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Is the search for cerebral palsy 'cures' a reasonable and appropriate goal in the 2020s?

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ABBREVIATIONS

ASD Autism spectrum disorder
Strategy Australian and New Zealand
 Cerebral Palsy Strategy

In the field of disability research and advocacy, the notion of 'cures' is contentious. Cerebral palsy (CP) is no exception. In this narrative review, we combine perspectives gained during community consultation undertaken for the Australian and New Zealand Cerebral Palsy Strategy, 2020 with those published in the scientific and grey literature to understand whether 'cures for CP' is a reasonable and appropriate goal. We frame these perspectives through the lens of several ethical principles central to the discussion. These include maintaining hope while also being realistic, sensitivity to sharply different viewpoints amongst people with disability and their families, and responding to community priorities, societal attitudes, and identity. Through this exploration of the literature and perspectives, we arrived at a definition of 'cures for CP' that is pluralized and focuses on functional improvement and/or symptom reduction whilst still acknowledging the potential for neural repair/regeneration strategies.

Cerebral palsy (CP) is a lifelong neurological condition, and while research and advocacy has resulted in the development of a range of interventions, assistive devices, and preventive strategies, the notion of a 'cure' for CP remains contentious.

CP is an umbrella term that describes a group of conditions affecting an individual's movement and posture.¹ People with CP also experience higher incidence of pain, epilepsy, cognitive impairment, and sleep, communication, and eating difficulties, as well as difficult behaviours, than people in the general population.² CP is caused by non-progressive damage to the developing brain before 2 years of age. However, the complex causal pathway leading to the brain injury is often unclear. A number of risk factors for CP have been identified, such as preterm birth, low birthweight for gestational age, and multiple births.³ Genomics likely plays a role for a subset of people with CP.⁴ For most, it will be a combination of factors that form a causal pathway to CP.

Despite advances in the field, such as earlier diagnosis and a reduction in the rate and severity of CP,³ people with CP continue to experience significant barriers in everyday life. Complex and lifelong physical, medical, educational, and social needs associated with CP often

remain unmet. Moreover, current intervention strategies for CP are limited, typically requiring significant and sustained commitment with small functional gains.⁵ It is therefore not surprising that a 'cure' would be of interest to many in the CP community. Recently, the cure debate was reignited during development of the Australian and New Zealand Cerebral Palsy Strategy (hereafter referred to as the Strategy),^{6,7} a document that was codesigned and authored by a range of stakeholders in the CP field including people with lived experience. The Strategy is a comprehensive document outlining the key priorities for the field of CP. With an overarching goal of improving quality of life, the Strategy is comprised of four key goal areas: (1) inclusion and engagement; (2) health and well-being; (3) intervention and disability support; and ultimately, after lengthy and at times heated debate, (4) prevention and 'cures'. For the purposes of the Strategy, 'cures for CP' was defined as any highly effective treatment(s) (including potentially neural repair/regeneration strategies inserted postscript), that convey significant long-term improvements in function and/or reduction of symptoms, such that the person exhibits reduced or no clinical symptoms necessary to meet the diagnostic criteria for CP. This was further refined to include that these

improvements must be replicable in multiple groups of people with similar characteristics.

There currently exists no synopsis of the background of cures for CP, nor a summary of current opinions in the field. The purpose of this article is therefore to provide a brief overview of the 'cure for CP' discussion to date as well as a contemporary summary of ethical principles on the topic. Ethical principles articulated in this review were shaped by perspectives raised during community consultation specifically conducted during development of the Strategy,⁶ as well as the subsequent discussion and debate among key stakeholder groups, many of whom are represented in our authorship group, that brought and represented a diversity of perspectives.

METHOD

This review aims to use the experiences of the authorship group when working together to develop the broader Strategy, to consider the issue of a cure for CP as a priority for the field. The methods of gathering and synthesizing information are not all consistent with a prospectively designed study, but are likely consistent with international discourse in the field of neurodevelopmental disability. The authors have taken a reflective and critical stance to bring together a wide range of perspectives derived from community consultation, in-depth engagement and discussion with multiple stakeholders, and a review of the literature.

