

An Ethic of Connectedness: Book Review of *The Connected Self: The Ethics and Governance of the Genetic Individual*

COMPTE RENDU / REVIEW

Vasiliki Rahimzadeh¹

Reçu/Received: 20 May 2014

Publié/Published: 1 Aug 2014

Éditeurs/Editors: Zubin Master & Marleen Eijkholt

2014 V Rahimzadeh, [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/)

Résumé

The Connected Self: The Ethics and Governance of the Genetic Individual met les lecteurs au défi de réfléchir à la fois à la complexité des enjeux sociaux et scientifiques liés à la recherche sur le génome humain et à leur influence sur les conceptions du soi. L'auteure, Heather Widdows, propose que les principes courants de la bioéthique (gouvernant la recherche biomédicale) ne reflètent pas suffisamment l'interaction des individus avec leurs communautés et les réseaux sociaux. Selon elle, la reconnaissance de telles interactions dans la compréhension de la génétique et de la santé est nécessaire afin que les politiques protègent réellement les participants des dommages qui pourraient en résulter.

Mots clés

génétique, gouvernance, éthique de la recherche, autonomie, boîte à outils

Summary

The Connected Self: The Ethics and Governance of the Genetic Individual challenges readers to engage in both the social and scientific complexities of researching the human genome, and how they influence evolving conceptions of the self. Heather Widdows proposes that the existing principles of bioethics, which govern biomedical research, insufficiently reflect the interactions of individuals to their communities and social networks, and argues that recognition of such interactions in understanding genetics and health is necessary for policies to effectively safeguard research participants from harms that may result.

Keywords

genetics, governance, research ethics, autonomy, toolbox

Affiliations des auteurs / Author Affiliations

¹ Centre of Genomics and Policy, McGill University, Montreal, Canada

Correspondance / Correspondence

Vasiliki Rahimzadeh, vasiliki.rahimzadeh@mail.mcgill.ca

Remerciements

L'auteur aimerait remercier Denise Avard, Ph.D., de lui avoir fait connaître *The Connected Self* et d'autres écrits de Dr Widdows, ainsi que de ses contributions conceptuelles relatives à la publication de ce compte-rendu.

Conflit d'intérêts

Aucune déclaré

Acknowledgements

The author would like to thank Denise Avard, PhD for introducing him to *The Connected Self* and other works of Dr. Widdows, as well as for her conceptual contributions in the publication of this review.

Conflicts of Interest

None to declare

Introduction

In her book, *The Connected Self: The Ethics and Governance of the Genetic Individual*, Heather Widdows challenges readers to recognize the imperative of reconciling the social and the scientific in the genomic era [1]. She makes the case for how healthcare decision-making is problematized – nay, misguided – by the overemphasis on individualist autonomy that contemporary bioethics espouses. Put simply, Widdows contends that the biomedical consent models established in the post-Nuremberg period have not been adapted in parallel with the new technological capabilities of the emerging 'omics' disciplines. Her call to make the neoliberalist view of autonomy and consent a bioethical artefact of this post-war period, is predicated on the idea that they no longer serve their intended purpose given the contemporary clinical or biomedical research landscape. While genomics research

is witnessing a ubiquitous translation into clinical medicine [2-6], antiquated conceptions of autonomy should plan their exit, making way for consent models that better reflect the interconnected ethos of genetic communities.

This book review summarizes Widdows' proposed ethics 'toolbox' and greater application of relational autonomy in the clinical translation of genomic/genetic research. The 'toolbox,' according to Widdows, better addresses the ethical challenges posed by the evolving landscape of genome-oriented medicine and public health. This review offers supportive commentary on the theoretical foundations used to construct her toolbox – namely how prevailing notions of autonomy are problematized in the context of public health genomics and should be modified accordingly. In my opinion, Widdows rightly identifies the most pressing issues facing these disciplines, though emphasis on normative theories of relational autonomy is not new to bioethics, and certainly not to feminist ethics discussions on consent or vulnerability. Nevertheless, *The Connected Self* makes an important field-specific contribution to broadening ethical discussions of genetic governance in the post-genomic era.

