The Ethical Dangers of Facial Phenotyping through Photography in Psychiatric Genomics Studies[1]

Abstract

Psychiatric genomics research protocols are increasingly incorporating tools of deep phenotyping to observe and examine phenotypic abnormalities amongst individuals with neurodevelopmental disorders. In particular, photography and the use of two- and three-dimensional facial analysis is thought to shed further light on the phenotypic expression of the genes underlying neurodevelopmental disorders, as well as provide potential diagnostic tools for clinicians. In this paper, I argue that the research use of photography to aid facial phenotyping raises deeply fraught issues from an ethical point of view. First, the process of objectification through photographic imagery and facial analysis could potentially worsen the stigmatisation of persons with neurodevelopmental disorders. Second, the use of photography for facial phenotyping has worrying parallels with the historical misuse of photography to advance positive and negative eugenics around race, ethnicity, and intellectual disability. The paper recommends ethical caution in the use of photography and facial phenotyping in psychiatric genomics studies exploring neurodevelopmental disorders, outlining certain necessary safeguards, such as a critical awareness of the history of anthropometric photography use amongst scientists, as well as the exploration of photographic methodologies that could potentially empower individuals with disabilities.

I. Introduction

Psychiatric genomics research increasingly uses deep phenotyping, in which phenotypic abnormalities are comprehensively observed and analysed through the use of photography and 3D facial analysis. These deep phenotyping tools are thought to help generate further insights into the phenotypic expression of the underlying genetic makeup of neurodevelopmental disorders, also potentially providing diagnostic tools for clinicians through facial phenotypes associated with disorders such as autism and fetal alcohol syndrome [1, 2]. Facial phenotyping through photography could be particularly useful in rural low-resource settings where more expensive diagnostic tools (such as genetic testing) remain largely unavailable.

However, the incorporation of photography and facial phenotyping within psychiatric genomics research protocols raises ethically fraught questions which demand critical scrutiny. Generally ethical discussions associated with photography in medicine focus the need for stringent informed consent procedures and explicit conditions of use and storage. In this paper, I set aside those procedural discussions and focus more on the substantive problems associated with the use of photography and facial phenotyping, particularly in replicating the stigmatisation and objectification of persons with

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neurodevelopmental disabilities. Though these problems are not unique to this context, I highlight some aspects which are distinctive to the facial photography of those with neurodevelopmental disorders, such as the close association between face and identity. Awareness of these ethical dangers are all the more pressing in light of the historical misuse of photography and facial phenotyping to advance a eugenics agenda premised on deeply offensive views around race, ethnicity, and intellectual development – issues that become particularly acute as psychiatric genomics studies move into different cultural settings. As such, the ethical difficulties associated with photography for facial phenotyping represent a case study for deeper, more profound tensions at the heart of psychiatric genomics research. I gesture towards these without resolving them in this paper.

Section II outlines the clinical scientific case for the putative benefit of photographic imaging to facilitate deep phenotyping in psychiatric genomics studies of neurodevelopmental disorder, particularly amongst non-Caucasian populations. Section III questions more directly the ethical justification of photography use for facial phenotyping, particularly in light of context of genetic research and some uncomfortable overlap with anthropometric and composite photography used historically for eugenic purposes. This leads to the conclusion in Section IV that extreme caution must be exercised if photography is to be used for purposes of facial phenotyping in genomics studies exploring neurodevelopmental disorders. I outline several ethical safeguards which must be in place if such methods are to be incorporated in future psychiatric genomics research protocols.

II. Scientific Case for Facial Phenotyping of Neurodevelopmental Disorders

Clinical research increasingly uses facial analysis and phenotyping as a diagnostic tool to identify genetic conditions, particularly in individuals with neurodevelopmental disorder. Baynam et al state,

> Our face is […] a biological billboard that advertises our physical and mental wellness, our aging, and our disease. We commonly say, "you look ill," "you look well," "you look in pain," and we can, for instance, readily recognize a child with Down's syndrome by their facial features. Objectively documenting and harnessing these facial clues that underlie common parlance and innate recognition capacities, can be used to inform, educate, and empower people for health. [1, p. 3]

As facial development is connected to brain and heart development, phenotypic descriptions of children with developmental delay often cite facial differences from typically developing children [3]. Facial dysmorphism has been shown to relate to a spectrum of neurodevelopmental disorders, and the degree of facial dysmorphia may correlate to the severity of the condition [3, 4]. In particular, facial phenotyping is thought to generate useful biomarkers for early diagnosis of autism as well as prediction

of its severity and the onset of behavioural phenotypes (such as language delay) where there is familial risk for the condition [4, 5].

