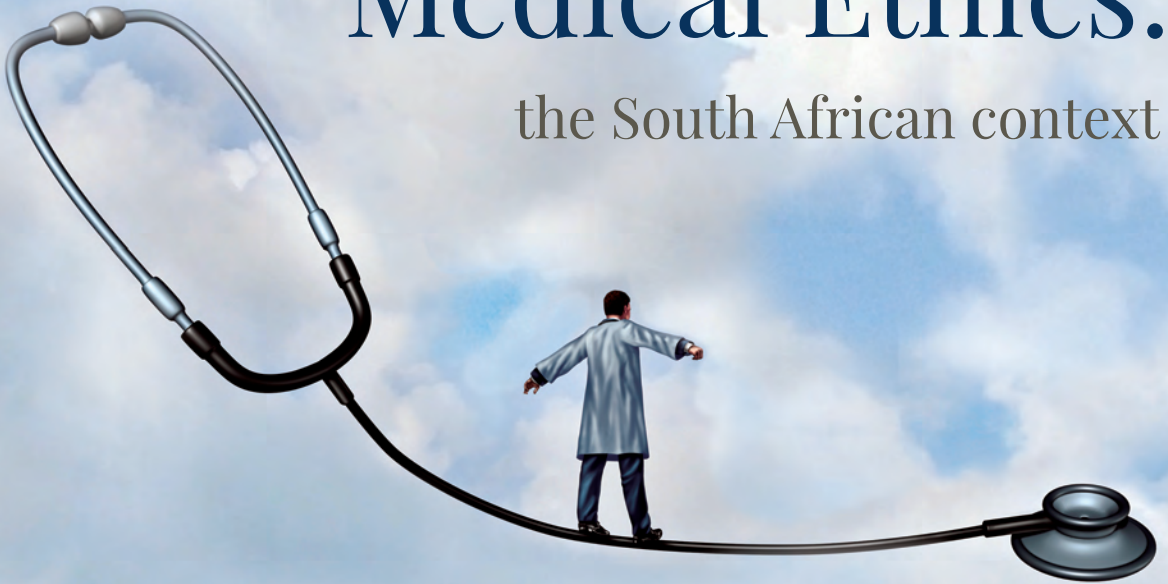


Challenges in Medical Ethics:

the South African context



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Towards a More Globally Inclusive and Relevant Neuroethics

Considerations for developing the field in Africa

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Keywords: equity; ethics of neuroscience; global mental health; inclusivity; neuroethics; neuroethics activism; neuroethics in Africa; neuroscience of ethics; solidarity

9.1 INTRODUCTION

Neuroethics is an interdisciplinary field, encompassing the full array of ethical, legal, and social implications (ELSI) of our study, understanding and deepening knowledge of the human brain, as afforded by the neurosciences, including our ability to increasingly and potentially alter or enhance our brains, by way of neurotechnologies. Neuroethics, as a distinct field of focus, originated in 2002 following various conferences held in the United States and Canada, all of which focused explicitly on the ELSI of developments in neuroscience.¹ These developments, and increased ethical interest, followed progress made during the ‘decade of the Brain’ in the 1990s, a movement initiated by the Library of Congress and the National Institute of Mental Health in the United States, and subsequently embraced across the globe (Buniak, Darragh & Giordano, 2014; Tandon, 2000). The aim of declaring the decade of the brain was twofold: to provide more impetus and funding for research of the neurobiological basis of

1 Most notably, the Dana Foundation’s (2002) *Mapping of the Field* conference which included many of the thinkers who have subsequently become renowned in the field. For more information about the participants in this conference see: <https://www.dana.org/article/neuroethics-mapping-the-field/>

various disorders, with implications for improved treatment, and to improve public understanding of the human brain.² The scope of the field of neuroethics has grown significantly in subsequent decades, as neuroscience itself advances, and increasingly includes non-medical applications, as well as more philosophical and speculative areas of interest.

While the field of neuroethics is broad in scope, its conceptualisation and dominant areas of interest have been largely shaped by the input of those situated in high income countries (HICs), with less participation from ethicists working in low-resourced contexts (Lomber & Illes, 2009). In particular, participation of African scientists and ethicists in neuroethics discussions has been lacking, although this seems to be gradually changing, given recent contributions.³ There are various possible reasons for these low levels of participation, but it is likely due, in part, to the specialised nature of the field, coupled with the fact that there are fewer trained bioethicists in resource strained contexts, like Africa (Andoh, 2013). It may also be that some of the concerns that have dominated the field of neuroethics are regarded as less pressing in contexts where neuroscience is not established to the extent that it is in HICs (Maina et al., 2021), or where more urgent concerns compete for ethicists' attention. Given that neuroethics responds to developments in neuroscience, it is likely that interest will grow as neuroscience becomes more established in African contexts.

