Pondering Prophylactic Mastectomy: 
Social Relations of Medical Technology in the Genomic Age

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Abstract:
Bilateral prophylactic mastectomy (BPM) is a preventive option for women at high risk of familial breast cancer, entailing the removal of both the left and right breast. Despite an absence of randomised controlled trials (level I and II evidence), it appears that BPM is being undertaken at dissimilar rates across countries; France is resisting the procedure, regarding it as a radical if not totally undesirable option, yet America provides such treatment on demand (Eisinger et al. 1999). A research project is proposed to investigate this treatment rationale in Australia. Via in-depth interviews with up to twelve women (18-40 years old) with a family history of breast cancer and up to six breast oncologists and surgeons, the decision-making landscape will be explored across both personal and professional domains. Focauldian and Beckian frameworks will inform subsequent thematic analysis. In tandem, the validity of lived experience versus that of evidence-based medicine will be explored.

Introducing prophylactic mastectomy

‘…from a public health point of view, the impact of any treatment depends not only on efficacy, but also on availability, affordability, and acceptability of the procedure’ (Eisinger et al. 2000: 202)

As genomic diagnosis becomes increasingly sophisticated and all encompassing, it is vital that the mechanisms by which it informs both individual and professional treatment choice are better understood. Breast cancer is the most common cancer amongst women (Iredale et al. 2002: 1) and the second leading cause of cancer-related mortality in women (Bouchard et al. 2004: 1085), thus there exists clear stimulus for global effort to understand its clinical manifestation and effective treatment. An upstream public health approach also demands successful prevention strategies.

Prophylactic mastectomy (PM) refers to the mass surgical removal of breast tissue, a primary prevention treatment option for women at high risk of breast cancer. Bilateral prophylactic mastectomy (BPM), popularly termed double prophylactic mastectomy, entails removal of both the left and right breast. Observational studies suggest that
BPM reduces both incidence of breast cancer and disease-specific mortality in women, including those individuals with mutations in the breast cancer susceptibility genes BRCA1 and BRCA2 (Lostumbo et al. 2004). Genetic mutations as such account for 5-10% cases of breast cancer (Fentiman 1998: 1402).

Despite an absence of randomised controlled trials and resulting lack of Level I or II evidence (National Health and Medical Research Council 1999), BPM is being undertaken at dissimilar rates; France resists the procedure, regarding it a radical if not undesirable option, yet America provides BPM on demand (Eisinger et al. 1999). These approaches have been articulated in the guidelines of respective expert panels (Rashid et al. 2006). Framed by this international context, Australia’s BPM treatment rationale awaits exploration.

**Unravelling the socio-cultural nuances**

A research project is hence proposed that will explore the social experiences confronted by women with a family history of breast cancer. Specifically, the researcher intends to depict the decision processes surrounding BPM. How are women making decisions about primary prevention options? How are practitioners supporting women to reach such decisions? These questions present a range of issues suitable to sociological exploration, which may collectively illustrate the prophylactic mastectomy trajectory. The intersection of medical and personal decision-making and the related validity of lived experience versus that of evidence-based medicine are points of key interest. The concept of a ‘medically appropriate’ (Rashid et al. 2006) action will be examined. Can the dynamics of the practitioner-patient relationship be explained in terms of synergy or antagonism? The value of lay knowledge and practitioner expertise will be interrogated, in tandem with the potential fluidity of levels of evidence when a health predicament does not lend itself to exploration via randomised controlled trials.

It is intended that consideration of these issues will permit the articulation of women’s decision-making needs, informing recommendations for service provision in Australia and ultimately contributing to improved public health outcomes. It is envisaged that these be extended beyond a lens of cancer mortality rates to a holistic approach, incorporating increased mental health and wellbeing.
Defining the problem

Geoffrey Rose (1981) described the routine measurement of a man’s blood pressure. Hypothetically, if the reading indicated raised blood pressure, the man was transformed from healthy to non-healthy – a conversion to patient, hinged upon the medical encounter and reinforced by the provision of medication. Although Rose (1981: 1848) emphasised that such a scenario illustrates ‘preventive medicine, not therapeutics’, this process of scripting echoes Parson’s (1951) notion of the sick role and an individual’s consequent induction into a patient career path (McKinlay 1971).

