Title: The unintended effects from prioritizing health care efficiency over equity

Introduction:

In 2011, allegations of inappropriate expedited treatment for Very Important Persons (VIPs) scandalized Alberta Health Services. National and international headlines condemned Alberta Health Services for preferential care given to politicians, well-connected citizens, and the Calgary Flames. The public was outraged at the corruption of the health care system. This is easily understandable given doctors made statements to the press such as: “...we know everyone’s not equal. It’s naïve to think that Stephen Harper’s wife is going to be treated the same way as the woman on welfare” (1).

Response to accusations of inequity culminated in a government inquiry (2).

The inquiry identified that multiple health care workers, administrators, and politicians peddled their influence to expedite treatment for friends, family, or benefactors (3). Physicians and administrators bypassed inefficiencies in the system to benefit those who lobbied for their help. The report went as far as accusing physicians of abusing “the historical accommodation of Canadian Medicare that protects physician autonomy at great cost to the taxpayer and patient” (2). While the individual actions were inexcusable, I believe the inquiry’s conclusion was short-sighted. By focussing on individuals, it did not critically evaluate the system which led to these events.

In this paper, I will argue that prioritizing efficiency over equity leads to preferential health care at a systemic level. Efficiency policies preference diseases with effective lobbying groups. In a system with fixed resources, these diseases become privileged at the expense of others creating Very Important Diseases (VIDs). VID become resourced beyond what is required for medical need. Consequently, patients with a VID,
such as arthritis of the hip, receive preferential treatment. Conversely, patients with a stigmatized disease, such as depression, face unjust barriers to treatment regardless of prevalence or severity. To understand this phenomenon, I will consider the concepts of preferential care, health care equity, political influence on resource allocation, and the effect of emphasizing efficiency. I will ground this argument using the ethical rationale of justice as described by Rawls' social contract theory.

Preferential management:

In the ethical analysis of the Alberta inquiry, Reid defines preferential access as “differential access to any of a comprehensive set of medically necessary healthcare services, where that differential access is based on medically or ethically inappropriate criteria” (2). Preferential care violates a key principle of the Canada Health Act: accessibility (4). The principle of accessibility holds that health care resources should be allocated fairly based on medical need alone. Further, since health care is publically financed via taxation, an obligation exists for equitable disbursement to the population in accordance with the social contract. Physicians who enable preferential care are labelled ‘bad apples’. I propose there may be a ‘bad barrel’ allowing systematic discriminations that conflict with the social contract. Inequities arising from preferential treatment of hockey players are no different than if stigmatized diseases are underfunded and valorized diseases are overfunded.

Health Equity:

The core principle of publically funded health care, such as in Canada, is equitable provision and access to care. Health equity can be defined as access to healthcare based on medical need alone to the opportunity for the best achievable health (2).
Equitable provision of health care requires that services reflect actual need or burden of disease (5). Health care should not be influenced by individual factors such as gender, race, or income.

In A Theory of Justice, Rawls argued that social and economic inequalities may be justified as long as they may benefit the least advantaged and are accessible to all (6). Rawls explained this permission of hierarchy with the concept of fair equality of opportunity. Equality of opportunity allows social mobility based on a transparent contest in which all members of society compete on equal terms (7). Health care is omitted from this analysis, but Daniels has argued that it is a natural extension (8).

Daniels maintains that health care is special, unlike other goods and services (9). This specialness means that tolerable inequalities in other arenas are inexcusable in health care. Daniels argues that health, and therefore health care, must be universally accessible to maintain a fair equality of opportunity (8, 10). As Meadowcroft explains, “while no one would consider it an injustice for chocolate cake to be provided by the market and thereby only be available to those people willing and/or able to pay for it, it is widely held that an injustice is done when healthcare resources are allocated unequally” (11). Daniels maintains that good health is required for normal functioning. Normal functioning is necessary to protect an individual’s range of opportunity. If, as Rawls suggests, we have an obligation to protect the opportunity range available to individuals, we are therefore obliged to promote normal functioning to the extent that we can control as a society (5). Since health care is a socially controllable factor, by this logic, universal access to reasonable health care is a societal duty. Wolff takes this argument further to conclude that health and healthcare are basic human rights (12).
There are two significant problems in the application of Daniels’ concept. First, the bar that sets the standard for ‘good health’ is inconsistent and relative. For instance, how do you prioritize knee surgery for an Olympic athlete vs a grandmother? Who has the greater demonstrated need for priority care? If the goal is to allow ‘normal’ functioning, one can argue that the athlete should never receive treatment to maintain supra-normal function. Rawls and Daniels do not account for individual desire to achieve greater than normal function. However, while Daniels might agree that his argument stunts ambition, he would maintain that we are not obliged to “determine what we owe each other by measuring our satisfaction or welfare” (8). While patient satisfaction is important and wait times may cause psychological distress, the obligation of health care is to protect opportunity range not maximize efficiency.