The reasons for this underrepresentation aside, it has been argued that the field of neuroethics suffers from a lack of global diversity (Buller, 2020; Matshabane, 2021) and that a "more inclusive ... 'cross cultural', 'global' or 'international' neuroethics is needed" (Lanzilao et al., 2013; Salles, Herrera-Ferra & Cabeta, 2018). However, it is not self-evident what would constitute a more globally inclusive and diverse neuroethics, or what would suffice as having made inroads in this regard (Lanzilao et al., 2013; Salles et al., 2018). At the very least, it would firstly necessitate more equitable participation and collaboration between scientists and neuroethicists from different contexts, thereby ensuring that the

- 2 This focus has continued in the United States with the establishing of the National Institute of Health's Brain Initiative in 2013, which includes a neuroethics working group. The International Brain Initiative (IBI) was formed in 2017 and includes members from Japan, China, Korea, Europe, the US, Canada and Australia. The IBI also includes a neuroethics working group.
- 3 See various chapters in the recent volume *Global Mental Health and Neuroethics* (Stein & Singh, 2020) and Cordeiro-Rodrigues and Ewuoso (2021) which explores an *Afro-Communitarian Relational Approach to Brain Surrogates Research*. There is also a strong interest in the philosophical and ethical implications of cognitive enhancement in South Africa, for example, see Beyer, Staunton and Moodley (2014), and Verster and Van Niekerk (2012).

field considers an array of perspectives, methodologies, and concerns. Secondly, it would also likely entail paying more attention from an ethical perspective to gaps in the availability of neuroscience technologies, resources, and research capabilities between HICs and low-resourced countries, and the medical and scientific priorities pertaining to brain and mental health in these latter contexts. Thirdly, an evidence-base can be built comprising the perspectives of underrepresented populations on established neuroethics concerns, so that findings applicable to HICs are not erroneously generalised to other contexts. Fourthly, there is also the more ambitious task of reconfiguring the normative foundations, or underlying moral framework of the field, to encompass a more global focus and relevance (Shook & Giordano, 2014). These are just four potential ways in which the field of neuroethics stands to be enriched and diversified that will be considered in the second half of this chapter, but there are likely to be many more options.

In light of these observations, the point of departure in this chapter is that there is a need to critically engage with neuroethics, with the aim of working towards a field that is more globally informed and inclusive of a range of concerns and perspectives. Given that neuroethics is not well established in South Africa, in the first half of this chapter I provide an overview of the field, including an outline of its traditional conceptualisation, with examples of the areas in neuroscience that are typically identified as ethically concerning or interesting.⁴ In the second half of the chapter, based on the four possibilities mentioned above, I provide four suggestions for developing the field in African contexts, thus working towards increasing its global relevance. My suggestions include: building neuroethics capacity through the growth of neuroscience research collaborations across the African continent; exploring congruence with the global mental health movement to engage in neuroethics activism to address brain and mental health research and treatment priorities in Africa; drawing on the strong tradition of empirical ethics research on the continent to establish an evidence-base comprising the perspectives of underrepresented populations on established neuroethics concerns; and finally, engaging with the underlying moral framework of neuroethics by drawing on African moral frameworks.

While developing neuroethics in Africa will benefit those who are impacted by its reach in African contexts, the field itself also stands to benefit, insofar as it is recognised that any field or area of focus is improved by including a plurality of perspectives, concerns, and input.

4 Given the vast terrain of the field of neuroethics, I will not attempt to be exhaustive in this overview.

9.2 DEFINING THE FOCUS OF THE FIELD

While there are various definitions that may give us an idea of the focus and scope of neuroethics, one has been particularly influential. Based, in part, on the input of participants in attendance at one of the seminal conferences which marked the formal start of the field of neuroethics in 2002, Adina Roskies offered two distinct areas of focus the field should concern itself with: “the ethics of neuroscience” and “the neuroscience of ethics” (2002). This clever distinction has largely informed the conceptualisation of the field going forward and will be discussed next.⁵

9.2.1 The ethics of neuroscience

The ethics of neuroscience encompasses two subdivisions. The first focuses on the ethical concerns associated with neuroscience-related research, or more specifically, ethical research design of studies of the brain, including translational and clinical studies. This includes a focus on cross-cutting ethical issues such as minimising risk for research participants, feedback of incidental findings (Illes et al., 2006), ensuring the privacy of participants in the context of data sharing, given the sensitivity of information about the brain (Fothergill et al., 2019; White, Blok & Calhoun, 2022), and challenges with securing informed consent, particularly in cases where participants may have impaired decisional capacity due to neuropsychiatric disorders (Vaishnav & Chiong, 2018), among others. In this area there is much overlap with traditional research ethics, and in particular, with the ethics of genetic studies (Tairyan & Illes, 2009). This practically-oriented domain of neuroethics also includes ethical issues arising from clinical care and practice in the fields of neurology, neurosurgery, psychiatry, and their paediatric specialisations (Chatterjee & Farah, 2013).

The second subdivision of the ethics of neuroscience is vast in its scope and focuses on the ELSI of the findings and applications of neuroscience-related

5 While this distinction has been extremely influential, it should not be taken as implying that these two areas bear no impact on each other, or that one is descriptive whilst the other is normative (Shook & Giordano, 2014). In fact, there is much interplay between the two domains and the belief in a ‘purely descriptive’ neuroscience of ethics vs a normative ethics of neuroscience belies the fact the normative underpinnings of the former are simply better hidden, but nevertheless reflect a particular perspective on morality (Shook & Giordano, 2014). As posited by Shook and Giordano, even the assumption that neuroscience can inform or alter our self-understanding is a normative one.

research and neurotechnologies.⁶ There is consensus that this area of neuroethics elicits unique ethical concerns due to the inextricable relationship between the mind and the brain,⁷ so that information about the brain tends to deeply impact our sense of self, and concomitantly, our conceptions of identity, personhood, and agency, with various implications. One of these implications is a more “mechanistic understanding of brain function” and the self (Roskies, 2002:21). In this regard, there is a strong focus on the communication and interpretation of information about the human brain in public contexts and the way in which this increased knowledge could, and should, impact our social and legal institutions (Illes & Racine, 2005).⁸ To ascertain how information about the brain is interpreted by laypersons, this area of the ethics of neuroscience includes an emphasis on the importance of qualitative studies, also known as empirical ethics, to investigate the interpretations and views of populations in different socio-cultural contexts with implications for health outcomes and addressing stigma, among others. It is not only the implications of public interpretations – and misinterpretations – of this increasingly sensitive and improved knowledge of the brain that is a topic of focus, but also the uses this knowledge could be put to that is of ethical interest. In what follows, I provide a few examples of the kinds of topics that have dominated the terrain of the ethics of neuroscience.

