Zero’, monitors her status through techno-scientific means (semi-annual mammograms and blood tests), and interprets her embodied experiences through specialised language that requires ongoing self-education. She calls herself an advocate who teaches others how to do what she did. She carries two summaries on DCIS/LCIS:
I have two versions...the simple version and the version that has some more technical terms in it. I did that...to be able to give to people a...brief overview...so...they would understand what...I was talking about. I carry that with me all the time.

The social status attributed to medical science transfers to those who understand and know how to use it. Samantha believes that using the language of medical science in medical encounters increases the likelihood that people will feel empowered, ask questions, and make their interests count. Samantha’s effort to remind herself of her LCIS/DCIS status is evident in her desire to discuss the technical details in brief with almost anyone she encounters. Samantha’s biomedical classification has become part of her illness identity.

When individuals immerse themselves fully in technoscientific information that is supported by doctors, biomedical discourse, or elsewhere in the medical system, they develop the potential for developing a TSI. Most participants discussed the pressure to use information to become active in managing their illness. But for some, information immersion and self-location in the biomedical framework was overwhelming. These women never reached the point of integrating biomedical classifications into their sense of self. Clarissa was diagnosed six years prior to our interview, at age 46. At that time, ‘there was no place to go for information about the science and the research...None of the support groups in the area had that, and the doctors tell you what they want you to know and never seem to offer much more.’ Unlike those who do extensive research to learn the language of technoscience, Clarissa ‘didn’t even know where to look’. When asked how she made treatment decisions, she said:

I just did what the surgeon recommended...I just couldn’t seem to do the research on my own...I got completely overwhelmed and confused...I didn’t know what to believe and what not to believe, what applied to my diagnosis, or what else I could do besides medical treatment to improve my health and chances of recovery...I was at the mercy of the system.

Clarissa’s statement illustrates feelings of disempowerment and a belief that understanding biomedical information is necessary for empowered decision making. Following medical recommendations without doing research is a substandard choice.

Two years after Clarissa’s diagnosis, ecologist Sandra Steingraber gave a lecture about her book, *Living Downstream*, which traces connections between cancer and the environment. Steingraber had been diagnosed with cancer in her twenties, so she had a unique perspective that combined extensive scientific training with research and personal experience. Clarissa said, ‘I was transformed...’ After the lecture, two dozen women lingered for several hours. Clarissa met women with ‘lots of information and understanding.’ One woman was a biology professor at a local college.

We were...amazed by how much research she had done on her own...She understood...medical reports, clinical trials, all this stuff. One woman suggested that we...meet with the professor periodically...There were about 15 women who wanted to come.

The professor agreed, and we ended up forming a group and meeting monthly at the college where [the professor] taught. [emphasis added]

Clarissa was not confident in her ability to synthesise scientific information, so she valued the professor’s ability to do this ‘on her own’, revealing the importance of independent learning.
With the right guidance, Clarissa could access biomedical information. The professor helped her assess information and understand what applied to her. Three years later, Clarissa took a course through the National Breast Cancer Coalition (NBCC) called Project LEAD.

I attended four days of highly structured learning on the science of breast cancer…Most of the participants were breast cancer survivors and some ran agencies concerned with breast cancer issues. They were highly motivated and we learned much from each other in our small task groups. It was exhausting, yet fascinating to learn how each group utilised their different strengths and skills.

Over time Clarissa developed a greater understanding of biomedical information. The more she learned, the more at ease she felt about her decisions. In turn, she began to share what she learned. Clarissa’s example shows that TSIs are an identification for those who have the privilege to access biomedical information, the ability to educate themselves, and the intention to immerse themselves on an individual level. Whereas the professor researched information in isolation and then shared it with others, Clarissa learned in relation to others so her knowledge remained external to her sense of self. She did not use her biomedical classification as a framework for developing an illness identity.