How does a woman first realise that she is potentially ‘at risk’ of familial breast cancer? Knowledge of a positive family history may trigger investigation of genetic testing – already a healthy individual is dancing with uncertainty and a possible departure from health (Robertson 2000). If the test is positive for BRCA1 or BRCA2 mutation, she is not unhealthy – she is somewhere between normalcy and other (Gifford 1986; Lemke 2004). Should cancer manifest, she may be considered unhealthy. Currently she is at a defining decision point – whether to modify her lifestyle, pursue preventive surgery, undertake high surveillance, adopt watchful waiting or enter a state of denial. Arguably, each choice may result in a different variation of patient status. Consider for instance, the anti-patient, a role assumed by concerted avoidance of the sick role, with effort made to instead secure an ever-well health status; the surgical patient, health care consumer by virtue of amputation services sought; the self-defined patient, a role allocated by the discovery of a lump during examination; the bodily healthy yet highly anxious individual, erring on a psychological patient role; and the non-patient, escaping definition until a challenging health event returns her to the practitioner-patient interface. The dynamic nature of the individual’s wellbeing experience is fundamental to the current research project; health and illness will be explored as fluid processes, rather than discrete events.

Sourcing the medical evidence

Lostumbo et al (2004) conducted a systematic review to establish whether prophylactic mastectomy reduces all cause mortality, both in women who have never had breast cancer, and those with a history of cancer in one breast. The review also intended to reveal the impact of prophylactic mastectomy on breast cancer mortality,
breast cancer incidence, disease-free survival, physical morbidity and psychosocial outcomes.

Although randomised control trials provide the highest level of evidence, the reviewers acknowledged it was unlikely that any such trials had been undertaken. Thus the search criteria were expanded to include studies of any design type, including cohort studies, case control studies and case series that had at least ten participants. All types of prophylactic mastectomy were included in the review (e.g., total or simple mastectomy, subcutaneous mastectomy and radical mastectomy). Studies across countries and time periods were included, providing they were reported in English.

The search strategy adopted explored the following databases: The Cochrane Central Registry of Controlled Trials, MEDLINE, CancerLit and EMBASE. Neither grey literature nor unpublished works were sought for inclusion in the review. Similarly, no personal contact was established with experts. By the reviewers’ own admission, some studies concerning psychosocial measures may have been neglected, as PsychINFO was not included in the search. Unfortunately quantitative analyses were not viable, due to the heterogeneity of study designs, thus the data of each study was instead described qualitatively.

In summary, the systematic review (Lostumbo et al. 2004) found that the majority of studies reported satisfaction with the decision to pursue PM. Worry was reduced following PM, compared with baseline groups and those women nominating surveillance rather than surgery. The reviewers advise however that women need to understand the true risks in the first instance. Superficially, these findings indicate that survival was enhanced while anxiety was simultaneously lessened - a dual effect of increased life expectancy and increased quality life. Yet, the seesaw is tipped again by a post-PM decline in cosmetic satisfaction and body image.

Exploring the sociological literature

As genetic testing is a method of bodily surveillance, a Foucauldian framework may initially prove a tempting approach for the current study, enabling the exploration of the practitioner’s transformative gaze and the resulting medicalisation of a woman’s breasts. Foucault (2003: xvi) defines the intersection of patient and practitioner as a point of information asymmetry - the patient endures the immediate experience of the
illness and associated symptoms, whereas the practitioner must rely upon interpretation and diagnosis, via both direct observation and indirect questioning.

Foucault (2003) contests that in the clinical scenario the patient is an accident of the disease, pounced upon as a passive host so that the disease may flourish. The patient is then charged with the role of transporting the disease into the spotlight for enhanced inspection, in a moderated environment.

Such observation and investigation have ramifications for the status of the patient. In the tumult of daily life, the suffering individual is but a pitiful tragedy – the victim of illness. This scenario does not allow for the element of possibility inherent in risk. The purely ‘at risk’ woman experiences no symptoms and although she depends upon a practitioner’s expertise for the provision of genetic information and related guidance, she is at liberty to pursue preventive treatment options. Foucault’s description lacks the sense of agency (e.g., Butler 2004: 186) inherent in a risk-informed woman’s decision to pursue prophylactic surgery. Foucault declares that the patient behaves so as to fulfil prescribed societal expectations (e.g., Petersen and Lupton 1996; Rose 1989). Parson’s sick role is associated with a similar insistence that the individual wishes to be well again and will thus undertake actions to restore health (Shilling 2003). Can the individual’s attempt to reshape medical destiny by prophylactic surgery be reframed? Is there an alternative representation that captures intent, rather than assumed self-governance or obligation?

As citizens of Ulrich Beck’s (2000) risk society, we are subjected to a tension (Turner 1997) between ‘responsible choice’ (Beck-Gernsheim 2000) and freewill. Do we own our health choices or are they merely products manufactured by our industrialised nations - the only pragmatic course of action given a supposedly threatening future? Conversely, must all risk represent potential catastrophe or can it be inverted and equate instead to an opportunity for self-care?

