

SOCIOECONOMIC HEALTHCARE DISPARITIES IN PERSONALIZED MEDICINE

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By

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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HEALTHCARE DISPARITIES IN THE UNITED STATES AND THE RISE OF PERSONALIZED MEDICINE

In 2015, President Barack Obama announced a Precision Medicine Initiative to set the United States on the path to “lead a new era of medicine” (Obama, 2015). Precision medicine has been an emerging technology over a decade; its use has the potential to drastically change the healthcare landscape. Precision medicine, also known as personalized medicine, is the use of personal information, such as genomic data, to guide treatment protocol and tailor therapies to the patient. Personalized medicine reflects a new model for healthcare, going beyond the current one-size-fits-all method. This paper will use a sociotechnical perspective to identify and explore how to mitigate potential negative impacts of personalized healthcare practices on socioeconomic healthcare disparities. The Social Construction of Technology framework will be used to analyze relevant social groups related to personalized medicine (Pinch & Bijker, 1984).

Health and healthcare disparities are prevalent in the United States and globally (United Nations Children’s Fund (UNICEF) et al., 2019). Technology is a driving force in the quality of life and the availability of healthcare. The technical project will produce a computational pipeline for use as a generalized technology to guide manufacturing of custom therapies. Using this pipeline, biotherapeutics could be developed that are targeted to a specific subpopulation via genomic analysis, which is an application of personalized medicine. This pipeline may also help increase manufacturing efficiency, and thereby reduce the cost of biotherapeutics. These projects are loosely coupled. Both projects address the burden of economic hardship on the quality of health and healthcare in personalized medicine.

HEALTHCARE DISPARITIES RELATED TO SOCIOECONOMIC STATUS AND THEIR ROLE IN THE QUALITY AND AVAILABILITY OF HEALTHCARE

The National Institutes of Health (NIH) define health disparities as “differences in incidence, prevalence, morbidity, mortality and burden of diseases and other adverse health conditions that exist among specific population groups in the United States” (U.S. Department of Health and Human Services, 2002, p. 7). In contrast, healthcare disparities are differences in access, use, and quality of care. This thesis will focus specifically on healthcare disparities, rather than health disparities, with the acknowledgement that the two disparities are tightly intertwined and are often prevalent in similar subpopulations.

Current Status of Socioeconomic Barriers in Healthcare

Socioeconomic barriers in the American healthcare system include affordability and accessibility of healthcare, health literacy, and differences in patient perceptions and the patient-physician relationship (Fiscella et al., 2000). While there have been ongoing public and private efforts to eliminate these barriers, much work remains.

Affordability of healthcare. The United States does not have a universal healthcare system, and thus citizens must often be able to pay directly for treatment. Many low-income Americans qualify for Medicaid, which provides healthcare coverage for over 60 million people (*December 2019 Medicaid & CHIP Enrollment*, 2019). However, there are still substantial out-of-pocket medical expenses that can pose significant limitations on healthcare access to low-income patients (Broaddus & Ku, 2005). Moreover, despite spending the most in the world on healthcare expenditures per capita, the United States does not lead in health quality, indicating that Americans consumers pay more to receive sub-standard to standard improvements in health and quality of life (Burke & Ryan, 2014). These high costs of healthcare can be crippling to low-

income patients. Hospital systems in the United States have been accused of being exceedingly rapacious, using aggressive debt collection tactics and withholding information about financial assistance options (McCarthy, 2015; Silver-Greenberg, 2012). These actions deter low-income patients from using healthcare resources for fear of future financial distress or the immediate inability to pay for services.

Accessibility of healthcare. Beyond the primary cost of care barrier, there are numerous other accessibility barriers associated with socioeconomic status, including transportation and health literacy barriers. A primary transportation barrier closely tied to socioeconomic status is the lack of vehicle access. Especially in rural communities, patients without a vehicle are unable to access necessary healthcare resources. In addition, patients may experience prohibitive transportation expenses such as parking fees, bus fares, and gas money. Furthermore, low-income patients may have fewer options for healthcare centers and may have to travel further to centers which accept their insurance. A confounding variable is the limitations on which resources patients are allowed to use; physicians and hospital systems can be selective in which insurances they take, with some only taking private insurance due to the low reimbursement rates of public insurance (Arpey et al., 2017). Overall, patients with inadequate access to transportation are more likely miss doctor and clinic appointments, be limited in their access to pharmacies, and experience longer travel distances and travel times (Health Research & Educational Trust, 2017). These outcomes demonstrate an increased physical and economic burden on low socioeconomic status populations.