An area of considerable interest is the ELSI of neuroimaging studies, and in particular, functional magnetic resonance imaging (fMRI) correlation studies, which measure and map brain activity while a participant performs a particular mental operation of interest. While there is a strong focus on ethical issues elicited by the potential of imaging modalities for improved screening, diagnosis, and prediction of risk for neurological and psychiatric disorders (Illes et al., 2007; Lane, Hunter & Lawrie, 2020), what is of particular interest to many neuroethicists is the use of fMRI to identify the neural correlates of certain non-medical mental states, socially-oriented dispositions, and behavioural traits. For example, studies have detected the neural correlates of mental states and traits ranging from implicit racial bias, sexual preference, deception, risk aversion,

6 See Martin et al. (2016) and Becker et al. (2017) for a systematic survey of the literature pertaining to the two subdivisions of the ethics of neuroscience.

7 While it is unlikely that there will ever be agreement about the mind-body problem, referring to the question of how conscious, immaterial, mental states arise from the brain, which is physical in nature, it is undeniable, at least in terms of current capabilities, that without a brain there can be no mind. In this way, it is uncontroversial to describe the mind and the brain as inextricably related.

8 The belief that advances in our understanding of brain structure and function can add to our understanding of complex behaviour, and transform our institutions, is evidenced by newly formed fields such as “neurolaw, neuroeconomics, neurophilosophy, neuromarketing, and neurofinance” (Schultz, 2018).

trustworthiness, cooperativeness, and religious experience, to predisposition for certain behaviours, such as criminality or likelihood of recidivism (Racine, Bar-Ilan & Illes, 2006). Of course, fMRI requires a high degree of interpretation and inference (Roskies, 2008), and is not yet sufficiently robust to be used outside of research contexts.

However, as these technologies improve and concomitantly, our ability to monitor, identify, and predict mental states and behaviours such as the aforementioned, this may have significant future implications for mental privacy and a potential for misuse in insurance or employment contexts. Should these findings become sufficiently robust in the future, some of the issues that will have to be addressed will be: how, to what extent, and in which contexts imaging findings should be used and when, if ever, should we act upon risk or susceptibility information (Fitzpatrick, 2006).

At an even more fundamental level, evidence of processes in the brain, over which there seems to be minimal control, implies a need to reconsider certain assumptions regarding agency and possibly free will (Levy, 2012). Of course, the challenge posed by these findings may be a case of ‘old wine in new bottles’ insofar as our existing frameworks of free will are able to accommodate them without significant disruption.⁹ However, newly established fields such as neurolaw and neurocriminology imply that many think the legal system stands to be impacted, in some way, by neuroscience study findings, indicating the neurobiological underpinnings of criminal behaviour (Glenn & Raine, 2014; Straiton & Lake, 2021). Difference does not imply dysfunction, and the causes of criminal behaviour are undoubtedly complex, however, the question of whether, and to what extent, our notions of moral responsibility and concomitantly, culpability and blameworthiness, should be reconfigured to account for these differences in some way, remains a valid area of discussion.

Other philosophical concepts stand to be challenged due to the implications of the use and effects of certain psychopharmacological interventions and neuro-technologies for both treatment and enhancement purposes. In terms of the former, much has been written about the perceived impact, on personal or narrative identity, of interventions like deep brain stimulation (DBS), which is

9 The main challenge for accounts of free will has been to provide a theory that preserves it, given the recognition of determinism. Compatibilism is the view that free will exists despite determinism and there have been effective arguments in support of this view, which is the dominant view in analytic philosophy. As pointed out by Wassermann and Johnson (2014), the question that requires answering in neuroethics is whether “neuroimaging pose[s] new challenges to the compatibilist views that have predominated in moral and legal thinking for the past fifty years.”

generally used to treat severe motor dysfunction associated with conditions such as Parkinson's disease and other movement disorders, as well as treatment resistant psychiatric disorders.¹⁰ Impacts on identity are attributable to the sometimes significant and abrupt personality and behavioural changes that follow from DBS (Jotterand & Giordano, 2011). While it has been argued that the threat to identity posed by DBS has been overstated and applies to a static and thin conception of identity (Baylis, 2013), the personality changes associated with DBS undoubtedly provide us with opportunities to advance our understanding of the neurobiological basis of identity and our metaphysical notions of free will and agency (Lipsman & Glannon, 2013).

The ethical implications of neuroenhancement, not only through off label use of medications, but in the future, through various neural devices and technologies, currently in development for treatment purposes, is also another area that has received considerable attention.¹¹ Bioenhancement is generally defined as using biomedical interventions to improve species' typical or 'normal' functioning and capacities. This is contrasted with the treatment of disease, disorder, or dysfunction to restore functioning to such levels (Boorse, 1975; Daniels, 2000). This distinction has, however, been subject to extensive contestation, given conceptual challenges in establishing what constitutes normal mental functioning as opposed to dysfunction in the face of considerable human variation and the inescapably normative component of such a distinction (Bostrom & Roache, 2008; Buchanan et al., 2009; Harris, 2007; Kass, 1998; Savulescu, Sandberg & Kahane, 2011).