Such facial analysis is increasingly integrated within genotype-phenotype studies of neurodevelopmental disorders. Clinical scientists have stressed the need for precise and systematic means of measuring facial phenotypes associated with neurodevelopmental disorder, and two- and three-dimensional digital photography facilitates the rapid capture of facial images to measure and analyse facial morphology and detect visible signs of disorder [1, 2, 6]. In particular, 3-D photography helps record face surfaces so that linear and angular measurements between anatomical landmarks can be taken, enabling deep phenotyping of conditions such as autism. Facial phenotyping through photography is moreover thought to have an important clinical application: its provision of inexpensive and non-invasive diagnostic tools is potentially valuable in low resource clinical settings where advanced screening technology, such as genetic tests, remains difficult to access.

However, there is need establish a collection of normative and dysmorphic facial morphology of non-Caucasian populations in order to advance the clinical and research potential of facial phenotyping in the global setting. Such large-scale phenotyping of neurodevelopmental disorders will demand the use of photography to create an ethnically diverse facial database. At present, clinical databases severely lack ethnic diversity. Yet epigenetic expressions of facial phenotypes mean the facial dysmorphia of neurodevelopmental disorders will likely present differently depending on environment and ethnicity [1, 7]. As Chinthapalli et al explain, 'Ethnicity influences facial appearance, and at least in certain genomic disorders, either makes dysmorphic features less obvious or less easily detected by physicians' [8, p. 3112]. The scientific case for such ethnic diversity is also clear from the perspective of genotype-phenotype investigations. For example, differences in the clinical manifestation and outcomes of multiple sclerosis in Americans of African and European ancestry may be attributable to genetic factors [9]. Therefore, genotype-phenotype studies suggest ethnic variations are relevant for diagnostic purposes and developing therapeutic interventions.

III. Objectification and the Historical Legacy of Eugenics

Serious ethical issues are at stake with this type of photography used as a research and diagnostic tool. On one hand, photography has been embraced as a vital qualitative research tool which enables individuals with intellectual disability to participate in research and act as co-producers of knowledge. Through videos and photo diaries, photography has proven to be an important medium for non-verbal communication premised on the inclusion of and respect for individuals whose subjective perspectives are often disregarded [10, 11]. In short, these individuals are treated as respected persons who have their own viewpoints and perspectives which contribute to our knowledge and understanding about intellectual disability.

Yet, photography for deep phenotyping and facial analysis is qualitatively different in intent, where those with neurodevelopmental disorder and their facial features are effectively objectified through the photographic lens. Two meanings of 'objectification' are pertinent here: first, objectification denotes a particular epistemic status to a statement, utterance, or observation. When we look at something 'objectively', it implies we are capturing what is really true or what is really the case, uncoloured by subjective belief or bias. Objectification in this sense has figured prominently within the social meaning of photography more generally, whereby photographic images purportedly represent and signify the bias-free visual truth of its subject [12, 13]. This mode of objectification grounds medical photography for either research or clinical use, whereby photographic images are analysed to scientifically chart the progression of certain diseases (e.g. skin or orthodontal conditions) or facilitate common terms and measurements between clinical specialities (e.g. in surgical intervention) [14]. In the case of facial photography, '[o]bjective techniques for analyzing facial abnormality' are thought to include anthropometry, cephalometry, and photogrammetry [15, 16], so as to capture both normative facial morphology and dysmorphic features which are quantifiable through objective measurement, potentially revealing something about the underlying genetic makeup of the individual.

