

Research: An ethical answer in addressing our people's health problems and inequities

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Background

Research, in and of its very nature, intrinsically seeks to gain knowledge for the benefit of society (1). To achieve this, it aims to ask questions that perhaps no one has asked before; it does the necessary work to find the answer, and it communicates the knowledge acquired to a larger audience. In conducting this research, the methodologies used vary widely, and are largely determined by the background discipline. Research in science and engineering often involves conducting work in the field or in the laboratory. Research in the arts, humanities and social sciences may involve archival work in the library or on the internet, conducting surveys or in-depth interviews, or a wide range of creative and artistic projects.

Ethics is a branch of philosophy, thus most bioethics research is not empiric, but is literature-based and philosophical. This paper is no different. We should also note that research is not a solitary activity, but an act of 'community'. As members of the research community, researchers are building on the knowledge that others have acquired before them, and providing a 'road map' for those who will come after them. They are adding to a body of work that will never be complete, and are involved in an ongoing, collaborative process that has no finish line.

The research agenda of the Caribbean Public Health Agency

In its meeting in Aruba in 2012, the Executive Board of the Caribbean Public Health Agency (CARPHA) mandated the development of a research programme for the Agency. From that mandate, the CARPHA Policy Framework for Research was developed, with a revised version being formally adopted by the Board in April 2014. Due to its functions as a public health agency, the policy framework required that CARPHA foster and maintain a strong culture for research, achievable through the promotion of scientific and evidenced-based approaches to all of CARPHA's activities (2).

Given the nature of the Agency, the policy also dictated that only public health research be done at CARPHA, and that these should be guided by the "Health

Research Agenda for the Caribbean" that was in keeping with the Agency's Strategic Plan for 2014–2019 (3). It also mandated the continuation of the Annual Health Research Conference as well as other meetings that addressed priority health issues. Accompanying this, CARPHA would also have a role in promoting and facilitating the use of evidence gathered in research to help in healthcare decision-making at all levels – from the level of policy-makers, through programme managers, to healthcare providers.

The issue of public health

Alongside other descriptions, the term public health refers to the art and science of preventing disease and disease progression, prolonging life and promoting health through organized efforts of society (4). The term is underpinned by conceptions of the 'public good' and 'public services'. Significantly, in recent times, there has also been a growing interest in the ethical, legal and social aspects of public health policy and practice. Further, in the wake of various infectious disease outbreaks, there has been the increasing recognition that public health issues are inseparable from issues of human rights and social justice, problems of cultural and behavioural change, and environmental issues on a global scale (5).

So whilst public health and public health research deals with patterns of disease, and collective and institutional solutions to alleviate the risk or burden of disease in a population, they should not overlook the rights, interests and freedom of the individual. And so, whenever possible, public health goals and its research should also be reconciled with the promotion of human rights and the protection of civil liberties (5).

CARPHA's priority health issues

The Health Research Agenda for the Caribbean defies the regional priorities for health research that ought to be the special focus of countries, researchers and research institutions, and funding agencies (2). Consequently, this Agenda was adopted to provide the research focus and priorities for support and funding by CARPHA. Importantly, this Agenda would need to be updated periodically to keep pace with changes in health priorities. Underpinning such updates with some special ethical considerations is one aim of this bioethical treatise.

The platform for the current Health Research Agenda was determined by the Caribbean Cooperation in Health's identification of eight programme areas that were health priorities in the Caribbean Community (CARICOM) countries: communicable diseases, food and nutrition, chronic non-communicable diseases, human resource development, family and community health services, strengthening health systems, environmental health and mental health (6). In 2011, conducting research with policy-makers, programme managers, researchers and health professionals, the Caribbean Health Research Council (CHRC) developed the research priorities using the Delphi methodology (3).

The theme for this year's Annual Health Research Conference – *“Violence and Injuries: An Urgent Public Health and Development Issue”* – reflects the mundane reality that interpersonal violence has historically been a feature of interpersonal interactions in the Caribbean, but its escalation in recent times to feature as a primary public health concern begs further research in light of the ethical considerations I propose within this paper.