Community consultation

A community consultation was conducted for the purpose of developing the Strategy during 2017 and 2018. This consultation, undertaken by experienced independent consultants, followed a multiple methods approach, with the aim of eliciting the views of a broad range of stakeholders on a draft of the Strategy. Data were collected using open- and closed-ended questions asked in focus groups, interviews, webinars, an online survey, and via open submissions. Approaches were adjusted to meet communicative and cognitive support needs of participants. The consultation sought feedback on the entire draft Strategy, that included the concept of 'cure' as one goal, among many, for the field of CP (the full consultation report is available online).⁸ Data from across all data collection methods were pooled for analysis. Descriptive statistics characterized respondents' lived experience (person with CP, family member, support worker, professional), CP descriptors, community participation and living situation, and level of satisfaction with aspects of their lives. Qualitative data about the Strategy vision, mission, and goals were analysed thematically, and commonality of responses were summarized and considered from the perspectives of differing stakeholder groups. The focus of this article is on data generated, and discussion and interpretation of that data, on one aspect: that of searching for a cure for CP.

The consultation findings included varied, and sometimes strong, opinions about the notion of 'cure' which

What this paper adds

- There is a wide range of strong views on 'cures for cerebral palsy (CP)'.
- 'Cures for CP' was determined by most to be a reasonable and appropriate goal.

highlighted a number of 'ethical principles' (e.g. disability identity and societal attitudes) relevant to the 'cure' debate. It was also recognized that there was a need to define 'cure' for the purposes of the Strategy, so as to provide as much clarity as possible and not be misleading. Because of the differences of opinion expressed, further in-depth discussions on the topic of 'cure' were held with a reference group comprised of members from the Australian and New Zealand Cerebral Palsy Strategy Collaboration, a panel of experts in the field, and community advocates. It was during these in-depth discussions that the potential motivations behind various opinions were explored; these laid the foundation for the ethical principles featured in this article.

Literature review

To complement the perspectives raised during community consultation, a manual search of published (PubMed) and grey (Google) literature was conducted in October 2019 using the search terms 'cure' and 'cerebral palsy' or 'disability', as well as various other neurodevelopmental conditions for example Rett syndrome, autism spectrum disorder (ASD), fragile X syndrome, and Angelman syndrome. Because of the anticipated challenge of finding all relevant papers via strict keyword searching, hand-searching and citation chaining was the main search strategy used for this review. Identified literature was reviewed and key findings were extracted together with relevant quotations. Findings were then assembled according to the ethical principles identified during community consultation to form a narrative review.

BACKGROUND TO 'CURE FOR CP'

Until the late 1970s it was generally believed that CP resulted from birth asphyxia.⁹ With an assumed single causal event for CP, eliminating this source of injury was the primary focus of research and clinical efforts. By the late 1980s, data emerged suggesting that under 10% of CP was caused by birth asphyxia.¹⁰ This led to the improved understanding that CP is a group of conditions resulting from multiple aetiological pathways. This knowledge was the catalyst for substantial and sustained research aiming to identify the various causes and risk factors for CP as well as prevention strategies, and prompted the idea of curative strategies for one or more types of CP.

Although a number of treatments conceived and developed during the 1970s to the 1990s strived in pursuit of a 'cure for CP', there remain no widely accepted cures. As our scientific understanding of the brain injury (or injuries) underlying CP has improved, for example by advancements in neuroimaging, so too has our appreciation that 'curative interventions' for CP will require scientifically valid

mechanisms of action (regardless of whether the mechanism of action is targeting the underlying pathology or symptomatology). Stem cell therapy is one example of a mechanism-focused intervention for CP which is currently under investigation.¹¹ Stem cells offer a scientifically plausible treatment to reduce the severity of CP by directly targeting the underlying brain injury.¹² A recent systematic review with meta-analysis showed that stem cell therapy for children with CP has a small but significant positive effect on gross motor function compared to rehabilitation/standard care alone.¹³ Despite the lack of definitive, long-term efficacy data, demand for stem cell treatments is high; people with CP and their families are increasingly choosing to travel internationally to access unproven stem cell treatments from clinics that engage in direct-to-consumer marketing.¹⁴ This highlights the hope the community has for the discovery of new, effective treatments that might ultimately lead to a cure for CP.

Regardless of the source of a potential cure, emerging research in this area has raised a number of ethical questions centred on whether the search for a cure for CP is a reasonable and appropriate goal. Underpinned by a desire to achieve the best outcomes (do good) whilst balancing hope and expectations (do no harm), researchers and clinicians have commented on the best approach to navigating these ethical questions in relation to the idea of ‘cure’ for CP and other neurodevelopmental conditions.^{15,16}

As such, the remainder of this article aims to reflect the diversity of current opinions expressed on the topic of ‘cure for CP’ during community consultation as well as in the literature. Ethical principles, informed by community consultation, included defining ‘cure’ for CP, balancing hope and the proximity/likelihood of achieving cures, community-led research, priorities and practice, societal attitudes towards disability, identity, and choice. These principles provide a mechanism for presenting the main viewpoints raised in the ‘cure’ literature to date. Notably, many of the ethical principles raised, and the associated commentary, are not unique to CP. Learnings from other neurodevelopmental conditions, and the disability field more broadly, can be used to unpack the ethical principles surrounding cure, and these are considered in this article, where relevant. Finally, the rationale behind the ultimate decision to include ‘cure’ as a goal in the Strategy is outlined.