Second, treating or viewing another person as 'object' suggests instrumentality in that the person is merely a tool to be used for another's purposes [17]. Individuals are no longer approached or perceived as subjects with their own unique viewpoint. As Creighton et al write, '[t]he patient in a medical photograph is often seen as an interesting case or unusual finding rather than a living, feeling person [12, p. 67]. Facial phenotyping treats the facial features of persons with neurodevelopmental disorder as illustrative tools or examples, to aid higher order clinical or scientific research goals that are often unrelated to the subjective wishes, values, or desires of the actual person at the other end of the photographic lens. For instance, the aim of improving diagnostic tools and even developing preventative treatments or early detection can be in tension with the aims of those living with neurodevelopmental diagnoses, which revolve around the desire for respect, acceptance, and accommodation for neurodiversity [18, 19, 20].

Clearly, some dimension of objectification is unavoidable in any clinical scientific study – indeed, one could argue that the instrumentalising lens is part and parcel of the scientific imperative in order to generate verifiable data. It also has to be acknowledged that clinicians frequently use facial expressions to aid the diagnosis of patients with particularly striking features. My purpose isn't to critically examine this framework or clinical practice in any general sense here. But arguably, there is an important qualitative difference between the objectification of the face as opposed to other, more value neutral, parts of one's body. Comparison with other conditions will help draw out the higher ethical stakes.

On one hand, the deeper social and value-laden meaning associated with different parts of the body means that photography of other conditions can pose similar ethical difficulties to that associated

with the facial photography of neurodevelopmental disorders.[2] White blood cell counts, for example, hardly incite the significance that is attached to one's face or indeed, other more intimate parts of one's body, such as one's genitalia. A useful comparison to draw here is the clinical photography of intersex patients which has been known to cause a sense of humiliation, powerless, and trauma amongst patients [14]. Patients have expressed shock of such photos within their medical records, questioning their clinical purpose 'other than as some kind of "freak show" for other medical professionals' [14, p. 69]. As Creighton et al state, '[t]he patient is encouraged to expose the parts of her that she has been told are aberrant. These are documented and presented as her defining features' [14, p. 70]. Complex social and normative meanings are associated with one's genitalia (e.g. expectations of binary sex; norms of privacy, and in some contexts, associated shamefulness; cultural expectations around attractiveness and desirability; and so on). One's identity is effectively essentialised to the abnormal and deeply intimate part of the body, leaving individuals with the prevailing question, 'How bad am I that someone can make me feel like that'? [14, p. 70; also 21]. Thus, through the objectifying gaze of clinical photography, particular judgements about normality and abnormality are conferred onto already socially meaningful body parts which individuals then internalise as a type of shame that impacts on their personal identity and sense of self.

Facial photography of neurodevelopmental disorder potentially raises very similar problems. Like intersex conditions, the process of objectification intersects with complex social meanings around the face. Our faces are an important part of personal identity – they represent what is uniquely ours. But they are also socially constituted, in so far as they reflect absorbed social meanings in the outward presentation of self: we portray certain images of ourselves in particular contexts to fit in, to stand out, and so on; we mirror others and respond in certain ways through our faces, through expressions of emotion or empathy towards others. Social expectations around beauty, desirability, and normalcy dictate how we perceive our face, how we present it, and indeed, how others react to us. Moreover, through our faces others typically make valid and invalid inferences about our personality and identity, at times, with deeply harmful consequences [22]. For instance, facial differences often lead to the stereotyping of individuals, resulting in bullying, social isolation [23], psychological distress, and poor self-esteem [24-26]. Thus, facial photography risks reducing persons with neurodevelopmental conditions to their putative facial differences, much like intersex patients and their genitalia. Particularly instructive here is the language used in facial phenotyping: words such as 'atypicality', 'dysmorphia', and 'abnormality' identify facial features of persons with neurodevelopmental disorders as though these are objectively given facts [1, 3, 4, 6, 8, 27]. Such language communicates that persons with neurodevelopmental disorder possess negative attributes outside the accepted range of 'normal' or 'normative' facial morphology, thereby reinforcing rather than challenging already pervasive social narratives of their physical strangeness [28].

[2] My thanks to a reviewer for pushing me on this point.