These challenges aside, areas of neuroenhancement that have been discussed, in terms of their ethical implications, include various aspects of cognition, including memory and attention (Racine, Sattler & Boehlen, 2021), wakefulness (Ravelingien & Sandberg, 2008), mood (Palk & Stein, 2020a), and even pro social attitudes like empathy, referred to as moral bioenhancement (Persson & Savulescu, 2012). Cognitive enhancement, however, receives significant attention in discussions of neuroenhancement. Arguments in support of neuroenhancement generally invoke a right to cognitive liberty, referring to the view that the decision of whether or not to enhance is an individual one that should be made without external interference. Arguments against enhancement encompass a range of both practical, consequentialist concerns, which hold in common the view that, in some way, enhancements will render us worse off, and in-principle

10 See Martin et al. (2016) for a list of papers on this issue.

11 See Becker et al. (2017) for a comprehensive list of publications that have focused on the ethics of various forms of neuroenhancement.

concerns,¹² which draw on non-consequentialist approaches such as concerns about inauthenticity or the unnaturalness of biomedical enhancements (Fukuyama, 2002; Kass, 2003; Sandal, 2007).

9.2.2 The neuroscience of ethics

The above examples are just a few areas of focus within the vast domain of the ethics of neuroscience. The second distinction identified by Roskies (2002:22), the neuroscience of ethics, and morality itself is narrower and more specialised in its focus.¹³ This area aligns with the fields of neurophilosophy or experimental philosophy (Klar, 2021). Studies in this domain aim to identify the neurobiological underpinnings of moral cognition and emotion, and to deepen our understanding of how this informs our moral judgements and social behaviours.¹⁴ As Giordano, Becker and Shook (2016) put it: “mapping the ‘moral brain’”. However, this description should not be taken as indicating that there are mechanisms and processes in the brain dedicated solely to moral deliberation. Rather, what seems to be the case is that the neural bases of moral judgements are largely the same as those involved with the deliberation of matters deemed salient to individuals and which require them to assess the advantages and disadvantages associated with particular courses of action (Giordano et al., 2016).

Of particular interest is the relationship between this potential ‘neuromorality’ and our approaches to ethical decision-making, which have traditionally fallen with the domain of moral philosophy. The various moral theories which have dominated the field of ethics are themselves informed by widely held moral intuitions and assumptions regarding the appropriate basis for moral decision-making. However, these approaches presuppose certain metaphysical notions such as the freedom of the will to form intentions which can be deliberated and acted upon in a rational and relatively straightforward manner. They also presuppose a relatively strict delineation between cognitive and affective processes in moral decision-making. These assumptions, and in particular the reliability of the moral

12 The distinction between in-practice and in-principle ethical concerns is a useful one suggested by Agar (2015). While in-practice concerns are consequentialist in nature, in-principle objections draw on non-consequentialist approaches and generally provide arguments to support the position that neuroenhancement is ethically undesirable, regardless of any practical benefits or avoidance of harms that it may produce.

13 See Darragh, Buniak and Giordano (2015) for a systematic survey of the literature addressing the neuroscience of ethics and Racine et al. (2017) for a critical discussion of the kinds of studies that comprise the field.

14 This focus ties in with that of the recently formed, and wider, field of social neuroscience which investigates the relationship between brain structure and function and social behaviour and interactions.

intuitions that inform certain theories, have been challenged by neuroscience study findings (Cushman, Young & Greene, 2010). The neuroscience of ethics thus includes both the empirical study of moral decision-making processes and behaviour, including studies of neurological conditions and damage that impact these processes and behaviour (Damasio, 2007) and the often controversial, normative interpretations, inferences, and discussions of these study findings (Churchland, 2013).

While there is optimism regarding the potential of the neuroscience of ethics to contribute to our understanding of morality, these studies, and the conclusions drawn from them, have not been without criticism (Berker, 2009; Racine et al., 2017). In this regard, we should not overstate what such studies can tell us. As pointed out by Damasio (2007), such studies have primarily focused on “reveal[ing] patterns of neurobiological activity in response to, and involved in certain types of situations, dilemmas, and activities that are construed to be moral and/or ethical”.¹⁵ However, criticisms aside, the neuroscience of ethics arguably remains an area of potential long-term significance and interest.

¹⁵ Joshua Greene’s research is frequently cited as it was the first of its kind in what came to be known as the neuroscience of ethics, but also due to the controversial normative inferences that Greene makes elsewhere (Greene, 2008). Since 2001, Greene has used fMRI to study the brain activity of research participants when responding to moral dilemmas, with preliminary findings indicating that both cognitive and affective responses play a pivotal role in moral judgements (Greene et al., 2001). More specifically, Greene posits that his studies show that differences in participants’ responses to dilemmas, such as the two famous variations of the Trolley problem, are informed by the strength of participants’ emotional responses to the dilemma, rather than the reasons which are typically offered. The more personal or direct the involvement of the participant with the dilemma that is sketched out, the stronger the emotional response and vice versa. Greene posits that certain moral judgements, particularly those which involve the violation of deontological restrictions, typically associated with Kantian style, “higher order” reasoning, are, in fact, a product of the strength of the emotional response which is then rationalised post hoc. But, he points out that imaging indicates that “typically consequentialist”, utilitarian judgements indicate the presence of the kind of cognitive processes typically associated with deontological approaches. Greene then argues that these findings have normative implications for the suitability of deontology as an approach to morality. Insofar as automatic emotional responses are the product of biases, social conditioning, and various other factors, the argument is that an approach such as consequentialism which is characterised by more cognitive processing and slower reactions to the moral situation in question would be a preferable form of ethical decision-making in contemporary contexts (Greene, 2008).