Health literacy. Health literacy barriers arise from language and education disparities. Language barriers disproportionately affect migrants whose first language is not the majority language. These barriers affect many aspects of the patient experience, ranging from navigating

to the intended resource, giving informed consent, relaying information about family history, symptoms, and past treatment, and communicating with the healthcare provider about treatment plans and associated risks of treatment. In addition, studies have shown that low health literacy is primarily associated with a low level of education attained, a factor in low socioeconomic status (Paasche-Orlow et al., 2005). Thus, low socioeconomic status populations are disproportionately burdened by health literacy barriers.

Patient perceptions and the patient-physician relationship. Patients of lower socioeconomic status may have a less trusting relationship with their healthcare provider, which can result in worse health outcomes (Arpey et al., 2017). Patients may also be faced with the consequences of implicit bias; a recent study of American surgeons showed 90.7% of participants displaying “an implicit preference toward upper social class persons” (Haider et al., 2014, p. 412). These factors may make it “less likely for patients to comply with medical advice and return for follow-up visits” (Arpey et al., 2017, p. 169). Thus, these nuanced factors of patient-physician relationships prevent low socioeconomic status groups from receiving the same quality of care as other groups.

POTENTIAL CONSEQUENCES OF WIDESPREAD APPLICATION OF PERSONALIZED MEDICINE IN A SOCIOECONOMICALLY DIVERSE POPULATION

The thesis aims to analyze how socioeconomic status may affect the adoption and use of personalized medicine applications. Analysis will be carried out using the Social Construction of Technology (SCOT) theory (Pinch & Bijker, 1984). In SCOT, technology development is influenced by society, and adoption of technology influences social change (Johnson, 2005). As

personalized medicine continues to develop and be adopted into clinical care practices, SCOT provides a framework to analyze the social groups relevant to personalized medicine, and how they influence and are influenced by the technology. Outlined in Figure 1 is a representation of the problems and social groups that will be analyzed.