The second problem involves the assertion that there are objectively measurable health needs which enable maintenance of a normal range of opportunities (10). In reality, there is a wide range of differing definitions for ‘health need’, and objective and fair quantification is difficult. While Rawls theory frames the just allocation of resources, neither Rawls nor Daniels provide helpful criteria with which to judge individual health needs. To quantify differences in health need in a comparable form useful for decision analysis, the Disability Adjusted Life Year (DALY) was created. Admittedly, to judge health care need objectively is imperfect. More alarming, even in relatively clear cut difference between burdens of disease, the diseases and treatments that experts and policy makers label as meritorious is subject to significant geographic and cultural variation (11).

The political process of priority setting:
Based on Rawls’ theory, health equity requires that patients receive treatment based on medical need. Here in Canada, the Canada Health Act requires that access to publically funded health care be determined by medical necessity (4). One would therefore expect that allocation of resources is based on a known existing or projected burden of disease. It is contradictory to find that certain diseases are resourced at a level incommensurate to burden of those diseases. Given that priority setting dictates funding, how policy makers define ‘necessity’ and ‘illness’ affects health care equity. Groups who are able to have their interests heard by the deliberative process have an advantage in securing treatment resources.

In an analysis of funding from the American National Institute for Health (NIH), funding was unrelated to disease incidence and prevalence (13). DALYs accounted for only 41% of the funding variations in this study. The attached figure from Gillum shows the difference between anticipated spending based on burden of disease, and actual spending (13). The authors identified a bias towards underfunding of stigmatized diseases such as depression (-$718 million), substance abuse (-$202 million), lung cancer (-$364 million), and chronic obstructive lung disease (-$613 million). Similarly, in Canada, while accounting for about 10% of the burden of disease in Ontario, mental illness only receives 7% of health care dollars and is underfunded by about $1.5 billion (14, 15).

Gillum’s study found a disproportionate overfunding of diseases with strong lobbying bodies such as breast cancer (+$258 million) (13). The largest discrepancy in funding is for AIDS. It received +$2,474 million more funding than burden of disease and has
accounted for 10% of the NIH budget since 1984 (13). This is likely due to AIDS being the first disease to inspire public advocacy bodies.

If resource allocation is a political process, then we should find a “Disease Olympics” in which disease-specific lobbyists must vie for health care dollars (16). Indeed, there are multiple examples. The Recalcitrant Cancer Research Act was a bill to divert $888 million of research funding into pancreatic cancer in America. This was an increase of $776 million dollars from previous funding. Hughes identified that the inception and success of this bill was directly due to lobbying from the Pancreatic Cancer Action Network (16).

Another example from the UK is Sunitinib, an expensive drug to treat kidney cancer. After reviewing the cost and associated benefits (improved survival by 3 months), the UK’s drug rationing body, NICE, denied coverage. Patient advocacy groups launched a publicity campaign leading The Telegraph to announce that NICE “would condemn many sufferers of kidney cancer to an early death” (17). Within a year, the drug was available for treatment.

These examples reflect the suffering of real people which prompted public action. They are not meant to diminish or devalue the distress these patients experienced. They are used to highlight the influence of public interest groups on government funding. Health care funds are not unlimited. Increasing resources to one area will always decrease resources in another. This raises a question: what about those diseases without a lobby group? It is hard to imagine the same political organization amongst a group of patients with advanced dementia or psychosis. After the UK approval of sunitinib, three other drugs with nearly identical cost and benefit, but which
treat conditions with more public stigma such as lung and colorectal cancer, remain denied (18).