DEFINING ‘CURE FOR CP’

Although CP is a neurodevelopmental condition caused by an injury or maldevelopment to the developing brain, it is actually a clinical description, with detectable motor impairment required for diagnosis. Therefore, defining ‘cure’ in the context of CP is not straightforward, with some definitions focusing on remedying the underlying neuropathology and others on the clinical presentation. The ASD community, where clinical presentation is also a necessary diagnostic criterion, have similarly grappled with defining the term ‘cure’. One suggested approach put forward by the ASD community is:

Although ASD is viewed as a brain-based disorder of complex origin, it is an exclusively behaviorally defined disorder ... In the absence of clear etiologically or diagnostically informative biomarkers, defining change and cure in ASD is restricted to behavioural phenotypes.¹⁷

The same argument could be made for CP. While some have stated that a ‘cure for CP’ necessitates remediation of the underlying neuropathology – ‘It means the brain lesion is healed and the CP has gone’¹⁶ – it is also acknowledged that this may not be practical for a heterogeneous condition:

Given the severity and heterogeneous nature of the brain lesions that cause CP, I believe that there is no place for using the term ‘cure’.¹⁶

This raises an important point in defining ‘cure’ for CP – the multifaceted nature of the condition. Because CP is an umbrella term with multiple aetiological pathways, a singular cure for all CP is not feasible, and instead different ‘cures’ are likely to be required for different causal pathways and resultant injuries. Cures as a pluralized and symptom-based definition was supported by people with CP and their families during our subsequent discussions and debate that occurred after development of the Strategy. Thus ‘cures for CP’ is a more accurate way to frame the discussion, and features clearly in our proposed definition. In producing the Strategy, arriving at this definition was an important contributor to achieving consensus on the topic of cures for CP.

BALANCING HOPE AND THE PROXIMITY AND LIKELIHOOD OF ACHIEVING CURES

An important consideration in the ‘cures’ discussion centres on whether it is fair and reasonable to offer the hope of cures for CP if these are either a long way off or unlikely to ever be achieved. It is fair to argue that false hope should be balanced with the importance of providing hope:

We must avoid parents’ hopes being dashed. A good start would be not using the term ‘cure’ in the context of CP ...¹⁶

As famously postulated by Trudeau, we are compelled ‘to cure sometimes, to relieve [alleviate] often, to comfort [support] always’. We must support people with CP and their families to maximize opportunities by providing best practice, evidence-based interventions and supports, a sentiment very much aligned with Mac Keith’s 1967 editorial.¹⁸ This, however, should not preclude a simultaneous field of work from investigating potential curative treatments, nor should we limit what we strive to achieve. Our role is to support people with CP and their families to make informed decisions, and balance hope and expectations, by continuing to work collaboratively and effectively disseminating the ever-evolving evidence-base.

Moreover, while we do not know when or how curative treatments for CP may become available, this is not a

compelling reason against striving to discover them. If we do not aim for cures, it is unlikely that we will get closer to achieving them. Aiming for cures means that even if we are not successful in the short term, the treatments we do discover along the way may have increased efficacy than if we aim for intervention and supports alone.

For example, one discussion point that arose during the preparation of this article was the concept of incremental discoveries underpinned by neural repair/regeneration strategies. The idea of incremental gains is integral in shifting thinking away from a cured/not cured dichotomous outcome, to one where access to potentially 'curative' interventions may result in a continuum of functional impact, with 'cured' being at the upper end of that continuum. While we ensured that our definition of 'cures for CP' did not require the underlying brain injury to be healed, the concept of neural repair/regeneration is relevant from a neuroscience perspective. Indeed, the shift away from a cured/not cured dichotomy may help to moderate some of the contention that surrounds this topic.