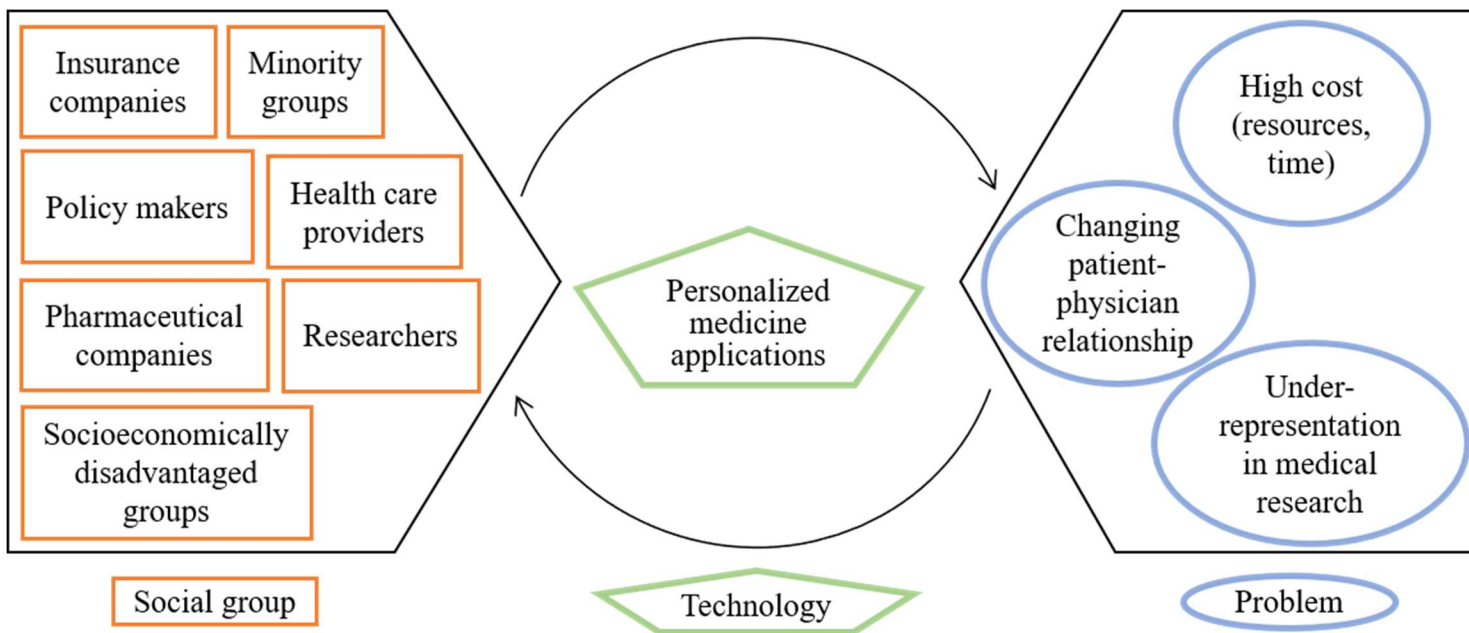


Figure 1. Social construction of personalized medicine. The figure shows a visual representation of the problems and relevant social groups of personalized medicine within the scope of socioeconomic limitations (Bereuter, 2019).

Negative Impacts of Personalized Medicine

Literature has consistently cited high cost, changing patient-physician relationship, and under-representation in medical research as potential negative impacts of personalized medicine (Brothers & Rothstein, 2015). These issues may disproportionately burden low socioeconomic status groups. Investigation into these impacts may help to increase awareness of the role of personalized medicine in healthcare disparities and help to inform government and industry in their decision-making regarding personalized medicine.

High cost of personalized medicine. Personalized medicine requires additional steps to acquire health information about the patient. Genetic screening methods are the primary

additional step for data acquisition. While these screenings can provide important information to providers, the patients incur an additional cost. Another cost that is more difficult to quantify arises from the increased burden that personalized medicine puts on healthcare providers through the additional tasks of counseling, interpretation and application of genetic screening results (Brothers & Rothstein, 2015). Before genetic testing is administered, patients undergo genetic counseling to ensure they understand the potential impact and implications of genetic testing. Moreover, genetic counseling is predicted to become increasingly complex, as advances in technology increase the amount and complexity of data obtained from genetic tests (Yang & Kim, 2018). After a genetic screening is administered, there are follow-up appointments, where physicians must relay their interpretations of genetic testing to patients, as well as time spent analyzing these interpretations and applying insights gained to the treatment plan (Brothers & Rothstein, 2015). These steps require additional time and personnel, which in turn increases the cost to the patient.

Changing patient-physician relationship. As personalized medicine is integrated into the healthcare system, there are new issues arising concerning potential litigation and privacy, as well as potential discrimination by healthcare providers. As the amount of personal health data increases, physicians face additional liabilities. First, there is more information that must be protected and remain private. Moreover, more information increases the number of variables physicians must consider when pursuing treatment. Thus, each decision a healthcare professional makes becomes more complex, and there is more room for scrutiny should there be litigation. Finally, as mentioned earlier, personalized medicine creates additional responsibilities for healthcare providers. Thus, there will be tradeoffs. Physicians may not have as much time to interact directly with patients, leading to rushed and shorter visits (Brothers & Rothstein, 2015).

As intuition implies and research has shown, shorter visit times are linked to decreased patient satisfaction and health status (Dugdale et al., 1999).

Under-representation in medical research. Under-representation in medical research refers to the well-known disparities in enrollment in clinical trials “among adults with low socioeconomic status, racial and ethnic minority groups” (Davis et al., 2019). Under-representation in clinical studies can have a downstream effect on the accessibility and applicability of treatment for specific groups. As noted in Bentley et al., “conducting genomic research in diverse populations is ... important in ensuring that the genomic revolution does not exacerbate health disparities by facilitating discoveries that will disproportionately benefit well-represented populations” (2017, p.1). In other words, studies should be performed on diverse populations to ensure that findings, when translated to technologies that may benefit patients, are applicable not just to the genetic profile of the majority population but to profiles of under-represented groups. Personalized medicine relies on research that ties a specific characteristic, usually a genetic trait, to a specific therapy. Thus, more so than other methods, personalized medicine relies on a diverse research population to treat a diverse patient population. If research upstream of personalized medicine applies only to a specific population, only that population will be able to receive its benefit.