These questions are particularly weighty when applied to BPM as the procedure is more dramatic than that recommended for women with a recognised malignancy (Tucker 1999). It will be fascinating to explore the justification of such invasive treatment from both practitioner and patient perspectives - particularly in light of the observation that ‘physicians tend to have a vision couched mainly in terms of medical prognosis, while patients are likely to see the future course in existential, functional
and social concepts’ (Diederiks and Bal 1997: 170). Although this comment was made in reference to chronic illness, it may also apply to preventive measures. It may also prove intriguing to gauge the space allowed by breast surgeons and oncologists for layperson knowledge, and vice versa, given patient health and wellbeing is traditionally the domain of an omniscient physician (e.g., Waitzkin 1991). Clinicians may arguably have hoped that evidence-based medicine would transform individual treatment decisions into a process hard logic.

Robertson (2000) introduced the term ‘breast worry’ to describe the ever-present concern that breast cancer is looming on the health horizon; upon genetic diagnosis, previously healthy breasts may be transformed into ticking bombs. How do women process and manage risk that is existential, rather than environmental? This notion of corporeal or embodied risk (Kavanagh and Broom 1998) will be analysed, in tandem with consideration of the breast’s role (e.g., Davis 1995).

**Sharing the stories of scars and beyond**

A convenience sample of up to twelve younger women (aged 18-40) who are at high risk of familial breast cancer and have not been diagnosed with cancer will be recruited to the study, via advertisements circulated at familial cancer centres. This age group is of interest as although PM is reportedly particularly effective for women younger than 35 years, Eisinger et al (2000) found that the vast majority of both patients and practitioners regarded the treatment an unacceptable option for this age group. Paradoxically, younger women exhibit denser breast tissue, thus the high surveillance alternatives of mammography and self-examination are less reliable (e.g., Lucassen et al. 2001).

The researcher will meet with individual women for one-on-one in-depth interviews, 60-90 minutes in length, at a location nominated by each participant. Personal opinions, experiences and decisions in regard to familial breast cancer and its prevention will be discussed. In particular, women will be asked how they informed their decisions (e.g., specialists, general practitioners, popular media, internet, support groups or confidantes) and who represented stakeholders in the decision outcome. As the French approach dictates that a multidisciplinary team supports each individual (Eisinger et al. 1998), the researcher is particularly interested to learn of the Australian dynamic – does this multidisciplinary, circular team exist or is there
instead a linear model? Does the entry point to the clinical network impact upon the individual’s final decision? Up to six of breast oncologists and surgeons will be invited to participate in one-on-one in-depth interviews, approximately 60 minutes in length, designed to detail the decision-making landscape of the professional domain. In particular, the researcher is intrigued by how practitioners may perceive and manage their own emotional and legal risks (Gifford 1986: 224).

The qualitative research format will permit a flexible approach, allowing participants to simultaneously shape the flow of discussion and unpack the concepts within, beyond parameters possibly imposed by a quantitative model. In this manner equal consideration will be given to both the decisions made and the underlying personal reasoning. It is thought that a quantitative approach may instead frame the former as ‘hard’ data and the latter as ‘soft’ or ‘secondary’ – an undesirable effect in this instance. The interviews will be recorded and subsequently transcribed. Data will be analysed via thematic analysis.

Speculating the plausible

As the proposed project represents an exploratory piece of research, there is no explicit hypothesis per se. More broadly however, it is expected that those women who have elected PM may have witnessed the cancer experience of family members and wish to avoid such an encounter themselves (e.g., Erblich et al. 2000). In tandem, it is believed that these women will have nominated surgery in a pro-active mindset of risk management, attempting to restore order rather than live under the question mark of probability (Lemke 2004). Finally, it is also thought that women who have elected BPM will, upon reflection, feel that this was indeed the best decision (e.g., Edwards et al. 2004). Here, links may be made with cognitive dissonance theory.

Previous socio-cultural research comparing the breast cancer treatment decision-making experiences of African American, Hispanic and rural breast cancer survivors, reported greater variation within demographic groups than between (Wescott et al. 2005). With this in mind, it is thought that the commonality may be the very differences; strength may come through the diversity of individual styles of problem-definition, coping and decision-making, a feature perhaps consistent across cultures. Future research must interrogate the broader influences that shape the differing reactions to PM in France, America and potentially, Australia. Who or what is
dictating the PM agenda? That is, what is influencing the meaning and momentum of evidence across cultures?

**Guiding the public with the personal**

The proposed study, informed by Foucauldian and Beckian approaches, intends to provide a preliminary illustration of Australia’s bilateral prophylactic mastectomy treatment rationale.

Note: The research project detailed within has been provisionally approved by La Trobe University’s Faculty of Health Sciences Human Ethics Committee

**References**


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