COMMUNITY-LED RESEARCH, PRIORITIES, AND PRACTICE

Meaningful and authentic partnership with community in research and clinical practice is now recognized as best practice.¹⁹ Listening, acknowledging, and acting on the goals and priorities of people with CP and their families is critical to a discussion about cure. Much of the literature advocating for research into cures states that families and people with CP want to find cures, for example:

parents of children with cerebral palsy and individuals with cerebral palsy rightly demand more: improved treatments ... and, above all, a cure for the movement disorder.²⁰

This particular group of consumers provided a balanced continuum of priorities, ranging from prevention to cure and effective interventions across the lifespan.²¹

Similar sentiments were expressed by some during the development of the Strategy:

if we *really* want to improve the lives of people with CP, find out how to cure them.⁶

we need to have a closer look towards finding more information about what causes cerebral palsy ... and finally one day a cure.⁶

As expected, however, opinions of people with CP and their families are not unanimous, with some individuals sharing: 'You can't cure CP'⁶ and:

The term cure is particularly problematic. I question whether a cure is realistic within the timeframe of the Strategy. The term cure is offensive to people

with disability and has the potential to be quite damaging across the sector more broadly.⁶

Although varied views were expressed, the idea of aiming for 'cures' was endorsed by the majority of people who participated in community consultation for the Strategy.⁶ Thus, as we move into an era of community-guided research, cures for CP should remain on the research agenda.

SOCIETAL ATTITUDES TOWARDS DISABILITY

In some literature, the term 'cure' is associated with a medical, rather than a social, model of disability.²² The term 'cure' may therefore be deemed inappropriate for a condition like CP which is an umbrella term for a group of conditions. Bio-psycho-social models, such as the International Classification of Functioning, Disability and Health framework,²³ are more appropriate than medical models in conditions like CP.²⁴ Because the term 'cure' is associated with disease it can pathologize a condition, in contrast to perspectives that focus on individual strengths and potential. This focus may contribute to stigma associated with having CP, such as was expressed during community consultation for the Strategy:

Whilst finding a cure sounds great, I feel this statement may be negative towards some people currently living with CP as they may not feel they need to be cured but rather supported to reach their potential.⁶

When conditions are pathologized, the focus is on trying to make a person 'better' rather than on how we could improve society to better support, include, and engage people of all abilities. Moreover, some have expressed concern that by focusing on a cure, we may not be doing our best to develop interventions and provide support for those living with CP. Again, these sentiments are not unique to the field of CP, but instead are applicable to how we, as a society, view disability more generally:

Instead of assuming that all disabled people want or need a cure to 'fix' their disabilities, society must focus on dismantling ableism and actually improving accessibility and quality of life for all disabled people.²⁵

there should be a focus on changing negative societal attitudes and increasing social infrastructure to properly support individuals with Down syndrome and their families, rather than trying to change individuals ...²²

Although we acknowledge there are different, valid interpretations and connotations associated with the term 'cure', supporting the search for 'CP cures' does not mean that we, as a community, cannot continue to advocate for a society that better supports people with CP and their families to reach their full potential. It is society which too often disables people with disability and so both goals are

needed, and will hopefully lead to the best outcomes for people with CP and their families.

IDENTITY

When discussed during community consultation for the Strategy, some people described that they felt ‘cures’ insinuated that something was wrong with them or that they were ‘less’ than their peers without CP. When considering cures for CP, identity and the timing of treatment resulting in potential cures is critical to the discussion. CP is a child-onset, lifelong condition. Therefore, unlike conditions diagnosed in adulthood (e.g. multiple sclerosis, adult stroke), people with CP and other neurodevelopmental conditions grow up with their condition forming one of the many parts of who they are. Proposing to cure part of someone’s intrinsic identity can be experienced as insulting. Moreover, diagnosis and the concept of cure is complex in terms of self-discovery and acceptance. This may be particularly true for adults who have accepted their condition and have an established sense of identity.

Ethical principles in relation to identity are not unique to the field of CP; identity is an important factor in the discussion of cures for a number of other conditions including Down syndrome²² and ASD,²⁶ for example:

Autism is viewed as a difference, a neurological variation, a fundamental part of the person, not a disease in need of a cure.²⁶

Moreover, a study which surveyed 156 members of a disability activist organization found that earlier age of disability onset was associated with positive identity, and that these factors contributed towards reduced likelihood to support the notion of ‘cure’.²⁷

These opinions and viewpoints are valid and integral to the discussion of whether cures are a reasonable and appropriate goal for CP. It is important to balance these views with those who advocate for cures. One way to do this is to consider personal choice, and the role it plays in the ‘cures’ discussion.