Connectedness

The genetic architecture of our genomes epitomizes complementarity and networking that direct cellular behaviours in our bodies. From *The Connected Self*, readers take away Widdows' recommendation that to envisage complementary ethics policies for guiding the uncertain technical futures of genome-oriented sciences is to appreciate how our genetic selves connect us to wider socio-political processes. In line with this view, genetic exceptionalism and reductionism runs afoul the cultural pluralism around definitions of 'health' and 'disease'. Central to Widdows' thesis is, therefore, that the self is a profoundly interrelated one that is embedded in a complex web of social and biological relations. This idea is grounded in moral philosophical traditions, yet has wider practical and empirical significance for future policies concerning genetic governance. Widdows argues: "Interrogating the pictures of the self upon which governmental mechanisms are built is not a dry or hypothetical philosophical discussion. Rather it affects real world policy and practice" [6]. Yet, individualist models of an (un)connected self underlie legal and governmental systems, and herein lies the problem. Widdows therefore makes clear in *The Connected Self* why it is critical to reshape discussions of autonomy, public goods and public health ethics that reflect the implied connectedness of our genetic selves. She argues that two intrinsic features of genetic information testify to this need: that, by nature, genetic material is both shared and identifying. Thus bioethical principles that appreciate the shared and identifying nature of genetics should be adopted if they are to complement the "correct picture of the self," [p. 30] according to Widdows.

Widdows furthermore draws attention to the historical legacy of the connected-self thesis, which finds its ancient and more recent conceptual roots in virtue ethics and feminist ethics, respectively. Despite this historical basis, bioethics disciplines continue to promote scholarship, policies and practices that "wholly disregard" the interests of genetically connected communities. She writes, "In fact so extremely biased has the [bioethics] framework become that often all that is protected are individual goods, and even then only those individual goods which are protected by choice...The bias towards individualism in bioethics is so ingrained that it is generally unquestioningly assumed" [p. 16-17]. Widdows chronicles the emergence of an individualized and principlist bioethics, and offers evidence of how healthcare professionalisms and methodologies perpetuate, rather than challenge this approach. The individual choice model is hence the barrier precluding reform, according to the author.

In response to the aforementioned concerns and failings of the predominant choice models, Widdows proposes an ethical toolbox inspired by a connected-self framework of goods and harms. She identifies five key advantages to adopting the toolbox approach, namely that it 1) always recognizes the connectedness of the genetic self, 2) offers sustainability and flexibility to evolve over time, 3) adapts accordingly to goods of all types (individual, community, institutional etc.), 4) promotes

ownership among participants without appealing to rights of propriety, and finally 5) contributes to social capital and engenders trust.

For example, Widdows argues that the ‘toolbox’ can be used to more thoughtfully reason through the ethical tensions between the rights of the individual and the community in debates on routine vaccination. Accepting the reality that a mix of threats to certain liberties exists in society – as opposed to relentless conflict between them – is where the ‘toolbox’ makes a valuable contribution to public health ethics discourse. Widdows argues that ethical analysis too often begins with identifying an appropriate framework and assuming that a particular dilemma will fit. The ‘toolbox’ aims to reverse this practice to ensure that ethical practices indeed meet the situation-specific needs of the case. The ‘toolbox’ then allows, as a critical first step, to identify the nature and distribution of goods and harms. As such, the toolbox is responsive rather than prescriptive.

Debates of Feminist Pasts

Widdows is not the first to suggest abandoning the narrowed version of autonomy long championed by bioethics scholars. Nor are the critiques of the informed consent process based on the individual choice model entirely unique [7, 8]. Actually, qualitative researchers have perhaps cried the loudest against such models [9]. Widdows admits this in her introduction to feminist ethics theory, citing the important works of Held, Gould and Noddings to name a few. Feminist ethics is indeed credited with introducing the concept of relational autonomy, the true mechanism by which individuals discern what is morally “correct” through the social relationships and ‘connectedness’ with others according the aforementioned scholars. Concern for the values and virtues of both the individual and community effectively lay the theoretical foundation for the connected-self philosophies based in the feminist ethics schools of thought. To be sure, I find it reassuring that there is a growing body of interlocutors – especially in bioethics and genetics – who reinforce the truly relational nature of autonomy. In my view, advocates of such approaches to autonomy, including Widdows, however have yet to provide concrete solutions for the logistical challenges of operationalizing these approaches in clinical or research practice.

Rights of Young Connected Selves

Widdows argues that members within a group may evoke an individualist model of choice when group consent poses “non-trivial” dangers to the individual. Though Widdows briefly addresses this tension, I find the heterogeneity of groups – and qualitatively different perceptions of risk or danger that can arise as a result – should perhaps be the subject of more in-depth discussion in book. Children’s consent to non-therapeutic research, for example, illustrates this point. Children – often identified in healthcare settings as more or less undifferentiated groups of individuals – are unable to consent to valuable research in many jurisdictions. This includes research on at-risk behaviours such as substance abuse, sexual activity, but also on mental illness and end of life decisions. In my view, these circumstances complicate the use of Widdows’ ‘toolbox’ in that it has trouble responding to individual children’s needs outside institutional or social groups they associate with, including their family. Mason and Steadman speak to this issue in relation to children’s participatory agency, and (citing Makrinotti) describe how ‘familialism’ can be duly oppressive and overly simplistic [10].

Consent: A Point of No Return?

