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Severity of Scope Versus Altruism: Working Against Organ Donation's Realization of Goals- An Essay

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Abstract

The number of incidences of End Stage Renal Disease (ESRD) supports the case that it is a public health emergency. The burden is often quantified by rates, leaving many people cold and unresponsive, leading to, as Nordgren and Morris McDonnell (2011) state, “the diminishing identifiability of a large number of victims” snarled in the scope-severity paradox. The subject may identify with the disease or illness, but who are these ill-fated others? It must go beyond recognition that there is an ESRD problem at hand. “Strength in numbers” hurts---according to scope-severity paradox and its close kin, scope insensitivity. There appears to be less of an incentive to upset rational choice and side with emotion if enlarging health awareness is required to turn the tide of disease. But I argue that this emotive will more likely activate a collective empathy if an ESRD patient that needs a kidney is personally known to us.

KEYWORDS: collective ethics, organ donation, End Stage Renal Disease, public health, altruism

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While academic thought still tends to compartmentalize into theoretical silos, health is acted out on a public stage, often affecting scores of others in the process.

As outgoing Hastings Center President Thomas Murray observed in a commentary to the Association of Psychological Science, bioethics is a ligand to the psychology's substrate (Murray, 2002). Right and wrong is not exclusively cognitive, but it is tackled in the grey matter at many time points. The thought of pro-donation or con-donation then becomes internalized as a personal belief, and then it is realized as a collective ethic that is to be negotiated (Battle-Fisher, 2010). We think and decide as persons as well as collectives. Public health by nature follows this collective. This essay will discuss the person vs. collective view of organ donation and the scope-severity paradox.

A recent article in *Social Psychological and Personality Science* written by Nordgren and Morris McDonnell (2011) posed a research question that should be central to public health ethics. (This was published in a psychology journal which may not be on the radar of many bioethicists.) Nordgren and Morris McDonnell (2011) posit that rationality is thrown out of the window when the burden of people afflicted by a crime becomes incomprehensible.

The basic premises of "scope-severity paradox" according to Nordgren and Morris McDonnell (2011) are:

1. We only connect emotionally with crime victims within our personal social network (i.e. family, clan, neighborhood, civic group) that we know and care about.

2. Increasing the number of victims decreases the perception of severity of the problem. 'Your problem, not mine' could be reworded as 'call me only if a loved one is directly affected, otherwise I am out to lunch forever.'

At a more elemental level, the lack of prowess in recognizing the gravity of an event would be explained by a presence of scope insensitivity. Desmentes et al. (2007) note the importance of personal gain versus loss in unraveling this scope insensitivity. But public health must find a way of emphasizing a collective gain/loss framing that is linked to personal actions. What would be the social cost for donating (gain for society and personal gain for patient)? Moreover, are we all not paying in the end by the lack of living donations (loss for society and personal loss for patient)? A central tenet of the Health Belief Model is perceived benefits where a health behavior must be framed as having a chance of affecting change in order to support the utility of that decision (Jan & Becker, 1984). This would be an individualized framing of gain and loss. Does this cover all of bases of explaining the public's health? I say no. I would argue that while perceived benefits are individualistic, what is lost is the exploration of the grand scope of the health concern on decision making. Acknowledging that there may be "scope insensitivity" cries for viewing a lived experience of one patient as affecting the rest of society. But one must reframe the problem and conquer the hurdle of the massiveness of the need. We must overcome the chasm of scope. Psychology can be married to bioethics and for good use in this case.

According to the scope-severity paradox, we do not easily care about those that we do not know, especially when it affects masses of far-flung individuals. I add, how much emotional energy can each of us realistically give, especially if specific energy needs to be directed to an unimaginable host of others when we have a network demanding personal attention? A lesson could be learned here in terms of framing scope-severity paradox around public health ethics. We are back to a spin on the autonomy-collective dualism that keeps

ethicists like me awake at night. How do we in public health solicit the compassion of concern for others when the burden of a disease is constructed as a systems level phenomenon? The question should be raised whether there can be sufficient saturation of altruistic compassion achieved in order to trigger widespread public health concern.