Thus, research and clinical focus on *certain* physical indicators can be particularly harmful due to the social meanings and significance attached to those parts of the body. As such, the ethical concerns around facial phenotyping might not seem especially unique. On the contrary, three distinctively worrying aspects distinguish photography use in this context from other equally problematic medical settings.

First is the exacerbation of the visibility/invisibility dynamic that supports stigmatising views around intellectual disability, whereby increased *scientific* visibility could inadvertently validate the *social* invisibility and disrespect that persons with disabilities already experience within their communities [20]. Facial phenotyping increases visibility of those with neurodevelopmental disorders in one sense. Attention is drawn to their undesirable difference – namely their facial features that visibly depart from the norm. But such visibility has concerning implications: the face is treated as an object that can be decontextualised and broken into separate components for clinical or scientific scrutiny, confirming stigmatising views amongst lay persons that individuals with mental and neurodevelopmental disorders are identifiable simply through their appearance [29, 30]. Even as some disorders are facially identifiable, to presume the same of other neurodevelopmental and mental conditions represents a slippery slope which could have profound consequences. Individuals with Down Syndrome, for example, can face pressure to alter appearance through contentious procedures, such as facial reconstructive surgery, in order to reduce stigma related to facial traits [31, 32]. Moreover, the objectification of facial features risks reinforcing common lay assumptions that intelligence and cognitive ability can be reliably inferred through facial attributes, often associating lower mental and emotional functioning with distinctive facial traits linked to neurodevelopmental disorder [33]. Clinical research which focuses on facial appearance does little to challenge these pernicious views, despite contrary evidence indicating that many individuals with neurodevelopmental conditions are capable of deep reflection, emotional connection, and intelligence [18, 19, 33, 34]. The goal may be to improve clinical understanding and diagnosis, yet it is unclear how facial phenotyping will help cultivate greater societal understanding and acceptance of individuals with intellectual disability.

Second, the genomics context of facial phenotyping indicates a distinctive intensity to the ethical danger of objectification in this field of study. Ethicists have already cautioned against tendencies to reduce complex mental and neurodevelopmental conditions to one's genes [35]. Psychiatric genomics research more generally must grapple with the spectre of genetic essentialism, with its dual claims of gene determinism (that genes cause species / group / individual phenotypes) and categories of homogeneity and difference (that genes describe relevant distinctions and commonalities) [35, 36]. Facial photography is often situated within genotype-phenotype studies that explore connections between particular appearance and behaviour-based traits with the presentation of certain genetic variations. The essentialising move comes when facial appearance is reduced to the level of one's very genes. The spectre of objectification is therefore especially thoroughgoing in comparison to

other forms of clinical photography, moving from facial features that are often constitutive of one's sense of identity, to the very building blocks of one's biological existence.[3]

Finally, ethical concerns around photography use for facial phenotyping are symptomatic of more profound questions to do with the research agenda of psychiatric genomics, both in terms of its principal aims and its medium. This research agenda is broadly committed to the prevention and early intervention of mental and neurodevelopmental conditions [39]. Moreover, the adoption of photography as one of the means in which to establish a scientific connection between certain bodily traits and genetic attributes resonates with a deeply uncomfortable historical legacy. Facial phenotyping adopts composite photography techniques pioneered by eugenics research in order to differentiate average measurements of 'typical' and 'atypical' groups, to help investigate the association between facial traits and the underlying genotype.[4] The historical legacy matters all the more as psychiatric genomics research broadens to the global context. The justification for facial phenotyping often revolves around the need to compile a large record of ethnic pictorial samples, with the promise of enhancing diagnostic tools in non-Western, low-resource contexts, such as in sub-Saharan Africa. Historically, facial photography of non-Caucasian populations and individuals with intellectual disability and mental disorder helped advance deeply questionable social Darwinist ideas about the distribution of intellectual abilities and cognitive skills, promoting ideas of health (through positive eugenics) as well as the containment of risks associated with criminal behaviour, heritable diseases, and racial miscegenation (through negative eugenics) [40]. Composite photography isolated distinctive physical traits of people thought to carry hereditary characteristics connected to positive and negative behavioural and health attributes, establishing the 'normative' face of the socially and physically acceptable alongside the typology of hereditary deviance and social pathology, and thereby creating a general sense of what a mentally diseased person or criminal looked like [40, 41].