Ethical Considerations of Personalized Medicine

Security and privacy issues related to data storage and access. A large component of personalized medicine revolves around the use of patient-specific data. These large quantities of sensitive data can create questions of storage security and access (Galetsi et al., 2019). For instance, genomic research powering personalized medicine often relies on a database of subject genomes. As current protocol in medical research, all subject data is de-identified before

publication to protect subjects' privacy. However, it is not possible to fully de-identify genomic information due to the nature of the human genome; each genome is unique to an individual and is inherently an identifier. Thus, the privacy of research subjects whose genomic data is publicly accessible has been breached, and the dilemma remains a serious ethical concern.

In addition, due to the increase in data readily available in genetic readouts, patients may be exposed to information about themselves and their background they may not want to be aware of (Presidential Commission for the Study of Bioethical Issues, 2012). For instance, a patient may have their genome sequenced to provide data to guide treatment plans for a presenting condition. With that genomic information could be information about genetic diseases or predispositions unknown to the patient. Physicians are then faced with an ethical dilemma. Patients may not want to be burdened with the knowledge of future adverse health conditions, but this deliberate lack of awareness could also result in poor future health that may be otherwise preventable (Presidential Commission for the Study of Bioethical Issues, 2012).

Increases in individual responsibility. As genomic information becomes more accessible, patients become more aware of their own risk factors and predispositions to disease. This may shift the responsibility of maintaining good health from healthcare providers to the patients themselves, as they become more informed about their own predispositions and can make more healthy behavior and lifestyle choices. Indeed, Peter Dabrock (2012), a public health and healthcare ethicist, posits that “[personalized medicine] should be understood as a health-scientific approach that enables as well as obligates patients and recipients of benefits to maintain or reconstitute their own health” (p.151). While these new-found obligations can help to empower patients to take control of their own health, they can also be a burden. Patients may not have the education or background to fully comprehend what new steps should be taken to

maintain a healthy lifestyle. In addition, they may not have the resources to enact these healthy behavior and lifestyle choices. In this scenario, those who lack these resources may be unfairly held responsible for their poor health status. As personalized medicine is still in its early years, there are currently no sanctions for failing to act in preventative health behaviors, based on genetic risk profiles. However, is it is not unreasonable to see how insurance companies could impose financial fines on the insured for not engaging in preventative behavior specific to their risk profile (Dabrock et al., 2012, p.157-158).

A Simplified Model of the Social Construction of Personalized Medicine

These challenges and ethical considerations can be condensed and put into a simplified model, as seen in Figure 2. Users affected by these challenges have no direct impact on the engineers and researchers that are developing the technology.



Figure 2. The current path of personalized medicine technology. The pathway is linear, and researchers and engineers develop personalized medicine applications and follow potential leads for technological improvements without direct input from users. (Bereuter, 2020a).

Especially at the basic scientific level, biomedical research can be far removed from its clinical application. It is not current practice for researchers to carefully examine the social implications of their research before embarking on a project or experiment. This is understandable, given that it may be years or even decades before research findings become relevant in the clinical landscape and become accessible via technology to patients and the rest of society. However, despite this gap, researchers and engineers must endeavor to understand the social impact of their work, and how it may impact different populations.

PROMOTION OF PRACTICES THAT PRIORITIZE AWARENESS OF AND RELATIONSHIPS TO DISPARATE COMMUNITIES

A potential solution to some of these challenges, shown below in Figure 3, is a concerted effort to connect researchers and engineers with the users, specifically a realistic and diverse population of users. This will provide researchers and engineers with more information to guide decision-making informing on-going studies and projects, upcoming iterations of current technologies, and future experimental plans. Medical technology is complex enough that most changes must be made before the technology is released for use in society; thus, the best way to implement change within the pathway is through the researchers and engineers.