Public health policy focusses on prevention, rather than treatment, on the population as a whole, rather than on individuals, and on the importance of collective effort. Good health is an instrumental prerequisite to constructive activities because it concerns people's normal functioning and capabilities. It is also central to making use of opportunities that are available in societies, and societal structures that do not provide people with fair and equal starting positions in the pursuit of such opportunities must be judged as being unjust (7). Therefore, as health is constitutive of people's overall well-being and affects their quality of life, the moral function of public health programmes must be to help guarantee fair equality of opportunity (7). Public health research should therefore play an important role toward this end (8).

The role of government is to provide certain essential services that should not be left to the market alone, and to establish rules under which different agents operate in such a way that it is compatible with population health and reducing inequalities. An important ethical goal of public health therefore is to reduce health inequities (7). This aims to improve health opportunities and outcomes in the most disadvantaged groups. Further, special care is also needed for the vulnerable, including children, the elderly, the socially disadvantaged, and those without sufficient healthcare-related knowledge to act as full autonomous citizens.

This matter is underscored by the United Nations' Declaration of Human Rights, which, by way of Articles 22 and 25, stipulates that every person is entitled to social security, economic, social and cultural rights and the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care (9). Further, Rawl's theory of justice holds that society has an obligation to correct

inequalities in the distribution of resources (10). Thus, those who are least well-off ought to benefit most from public services such as healthcare. This provides considerable support for maximizing benefits to socially disadvantaged persons, particularly if it can be demonstrated that aiding those who are least well-off ultimately benefits the society as a whole.

The same paradigm would exist for research. Our research endeavours in public health should, in the first instance, seek answers and solutions that would benefit those who are least well-off, with the aim of improving their health to a level commensurate with the rest of the population. In order to do so, however, we have to contemplate the prevailing social and economic structures within most of the CARPHA member states today, and the ethical, legal and social issues that underlie the problems in society.

The socio-economics of health – a need for further research

The prevailing socio-economic system in our countries is shaped and shepherded substantially by capitalism and capitalist inclinations. Within this system, the corporate sector has a special interest in maximizing profits for itself and its shareholders (11). However, this should not absolve it of its social responsibilities and the obligation to contribute to the welfare of those worse off in the society (7). Socially, our societies are generally structured along historic racial lines, where the paler the colour of one's skin, the more likely one is to be socially situated within the upper tiers of the society. The converse is also true – the darker the colour of one's skin, the more likely one is to be situated among the lower social classes of society. The economic structuring of our Caribbean societies likewise follows this paradigm (12).

Within this social order, the reality of historic discrimination by colour and race still exists amongst the peoples of the English-speaking Caribbean. Centuries ago, in the European quest for wealth, power and an easy life, the ancestors of people of African descent were rooted from their homes and forcibly transported to the West to serve as slaves to the greater ends of enriching the home countries of Europe (13). And whilst Rawlsian justice argues that those who are better off should assist those who are disadvantaged to better themselves, the slave-enriched mother countries of the Caribbean have not done any comparative investments in the countries that served to give them wealth (14).

This historic reality consequently set the stage for the current structure of capitalism, where there are enriched, developed countries and exploited, poor countries *ie* countries of the North, and countries of the South. The latter are inextricably linked and depend economically on countries of the North for perpetual loans and unbalanced and sometimes unjust trading agreements (15). Theoretical bioethics argues for normative standards in our

social structures and our interactions with each other. But how can normative standards be achieved when a historic unjust social order remains and thrives (16)? When the roots of power are deeply entrenched in the hand of the few; the so called 10/90 divide – where ten per cent of the world's population controls ninety per cent of the world's resources (17)? When the 10% who control power are not social constructivists willing to devolve any power or share any of their wealth (18)?

Inequalities in wealth are acceptable within a liberal framework only in cases where higher financial rewards for the better-off carry the implication that their specific work and performance actually contribute to improving the situation for those worse-off (7). This has to therefore translate into the general social welfare within a country whereby the work and contribution of the wealthy actually results in cheaper goods and services for all. If the latter situation does not obtain within a country, then a charge of exploitation of the lesser-off by the better-off within a capitalist system, with a widening of the 10/90 divide, could be made and argued successfully (19).