Correspondence with the Medical Authority
Information immersion, biomedical classification, information and support from the scientific and medical community are necessary for the development of a TSI. Patricia, previously a registered nurse, places herself at the biomedical level and interprets her embodied experiences in biomedical terms. Diagnosed at age 51, Patricia had worked with terminal cancer patients prior to moving to the US from Europe. She understood medical terminology, cancer progression, treatment protocols, and outcomes. With this background Patricia easily applied biomedical information to her illness experience:

With my knowledge…if I have a headache for a few days, I think, ‘Oh God, have I got a brain secondary?’ My friend who has no knowledge would say, ‘Oh, I had an awful headache the other day…’ Nothing…that used to be a headache is [just a headache].

Patricia gives herself three days to get over any perceived bodily malfunction before going to a doctor for laboratory confirmation. She monitors herself regularly and sometimes sees a doctor on a monthly basis. She has completely immersed herself in biomedical information and does not easily think of herself in other terms.

During her ten year association with breast cancer, Patricia’s knowledge sometimes interfered with the doctor-patient relationship. She recounts a conversation with her oncologist:

I said, ‘It could be widespread. We don’t know…I haven’t had my bone scan, so I haven’t had my tumor markers down.’ He said, ‘You have far too much knowledge.’ I said ‘But, I can’t not have the knowledge. You can’t suddenly pretend you don’t know what you know.’ He said [that] I was adopting an entirely negative attitude…It was really that they [wanted to] take over, and it would…be better if I would just shut up.

If a patient’s use of technoscientific information does not correspond with prevailing biomedical discourse, it can threaten medical authority and undermine the TSI. Despite negative interactions with this doctor, Patricia’s TSI was firmly incorporated and she was
willing to suppress her feelings and prioritise expert knowledge. She just found a different expert, an oncologist who was more sympathetic to her situation. This oncologist agreed to tumor markers and a bone scan, but the results did not warrant less aggressive treatment. Patricia believed in the technoscientific enterprise and was willing to adopt a treatment protocol that intuitively she did not want.

Patricia’s knowledge enabled her to voice her opinion and seek reinforcement for her TSI even when some doctors objected. Patricia was critical of Tamoxifen, a drug which has been a standard therapy for some kinds of breast cancer to reduce recurrence. The side effects include hot flashes, vaginal dryness and bleeding, blood clots, and endometrial cancer (Love 2005). Until recently, these and other side effects were not well documented. Patricia said, ‘I think it’s criminal that they’re giving people this stuff without real knowledge of what it does…they…do not talk about side effects.’ According to Patricia, a doctor at a breast cancer conference in 2000 told the audience that there were no side effects to Tamoxifen. Following his presentation, Patricia approached the doctor and said, ‘Well, I didn’t want to disagree [with you] in front of all of these people, but I’m on this drug and there are huge side effects’. He replied that it was ‘so rare, it’s not worth mentioning’. For Patricia, it was not only worth mentioning, it should have been studied, documented, and openly discussed with patients. Following this interaction, Patricia joined a community-based organisation committed to evidence-based medicine. There, she found a receptive audience for questioning Tamoxifen, and reinforcement for her TSI.

Classification versus suffering
When one develops a TSI, the classification (rather than the suffering) urges people to maintain the beliefs and practices to sustain it. In pursuit of a cause, several participants considered genetic testing. While only 2.5–5 per cent of all breast cancer cases involve an inherited BRCA₁ or BRCA₂ gene that has mutated, women from Ashkenazi Jewish families are more likely than other women to carry them. Studies of Ashkenazi Jewish women with breast cancer have shown that women with a mutation have a 55–85 per cent risk of developing breast cancer during their lifetime (King et al. 2003). The difference in these estimates is substantial, contributing to uncertainty about what to do if one has such a mutation. Risk anxiety may influence decisions to undergo genetic testing or surgeries thought to reduce risk (Hallowell et al. 2004). A participant of Jewish descent was convinced that genetic mutation was the cause of her breast cancer and decided to have DNA testing. Joyce, a college professor, was diagnosed at age 57.

