

The moral claim for obligatory dissemination of study results: part one

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INTRODUCTION

The process of taking data from a person or community when doing research, and then publishing such data and one's academic interpretation thereof in an academic journal, is usually well protected and scrutinised by several ethical checks and balances. However, to disseminate research findings back to the community in which the research was conducted is seen as a fundamental principle in ethical research practice that seldom materialises into reality. When researchers appropriately respect their obligation to do this, it is often filled with nuanced challenges.

Researchers must consider how to convey complex findings in a way that is understandable and actionable for the community. Different communities have different views on norms, values and communication preferences. Researchers must be culturally sensitive in how they share findings to ensure relevance and respect. Dissemination may require resources such as translation services, community meetings or educational materials. It's essential to share not only positive results but also negative or inconclusive findings. This avoids bias and helps the community make informed decisions.

Case study

A funded study was approved by the Ethics and Review Committee of a school of oral health sciences in South Africa. The objective of the research was to estimate the incidence of ameloblastoma and determine the predictors of poor clinical outcomes related to this condition. The study was undertaken in Limpopo province as this region is purported to have the highest prevalence of ameloblastoma in the country. The research team was aware of the entrenched chieftainship system, language and cultural diversity in the province. The study stipulated clearly how the dynamic of the individuals and the local traditional authorities would be handled in this governance system. Additionally, the research team indicated that "... the results of the study will be disseminated ..." and that the findings will "provide valuable insights to the clinicians and communities in improving the clinical outcomes of ameloblastomas". Data was collected using community-

based research assistants who were fluent in local languages, culture and practices.

Three years after the completion of the study, one of the chiefs complained that research results had not been shared with communities, yet two papers were published in high impact accredited journals. Similarly local clinicians and other stakeholders were in the dark about the implications of the study findings. The research participants and stakeholders viewed this research project as a betrayal of trust. As a response to these queries, the research team indicated that they lacked funding to host feedback sessions. Furthermore, the team could not circulate the journal reprints to stakeholders due to possible violation of intellectual property held by the journal.

It has been five years and the research results are yet to be disseminated to the participants and stakeholders. This paper seeks to argue that researchers indeed have a moral duty to inform participants and disseminate research findings to the participants and any affected groups. In this, part one, we address the questions below, while the remaining questions are discussed in part two of the series.

Questions

Do researchers owe participants and communities restitution and information about the study findings? In other words, is the moral claim for obligatory dissemination of study results defensible? If so, are there limitations to this moral claim? What are the limitations of the moral claim to disseminate research findings? What is the extent or scope of the information that is owed? Is there moral justification for withholding study findings from participants? Who should determine the target audience for the dissemination? What constitutes the most appropriate channels of dissemination?

DISCUSSION

The moral obligation for researchers to inform participants and communities.

While it is generally accepted that information sharing is a critical part of the scientific research process, study results are seldom disseminated to study participants. Failure to inform participants about the research findings is particularly prevalent, especially at the terminal stages of the studies, because "patients are not needed anymore", and the researchers "got what they wanted". We argue in this paper that researchers indeed owe participants sufficient information, and throughout the entire research process. In other words, researchers have a moral obligation to disseminate research findings to communities. Our defence of the thesis above is based on the ethical principles: (i) autonomy (respect for persons) (ii) beneficence and non-maleficence (favourable risk-benefit ratio) and (iii) justice. It is hence our contention that it is morally unjustifiable for

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researchers to withhold any information or fail to disseminate research findings to participants and communities.

1. Respect for persons – a sufficient moral foundation of research in humans

The philosophical concept of respect for persons is well described in Immanuel Kant's classical statement "Act so that you treat humanity, whether in your own person or that of another, always as an end and never as a means only".³ Kant also claims that "Respect ... is the acknowledgment of the dignity of another man, ie a worth which has no price, no equivalent for which the object of evaluation could be exchanged".⁴ Kant asserted that persons have a special moral status which obligates others, including researchers, to acknowledge their agency and respect their rights and choices. Special protection should therefore be ensured, especially in cases of limited self-determination and incapacity. This means that the wants, desires and interests of others, especially the vulnerable, should always be a primary consideration, especially in research.