Moreover, Widdows assumes consent is a one-off event, taking place at a single moment in time. Rather, it is widely recognized in the literature that the gold standard for consent is an iterative and continual process, particularly for genetic research involving vulnerable groups [11]. Although this does not change the relational aspects of consent or the sociocultural influences of decision-making that underpin it, the distinction is an important one for a number of reasons. First, consent as a

process departs from the individualistic construction of autonomy that Widdows contests. Second, it places a responsibility on researchers to minimize the effects of response biases and power differentials that are often characteristic of participant-researcher interactions. Participants are afforded the opportunity to evaluate their willingness, and the consequences and benefits of their participation, at iterative stages in the research process.

Conclusion

The richness of Widdows' analyses is clear. Her sobering perspectives on the future directions of public health ethics in genetics sounds an important wake-up call for scholars and scientists in the field alike. Her reflections and insights for genetic governance in *The Connected Self* should be recommended to emerging practitioners in genomics, law and/or health policy. Though not the first to employ feminist ethics theories on autonomy and choice, Widdows' confirms their permanence in discussions on genetic governance in the post-genomic era. The circumstance-specific challenges of her proposed ethical 'toolbox', namely as they relate to consenting minors, do not however take away from its ability to offer a guidance framework for policy concerning genomic research and medicine. In this regard, *The Connected Self* is provocative, forceful and brave. No doubt, the book makes a valuable contribution to the movement towards a more inclusionary, reflexive and contextually embedded bioethics for genetic governance.

List of References

1. Widdows H., [*The Connected Self: The Ethics and Governance of the Genetic Individual*](#) Cambridge: Cambridge University Press; 2013
2. Sander C., Genomic Medicine Health and the Future of Science, *Science*, 2000; 287(5460): 1977-1978.
3. Guttmacher A., [Genomic medicine—A Primer](#). *N Engl J Med*, 2002; 347: 1512-1520.
4. Green E.D., Guyer M.S., National Human Genome Research Institute, [Charting a Course for Genomic Medicine from Base Pairs to Bedside](#), *Nature*, 2011; 470: 204-213.
5. Manolio T. A., Chisholm R. L., Ozenberger B., Roden D. M., Williams M. S., Wilson R., Bick D., Bottinger E P., Brilliant M. H., Eng C., Frazer K. A., Korf B., Ledbetter D. H., Lupski J. R., Marsh C., Mrazek D., Murray M. F., O'Donnell P. H., Rader D. J., Relling M. V., Shuldiner A. R., Valle D., Weinshilboum R., Green E. D., Ginsburg G. S., [Implementing Genomic Medicine in the Clinic: the Future is Here](#), *Genet Med*, 2013; 15(4): 258-267.
6. MCGowan M.L., Settersten R. A. Jr, Juengst E.T., Fishman J.R., Integrating Genomics into Clinical Oncology : Ethical and Social Challenges from Proponents of Personalized Medicine, *Urol Oncol*, 2014; 32(2): 187-192.
7. Appelbaum P. S., Roth L. H., Lidz C. W., Benson P., Lidz W., Roth H., False Hopes and Best Data: Consent to Research and the Therapeutic Misconception, *Hastings Cent Rep*, 1987; 17(2): 20-24
8. Corrigan O., [Empty Ethics: the Problem with Informed Consent](#), *Sociol Health Illn*, 2003; 25(3): 768-792
9. Guillemin M., Gillam L., Ethics, Reflexivity, and "Ethically Important Moments" in Research, *Qual Inq*, 2004; 10(2): 261-280.
10. Mason J., Steadman B., [The Significance of the Conceptualisation of Childhood for Child Protection Policy](#), *Family Matters*, 1997; 46: 31-36.
11. Geller G., Botkin J. R., Green M. J., Press N., Biesecker B. B., Wilfond B., Grana G., Daly M. B., Scheneider K., Kahn M. J., [Genetic testing for susceptibility to adult-onset cancer. The process and content of informed consent](#). *JAMA*, 1997; 277(18): 1467-1474.

Further readings

Books

1. Held, V., [*The Ethics of Care: Personal, Political, and Global*](#), Oxford; Oxford University Press; 2005
2. Gould, C.C., [*Interactive Democracy: The Social Roots of Global Justice*](#), Cambridge; Cambridge University Press; available from September 2014
3. Noddings, N., [*Starting at Home: Caring and Social Policy*](#), Berkeley, CA.; University of California Press; 2002

Book reviews

1. University of Birmingham, [News: The Connected Self: The Ethics and Governance of the Genetic Individual](#), University of Birmingham, 2012; October 24
2. Simkulet W., [Review - The Connected Self: The Ethics and Governance of the Genetic Individual by Heather Widdows](#), Metapsychology Online Reviews, 2013; 17(48)