We [the oncologist and I] just got the results of the genetic testing which is negative, but that doesn’t tell the whole story because we have not identified all possible mutations...If you look at family, my mother had two sisters who died of cancer, one of breast and one of ovarian. I have four first cousins with breast cancer. And we’re Ashkenazi Jews. Apparently the incidence is 30 per cent greater among Ashkenazi Jews...By the way, I don’t know if you’ve heard this, but...I’ve heard that BRCA₃ is just about to be announced.

As a person with a TSI Joyce assesses, regulates, and controls her body with the desire to transform it with medical knowledge. Even though the results from genetic testing revealed that she did not have a mutation on either breast cancer gene, she is convinced that there are mutated genes scientists are searching for and will eventually find. Her belief corresponds with prevailing medical discourse and cultural messages about the inevitable progress of medical science.
By sharing this new and privileged information with me about BRCA\textsubscript{3}, Joyce engages her TSI as a person at risk. Joyce had completed treatment and had no signs of disease at the time of our interview. Yet, she believed that her genetic material increased her risk of recurrence, and that she passed an increased breast cancer risk to her daughter. Joyce continues to discuss the possibility of a BRCA\textsubscript{3} discovery and its implications:

I will then have to decide if I want to be retested for BRCA\textsubscript{3}. This is very expensive stuff, of course, and I would not have done it if I didn’t have a daughter, because it doesn’t do anything for me…What it would do for my daughter is the following…

Before Joyce tells me what the discovery of BRCA\textsubscript{3} would do for her daughter, she digresses:

What we’ve already done is put her on birth control pills [to] try to reduce the number of ovulations. I was still — at the age of 56 when I started chemo — menstruating regularly and had already been having hot flashes for twelve years…The estrogen was…pouring through the system…I’m now on the estrogen suppressant …Femara …they just stopped a study at the two-year mark, [where] the women were getting Femara after Tamoxifen. I’ve been on [it] for 14 months. They don’t know what it does without having had the Tamoxifen beforehand. Am I not a walking encyclopedia here?

The amount of detailed and specialised information Joyce conveys in the midst of answering a question about genetic testing for her daughter, reveals that she is trying to obtain enhanced knowledge about her risk status. In taking responsibility for her diagnosis and her daughter’s, should it develop, she gains a semblance of control (See Finkler 2000), and she actively (re)constructs her TSI. Joyce is conscientious and reflexive about having become a ‘walking encyclopedia,’ a category she later attributes to ‘mov[ing] through the [medical] system and get[ting] more and more treatment.’ Joyce deeply identifies with a potential genetic mutation. This identification further intensifies her development of lay and professional expertise, which grounds her solidly within the medical system at a biomedical level.

Unlike Joyce, Angela represents a partial adoption of a TSI. She seeks expert information, locates herself within the technoscientific framework, and uses expert information to make decisions and influence doctor-patient interactions. Angela never fully considers her biomedical classification to be the most important aspect of her illness experience. Angela’s diagnosis of inflammatory breast cancer occurred across a two-year period, following a ‘watch and wait’ protocol. She had mammograms every six months. Between visits she noticed a thickening in her breast, followed by swelling and redness. She had another mammogram and ultrasound, followed by a biopsy. Before the results were in, Angel searched the Internet:

Symptoms were a lot like mastitis…I also was reading about something called inflammatory breast cancer, which sounded an awful lot like it. In the end…there really was never able to be a definitive diagnosis…I guess it…isn’t always decisively diagnosed…it didn’t seem to matter…the treatment would be the same.

Despite the uncertainty of her diagnosis, Angela researched how to get a consultation from a comprehensive breast cancer centre. Before she received the biopsy results, she had an appointment with a specialist for a second opinion. Angela believed that becoming more knowledgeable would help her survive:

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Angela: When we went to [the comprehensive breast cancer center] the doctor suggested a chemo regimen that was not standard. It wasn’t experimental, but wouldn’t be [what] the basic...oncologist might pull off the shelf. This doctor had reason to think it might be a good approach. We taped the session...(my husband and I), listened to all the reasons, and it sounded pretty good to us. When we came back [home], we needed to find an oncologist who would do what we wanted to do. With the information I had, I was sort of coming to them with things, saying ‘here is what I want to do.’

