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The Work of Hope in Discovering a Biological Explanation of Stuttering

Abstract

Discovering developmental stuttering's biological explanation has been an enduring concern. Novel advances in genomics and neuroscience are making it possible to isolate and pinpoint genetic and brain differences implicated in stuttering. This is giving rise to a hope that, in the future, dysfluency could be better managed if stuttering's biological basis could be better understood. Concurrent to this, there is another hope rising: a hope of a future where differing fluencies would not be viewed through a reductive lens of biology and associated pathologies. The central aim of this paper is to edge out ethical implications of novel research into stuttering's biological explanation. In doing so, the paper proposes to look beyond the bifurcation sketched by the medical and social model of disability. The paper demonstrates how the scientific hope of discovering stuttering's biological explanation acts as an accessory of disablement due to the language of 'lack' and 'deficit' employed in reporting scientific findings and proposes participatory research with people who stutter as an antidote to manage this disablement.

Key words

Stuttering; Ethics; Neurobiological research; Neurodiversity; Critical disability studies

1. Introduction

Developmental stuttering, or childhood onset speech fluency disorder (stuttering, henceforth), is a fluency disorder. Arriving at stuttering's definitional certainty has been a longstanding concern (Tichenor & Yaruss, 2018:1181). The WHO defines stuttering as:

> "Speech that is characterized by frequent repetition or prolongation of sounds or syllables or words, or by frequent hesitations or pauses that disrupt the rhythmic flow of speech" (WHO, 2010 in Onslow, 2020:5)

5% of children between the ages of 3 and 6 will exhibit dysfluencies to a degree that their speech will be judged disordered (Sommer et al., 2021). While majority of children will go on to achieve fluency, for 1% of the general population dysfluencies will be significant enough to culminate in stuttering (Yairi & Ambrose, 2013). If qualitative research on stuttering sheds light on the lived experiences of people who stutter (Klompas & Ross, 2004; Kathard et al., 2004; Scharf, 2017), there is lack of research on the role played by genomic and neuroscientific knowledge in framing stuttering as a disability. An example of an exception to this are two studies by Boyle (2016; 2020): through these survey-based studies it was concluded, among other things, that "biological models of stuttering have the potential to be a de-stigmatising factor for people who stutter" when compared to non-biological models e.g., psychological and psychobehavioural models (Boyle, 2020:441). Concurring with these findings, however, we argue that biological explanations that aim to unearth stuttering's cause are seen to be

‘reasonable’ because they promise a future where these findings can result in rehabilitation. Furthermore, it is opinioned that knowledge dissemination that does not resort to the language of ‘lack’ and ‘deficit’ could positively contribute to further de-stigmatisation of stuttering i.e., a future where stuttering is not something to be managed and corrected — a ‘lack’ not be to be coped with and a ‘deficiency’ not to be remedied. Another important point of note: making a case against knowledge dissemination that is rooted in the language of ‘lack’ and ‘deficit’ is not to negate the lived experiences of people who stutter i.e., the loss of control and struggle that people who stutter feel and experience in their everyday speech. On the contrary, it is to acknowledge and cement the interactional nature of stuttering. For example, in a recent study (Jackson et al., 2022) it was found what was already known anecdotally: adults who stutter do not stutter when alone; thereby, leading one to make a cautious conclusion that the loss of control and the experience of struggle are highly context dependent. It will be interesting to see how biological models of stuttering premised on ‘lack’ and ‘deficit’ respond to this paradox, and whether a biological explanation can be found for the absence of stuttering during private speech.