Research of health and income inequalities

In this dispensation, the moral function of public health programmes must be to help guarantee fair equality of opportunity, and research should seek the best ways of doing so (8). Eliminating or at least reducing unfair health inequalities is a feature that has to be underscored in the list of goals of public health programmes, and by extension, public health research. So the primary end-point of outcomes-focussed approaches in public health is to identify those outcomes that are modified by factors that are regarded as unfair and that can be changed through appropriate policy (7).

Of note, health equality might be said to exist as long as there is access to a 'decent minimum' of care, such as a health service that is free at the point of 'need' (15). But health equity might require a far more extensive scenario, where all citizens in a country or those residing within a state have equal access to equally conducive work and living environments.

As well as the 'equality of what' dimension, we may ask, 'equality among whom?' Health outcomes often differ across subgroups of a given population, and so in seeking to create equality among these groups, one may focus on a range of different criteria that include age, gender, socio-economic status, racial and ethnic background, disability and geographical location. Analysing inequalities of status between such groups allows us to identify those groups that suffer, or are at particular risk of suffering poor health. Further, it allows us to focus on those inequalities that are particularly unjust and thus inequitable (20).

Ways of reducing inequities

In principle, it should be possible to achieve equality either by lifting the level of welfare or opportunities of those that

public health research has found to be worst off, to the level of those who enjoy the highest standards, or by lowering the welfare of those at the top. Unfortunately, however, we are likely to find the latter task impossible to achieve within the current power structure of the capitalist system. There is likely to be ferocious criticism and entrenched resistance of this 'levelling down' or egalitarian approach that seeks to even out inequalities (7). An alternative option might be setting a prioritization strategy that focusses not on relative health status, but on the absolute position of those 'worse off', and what are the immediate practical interventions that can be made on their behalf, to raise their socio-economic and consequent health status. Such an approach, however, may have different consequences in practice, and so the implications need to be monitored closely.

Therefore, when we speak of existing health inequalities, most or all of our Caribbean countries do not have equality of health outcomes across their population. Evidence-based measurable data such as life expectancy and blood pressure reflect this reality of great divergence of results between the very rich and the very poor. Within our CARPHA member states, health outcomes differ across subgroups within the population, reflecting socio-economic status and – to a lesser extent but historically linked – people's racial background. Thus, in attempting to address the public health needs across our Caribbean societies, we must further research and analyse the inequality of status between subgroups of the population to help us identify those groups that suffer or are at particular risk of suffering poor health (21).

Studies of vulnerable populations

Many public health studies and interventions target vulnerable groups such as children, pregnant women, the elderly, people with diminished capacity and those who are institutionalized (22). Members of these groups are considered vulnerable because of an increased potential for risks and harms that they have, or a decreased capacity for understanding (23). Understanding the risks and potential benefits of an intervention is an essential element of informed consent requirements, and so research amongst these groups raises a number of ethical issues that all researchers and potential researchers should be aware of (24).

Individuals who participate in HIV/AIDS research studies may be burdened by time spent completing interviews and undergoing examinations, by a loss of privacy and by adverse psychological effects such as anxiety and grief. Other risks include stigmatization and the potential loss of employment or insurance resulting from breaches of confidentiality. Other ethical concerns also relate to blinded HIV antibody seroprevalence studies that serve an important public health purpose. Researchers should therefore be cognizant of these, and institute special safeguards

to protect the welfare of participants while conducting the essential research (25).

Conclusion

Ethical considerations should always be at the core of everything that we do (26). Public health research is essential and its focus needs to be regularly revised to reflect changing health priorities within each society. Underlying this research thrust should be the aim to help those most socially disadvantaged to achieve a fair opportunity to realize good health and well-being. To this end, ethically, health research should be primarily aimed at further elucidating the social determinants of health which result in health inequities, and determining the best mechanisms or interventions for mitigating their effects on health and well-being.

Those who are least well-off ought to benefit most from public services such as healthcare and public health research. This ethical approach provides considerable support for maximizing benefits to socially disadvantaged persons, particularly if it can be demonstrated that aiding those who are least well-off ultimately benefits the society as a whole. Consequently, research that identifies the subgroups most disadvantaged in each society, their current health status and possible interventions that would alleviate their poor socio-economic and health status will be most beneficial.

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