The effect of lobbying can be seen in government spending on health research as well. In Canada, after public demand for Liberation Therapy, a contentious, scientifically dubious treatment for multiple sclerosis, significant government funding was diverted into researching this treatment (19). As another example, breast cancer is the second most common cancer and colorectal cancer is the third (20). According to Statistics Canada, the mortality rate for breast cancer is approximately 20%, while colorectal cancer is approximately 40%. There is disproportionately more federal research funding in Canada for breast cancer, which has an excellent advocacy group. In 2013, for example, breast cancer received about 75 million dollars while colorectal cancer received 18 million (21).

In the UK, spending on infectious disease research does not reflect disease burden or projected outbreaks (22). Diseases which disproportionately affect poor populations, such as tuberculosis, are particularly underfunded. A notable exception to the underfunding of tropical diseases is the case of Malaria, which receives 20% of the research funding for infectious diseases (22). This is a 10-fold increase over the last decade and is largely due to advocacy from the Bill and Melinda Gates foundation (23).

Beyond the influence of lobbyists, funding is influenced by trends in public interest and even fear. Funding for treatments and research focussed on anthrax dramatically exceeded any reasonable expectation of disease burden after the bioterrorist attacks of 2001 (13). A similar occurrence was seen with the Toronto Severe Acute Respiratory Syndrome outbreak of 2002 (13).
Efficiency

An ideal health care system would be equitable and efficient. However, by overemphasizing efficient health care delivery, policy makers are unintentionally creating inequities. How outcomes are valued impacts priority setting. Which is more important: overall outcomes, acute care hospital outcomes, number of people treated, or wait times reduction? Depending on which model shapes policy, certain conditions benefit at the expense of others. By preferentially resourcing certain diseases based on political process, patients with those diseases receive unequal and inequitable utilization of the medical system.

Most disease progress very slowly. Even cancers take many months, if not years, to sojourn from stage to stage. Appropriate use of health care resources is poorly evaluated using timely access as the only marker. Even long wait times may have little reflection on appropriate system utilization rates. For example, a patient may wait 6 months to have their gallbladder removed. While this may impact satisfaction, if the numbers of gallbladders removed yearly are reflective of disease burden, then utilization of system resources may be appropriate. Further, a long wait time may be equitable if it maintains equal opportunity for all. If symptoms are manageable, waiting 1 year to have your hip replaced may be ethically acceptable in a system with finite resources provided that resources are distributed fairly. If, however, gallbladder removal is under-resourced and hip replacements are over-resourced inconsiderate of suffering and population need, then this would be inequitable.

Wait times should be assessed based on the speed of disease progression, the associated burden of disease in the population, and the individual’s circumstances.
Traditionally, physician-directed wait times took these factors into account. Some hips would be operated on within weeks, others many months. Enforcing rigid wait time rules imposes unequal opportunity and access for those who fall outside the rules.

This is precisely what has happened in Canada with attempts to reduce wait times by volume-funding certain conditions. In 2004, the Canadian government agreed to a 10 Year Plan to Strengthen Health Care. Its major focus was wait time efficiency with priority funding for cancer, cardiac care, diagnostic imaging, hip and knee replacement, and cataract surgery (24). This initiative was successful in decreasing wait times for these priority areas, but produced a slow and steady decline in the volume of non-priority surgery such as gallbladder removal, foot and ankle surgery, and gynecological surgery (25). This is independent of any change in prevalence of disease or burden of disability.

Conclusion:

Prioritizing efficiency metrics like wait times underappreciates person and population focused health (26). This leads hospitals with cash strapped budgets to encourage their doctors to treat more volume funded diseases, such as cancer, and chastise them for treating other conditions regardless of prevalence or morbidity. This imposes disproportionate suffering on people who have no additional politically-mandated resources. At a population level, preventative public health efforts such as vaccination or school lunch campaigns become under-resourced compared to disease specific efficiency metrics.

The Alberta inquiry into VIP care began because insiders used privileged access to bypass system inefficiencies. Ironically, inefficiency is created for some diseases by
current habits of priority setting which preferentially fund and resource certain VIDs. More important than inefficiency, however, is the injustice done to patients by policies focussed on squeaky wheel lobbying. This creates unfair opportunity for diseases with an articulate, organized advocacy group. As Daniels puts it: “our social obligation is to provide institutions that protect opportunity, not to achieve efficiency above all else” (8).
References


Figure from: Gillum et al, 2011. NIH disease funding levels and burden of disease.(13)