This, then, is the aim of the paper: it will opinion that in the hope of establishing stuttering’s definitional certainty, and for this hope to be seen as reasonable, genomic and neuroscientific research on stuttering employs a language that is premised on assertations of ‘lack’ and ‘deficit’. The opinion will unfold in the three steps: first, in *Hope Rises*, the paper will summarise the recent scientific undertakings. Second, in *Hope Disables*, it will demonstrate how this hope

functions as an accessory of disablement: for this hope to be seen as reasonable, it must portray stutter as a 'deficit' and the person who stutters as 'deficient'. In the final section, *Hope Managed*, it will be argued that, going forward, scientific research on stuttering must do more to adopt a participatory framework that includes the voices of people who stutter. This suggestion recognises that many researchers working on stuttering, some of them cited in this paper, are themselves people who stutter. However, a participatory framework being advanced here refers to a call for people who stutter to be active members in deciding the nature of research on stuttering. Moreover, views of people who stutter, which would of course differ, should also be sought on how and in what discursive registers are the results of such scientific undertakings disseminated. This means that views of people who stutter, researchers and otherwise, should be incorporated into the research agenda from its inception and throughout i.e., people who stutter should not just be seen as subjects for/through whom knowledge is generated but also as equal epistemic partners in research.

2. Hope Rises

Given the novel advances in genomics and neuroscience, the matter of dysfluency is progressively being framed in biological terms. Current genetic evidence points to the polygenic and multifactorial nature of the disorder and new genome-wide association studies are currently underway (Yairi & Ambrose, 2013). Candidate

gene analysis has recognised mutations in four genes: GNPTAB, GNPTG, NAGPA, AP4E, and subsequently, new animal models of stuttering have been proposed (Barnes et al., 2016). The 'Genetics of Stuttering Study' is being co-ordinated in eight different sites worldwide including Australia, New Zealand, Belgium, and the Netherlands. It describes itself as the largest study of its kind with volunteers aged seven or above and a mission to ''pinpoint the genes that predispose individuals to stuttering'' which could ''revolutionise future research into the causes and biology of stuttering'' (Genetics of Stuttering Study, 2021). Increased attention is also being paid to neurobiological underpinnings of stuttering (Etchell et al., 2018; Chang & Guenther, 2020). Broadly, this research aims to highlight differences in neural activity in those who stutter and those who do not stutter in three related contexts: resting state, speech tasks, and non-speech tasks. Findings can be summarised as follows: TMS, M/EEG, and fMRI studies indicate reduced excitability in motor areas preceding speech production; adults who stutter display atypical activation in the left inferior frontal gyrus and right auditory regions (Belyk et al., 2014); and, if measured by grey matter volume, structural 'abnormalities' in the left inferior frontal gyrus. Due to lack of neuroimaging data of children who stutter, what is less clear is whether these 'anomalies' are a cause or consequence of stuttering.

Taken together, scientific advances aim to decipher and develop a causal link between certain genomic and neurological differences and dysfluent speaker's inability to produce fluent speech. The rationale provided for such advances is that aetiological findings can lead to better rehabilitation practices: pharmacological

(Maguire et al., 2020; Maguire et al., 2021), speech therapy and mental health (Gunn et al., 2009; Fry et al., 2014), and transcranial direct current stimulation (tDCS) (Chesters et al., 2018).

Consequently, the hope of discovering stuttering's biological underpinnings conceals within it two different hopes: 1) novel data should facilitate those with dysfluent speech to move beyond antiquated ideas of possessing a 'nervous disposition' or of it being an issue of 'impaired temperament' (Jones et al., 2014); and 2) novel findings could lead to better speech treatments in the form of pharmacological (Rabaeys et al., 2015; Maguire et al, 2020) and brain stimulation interventions (Garnett et al., 2019). However, the proprietary nature of these hopes and what function they play in the present is not readily apparent i.e., from where and from whom do these hopes arise? This could indicate a lack of first-person narratives of how those who stutter understand the genetic and brain science research on stuttering. This, then, gives rise to an ethical concern of pathologizing genomic and cognitive differences and raises a question: to what extent it is responsible to pathologize natural human variation? This question is in line with the neurodiversity movement i.e., 'rather than focusing on pathology and impairment, neurodiversity emphasizes natural variation and the unique skills, experiences, and traits of neurodivergent individuals' (Constantino, 2018). Viewed through a traditional disability studies lens there is a distinction between impairment and disability: while impairment is equated to functional limitations, disability is born when an impairment collides with the social (Barnes & Mercer,

2005). These distinctions between neurodiversity, disability and impairment will be reflected on throughout the paper.

