Factors Influencing Patient Treatment Decisions in Breast Cancer

A Research Paper submitted to the Department of Engineering and Society

Presented to the Faculty of the School of Engineering and Applied Science
University of Virginia • Charlottesville, Virginia

In Partial Fulfillment of the Requirements for the Degree
Bachelor of Science, School of Engineering

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Spring, 2020

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Introduction to Breast Cancer Therapies and Co-Production:

Breast cancer is a deadly disease that affects 12% of American women in their lifetime, for which no cure is currently available (*U.S. Breast Cancer Statistics | Breastcancer.org*, n.d.). In the search for a cure, many treatments have been developed including chemotherapies, radiation, therapy, and immunotherapies. As new treatment options emerge, their ultimate success is based upon the number of patients who choose to undergo them. However, patients are often not familiar with the specifics of individual cancer therapies which they must choose. Thus, it is important to understand the social and technological factors that influence a patient's treatment choice in order to better educate patients about their options. The development of cancer therapies available to patients can best be described in the context of the co-production model. Co-production, as described by Sheila Jasanoff, is the process of the "natural and social orders being produced together" (Jasanoff, 2004). Cancer therapies shape the medical field by providing alternative treatment options that can serve patients in new ways but the needs of patients and the medical community also inspire research into particular medical technologies. This paper aims to explore the question: "What are the factors that impact a woman's decision on which treatment to receive for breast cancer?"

Research Question and Methods:

In order to answer the question of what factors impact a woman's decision in breast cancer treatment, online tools were used to collect information. Initially, peer reviewed scientific literature focusing on the relationship between doctors and patients was investigated. This search was done through search engines using key words such as "doctor patient relationship" and "breast cancer patient treatment decisions," as well as various combinations of those words.

These terms were searched to find data investigating how patients and doctors interacted as well as meta analyses of breast cancer patient treatments while excluding research on the efficacy of specific breast cancer treatments such as novel chemotherapeutics. Later searches used key words such as “mastectomy recovery” and “breast cancer social impacts” in order to find more articles on which technologies have become available as a result of certain breast cancer therapies and the needs of patients. The citations of each of the articles analyzed were examined to find potentially relevant studies. Search engines were used to search for breast cancer support blogs and while several blogs were read, they did not appear to be immediately necessary for the following discussion. The research analyzed focused primarily on former breast cancer patients or women at risk of developing breast cancer.

Breast Cancer Therapy Decisions:

Breast cancer is the most common cancer in women as approximately 1 in 8 women in the developed world are diagnosed in her lifetime (*U.S. Breast Cancer Statistics | Breastcancer.org*, n.d.). Breast cancer represents a significant disruption to everyday life due to the medical requirements. However, most people diagnosed with this disease must undergo extreme treatments and over 40,000 breast cancer patients die each year in the United States alone (*Cancer of the Breast (Female)—Cancer Stat Facts*, n.d.). Due to the heterogeneity of breast cancers, no two cases are exactly alike and the best treatment for one person may not work for another. Furthermore, there is simply no sufficient treatment. Thus, many treatment technologies for breast cancer have been developed including hormone therapy, chemotherapy, radiation, surgery, and immunotherapy. To further complicate treatment, each of the above categories has a plethora of specific therapies that may be used individually or in combination in order to treat a patient’s breast cancer. However, each of the above therapies has their own risks and benefits that must be considered on a case by case basis to determine the best possible treatment. Unfortunately, the vast majority cancer patients lack the extensive medical knowledge necessary to navigate these complexities without relying on outside assistance in their decision making (Waljee et al., 2007). Thus, it is important to understand what factors are influential in the decision-making process in order to ensure that it can be effectively navigated by patients who already have a life-threatening disease.