9.3 CONSIDERING A GLOBALLY INCLUSIVE AND DIVERSE NEUROETHICS FROM AN AFRICAN PERSPECTIVE

As mentioned above, with the field of neuroethics entering its third decade, there have been increasing calls advocating for a more internationally or globally relevant neuroethics. It is likely that this internationalisation of the field will progress in a piecemeal manner as awareness of this important goal grows and more contributions are made. In terms of the potential trajectory of an increased neuroethics engagement in African contexts, two points of meaningful entry into debates seem appropriate.

Firstly, given resource scarcities that significantly impact access to treatment and research of mental disorders on the continent (Sankoh, Sevalie & Weston, 2018), neuroethics engagement that is responsive to these more immediate and practical concerns seems fitting. This would include neuroscience research ethics issues related to mental health studies in African contexts as well as establishing an evidence-base through conducting empirical studies to assess the beliefs and attitudes of populations regarding neurological and psychiatric disorders, and their interpretations of such study findings, which stand to have implications for health outcomes.

Secondly, the rich variety of African moral frameworks and theories which respond to ethical challenges from a more communitarian or relational perspective offer an appropriate foundation for engaging with neuroethics concerns in these contexts. However, there is also a significant contribution to be made conceptually, and foundationally, in terms of articulating the principles and values prevalent in African contexts that could enrich the dominant bioethics paradigm itself, which has largely relied on Beauchamp and Childress' principlism (2019), and which informs neuroethics, as part of bioethics. The above areas of focus are likely to be followed by engagement with the wider societal implications of neuroscience study findings and neurotechnology applications in various areas, including their impact on notions like personhood and identity in these contexts.

In what follows, I provide suggestions for establishing more of a neuroethics presence in African contexts, as well as some potential areas in which local bioethicists could make significant contributions, thus enriching the field of neuroethics. I have grouped my suggestions in accordance with the four possible approaches to developing a more globally relevant neuroethics, mentioned in the introduction.

9.3.1 Building neuroethics capacity through the growth of neuroscience research collaborations across the continent

Working towards a more globally relevant and diverse neuroethics, inclusive of an array of perspectives, methodologies, and concerns, requires, first and foremost, focusing on the practical goal of increased and meaningful participation of bioethicists and neuroscientists (with an interest in neuroethics) from underrepresented contexts, such as Africa. As mentioned above, a growth in engagement with themes in neuroethics in Africa is likely to be proportionate to the growth of neuroscience on the continent.¹⁶ Neuroscience research in Africa, however, remains comparatively minimal¹⁷ due to various factors, including a lack of resources, funding, infrastructure, and scientists specialising in the requisite areas (Maina et al., 2021). Despite this, there have been concerted efforts to address the African neuroscience research gap in recent years (Yusuf, Baden & Prieto-Godino, 2014; Karikari, Cobham & Ndams, 2016; Balogan et al., 2018; Baden et al., 2020),¹⁸ with cause for optimism given indications of a decisive increase in publications of studies led by African scientists in recent years (Maina et al., 2021).¹⁹

International research collaborations involving multiple study sites and partners, not only globally but also across the African continent, are another effective way of fostering neuroscience networks and research capacity as well as cultivating

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- 16 The recently inaugurated Neuroscience Institute at the University of Cape Town and the subsequent establishing of an arm within the associated Brain Behaviour Unit, focused on advancing neuroethics in Africa, provides support for this assumption.
 - 17 A recent survey of the neuroscience-related literature between 1996 to 2017 identified 5 219 publications led by African scientists, with 77% of these publications produced by only five African countries (Egypt, South Africa, Nigeria, Morocco, and Tunisia) (Maina et al., 2021). The predominant focus of these studies is on neurodegeneration and brain injury, which is appropriate, given figures indicating that by 2050 just under three-quarters of persons living with dementia-related conditions will reside in LMICs (Baden et al., 2020).
 - 18 An example is the formation of the UK-led non-profit organisation, TRenD in Africa (Teaching and Research in Natural Sciences for Development in Africa) in 2011. This organisation comprising volunteers from various universities across the globe and partners from African universities, focuses on capacity building of scientists (including neuroscientists) from Africa with the goal of promoting independence, empowerment, and scientific exchange as well as public and policy engagement on neuroscience-related issues (Baden et al., 2020).
 - 19 Evidence of the growth of neuroscience on the continent is also indicated by increased attendance at conferences presented by the Society of Neuroscientists of Africa (SONA) which operates as an overarching organisation for various neuroscience groups throughout Africa, as well as increases in applications for neurosciences study programmes in African institutions (Maina et al., 2021).

an interest in neuroethics on the continent. As mentioned above, developing research ethics capacity related to neuroscience studies of this kind would be an obvious point of meaningful entry into the field for local ethicists, given the urgency of the psychiatric and neurological disease burden on the continent. Global neuroimaging genetics networks such as ENIGMA (Enhancing Neuroimaging Genetics through Meta-Analysis), comprising scientists from over 45 countries, are an example of such a collaborative endeavour (Palk et al., 2020).²⁰ While international collaborations of this kind hold great benefits in terms of collectively addressing global mental health inequities and fostering science diplomacy insofar as they are led and funded by HICs, attention must be paid to issues such as equitable data sharing, among others (Palk et al., 2020). However, with over 50 working groups focusing on various neurological and psychiatric disorders, consortia such as ENIGMA are in a good position to contribute towards neuroethics capacity building in underrepresented contexts (Palk et al., 2020).