3. Hope Disables

The hope of providing a biological answer to the question ‘what is stuttering?’ is to be understood as a valiant exercise in scientific discovery. As argued previously, if fulfilled, the culmination of this hope will not only provide a biological explanation for/to the people who stutter, it will also contribute to the progress of new therapeutic interventions. All in all, this hope provides a momentum towards a future where dysfluency could be better managed if its biological underpinnings are better understood. However, for this hope to be constructed as rational, the significance of a future where the problem of dysfluency can be better managed, must be seen to be reasonable. For this criterion of reasonableness to be realized, stuttering is often portrayed as a ‘deficit’ and the person who stutters as ‘deficient’.

The reason that aids in fulfilling the scientific hope’s reasonableness criterion is one of imagining a future where unearthing stuttering’s biological explanation could result in refined techniques of rehabilitation. Rehabilitation presumes that something needs to be ‘managed’, ‘taken care of’, or put differently: to restore something to its natural or functional state. Thereby the hope of rehabilitating people who stutter through advanced techniques gains its epistemological credence through constructing stuttering as a ‘deficit’ and the person who stutters as ‘deficient’ – in short, a discourse that champions the claim that the body could be

rescued if speech could be corrected. Rehabilitation of a trait that is innately ambiguous, in this case dysfluent speech, can be argued to be problematic. Moreover, dysfluency is increasingly being framed in positive terms, i.e., the desire of some people who stutter to stutter more (Alpern, 2019). This is not to suggest that *all* people who stutter want to stutter more and ignore the material realities of dysfluent speakers' everyday struggles e.g., the of loss of control and experience of physical struggles in speech; rather, it is to highlight the paradoxical nature of dysfluent speakers' experiences which do not adhere to a unidirectional view of stuttering as a 'thing' to be rehabilitated upon which the current scientific discourse rests. Moreover, scientific undertakings which are driven by and rest on a unidirectional hope of rehabilitation actively negate a hope for the future where stuttering can be appraised as a mere difference in speech pattern – a normal human variation – and not a 'thing' to be corrected by excavating its biological cause.

Let us look at some examples of how stuttering is defined in the most recent scientific literature:

"Stuttering is a neurobiological lack of integration of the underlying processes of planning and producing language and speech…'' (Jackson, et al., 2015).

"…stuttering subjects who carry such mutations and have been examined clinically have displayed no neurologic or other clinical deficits other than stuttering" (Frigerio-Domingues and Drayna, 2017)

"Engineering a mutation in…GNPTAB found in humans who stutter into the mouse *Gnptab* gene resulted in deficits in the flow of ultrasonic vocalizations similar to speech deficits of humans who stutter" (Han et al., 2019)

As can be seen from the above quoted passages, the language employed of 'deficit', of 'lack', and many others, signal stuttering to be notably a "lack that is rooted in biology", and thereby, "the secondary features of stuttering like communication avoidance and quality of life…trace back not to structural issues in society but to the abnormality of the stuttering body" (St. Pierre, 2019). Now, it could be argued that the language of science is of a specialist register whose meanings do not map onto our colloquial employment of these terms. This contention, however, ignores the relational historical contingency of scientific language. These descriptions do not merely describe, rather, their description is seen to be 'safe' because they rely on an idealist understanding of what 'normal' speech *should* look and sound like.

It could also be contended that the argument this paper has been advancing ignores the material and lived realities of people who stutter. We can assume that some people who stutter do hope for and look forward to a future where scientific advances can aid their speech, and hence, reduce the associated stigma and negative effects. We can also assume through movements such as 'stammering pride' and assertions like 'stutter more' (Alpern, 2019) that some people who stutter wish to embrace their stuttering. However, the argument being advanced is not to suggest what a person who stutters *should* do and think about their stutter. Rather, it is to suggest that driving forth an understanding of 'stutter as a deficit and the person

who stutters as deficient' has ethical consequences for the manner in which we come to comprehend bodies for this understanding forecloses the possibility for alternate hopes to stabilise, i.e., the hope where dysfluency is not a pathology to be managed.