This Kantian explication of respects for others is widely referenced and cited for its general applicability. However, the Kantian conceptualisation of respect for persons as applicable to this case lacks specificity and appropriateness in two ways. First, "respect" is not specific or distinguished from other forms of admiration, reverence, awe or fear. Second, the notion of "respect" does not place any tangible worth, value or restrictions on the attribute to be respected. In other words, Kant does not place conditions for respect for persons. Instead, Kant bestows special moral status and consequent respect of persons without any cause. To mitigate the deficiencies in the conceptualisation of respect for persons, the Cranor model⁴ for respect-for-persons offers an alternative explanation. This model is based on conditions that are necessary and jointly sufficient to evaluate a person with attributes, traits and abilities worth respecting. Ultimately, the "respect for persons" should be premised on the notion that one cannot respect a person without any reason at all. Hence the assertion by Cranor that three (3) conditions must be satisfied for respect to be earned and afforded.

Cranor's respect-for-persons model unpacked

1. There should be an attribute (A) to be respected.

The respector (R) ought to believe that the person (P) has a good attribute (A). The evaluation of the attribute as "good" or "bad" may be based on its inherent moral, non-moral, aesthetic, practical characteristics. This phase of the model does not require concrete evidence about the attribute. The mere inclination about the goodness of the attribute (A) is sufficient.

2. There should be reasonable knowledge and appreciation of the nature of the attribute (A) to be respected.

The respector (R) must demonstrate knowledge and appreciation of the nature of the attribute (A). This evaluation goes beyond mere admiration, awe or fear of the person (P) with the attribute (A). There should be sufficient knowledge that the possession of the attribute (A) could enable the person (P) to do good or achieve the expected outcomes. As a condition for respect for persons, the respector (R) must gather evidence about the goodness of the attribute (A) and be convinced that having the attribute (A) could result in some good worthy of respect.

3. The respector (R) is predisposed to rely on the person (P) with the attribute (A) to discharge their duties accordingly and achieve the desired outcomes.

The respector (R) is inclined to confide in the person (P) to do good given that they possess the attribute (A). Consequently, the respector (R) may show commitment to, and place their welfare and wellbeing with, the person (P). This step marks the intentional genesis of the doctor-patient relationship or researcher-participants mutual engagement.

The formula for respect-of-person by Cranor can be summarised as follows: The conditions should be conducive for the individual (R) to trust, believe and confide in the person (P) endowed with a good attribute (A). By acknowledging and recognising the good disposition of the person (P), the respector (R) could (a) emulate the actions of the respected person; (b) heed their desires, wishes and commands; and (c) honour the respected person in various ways, such as titles and mannerisms.

What does participation in research really mean?

By "consenting" to participate in a study, the research participant assumes a vulnerable position, relinquishes their agency and surrenders their personhood, literally. According to the respect-for-persons model by Cranor, the research participant goes through several agonising steps: First, the research participants must believe that the researcher (Re) has the requisite disposition and traits to undertake the study. Second, the research participants must contend with evidence (or lack thereof) regarding the ability of the researcher (Re) to execute the study; prevent or minimise harm; and confer benefits to the participants. In most cases, indigent and vulnerable research participants lack the agency to satisfy themselves with the research processes. Third, the participants must trust that the researcher (Re) possesses the requisite attributes and has the intention to achieve the desired outcomes of the study. Unfortunately, the credentials of researchers (Re) are not readily available, and could be cryptic to decipher and comprehend by lay persons. Fourth, the majority of clinical trials require clinical equipoise in order to meet the ethical master.⁵ This means the researcher (Re) must be in a state of genuine uncertainty "... regarding the comparative therapeutic merits of each arm in a trial". Therefore, the researcher (Re) will have no preference, no evidence and no offer of benefit but uncertainty about a trial. Clinical equipoise does not offer research participants any objective level of beneficence, except equality of interventions. Yet there is an expectation of these subjects to leap in faith and trust, and thus subject themselves to the research process. It is hence critical to reciprocate participants' selfless acts through investment in beneficial research activities. Therefore, every step of the research process must reflect the sacrifice of the research participants including once the project is completed. The potential risks incurred by study participants should be balanced by the benefit of contributing to publicly available knowledge.⁶

