What kills us and what costs us

An examination of the ALS Ice Bucket Challenge

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DISEASE BURDEN: A CHANGING LANDSCAPE

Over the 85 years this journal has been publishing, medicine has adapted to the changing landscape that is disease burden. In 1930, the majority of diseases that medicine fought were infectious in nature. Influenza, pneumonia, tuberculosis, and gastrointestinal infections were the top killers. After 85 years of scientific advancement, infectious diseases have become well controlled in the developed world, and the population no longer fears these ailments. In 2015, different beasts threaten our lives—heart disease, cancers, and chronic airway diseases comprise the majority of our disease burden.¹ *Valar morghulis*—all men must die. As medicine saved patients from acute conditions, they began living long enough to die from chronic diseases. As the disease burden shifted, so too did the attention and anxiety of the population, which in turn shifted one of the most important drivers of medical progress: funding.

A FUNDING DISPARITY

According to Jones and colleagues, the “goal [of medicine] should be an integrated policy under which health care and public health programs together fully address the disease burden.”¹ This implies that funds should be allocated in proportion to the disease burden they represent; for example, since heart disease is the major contributor to disease burden in North America, it should receive the greatest amount of funding. However, this is not the case. According to the NIH, while heart disease causes more deaths than any other disease, in 2006 it received only 3.3% of NIH funding (\$398 million), while HIV/AIDS, with a prevalence ten times lower, received seven times more (~\$2.9 billion). The funding disparity is pervasive: together, HIV/AIDS, diabetes mellitus, perinatal conditions, dementia, and alcohol abuse account for 49% of NIH research funds, but none of these conditions are listed in the top ten causes of mortality.²

ALS ICE BUCKET CHALLENGE – A CASE IN POINT

This funding disparity extends beyond government funding to publicly raised charity funding. The most recent example of a disconnect between disease burden and funding raised through charitable donation is the viral phenomenon of the ALS Ice Bucket Challenge. Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s Disease for the baseball player who made it famous, is a progressive, incurable, neurodegenerative disorder causing muscle weakness and eventual death. It is the most common form of motor neuron disease and upon diagnosis, it has a median survival of 3–5 years. Prevalence rates range between 2.7 and 7.4 per 100 000 across North America and Europe, with the disease being slightly more common in men (M:F ratio of 1.3–1.5:1).³

ALS recently made waves in the media through a viral fundraising campaign involving filming the dumping of a bucket of ice water on someone’s head in an effort to promote awareness of ALS and subsequently raise money for research. Most videos end with a challenge to others to follow suit.

The phenomenon began in Florida in July 2014 when a local golfer, Chris Kennedy, was nominated to do the Ice Bucket Challenge or donate money to a charity that benefitted a local child with cancer. When Kennedy passed the challenge along, he chose a charity benefitting ALS because he had an afflicted relative. A video posted to YouTube on July 15, 2014 appears to be the first incidence of the Ice Bucket Challenge being connected to ALS. Through social media, the trend exploded and spread across countries and organizations.⁴

According to CBC, more than 260 000 Canadians took part in the Ice Bucket Challenge and raised over \$16.2 million for ALS, ~\$10 million of which will go directly to research, and ~\$6 million of which will go to supporting those living with ALS. The Canadian government also contributed \$10 million to ALS.⁵ This is undoubtedly an impactful contribution but the Ice Bucket Challenge is wrought with issues.

Paradoxically, the usual challenge is to perform the Ice Bucket Challenge within 24 hours or make a charitable contribution to ALS, in other words allowing people to forego donation if they complete the challenge. Many people throughout the campaign raised concerns, especially since every video showing the challenge being completed seemed to imply that dumping cold water on your head is preferable to donating to ALS. Several individuals suffering from ALS have also spoken out that the campaign reduces a debilitating and lethal disease to a social bandwagon onto which people eagerly jump without any real regard for its purpose.⁶ However, there is a more worrisome issue at the heart of the ALS Ice Bucket Challenge.

According to Statistics Canada, the number of Canadians reporting charitable contributions on their income tax is decreasing (down 0.6% from 2010 to 2011), suggesting that fewer people are donating money to charity. However, the rise in charitable contributions suggests that fewer people are donating more. Further, only 15% of Canadian donations are to healthcare organizations, amounting to \$1.59 billion. Charitable donations are affected by economic conditions such as the recent economic downturn, suggesting that the surge in funding for ALS may represent an equal decrease in contributions to all other healthcare charities.^{7,8} This opportunity cost is the most troubling aspect of the Ice Bucket Challenge.

In 2011 (most recent data), 47 627 Canadians died of heart disease, accounting for 19.7% of deaths, yet the Canadian Heart and Stroke Foundation received only \$114.5 million in fundraising donations, equivalent to approximately \$2404 per individual death.^{9,10} By comparison, between 700 and 1100 Canadians die of ALS each year, while the Ice Bucket Challenge alone (not counting donations outside of the challenge) raised \$16.2 million in Canada; equivalent to between ~\$16 200 and ~\$23 150 per individual who died.^{5,11} Moreover, economic costs due to cardiovascular disease in Canada in 2000 totaled \$22.2 billion, representing 17% of all hospitalizations (2005-2006) and 10% of all visits to community physicians (2007).¹² Contrast this with ALS, with an economic burden amounting to approximately \$182 million.¹³ The discrepancy between what kills us and what costs us, and where we donate is a costly one, in terms of both dollars and lives.

Of course, the question must be raised: if we divert funding to the most lethal and burdensome diseases, what becomes of the rare diseases like ALS? Research and treatment for rare diseases remains incredibly important, and funding is scarce by comparison to the major destinations of Canada's health research funds. The top disease groups funded by Canada's health research funding agency, the Canadian Institutes of Health Research, are cancer, diabetes, cardiovascular disease, and respiratory health, representing the major disease burden in Canada.¹⁴ This means that rare diseases like ALS need to be funded almost exclusively by charitable contributions. In fact, ALS Canada has successfully raised substantial amounts of money towards research. In 2013, over \$3.8 million was raised to support ALS research—a modest sum compared to the ~\$16.2 million raised by the Ice Bucket Challenge alone—however, one that is more in keeping with the proportional impact of ALS on the population.¹⁵

CONCLUSIONS

If we, as a society in Canada, wish to maximize the utility of our charitable donations, we might aim to be better informed as to what health problems are most pervasive and costly. The greater good of society should factor into decisions about where to direct charitable donations instead of relying solely on emotional or social motivations. Addressing this requires appropriate and balanced education. The recent ALS Ice Bucket Challenge phenomenon served as a great success for the fight against ALS, raising both money and awareness of the disease. However, it may represent a setback in the fight of society at large against the modern, chronic burden of disease. The goal is not to eliminate all funding for ALS, but rather to fund all diseases in proportion to their prevalence, economic cost, and mortality. A broad-minded society would attempt to erase the discrepancy between the diseases that kill us and cost us, and those which garner our attention. The final decision however, rests firmly in the hands of the donors.

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