4. Hope Managed

Two hopes concluded our discussion above. First, a hope that in the future stuttering could be better managed through advanced techniques of rehabilitation based on stuttering's biological underpinnings. Second, a hope that in the future where stuttering will come to be celebrated as a difference in speech. These two hopes follow from the established medical and social model of disability. The medical model emphasises disability to be fundamentally located within the individual and any subsequent disabling effects to be a result of individual pathological differences (Oliver & Barnes, 2012). On the other hand, the social model views the disabling effects to be a result not of individual differences but of social barriers faced by differently abled bodies (Oliver, 1990). Within this model, disability and impairment are distinct notions, in that impairment does not always result in disability. Through this model, the impairment for those who stutter is dysfluent speech that is transformed into a disability when in contact with disabling forces which are 'outside' speech:

> "I can push, pull, and do all sorts of things when I speak to try to get a word out the way I think it should sound, with the 'correct' rhythm, timbre and power. Struggle behaviour is a response to the disabling environment, experienced through the lens of internalised oppression. It is about desperately wanting to talk and be the 'correct' way. So struggle behaviour, and avoidance are an integral part of the disability process" (Bailey, Harris, & Simpson, 2015:15)

However, it could be asked to what degree dysfluency is an impairment. St. Pierre (2019) provides a lucid example: given that both stuttering and having red hair stem from genetic mutations roughly thought to be in one percent of the general population, why is it that the former is considered to be an object for the medical gaze, something to be corrected and managed, while the latter is seen as part of normal human variation. He suggests that this is "because 'abnormal' is not simply mathematical but always marks a hierarchy – a particularly *undesirable* deviation" (St. Pierre, 2019). This example could be extended further: what would happen if a 'treatment' could be devised that would 'correct' red hair and stuttering? Would it be a moral problem to do research on such a treatment? The answer lies not in responding to the question in the affirmative or the negative, rather, in asking why such a question is seen to be desirable and epistemologically safe. It would be safe to assume, on balance of probabilities and as discussed above, that some in the stuttering community, or those with red hair, would welcome such a move, a 'correction'; however, the move would not be a result of medical necessity, for example treatment for cancer, but a result of desirability borne out of stigmatisation of difference and of monopoly on what is considered 'normal'. Therefore, not only is the medical discourse concerning stuttering and normalcy never neutral and

always socially motivated; social discourse too is influenced by how science views, constructs, and 'acts' on those with dysfluent speech.

4.1 De-modelling stuttering

Societal barriers of disablement as experienced by dysfluent speakers have been documented through illuminating personal narratives (Campbell, Constantino & Simpson, 2019). However, there are no sustained narratives on how those who stutter ethically reflect on recent genomic and neuroscientific research on stuttering. The oppositional thinking, however, makes the medical and social model ill-suited for discussing the ethical questions raised. This is not to suggest that the social model should be abandoned: it has been fruitful in highlighting how society and infrastructures disable. It is to argue that models of disability should be seen as framing devices which succeed by reducing and purifying reality for the purposes of explanation (Schillmeier, 2010:103).

For research on stuttering, the models have materialised in conversations being held in echo chambers: on the one hand, the scientific community's insistence on excavating and discovering stuttering's aetiological certainty that can lead to refined rehabilitation, and on the other, the activist tendencies of the social model to displace the progress made by the scientific community which it views to be encrusted within the medical model. Put differently, the social model rests on the 'social' as an explanatory category, "which is understood as a self-sufficient matter of fact that acts as a universal explanans"; however, 'the social' itself is in need of an explanation (Schillmeier, 2010: 2). In a similar vein St. Pierre (2019) provides

two related critiques of the social model as applied to stuttering. First, the social model, for political purposes, fails to take impairment seriously i.e., the embodied nature of stuttering, which creates a divide between the biological and the social, and hence, takes away the agency of the dysfluent body to be considered as disabled, which is necessary for availing accommodations. Second, the social model does not provide room for personal narratives to flourish through its insistence on social barriers being hegemons of disablement:

> "people who stutter are disabled not only by society but also by the physical pain and frustration of trying to push out words. Even in a perfect world without discrimination stuttering bodies would cause discomfort" (St. Pierre, 2019).