Exemplars in the field of neuropsychiatric genetics that can provide a model for capacity building of neuroethics in Africa are the Human Heredity and Health in Africa (H3Africa) Initiative comprising genomic studies at multiple sites across Africa, focusing on various disorders and diseases, including mental disorders (Mulder et al., 2018) and the Neuropsychiatric Genetics of African Populations Consortium (NeuroGAP) which investigated psychotic and neurodevelopmental disorders with sites in four African countries (Stevenson et al., 2019). While both consortia are led and funded by institutions from HICs, what is significant for the topic at hand is that both formed dedicated ethics working groups, comprising bioethicists from across the African continent. These groups have focused on ethical and regulatory issues arising from the studies they are attached to, using ethical frameworks that are sensitive to the socio-cultural context, as well as conducting related empirical ethics research to ascertain the attitudes and beliefs of different populations about genetic information, particular explanatory models of disease, the stigmatising of certain disorders, and views about feedback of study findings, among others (De Vries, Landouré & Wonkam, 2020; Matimba et al., 2022; Ralefala et al., 2021). Along with the ethics and regulatory working group, H3Africa includes working groups focused on outreach and communication as well as ethics and community engagement (Tindana et al., 2015).

20 Imaging genetics combines imaging modalities with neuropsychiatric genetics study findings to decipher the role of genetic variation on brain structure and function, thus deepening our understanding of neuropsychiatric disorders. Such collaborations, in which brain imaging data is pooled and compared, and study findings can be replicated, are crucial given the significant costs associated with imaging studies, which restrict sample sizes, resulting in underpowered study findings (Thompson et al., 2020).

The NeuroGAP consortium includes the Africa Ethics Working Group (AEWG) which focuses explicitly on issues arising from neuropsychiatric genetic studies and findings in African contexts. Membership involves access to funding and training opportunities, establishing meaningful bioethics networks with colleagues in other African countries and globally, as well as capacity building of junior colleagues entering the field of bioethics.²¹ Establishing these kinds of working groups for neuroethics in Africa is arguably one of the most effective ways of encouraging the growth of the field on the continent in the same way that the ethics of genetic studies and practice, commonly described as ‘genethics’, has become a significant area of focus in this context.

9.3.2 Exploring congruence with the global mental health movement to engage in neuroethics activism to address brain and mental health research and treatment priorities in Africa

As mentioned above, the urgency of addressing inequities in brain and mental health research and treatment in Africa requires neuroethics engagement that is responsive to these medical and research priorities. The second suggestion therefore includes approaching the development of neuroethics on the continent using the tools of bioethics activism. Drawing from the related field of global mental health could also be useful in this regard and in particular, recent work which has explored the intersection between neuroethics and global mental health, including an entire volume dedicated to the topic (Stein & Giordano, 2015; Stein & Singh, 2020).

Global mental health has recently emerged both as an independent field and an increasing organised social movement, informed by the recognition of an ethical obligation to rectify unjust mental health inequities between nations, insofar as they were caused by exploitative conditions in the colonial era (Patel, 2012; Patel et al., 2018). The overarching aim of the field is thus to cultivate equity in access to mental health in low resourced contexts by means of “efficient, innovative, cost-effective approaches that are context-sensitive and evidence-based” (Palk & Stein, 2020b). Given congruence between this aim of global mental health and the need for a neuroethics engagement in Africa that is responsive to such needs, a “neuroethics of global mental health” (Stein & Giordano, 2015) is a fitting potentially fruitful domain within which ethicists working in these contexts could situate themselves. Moreover, this domain would include not only a focus on fleshing out this potential domain from the perspective of ethicists working

21 See Kamuya et al. (2021) for a discussion of the Africa Ethics Working Group (AEWG) as a model of collaboration for psychiatric genomic research in Africa.

in African contexts but equally important, it would benefit from neuroethics advocacy or activism.

As argued by Rogers and Scully (2021), insofar as it is directed at normative ends, “bioethics is inescapably partisan ... [w]here disagreement arises is over the degree to which bioethicists should be activists”. In certain areas, however, an activist approach is clearly justified and needed. Neuroethics activism may take many different forms, at various levels. Meyers (2021) considers activism in bioethics at “micro, meso, and macro” levels whilst Draper (2019) provides a taxonomy to identify what can be considered activism in bioethics. An obvious form of advocacy would be to create awareness in the public realm and the academic literature of the kinds of concerns that would occupy a neuroethics of global mental health and the need to develop the field in Africa.

Other options that have been suggested would be advocating for more international funding for collaborative neuroethics studies and projects led by researchers from underrepresented contexts and for increased participation and leadership roles in international neuroethics working groups, conferences, organisations, and programmes by researchers from these contexts (Matshabane, 2021). Bioethicists interested in developing more of a neuroethics presence in Africa should also put efforts into driving their own collaborations and developing their own positions within the field, from an African perspective.