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[3] This raises an interesting question as to whether objectifying behaviour is equivalent. To explore this question fully would detract from my primary focus here, but I have argued elsewhere [37**]** that behaviour is often subject to the same questionable objectifying moves discussed here, with worrying tendencies of decontextualisation and reductivism in describing and analysing the complex behaviours of those with mental and neurodevelopmental disorders. Psychiatric genomics research still requires a robust response to Troy Duster's question: 'What is the *theoretical* warrant for designating certain behaviors the subject of behavioural genetics while ignoring or dismissing other behavioural manifestations as unlikely to be caused by a genetic condition?' [38, p. 160). Objectification of behaviour and the face through assertions of links between genotype-phenotype are both similar cases of a foundational tension within psychiatric genomics research which is discussed here.

[4] I recognise that there are effectively two separate but related fields of research and clinical diagnosis. Researchers could argue that they have a more 'neutral' position in relation to facial photography; however, it is still the case that the research justification for such investigation is frequently promoted having an impact on clinical diagnosis. Thanks to an anonymous reviewer for reiterating this point.

These points do not mount an argument against psychiatric genomics research generally, nor am I suggesting that researchers using facial phenotyping techniques associated with eugenics research share its abhorrent social and political agenda. Indeed, laudable intentions to reduce suffering and improve treatment often lie behind the desire to enhance current diagnostic tools and understanding of these conditions, thus representing a key difference from the composite photography of yesteryear. And it would be a nihilistic argument to suggest that all genetic investigation should be halted due to its morally dubious history, not least because it would be a futile argument at this advanced stage. That said, this history has not stopped philosophers and scientists now debating about the ethical warrant of a 'new eugenics' [43-46]. What is concerning is how these features combined – of seeking genetic causes for intellectual disability, of objectifying the facial appearance of both those with neurodevelopmental disorder and of non-Caucasian ethnicity, through the uncritical adoption of photographic methods pioneered for eugenics purposes – represent a perfect storm in which one can inadvertently advance problematic assumptions about intellectual disability, about connections between facial appearance and genes, and about race. These assumptions are not necessarily value-neutral, nor has photography been an entirely value-neutral medium in this context, as clearly seen from the legacy of eugenics to the troubling ethics behind visually recording sensitive medical conditions. Perhaps unaware of how language echoes worrying strains of eugenics discourse, some scientists claim that the study of adult faces in order to identify subtle phenotypes (or single aspects of a disease) could indicate those 'who are at risk of having children later with full clinical manifestations' [47]. Closer critical scrutiny of the rationale and presumptions around facial phenotyping through photography therefore functions as an important case study which illustrates the need for extreme vigilance around the scientific narratives that are advanced in the course of psychiatric genomics research, as well as constant ethical reflection about the relationship between its agenda, its adopted protocols, and the subjective goals and lived experience of those with neurodevelopmental disorders.

IV. Potential safeguards?

Two competing imperatives frame the issue of facial phenotyping in psychiatric genomics research. On one hand, there are worries that the exclusion of certain population groups from genomics research could result in depriving them of potential benefits [7]. The need to secure fair and equitable future clinical benefits makes it even more important that historically oppressed and vulnerable groups are not left behind as psychiatric genomics research advances. On the other hand, it remains unclear from my foregoing discussion that the case in favour of photography for facial phenotyping has sufficient ethical justification. Much hinges on the speculative promises of *future* benefits, yet there is a general failure to clarify in what ways those affected with neurodevelopmental disorder – and even more controversially, those with such disorders of different ethnicities in postcolonial settings – stand to benefit *now* from such research methods. Indeed, as shown in analogous cases of intersex conditions

and Down Syndrome, individuals could stand to suffer greater, not less, social stigma and objectification. A much more robust ethical case must be made for the inclusion of diagnostic photography and facial analysis in psychiatric genomics research, developed out of first-order qualitative work seeking out the views of individuals with neurodevelopmental disorders as well as second-order ethical exploration of the overarching warrant for such methods. Until this work is carried out, researchers must make efforts to first, critically engage with the historical legacy of facial phenotyping; second, uphold the respect and dignity of persons as an overriding ethical consideration.