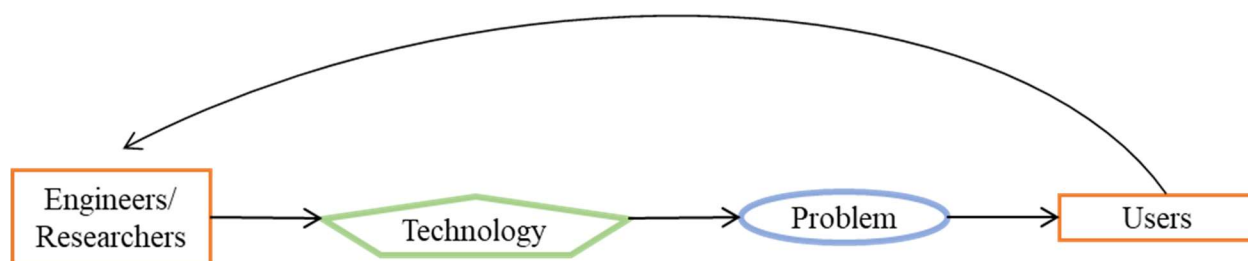


Figure 3. A modified pathway for the development of personalized medicine technology. In this pathway, engineers and researchers are informed by the users, and are thus better equipped to make design decisions that may affect challenges. (Bereuter, 2020b).

Pathways to a Solution

There are several ways to connect researchers and engineers with a diverse group of users, including diversifying research and design groups, incorporating community-based practices, and employing policies that encourage the recognition of the needs of all groups.

Diverse research and design groups. Diverse teams of researchers and engineers allow for more creative-thinking and inclusive problem-solving. This movement has already begun among healthcare providers; studies have shown that diversifying the workforce through recruitment and retention efforts have helped to alleviate healthcare disparities (Phillips & Malone, 2014). Physicians from underrepresented populations have been shown to have higher

cultural competence and are more likely to work in underserved communities (Smedley et al., 2001). To directly impact the problems brought about by personalized medicine technologies, similar diversity efforts must be made at the research and development level. A push for more diverse working groups has already begun; universities are looking to diversify their faculty and research community with recruitment that focuses on bringing in people from different backgrounds (Trejo, 2017). This allows for more diversity of thought and a widened perspective.

In addition, teams must become more interdisciplinary. Specifically, to combat socioeconomic accessibility challenges within personalized medicine, research and engineering groups should include social scientists on their teams. Diversity in professional background allows the problem space to be more widely defined, and innovators will use insight gained from outside professional opinions to inform their research plans and decision-making process. In addition, a more diverse perspective can challenge the assumption that “prominent theories and findings apply universally[,] instead ... recognizing that some apply only to more privileged groups” (McGarrity, 2014, p.393). Among a group of diverse peers, researchers are more likely to realize the social limitations of their work.

Incorporation of community engagement practices. Another method to make researchers and engineers aware of the diverse needs and challenges of the users is through community-based engagement. Institutions can hold events to connect researchers face-to-face with users and local communities. In addition, surveys and interviews with users can be performed with the results relayed back to researchers and engineers. While insight gained from user feedback may not affect current technologies, it could help to give engineers an idea of common challenges faced by different users and may influence how they think about the design of new innovations. Additionally, community engagement by researchers facilitates community trust, and has

resulted in gains in recruitment of minority populations (Holzer et al., 2014). Overall, community engagement practices can help to combat socioeconomic barriers by building trust, increasing representation in medical research, and improving health literacy.

Inclusive policies. Careful curation of policies that enforce researchers and engineers to perform due diligence on the impact of a technology or innovation on groups that face health inequalities will help to raise awareness and knowledge of the needs and challenges faced by different groups. Once instigated, these policies should mitigate disparities that are perpetuated by new technologies and drive insight into current challenges faced by subpopulations. In 1993, Congress enacted the NIH Revitalization Act, which “mandated the inclusion of minorities in all National Institutes of Health-funded research” (Chen et al., 2014, p.1). However, a study conducted in 2015, more than 20 years after the act was passed, found that it was inadequate in ensuring minority representation in cancer clinical trials. The authors called for more public policy changes, as well as for research journals to incentivize minority representation in article submissions by making it a requirement for submission (Chen et al., 2014). These steps for increasing minority representation in cancer clinical trials can be translated to similar steps for increasing socioeconomic diversity and representation in personalized medicine research and development. Public and research community policy reform to enforce equal representation at the research and developmental level can help to guide personalized medicine technology development to be more inclusive and will have a clear downstream effect on accessibility to diverse populations.

Equitable personalized medicine applications

Implementations of these solutions may result in more intentional and equitable personalized medicine applications. As researchers and engineers become more aware of diverse

user needs, personalized medicine technology may evolve to overcome some of the
aforementioned socioeconomic barriers, and accessibility to personalized medicine may increase.

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