I: Were they open to that?
Angela: The oncologist was a little taken aback...I don’t think it is every day that patients come in with these sorts of cutting-edge recommendations. She talked with doctors [at the center] and found out more about it. When she found out it was being done on a protocol, that it wasn’t just something off the top of my head, she was more open...In these oncology practices, I think they have a cookbook approach: ‘this is how we usually do this standard of care’. When trying to get somebody to deviate from that, sometimes it can take a little persuasion. She went along with it.

Angela was confident in her knowledge from research and consultation with specialists. By thinking of her suggestions as ‘cutting edge,’ she felt secure in evaluating treatment options and pressing for the protocols she wanted. Angela used the voice of medicine to convince her local oncologist that her decisions were sound, and she was not concerned that the oncologist cross-checked her information.

Angela is immersed in breast cancer, identifies with it, and orients much of her energy towards it. When asked about the role of breast cancer in her life, Angela is adamant that ‘it is not something that is behind me. It is everyday, all day, every day...It is...totally in the fabric of my life.’ Angela is referring to the fact that her daily activities and frame of reference revolve around her diagnosis and treatment (Charmaz 1991). Her work in health policy has also started to focus on breast cancer issues. Angela calls herself ‘terminal’ and participates in regular medical surveillance and intervention to manage symptoms and side effects, and to slow progression. Because of a terminal prognosis and an unmistakable level of biomedical uncertainty, Angela is not able to look towards scientific progress for an eventual cure. The fallibility of medical science is palpable enough that she cannot privilege biomedicine over the social aspects of her illness. Thus, she does not fully develop a TSI. Instead, social aspects comprise the bulk of Angela’s illness identity, not her biomedical classification. Her illness identity focuses on transcendence, helping other diagnosed women, and dying well. Although she has not disclosed this to anyone but her interviewer, Angela has planned her funeral and written her eulogy. Suffering and a deep appreciation of her mortality enable Angela to look beyond the biomedical aspects of her illness.

Discussion and conclusions

Whenever people interact with the medical system, there is potential for transforming or developing an illness identity. Individuals submit to the medical system’s practices and protocols, including professional evaluation, clinical intervention, and behaviour modification. Such processes impact on people’s lives beyond the medical encounter as they take medication, participate in rehabilitation activities, modify health risk behaviours, and adhere to a
variety of ‘doctor’s orders’. Although expert medical knowledge and surveillance technologies have been integral to this system, extensive reliance on biomedical technoscience has heightened their role. Breast cancer is currently understood through technoscientific knowledge, high technology, and biomedical health and risk surveillance. Despite technological advances, there is substantial uncertainty related to etiology, risk, diagnosis, and disease progression. Increasingly, doctor’s orders hinge upon the proficient interpretation of biomedical markers and histological representations patients may not understand. The diagnosed must work within this paradigm to understand biomedical information, make medical decisions, manage medical interactions, and make sense of their illness experiences.

The use of expert and lay knowledge to gain control over one’s illness experience is not uncommon for those dealing with chronic illness. Incorporating professional biomedical discourse into lay knowledge to understand their conditions in the same way their doctors do, can help people gain a sense of control when dealing with biomedical and personal uncertainty. A culture of medical consumerism further pressures people to seek information, learn about their conditions, and make empowered decisions. Most participants in this study wanted to be proactive, knowledgeable, and assert some control over their decision-making processes. They used expert knowledge to varying degrees to ask questions, sort out treatment options, and influence their doctors. Under certain conditions, some developed technoscientific illness identities as they began to think of themselves in terms of their biomedical classifications. When technoscience becomes part of an illness identity it grounds (bio)medicalisation firmly in the everyday lives of people beyond their illnesses.