First, it is vital that scientists remain critically aware of the historical misuse of photography as a scientific medium to advance eugenics, particularly against those deemed 'feebleminded' and of different ethnicities: scientists and regulatory ethics bodies *should* be mindful that facial phenotyping utilises similar techniques as anthropomorphic and composite photography used historically for eugenics purposes; moreover, they *should* be uncomfortable with the fact that the 'objective' language used to describe facial differences parallels eugenic descriptions of facial and cranial structures, to identify the healthy and desirable vs. social degenerates and racially / intellectually undeveloped peoples. Addressing questions of how diagnostic photography and facial analysis in genomics research diverges from historical abuses of this medium might seem beyond the remit of clinical science. However, such critical reflection is necessary, not least to heighten awareness amongst researchers of the ethical dangers surrounding these research methods, of *how* language is being used in an inadvertently objectifying and demeaning manner. Those who are unaware of history are doomed to repeat its mistakes.

Second, critical questions as to how photography as a scientific medium respects the dignity of persons with neurodevelopmental disorders must be addressed. Fundamentally different photographic methods may be needed if clinical research is to help mitigate rather than perpetuate stigma of vulnerable groups. Photography can be an important tool in facilitating empowering messages which convey the respectful treatment of persons with neurodevelopmental disorder as individual subjects with their own perspectives, values, and desires, particularly in cases where linguistic or verbal methods are inaccessible [10]. Mji et al [11] discuss the concept of 'photo voice', whereby persons with disabilities are willing to participate in photographic research which respects their dignity and increases their social visibility in depictions that portray them as active, competent, and socially valuable agents as opposed to helpless, useless, and passive burdens on society. For example, ethics committees could require the incorporation of qualitative studies which use methodologies such as 'photo voice' or other means, alongside research protocols involving facial photography for phenotyping purposes. Though how these photographic portrayals might be used alongside facial phenotyping is unclear, it would nonetheless go some way in redressing an unjustifiable imbalance towards the objectification of those with neurodevelopmental disorders, promoting holistic, interdisciplinary approaches that reassert the ethical significance of the lived experience and subjective voices of individuals who are so often marginalised in research and in society more generally. Moreover, it would be an important signal to

clinical researchers that photography as a scientific medium must carefully consider, learn from, and adapt methods that have been shown to empower persons with neurodevelopmental disorders.

V. Conclusion

This paper has explored the ethical problems that arise in the use of photography to facilitate facial phenotyping of persons with neurodevelopmental disorders. As psychiatric genomics research expands to different global contexts, issues of objectification, stigma, and the fraught historical legacy of anthropometric photography used for eugenic purposes, become all the more acute. Facial measurements putatively generate scientific knowledge *about* intellectual and neurodevelopmental disorders, whilst their identity and personhood – often seen as constitutive of the social meaning of the face – are stripped away in the process of scientific observation. Clinical scientists need to tread extremely cautiously, despite the hope that facial analysis could potentially function as a useful diagnostic tool in low-resource settings. All too often persons of different ethnicities and with intellectual disability have been dehumanised and reduced to their discrete body parts. It is vital that genomic scientists do not add to this historical legacy. Much more work needs to be done to ensure the intent and focus of photography for facial phenotyping properly respects the dignity of persons.

At root, the ethically fraught nature of facial photography functions as an important case study of the heretofore unresolved questions surrounding the broader ethical agenda and means of psychiatric genomics research, particularly in terms of how such research substantively advances the goals of societal recognition and acceptance sought by many of those with neurodevelopmental disorders. Facial phenotyping through photography distils foundational tensions that are at the heart of such research: on one hand, the imperative towards early intervention, prevention, better diagnostic tools and treatment options; on the other hand, the desire for social acceptance for neurodiversity, for different intellectual, behavioural, and emotional ways of interacting with the world. I have not been able to resolve such a fraught tension in this paper. In some respects, photography represents an area where such tensions are being negotiated. What is important to remember regardless is that behind the photographic lens lies a *person* and *subject*, and the language and protocols of psychiatric genomics research must ensure the dignity of such individuals is paramount.

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