Not all patients appear to have equal access decision-making resources. For example, breast cancer mortality has steadily decreased in white women but this trend is not reflected in African American women who have not seen significant improvements in mortality (Lannin et al., 2002). Some of the primary factors that appear to drive this racial disparity appear to be a lack of physician referrals for early care for African American potential-breast cancer patients and cultural attitudes that discourage African American women from seeking early care. African American women are less likely to be recommended for genetic screening for breast cancer associated mutations and they are less likely to receive testing after reporting symptoms to doctors (McCarthy et al., 2016). This delay in treatment can prove deadly, especially when combined with biological factors. The 5-year survival rate for breast cancers that have metastasized beyond the site of the primary tumor is roughly 25% compared to an overall 5-year survival rate of 89% (*Survival Rates for Breast Cancer*, n.d.). In addition, African American women are more likely to develop triple negative breast cancer which is very metastatically aggressive, further exacerbating the risk of distal metastases. When these factors are taken together, it becomes apparent that the treatment decisions of a woman are a matter of life or death and that understanding what influences that decision is of vital importance.

Co-Production of Breast Cancer Therapies:

The connections between the treatment decisions of breast cancer patients and the technologies that relate to them can best be understood through the co-production model. Co-production is an STS framework most notably characterized by Sheila Jasanoff. According to Jasanoff, co-production is the process of the “natural and social orders being produced together” (Jasanoff, 2004). According to this theory, scientific ideas and their associated technologies gain significance through their connection to the institutions of society that adopt them (Jasanoff & Kim, 2015). Technologies do not exist in a vacuum; they are created by a society and thus represent the values of that society – or at least elements of the society. However, when a society adopts a technology, that technology affects the society itself.

Co-production is generally regarded positively within the STS community with few significant critiques of Jasanoff’s work. Co-production as a model has been successful enough to see significant integration into a number of STS-adjacent disciplines including policymaking, governance, business, and healthcare (Filipe et al., 2017). However, it is critical to note that the definition of “co-production” may vary slightly depending on the field that is employing it (Filipe et al., 2017). The core definition in each field remains relevant as it describes the production of two major systems together, but the specific systems may differ. In the analysis of systems that rely upon services rather than goods – such as healthcare – co-production describes the way that “consumers and providers of services always work together to create value” (Batalden et al., 2016). Healthcare has undergone a paradigm shift in recent decades from emphasizing professional expertise in doctors with little patient input to focusing on the relationship between doctors and patients to create the best possible outcomes for patients (Berwick, 2016). This new understanding of healthcare as the result of a relationship between doctors and patients has allowed it to be analyzed in terms of a co-produced service (Batalden et al., 2016).

The concept of co-production is widely applied in STS theory to describe the methods that technologies and society simultaneously mold each other. Co-production is useful for the analysis of the above-stated research question due to the interplay between patients and medical technologies. A patient's decision is shaped and limited by the available technologies, but the patient - and other stakeholders in the patient's medical decision – have the ability to enact change in those therapeutic technologies. Thus, co-production may be used to answer the research question in order to better provide patients with the information necessary to choose the best treatment option.

Factors Influencing Patient Treatment Decisions:

Research into the most significant factors on treatment decisions in breast cancer highlighted the significance of the patient's relationship with their doctor, the characteristics of their cancer, education about their disease and treatment options, and the patient's race. These elements are among the most influential but they are by no means the only factors that can influence a patient's decision. Furthermore, each of these elements possess a connection with race which drives a difference in both the treatment that African American women select and the clinical outcomes. A thorough examination of the co-production STS framework provides valuable insights that improve understanding of these factors and inform future technological developments in cancer therapy to optimize the desirability and efficacy of cancer treatments.

The most important factor in predicting what treatment women will choose to treat their cancer is often their doctor's recommendation. Patients want to trust their doctor's decision since they are perceived as an expert on the medical field. Most patients self-report that they are not primarily worried about their doctor's ability to communicate with them, but are rather concerned with their apparent technical expertise and whether a doctor-patient bond formed

(Wright et al., 2004). A study performed by Siminoff et al. found that when patients trusted their doctor, they frequently followed the recommended care regimen rather than opting for an alternative treatment (Siminoff et al., 1989). Importantly, however, only 45% of the patients studied followed clinical trials when recommended. This finding is relevant to establish that factors other than a doctor's recommendation alone weigh into patient treatment decisions as they are clearly influenced by concerns about the safety and efficacy of the chosen therapy. Siminoff suggests that one potential reason for this disconnect is that "recommendations to participate in clinical trials were not communicated as effectively as recommendations for standard and nonstandard therapy" (Siminoff et al., 1989). In order for clinical trials to be successful, they often need to enroll many patients to establish clinical safety data and demonstrate efficacy. Thus, the willingness of patients to enroll in clinical trials is a large determinator of how quickly trials can progress and the technologies gain FDA approval. As a result of this process, the effectiveness of doctors at explaining the costs and benefits of the clinical trials to patients and patients' trust in these technologies plays a prominent role in determining what cancer technologies are available to patients through co-production.