9.3.3 Drawing on the strong tradition of empirical ethics research on the continent to establish an evidence-base comprising the perspectives of underrepresented populations on established neuroethics concerns

An area of focus that has received much attention in neuroethics debates is the nature of public interpretations of study findings about the brain, including widespread interpretations of information about the neural bases of neurological and psychiatric disorders. As mentioned above, these interpretations have various implications ranging from their impact on self-understanding, and other related philosophical concepts, to ensuring optimal clinical outcomes. However, as far as can be ascertained, no studies of this kind have been conducted in African contexts, with the result that assumptions informed by studies conducted in Western contexts are uncritically generalised to other contexts where they may not hold. The third important point of entry to establishing a truly global neuroethics, inclusive of African concerns and perspectives, is therefore building an evidence-base of the views and beliefs of local populations by means of qualitative studies. Given the strong presence in African contexts of bioethicists who engage in empirical ethics and conduct qualitative studies of this kind,

there is an abundance of researchers who could be enlisted in this important task, thereby contributing to developing the field in Africa. Studies of this kind would help to ensure that neuroscience-related study protocols are contextually sensitive and appropriate, and findings are communicated based on accurate information. Moreover, conducting studies in local contexts that gather evidence of views about the brain and notions of personhood, identity, agency, and morality itself will shed light on the extent to which certain ideas are subject to cultural variation, and impacted by more communitarian world views, and which are more universally held.

Tversky and Kahneman (1974) famously wrote about the fact that human beings are generally prone to certain cognitive biases or heuristics, referring to short cuts in our thinking that simplify complexity. The implications of these (mis)interpretations of complex information have been widely studied and discussed in subsequent decades, particularly in terms of their impact on how genetic information is understood. However, this is even more pertinent in the case of how information about the brain is interpreted, given the fact that the causal pathways between genes and phenotypes is more diluted and distal in comparison to brain physiology and phenotypes. In this regard, qualitative neuroethics studies have found that information about the brain is generally interpreted in essentialist ways. Neuroessentialism is the view that “for all intents and purposes, we are our brains” (Schultz, 2018), or put differently, that our psychological experiences are best explained with reference to, or are caused solely by, our brains. When essentialist interpretations hold sway there is a tendency to downplay or disregard the influence of environmental factors on mental and physical health, and behaviour in general (Schultz, 2018).

Essentialism may also inform neuroreductionism which is the “tendency to reduce complex mental phenomena to brain states, [often] confusing correlation for physical causation” (Savulescu & Earp, 2014). For example, as neuroimaging modalities become increasingly sensitive and improved, enabling the identification of the neural correlates of various mental states and traits, this information can be interpreted as indicating that certain experiences and feelings are reducible to, or nothing more than, brain chemistry or function. Reductionism is problematic, not only to the extent that it is incorrect, but particularly insofar as it disregards the fact that phenomena have multiple explanatory levels, and the biological level is only one possible way of understanding ourselves.

Neuroessentialism may also inform neurodeterminism which generally refers to the view that findings about the brain challenge our belief in our own agency or control over our health and behaviours (Schultz, 2018). For example, while

imaging genetics studies have deepened our understanding of how genetic variation influences brain structure and function, with implications for improving the understanding, diagnosis, and treatment of mental disorders, attention must be paid to the implications of how this information is interpreted by study participants and the public when it is communicated via the media. Given that neurological and mental disorders sometimes impact behaviour in significant and variable ways, such disorders are subject to a wide array of problematic, and possibly stigmatising, causal ascriptions (Nguie et al., 2010; Palk & Stein, 2021).

Initially, it was hoped that information about the neurobiological basis of certain mental disorders might decrease stigma. Some early studies gave cause for optimism in this regard insofar as they indicated that, in the case of disorders of addiction, this information seemingly correlated with increased tolerance and understanding, with subsequent decreases in stigma (Haslam & Kvaale, 2015). This was attributed to the fact that this information might support the view that it is unfair to blame individuals for their behaviours, if they had little choice in the matter, implying that agency is comprised or eradicated if the disorder has a neurobiological basis. The validity of such findings has however been increasingly contested by more recent studies which indicate that the opposite may be the case (Canadian Health Services Research Foundation, 2013; Hammer et al., 2013; Lebowitz & Ahn, 2014).²² These findings are congruent with other studies that have shown that information about the neural basis of other disorders, such as schizophrenia, is frequently interpreted in essentialist ways, which increase levels of stigma directed at such disorders, manifesting as the desire to avoid or distance oneself from the person in question (Loughman & Haslam, 2018; Schomerus, Matschinger & Angermeyer, 2014). Here the interpretation is that insofar as a disorder is “biologically” based, it is essential to the person in question and marks them as different or “other”. Importantly, insofar as information about the neurobiological basis of such disorders tends to be interpreted in essentialist ways, thereby increasing stigma, studies are needed in African contexts to ascertain the impact this information may have on the high levels of stigma associated with many such disorders in these contexts (Palk & Stein, 2021).

A further problem associated with these kinds of essentialist or deterministic interpretations is that they can lead to prognostic pessimism, which is the view that if a disorder or disease has a neurobiological basis, it is a fixed and unchangeable part of the person in question and will not be amenable to treatment or improvement (Lebowitz & Appelbaum, 2019). Again, given that the presence

22 See Heather (2017) for an interesting discussion of this issue in the context of models of addiction.

and influence of such neuroessentialist thinking is taken as self-evident in neuroethics discussions, based on study findings from HICs, it is crucial that similar studies are conducted in African contexts.