To the above-mentioned critiques of the social model, a third should be added: the understanding of 'stutter as a deficit and the person who stutters as deficient' being formed in light of novel research on stuttering cannot *just* be explained by an analytical move that resorts back to the 'social' and 'society' as an explanation for disabling practices (Latour, 2005). A move away from the 'social' as an explanatory category requires the agency of dysfluent speakers to be recognised and valued. Simply stating that those with dysfluent voices are disabled due to an ableist understanding of fluency and the social barriers, although an important recognition, is not enough at the level of practice. This necessitates a sustained effort on part of the research community to include voices of the people who are subject of these varied programs of action. This is important for two reasons: first, for the flourishing of ethical deliberation that is truly participatory in nature, and second, to close the gap between the medical and social realms of understanding stuttering.

A failure to head to this would lead to epistemic injustice: “a wrong done to someone specifically in their capacity as a knower” (Fricker, 2007:1). Originally formulated as a concept to describe situations pertaining to racial and sexual injustice, it argues that testimonies provided by marginalised groups, or groups under scrutiny, are rendered of reduced credibility by virtue of being prejudiced. Given the daily stigma (Boyle, 2018) and prejudice (Campbell, Constantino and Simpson, 2019) faced by those with dysfluent speech, it is crucial that the threat of epistemic injustice is addressed through novel participatory frameworks. Therefore, if the domain of genomic and neuroscientific research on stuttering is to be made secure from critiques of it being a device of disablement, which has been argued to be the case, then participatory ethics should be embedded within their research programme to understand how those who stutter reflect on their dysfluent speech in light of novel scientific advances which operate on the premise of ‘lack’ and ‘deficit’.

4.2 Participatory research

Given that research and practice on stuttering takes place outside the domain of the ‘clinical’, it has evaded the lens of critical bioethics enquiry. However, with novel therapeutic practices being developed, including calls for pharmacological treatment of stuttering, this evasion is increasingly hard to justify on epistemological grounds. This is where the paradigm of Participatory Bioethics Research (PBR) can be viewed as a critical intervention. PBR is embedded in the tradition of ‘responsive evaluation’ which arose to challenge the failings of evaluation as a method that trusts expert and professional knowledge more than it

does intersubjective knowledge (Abma et al., 2017:146). Thereby, at its core, it functions as an approach which aims to foster a culture of mutual moral learning. Given that what makes stuttering 'real', either now or in the future, is not *just* its causal explanation but the lived experience of those who stutter, PBR can be an appropriate response to the ethical concerns of hegemonic spokesmanship, pathologizing difference, and epistemic injustice. If studies such as by Boyle (2016, 2020) aptly demonstrate that biological explanations are less stigmatising than other explanations, this does not stand to mean that biological explanations employing a language of 'lack' and 'deficit', with a hope of rehabilitation, do not lead to *any* stigmatisation.

Consequently, novel genomic and neuroscientific data on stuttering call for contextualised ethical analysis which includes those who stutter as primary stakeholders. But what would such a platform, premised on PBR, look like? This approach places emphasis on exchange of experiences and perspectives between varied stakeholders to facilitate mutual moral learning and development (Landeweer, Molewijk, & Widdershoven, 2016). This will aid to unearth implicit and explicit norms embedded in current research on stuttering, some of which have been tentatively opinioned in this paper. However, it is important to note that adopting a dialogical approach does not mean that it aims to foster a consensus between stakeholders, rather its employment will highlight the dialectic between ethics and practice. Empirical research guided by a dialogical approach is appropriate to balance the validity of scientific claims and grant opportunities of participation and deliberation to those affected. Moreover, a dialogical approach

premised on a certain form of pragmatism not only takes novel scientific advances as having “legitimate claims”, but also underscores the epistemological limitation of these claims: that they are produced and function within a social milieu (Pavarini & Singh, 2018).