The characteristics of a patient's cancer is another key element in deciding on a treatment option. Different breast cancer variants may present in different ways or respond best to particular treatments. For example, triple negative breast cancer tends to be detected at a later clinical stage than other breast cancers which correlates closely to shorter patient survival times. Furthermore, triple negative breast cancer does not respond to hormone therapies used in other breast cancers that block the estrogen and progesterone receptors that other forms of breast cancer rely on for growth and proliferation signals. As a result, blocking those receptors in triple negative breast cancer patients does little to halt the progression of their disease. Doctors generally tend to base their therapy recommendations on the unique clinical appearance of a patient's breast cancer as a result. Since patients heavily rely on their doctor's recommendation as stated above, the clinical presentation of their cancer is a major driver of their treatment selection. These results are supported by Lee et al. when they found that a treatment decision between mastectomies and breast conserving surgery for patients was driven primarily by contraindications resulting in doctor recommendations rather than patient choice (Lee et al., 2009).

Patient education about cancer and their specific treatment options is also significant with respect to what their final treatment option is. Several genes are known to be associated with increased risk of breast cancer such as mutations in the BRCA1/2 genes (Scheuer, 2002). Patients who are aware of these genetic mutations sometimes choose to undergo radical mastectomies – removal of the breast tissue – in order to reduce their risk of developing breast cancer. It is not always possible to remove all breast tissue during these surgeries so patients sometimes develop breast cancer despite this surgery, but the risk is much lower (Scheuer, 2002). This form of preventative surgery became more common after genetic sequencing technologies developed, allowing patients to gain a more thorough understanding of their own predispositions to diseases such as breast cancer. However, many women are negatively affected socially and emotionally by their mastectomies as they feel that a part of themselves is now missing, resulting in loss of intimacy with spouses, social withdrawal, and decreases in their self-esteem (Koçan & Gürsoy, 2016). In order to overcome some of these issues, techniques such as plastic surgery or breast implants have been developed in a form of co-production where certain technologies drive patients to undertake particular actions while patient wants drive innovation in other areas of medicine (*An approach to the repair of partial mastectomy defects. - Abstract—*

Europe PMC, n.d.). In terms of patient selection of their therapy, the more educated patients are about certain techniques, the more likely they are to choose that treatment option. A study conducted from 2014-2015 in Saudi Arabia found that women who were at high risk for breast cancer and had heard of breast reconstruction as a post-treatment option were more likely to opt for that than women who were not familiar with breast reconstruction (Alkaff et al., 2019). This study was conducted at the King Khalid University Hospital which provides therapeutic treatment for free to patients who work in the university or the hospital, so ability to afford treatment did not skew these results. These results matched previous studies which suggested that providing women with decision aids such as pamphlets and other informational items were more likely to choose breast conserving surgery to remove a current breast cancer than radical mastectomy (Waljee et al., 2007). These studies suggest that patient education about their treatment options tends to influence their decisions, which may further influence the development of these technologies or medical technologies intended to remedy the problems. Other sources of information that cancer patients may turn to are support groups or blogs created by other breast cancer patients or the loved ones of those patients. Joining these groups frequently helps patients improve their understanding of breast cancer and treatments (Attai et al., 2015). The use of these groups reduced patients' anxiety levels and while the study did not investigate whether social media support groups significantly impacted treatment decisions, it did suggest that the majority of patients felt better informed about their treatment options after joining a support group. Based on the previously described data correlating increased education about a therapy with an increased chance of choosing a therapy, it is reasonable to hypothesize that these social support groups may play a role in the selection of a breast cancer therapy.