9.3.4 Engaging with the underlying moral framework of neuroethics by drawing on African moral frameworks

Ethical issues and concerns arising in biomedical research and health care are typically addressed in terms of the framework of principlism which has dominated globally since its inception in 1979 in the now famous *Principles of Biomedical Ethics* by Beauchamp and Childress, currently in its 8th edition. The principles of respect for autonomy, non-maleficence, beneficence, and justice are typically framed as informed by a common morality, thus carrying universal weight. This assumption has however been contested and principlism has been extensively criticised for its Western liberal individualistic foundations. Given the fact that a significant proportion of the world's population subscribe to a more communitarian and relational world view, the perceived overemphasis on respect for individual autonomy has received the bulk of critical engagement (Behrens, 2018). Beauchamp and Childress (2019) have paid attention to these criticisms and have provided comprehensive and nuanced responses in subsequent editions of their work, including engagement with relational conceptions of autonomy and emphasising that the four principles are equal. However, the ideal conception of principlism, as articulated by its authors, does not necessarily equate with how it is applied in practice across the globe, and in this regard, the principlist framework has become an entity that is independent of its authors. This point aside, any normative framework is, by definition, reflective of a particular perspective, and the dominance of principlism in bioethics, and its perceived association with a particular worldview, has stimulated thinkers in African contexts to make interesting and important contributions to the literature.²³

Engaging with such foundational concerns from the perspective of bioethics on the African continent can take many forms. It may include accepting principlism but applying it in a contextually sensitive manner to bioethical challenges in Africa (Kamaara, Kong & Campbell, 2020); developing a substantive moral theory or framework informed by insights and values prevalent in sub-Saharan Africa, as an alternative to principlism, which may be more appropriate for responding to bioethical challenges arising in African contexts (e.g., Metz, 2007 & 2010; Tangwa, 1996); or, articulating principles or values which could be used to adapt and enhance the principlist framework (e.g., Behrens, 2013; Rakotsoane

23 See Coleman (2017) for a review of some of these contributions.

& Van Niekerk, 2017). As part of the wider field of bioethics, neuroethics is also informed and founded on the principlist framework. Therefore, given that foundational level engagement is an established area of focus within bioethics in Africa, this is both an obvious point of entry into the field of neuroethics and an area where such a focus stands to enrich the field itself.

This aim is responsive to calls for engagement with the foundational assumptions and framework of the field to ensure its global relevance (Lanzilao et al., 2013; Shook & Giordano, 2014).²⁴ In this regard, the principle of solidarity has received attention in the international bioethics' literature (Prainsack & Buyx, 2012). The notion of solidarity is inherently relational and proactive insofar as it is understood as comprising "manifestations of the willingness to carry costs to assist others with whom a person recognises sameness of similarity in a least one relevant respect" (Prainsack & Buyx, 2012:346). Solidarity also occupies a central position in African moral world views, implying the value of acting with "good will" and "pro-attitudes" or care; "[b]eing invested in [the well-being of] others" (Metz, 2010). Moreover, from a global health perspective, solidarity has been recognised as a way of grounding a "united force against global health challenges" (Tosam et al., 2018) and an effective way of justifying the rectificatory obligation to redress health inequities – based on previous injustices – across the globe, in a more effective way than the dominant paradigm (e.g., see Benatar, Daibes & Tomsons, 2016). While the notion of solidarity requires more substantive work, it is but one example of a more relational principle that could enhance the dominant paradigm and could also be an area of focus in terms of articulating how it could inform a more globally relevant neuroethics.

9.4 CONCLUSION

In this chapter, I have attempted to provide some suggestions for developing the field of neuroethics on the African continent and examples of meaningful points of entry into the field in which local bioethicists could make significant contributions. This goal ties in with the broader task of cultivating a neuroethics that is more inclusive of diverse perspectives from a range of contexts and is thus more globally relevant. As neuroethics is not established in Africa, to the extent that it is elsewhere, I provided an introductory overview of the field with some illustrative examples, followed by four possible ways of increasing its presence on the continent.

24 Lanzilao et al. (2013) argue for a reframing of principlism to assist in advancing a more "internationally-relevant neuroethics" and develop an account of autonomy as self-creativity, beneficence as empowerment, non-maleficence as non-obsolescence, and justice as citizenship.

My suggestions included firstly, drawing on the ‘ethics working group model’ used by several international collaborative genetics studies to build interest, capacity, and participation in neuroethics, in the same way that this model has supported the development of ‘genethics’ expertise in Africa. Secondly, exploring congruence between the field of global mental health and neuroethics to address urgent medical and scientific mental health priorities in Africa as a form of neuroethics activism. Thirdly, harnessing the strong tradition of empirical ethics research in Africa to encourage studies that can build an evidence-base of the views of African populations on established neuroethics issues. Finally, utilising the work of thinkers in African contexts who have focused on improving and reconfiguring the normative foundations of bioethics to engage with the foundational assumptions of neuroethics.

In conclusion, as interest in neuroethics grows on the continent, it is likely that this will be beneficial not only for those participating in the field and those affected by its impact in Africa, but also for the field of neuroethics itself, insofar as the inclusion of a diverse array of perspectives and concerns increases the relevance and value of any discipline.

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