The development of TSIs involves four central processes: (1) individuals seek and become immersed in professional biomedical knowledge; (2) they use this professional discourse to locate themselves within a technoscientific framework; (3) individuals receive support for the emerging TSI from professional discourse and/or positive reinforcement from doctors, medical staff, or other validated support systems; and (4) they prioritise their biomedical classifications over their suffering, thereby creating a somatic self. Those who fully incorporate technoscientific classifications align their lay knowledge and embodied experience with professional knowledge. When participants did not have a deep understanding of biomedical technoscience information, held beliefs that conflicted with prevailing medical discourse, or experienced suffering that prohibited them from suppressing their embodied experiences, they were less likely to use biomedical technoscience as the frame for their illness identity.

An illness identity centred on biomedical, technoscientific information encourages people to assume ownership for understanding information, assessing their risk, and making medical decisions. Some are empowered to seek greater scientific knowledge, make medical decisions, and produce new knowledge. NBCC’s Project LEAD teaches lay persons to understand biomedical technoscience in ways that enable them to understand breast cancer and influence research agendas. The environmental breast cancer movement has used scientific research and biomedical knowledge of cancer-causing agents to understand the relationship between bodies and the environments in which we eat, drink, live, and reproduce. Collective mobilisation has resulted in new environmental policies and changes in how common products such as cosmetics and children’s toys are produced. Such actions suggest that a deep understanding of biomedical knowledge and technoscience can work toward the betterment of populations even if members of these collectivities develop TSIs or express individual anxiety about their health risks.

Those who believe in technoscience on multiple levels may have a greater sense of control when using the language of biomedicine. This illuminates the co-operative potential of doctor-patient interactions. After patients pressured their doctors to document the side
effects of Tamoxifen, clinical researchers started to examine whether other drugs with fewer side effects would be comparable (Baum et al. 2003). A person with a TSI may use technoscientific discourse to challenge medical authority and draw medical attention toward mitigating biomedical factors. However, personal responsibility on the part of the patient has the potential to prevent the medical system and its apparatuses from adequately addressing the role of biomedical uncertainty in shaping medical practices and understandings of health and illness. This study reveals that it may be difficult to challenge those who are part of the academic elite responsible for producing prevailing biomedical discourse. Users and borrowers of the discourse may be more open to challenge.

Without mitigating considerations TSIs can function as a means of surveillance and social control. First, if professional knowledge is synthesised into lay understandings of illness, reliance on medical science and high technology contributes to the professional colonisation of lay knowledge, shaping its discursive boundaries. Medical practitioners and patients alike 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. Secondly, processes of biomedicalisation involve corporatised and privatised biomedical technoservices that serve the interests of genetics laboratories, pharmaceutical companies, scientists, researchers, and corporations more than they do individuals (Rothman 2006). Susceptibility and potential pathology encourage TSIs even when people are asymptomatic or post-symptomatic, and reliance on biomedical frameworks and technologies reinforce them. Thirdly, TSIs promote behaviours that fortify the position of the technoscientific medical advances (e.g. genetic testing and screening technologies) that system agents promote. They draw attention away from social and cultural factors that contribute to health and illness, prioritising biomedicine over other healing practices and ideologies.

There is growing evidence that people want to play a more active role in medical decision making, and that they experience better health outcomes when they do. Half of the women in this study preferred a passive role. The other half wanted to use information to make decisions co-operatively with their doctors. Of these, younger women and those with higher education were more likely to immerse themselves in technoscientific information to such a degree that they developed TSIs. This may suggest a shift in the role of technoscientific information in medical decision making that is related to age and education level. Comparative studies of gender, race, and ethnicity are needed to learn how different groups access, assess, and use technoscientific information, and the impact technoscientific understandings have on their illness identities. In addition, the development of TSIs may vary among illnesses that have a lesser emphasis on genetic risk and recurrence. Acknowledging the complexity and multidimensionality of illness identity formation will shed light on the promise and pitfalls of technoscience and biomedicalisation.

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