The contention here is one of adequate representation and concerns answering the question: who should speak on whose behalf? If the stabilisation of the understanding of ‘stutter as a deficit and people who stutter as deficient’ has been prone to breakdown in the face of critiques from those within the stuttering community i.e., ‘stutter more’, then these dissident voices need to be included and highlighted in official channels of knowledge production. Decoupling the understanding of differing-fluencies-as-entrenched-pathologies-to-be-rehabilitated requires a platform where those with differing fluencies are given adequate representation and time in deciding the *meaning* and the *realness* of these pathologies. Participatory research which does not proceed by accepting a biomedical definition of stuttering, i.e., where the ‘deficit’ and ‘lack’ are not taken to be evident, but difference is, can bring about structural changes in the way we understand and comprehend stuttering. Hints of such participatory thinking are already mushrooming: STAMMA, the UK national charity for people who stutter, hosts a recurring ‘Research Arena’ where researchers talk about their work, many themselves people who stutter, and the audience made up of people to stutter provide their input on a wide variety of issues. Similarly, Action for Stammering Children, another UK based charity, recently put out a survey to solicit opinions of varied stakeholders on what they view as the most important research priorities.

Moving forward it is hoped that such practices should become an important aspect when screening research studies for their ethical robustness, thereby, ensuring a truly democratic research landscape.

5. By way of conclusion

Both hopes – the hope for a future where dysfluency could be better managed through advanced techniques of rehabilitation – and – the hope for a future where stuttering will come to be celebrated as a difference in speech, considered 'normal' and an effective form of communication – are reasonable hopes for they convey the desires of people who stutter. However, fulfilling the criterion of reasonableness is not enough. Hope should also be responsible (Coutellec et al., 2021). Responsible and responsive hope requires proponents on both ends to engage in a culture of mutual moral leaning. If those who desire to decode stuttering's biological underpinnings *feel* responsible to do so in order to aid those with dysfluency, then that desire must also contain responsible language and provide adequate opportunities for participation in scientific discourse for their hopes not to be construed as an accessory of disablement.

In short, the teleological nature of the first hope and its ableist premise cements a hierarchical formulation that is rooted in the language of 'lack' and 'deficit'. This was suggested not to portray science as an adversary of differing fluencies nor to

regard its work as less than commendable, but to highlight that the scientific enterprise that aims to unearth stuttering's biological explanation is often driven by a hope to rehabilitate. In a similar vein, a unidirectional focus on promises of the social model of disability not only fails to comprehend the embodied experience of stuttering but also portrays societal structures to be the only hegemons of disablement (for a more thorough discussion of stuttering and the social model please refer to Constantino, Campbell & Simpson, 2022).

Our aim has been to highlight the interconnectedness between the material and semiotic realms in which dysfluent speakers find themselves: expressing neural and genomic differences, the material, as a 'lack' and a 'deficit' are seen to be reasonable descriptors because stuttering has historically been categorised as a 'problem' to be fixed, the semiotic. However, this categorisation has been prone to breakdown with calls to celebrate and take pride in dysfluency. In doing so, we have shown that the unidirectional outlooks of the medical and social model fail to comprehend that people with disabilities have divergent understandings of what the future should and could hold. Not only is the paradoxical nature of 'hope in society' and 'hope in science' not a necessity, moreover, this paradoxical construction should be analysed for the function it plays in the present: of disablement. Therefore, if pharmacological and other interventions of the future are not to be seen as pebbles of the past, then the hope that these interventions are premised on should not just fulfil the criterion of being reasonable but also of being responsible.

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