Let us look at an issue increasing public health concern, End Stage Renal Disease (ESRD). In 2009, approximately 117,000 new patients began dialysis treatment (United States Renal Data System, 2011). It is well documented that many patients languish on dialysis with no viable kidney- that proverbial pot of gold- on the nearest horizon. According to the United States Renal Data System (2011), over 400,000 Americans were in some stage of dialysis treatment, with only 17,000 of those receiving a kidney in 2009. Now, plant the thought that there is need for organs and organs and donors will multiply based on an altruistic decision made by donors or their kin. Life will abundantly become more fruitful, with quality of life improving with each new graft as each ESRD patient joins a new fraternity of transplant recipients. Unfortunately, the rising action of this story often describes the shortcoming inherent to scarcity- the lack of the viable organ. The transplant never materializes. There is only fool's gold for most ESRD patients. Only half of dialysis patients who do not receive a kidney live three years after starting therapy (United States Renal Data System, 2011). Living- living paired donation schemes have been presented as possible solutions to the issue of finding organs but it is presently acting at a slow percolating (albeit promising) simmer, accounting for 277 of all transplants in 2009 (United States Renal Data System, 2011). Living donors have been more influential as of late , as there was been an increase of 7% in living kidney donations in 2009 versus a 1% downtick for deceased kidney donations during this same period (United States Renal Data System, 2011).

There are countless "others" living with End Stage Renal Disease (who are faceless but are captured by statistics). For the ESRD patient, these others demand the same gift of

life, pining after the same pot of gold that is coyly shining and promising riches of a kidney. The son and caregiver of an ESRD patient should theoretically covet a betterment of life for his mother under the scope-severity paradox. However, compassion from this son may wane under the stressors of the difficulty of caring for his mother. The heightened emotion of care giving over the extended time requested by ESRD (and earlier stages of chronic kidney disease) lacks the ability to predict if the son will act. Perhaps this compassion is inexplicably linked to creating and nurturing a strong bond that would be a prerequisite for serving as a donor.

Action (as a donor) is what is necessary for turning the tide of late-stage ESRD mortality. But more importantly for public health, what is to be felt for the mass of “others” languishing on dialysis and competing for the same precious organs as the son’s mother? There is no ethical edict that requires the son to give up personal autonomy to donate the organ even to his mother, let alone, a stranger. What of the altruistic donors if the son is not a match? Often these altruistic donors highlighted in the media have their own “kidney narrative”, a loss of a loved one to End Stage Renal Disease (ESRD) or something similar. This is a prime example of the gain-framed experience that perhaps is radiating from a personal loss. Organ donation is a situation with the best intentions (altruistic compassion), but does not automatically resolve with a saved life in the end. Is the son gaining a mother by donation (gain-frame) or losing a mother by not donating (loss-frame)? Or is it both? Donation is too complex to be framed in the same way of more conventional health behaviors for donation is what I term, an “anticipated health behavior”, one that cannot be practiced and reinforced through active trial and error of the behavior. What can change would be the donor’s state of mind as a potential donor, which is wedded to ever changing personal ethics (Battle-Fisher, 2010).

Public health needs patients, at-risk individuals and potential donors to care about the nameless others; if for no other reasons but to stifle the prevailing trends of disease and to decrease mortality. How can compassion be accomplished when issues of scarcity such as viable organs may cloud one's understanding of the plight of others sharing a similar narrative? By realizing the linkages of perception to scope of the incident, as Nordgren and Morris McDonnell (2011) contend, I assert that public health would need to champion the individual narratives. I purport that the closer the personal connection the better, especially when there are complications of scarcity of resources for this extremely vulnerable population (Battle-Fisher, 2010). By perhaps acknowledging the attributing influence of scope, this could increase compassion toward aiding others, and, therefore, assist in reversing large-scale public health disparities such as ESRD.

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