2. Beneficence – the essence of human research

The principle of beneficence is embodied in the three major normative moralities namely consequentialism, deontology and virtue ethics.⁷ The consequentialist beneficence promotes social good, hence the expectation for research endeavours to increase utility. A benefit act is altruistic or utilitarian, to the extent that it promotes the "greatest

benefit for the greatest number.”^{8,9} This Bentham morality compels research processes to ensure (i) the prevention of harm or evil; (ii) elimination of harm or evil; (iii) doing and advocating for good.^{10,11} Therefore, the conduct of research should be underpinned by clear and explicit enumeration and articulation of risks and benefits. Research participants should be aware and well informed of how the benefits will be maximised and risks minimised. The vulnerability of research subjects justifies the obligation of the researcher to optimise the benefits for participants. This includes dissemination of critical information to participants and communities.¹²

Benevolence can also be viewed from a deontological perspective. Kantian benevolence, as described by Korsgaard and Cumiskey^{13,14}, offers an alternative view of the consequentialist normative morality. According to these authors, humanity has a duty “to offer other’s ends, the same status as one’s own”. This means the best outcomes that we wish for ourselves should be extended to others, thereby equalising the “ends” through the similar “means”.¹⁵ In applying Kantian benevolence to research, it would be expected that researchers, as custodians of knowledge, share information with the participants and stakeholders. In so doing, they would be treating the participants’ “ends” the same as their own, and not as “mere means to an end”. Therefore, researchers must provide information to research participants in a manner that they would themselves expect, had they been in the participants’ shoes.

3. Virtue – the undisputable disposition for benevolence

Virtue ethics emphasises character and traits of the possessors as foundational for this moral theory. This philosophical approach differs from deontology, which recognises virtues as traits of those who follow rules and for consequentialism for those who maximise good. Virtue is a disposition or moral excellence that “goes all the way down”. As Aristotle said: “... virtuous actions, those that express a virtuous trait, must be chosen for their own sakes”. Virtues are more than habits, but a way of life, how one conducts oneself, what one values, feels, desires and chooses. Benevolence represents virtues such as kindness, generosity, sympathy, compassion, empathy, loyalty and integrity.¹⁶ These virtues are recognised as critical, especially for health professionals including researchers. The virtue of benevolence is concerned with conduct in relationships, and how behaviour contributes to others’ welfare. A question can be asked: what virtues should researchers have to act right? Some attributes increase the propensity to act right and some wrong. Based on this moral theory, researchers must possess and exercise both intellectual and moral virtues. These include the virtues of critical thinking, perseverance, curiosity and open-mindedness. Similarly, researchers must be honest, just, fair, truthful and kind.

4. Justice – foul is not fair

The principle of justice as embodied in the Belmont Report refers to (i) distributive justice (ii) procedural justice and (iii) compensatory (retributive) justice. The most widely applicable concept of justice in research is distributive justice, which entails fair allocation of benefits and burdens emanating from research. Fair distribution could mean equitable or equal distribution of risks depending on the

context. Therefore, the conduct of research should be devoid of discrimination and exclusion of groups with potential to benefit from research interventions. Justice demands not to unduly subject certain individuals and groups to disproportionate risks, or enrolling participants unlikely to benefit from the research. Similarly, individuals and groups may not be systematically recruited into studies because of their vulnerability, manipulability and or accessibility.

The principle of procedural justice demands for researchers to engage potential participants and communities in a meaningful participatory process. This process should be just and fair, including timely and sustained involvement of participants. It is hence imperative for researchers to find mechanisms that foster early and sustained dissemination of information without prejudice.¹⁷ The principle of retributive justice entails compensation of participants for enrolling in the research. The manner and nature of compensation of research participants should be commensurate with the inherent risks of the study. The dissemination of research findings can serve as a form of compensation for risks and disproportionate sacrifices during the research process. Given that research is a public good, the dissemination of study findings goes beyond the research participants to involve future and prospective beneficiaries. These parties are morally entitled to receive some form of restitution.

CONCLUSION

Scientific discoveries have limited benefit or no utility if they remain unpublished or masqueraded as jargon in professional journals. Rapid translation or conversion of science into practice is highly desirable and can benefit participants and society. In this paper we have argued based on principles why it morally unjustifiable to withhold information from study participants and communities. It is advisable, if not mandatory, for research proposals to have very clear mechanisms for dissemination of study results. Research and ethics review boards should be held accountable for approving research proposals which are deficient in how they plan to disseminate study findings.

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