Race played a surprising role in the selection of breast cancer treatments. Racial features had an interplay with each of the factors described above that could influence a patient's final decision on breast cancer treatment. African American women tend to receive worse prognoses than White women when they are diagnosed with breast cancer (Lannin et al., 2002). This is the result of a number of factors including the clinical stage and presentation of their cancer, the availability of screening materials, and their relationship with their doctors. African American women tend to be diagnosed with breast cancer at a later clinical stage than White women, which is partially explained by the difference in cancer subtypes (Lannin et al., 2002). African American women are more likely to be diagnosed with triple negative breast cancer, a particularly aggressive and metastatic cancer that is often detected later than other forms of breast cancer and has a lower 5 year survival (*U.S. Breast Cancer Statistics | Breastcancer.org*, n.d.). While this difference in stage of detection is at least partially explained by a later presentation of symptoms, a study by McCarthy et al. found that there is also a bias against African American women with respect to physician recommendations for early breast cancer screening and genetic testing for mutations such as the BRCA1/2 mutation (McCarthy et al., 2016). According to this study, different ethnic groups tended to see different surgeons and oncologists for their disease, but the difference in physicians alone was insufficient to explain the difference in genetic screening for the BRCA1/2 mutation. African American women were less likely to be recommended for genetic testing which is likely to result in delayed identification of their cancers and potentially worse clinical outcomes. Somewhat unsurprisingly, these racial biases appear to exist historically in the United States, as well. A study by Simon et al. found that from 1996 to 1997, clinical trials were less likely to be offered to older and African American women (Simon et al., 2004). Some of this difference in the offering of clinical trials appeared to be due to reduced organ function in the African American patients, which likely results from the increased prevalence of aggressive breast cancers in African American women. However, the exclusion of these patients from clinical trials reduces the likelihood of technologies being developed that could better treat their condition. New technologies in cancer therapy can evolve through co-production by FDA approval of a therapy allowing further advances to be made using that technology as a basis. In this manner, the therapies are produced for breast cancer patients who choose to use it, the needs of these patients become significant for the development of that technology, and future advances in that technology will focus on those needs. When certain groups of patients are excluded from the initial technology, their needs may not be met by future advances in the technology. Thus, new technologies may continue to ignore the needs of those patients. This co-production of technology with the exclusion of African American women helps to explain part of the racial disparity in breast cancer outcomes.

This project is limited by the use of secondary sources and difficulties disentangling the cause and effect of breast cancer prognoses. The majority of sources used in this paper are from peer reviewed scientific literature which contains a great deal of information but may distance data from the people and technologies who create that data. This emphasis on scientific studies rather than individual case studies makes it difficult to determine the reasons that specific women chose the treatments that they did. The use of more objective, distant sources has a benefit though in allowing more effective aggregation of data since each individual will have their own specific values that are involved in their decision-making process. It is far beyond the scope of this project to discuss those reasons with each and every woman who has received breast cancer treatment. A second difficulty in this work is that African American women tend to be diagnosed with more severe, aggressive cancers but also tend to be recommended for genetic screening less often. This difference in cancer type leads to challenges in determining how much of the overall worse prognosis comes from the cancer simply being more aggressive and metastatic and how much of the worse prognosis could be eased by earlier detection.

If this project were to be carried into the future, it should address the personal aspect of how patients choose therapies more directly. Interviews with breast cancer patients to obtain detailed case studies on individual women's decision-making process would provide further insight into the broader findings of this project. Further emphasis on these case studies would provide detailed explanations of how the aggregate data that has been analyzed impacts individuals. Another key piece of information that should be explored in future work is an explanation for the biases present in treatment of African American women. The work analyzed here suggested that a combination of factors influenced the difference in treatment and outcomes for African American women in comparison to other groups, indicating that differences in cancer types alone is an insufficient explanation. Thus, societal explanations are likely to be partially responsible and further research could discover ways to reduce the racial disparity in breast cancer outcome.

This project found that there are a variety of factors that can influence a breast cancer patient's choice of treatment. The most notable influencers are the physician's recommendation, the clinical presentation of the cancer (which often ties closely into the physician's recommendation), the patient's education about their available treatment options, and the patient's race. The race of a patient often ties into the other factors and must be considered. The decisions of patients often demonstrate co-production of cancer technologies which may be associated with some of the racial disparities as technologies often target groups other than African American patients. Thus, the treatment decisions of some patients may affect the available choices of other patients and co-production of these technologies may help or harm certain groups.

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