CHOICE

It is a basic human right for an individual to choose whether they want an intervention/treatment. The right to choose to not undergo curative treatments if/when available has been previously raised:

[I]t’s difficult to make people understand that some of us, even if given the opportunity, do not want to be cured.²⁸

As such, we must consider that introducing curative options may have negative social impacts on how people with a condition, who choose not to undergo curative treatments, may be viewed. This has been debated, often fiercely, with regards to the use of cochlear implants to treat deafness. Development of the cochlear implant revolutionized options for the deaf community; however, some rejected the implant fearing they would lose key attributes

and opportunities such as sign language and deaf culture.²⁷ As part of this debate, people questioned the degree to which society would be willing to continue to provide life-long services to those who decline curative treatment:

questions about the extent to which individuals with disabilities may decline treatments to ameliorate disabling conditions. When they do so, to what extent may they call upon society to provide supportive services and accommodations?²⁹

The right to decline curative treatments, however, must be balanced with the right to access. Again, this argument is not unique to the CP field and has been discussed in disability forums generally, with someone with lived experience of disability stating:

Even if there were a cure for any given disability, I know there are disabled people who would choose not to be cured. And that is their choice to make, no one else’s. Personally, I wish to get rid of the physical pain my disabilities cause me, but I can see why some people with disabilities would not want to change part of themselves.³⁰

Considering the significant potential benefit of cures to improve functioning, which may increase quality of life, and reduce comorbidities (such as pain) for many people, avoiding the quest for cures could be considered unethical.

In developing the Strategy, members of the Australian and New Zealand Cerebral Palsy Strategy Collaboration in addition to experts in the field and community advocates agreed that, while the potential negative implications that could arise from having cures for CP available are important and should be managed, the potential for good to come from cures for CP for the people who choose to receive them cannot be overlooked. Moreover, having the choice to undergo curative treatments is equally important as the choice to decline curative treatments, and therefore should not prevent the quest for cures for CP.

IMPLICATIONS FOR THE FIELD

As highlighted in this review, the topic of ‘cures for CP’ is extremely challenging, given the wide range of, often very strongly held, views. Although we approached this subject from an Australian and New Zealand perspective, the available literature, and the topic itself, is universal to all disabilities and settings. Whilst ultimately ‘cures for CP’ was determined by our Australasian collaborative to be a reasonable and appropriate goal for the field in the 2020s, the relevance of our stance to a broader geographical context is unclear. Differences in socioeconomic, political, and cultural factors could influence the transferability of our conclusion to other settings. Indeed, even within the context of our work, the definition of ‘cures for CP’ was limited by the breadth and depth of perspectives gained through our community consultations. As an example, we did not collect detailed data about participants’ cultural circumstances, so we cannot report on the extent of contributions from those

who are from Aboriginal and Torres Strait Islander, Maori, remote, or culturally and linguistically diverse communities. A full draft of the Strategy was reviewed and considered by representatives from Kāpō Māori Aotearoa in New Zealand and the First Peoples Disability Network in Australia; however, these groups were not specifically engaged in the discussion about cures. Future work could explore the relevance and applicability of our findings to other contexts. For instance, one aspect that has not been addressed in the literature to date is perspectives from low- and middle-income countries (compared to high-income countries), which may differ. Ultimately, however, by applying an ethical lens to the topic, we have proposed a definition of ‘cures for CP’ that we believe could be adopted more widely. Importantly, we advocate that discussions around ‘cures for CP’ should continue, as new insights, perspectives, and even scientific advances may change the appropriateness of our standpoint.

CONCLUSION

This article highlights that engaging broadly across diverse communities – and disability is always diverse – to set priorities for research, practice, and policy will inevitably mean that often fiercely different viewpoints will be heard. However, the complexity of making decisions, setting priorities, or coming to consensus, can be assisted by considering ethical principles to guide discussion, and being always open to and accepting of these different viewpoints, while also maintaining hope and being realistic. By having concerns and aspirations openly shared and objectives

agreed by all stakeholders, it is possible to present a strong and pluralistic voice to inform research.

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CONFLICT OF INTEREST

IN, MFE, IN, SM and NB are employed by Cerebral Palsy Alliance (CPA), CI is a Director of the Australasian Academy of Cerebral Palsy and Developmental Medicine (AusACPDM), AH is employed by The Cerebral Palsy Society of New Zealand (CP Society), and MB is employed by Ability First Australia (AFA). CPA, AusACPDM and AFA (via Cerebral Palsy Australia) provided financial and in-kind support, and CP Society provided in-kind support, for the development of the Australian and New Zealand Cerebral Palsy Strategy. At the time of writing, SC and SW were Collaboration Members with lived experience of cerebral palsy, or as a family member of someone with cerebral palsy, of The Australian and New Zealand Cerebral Palsy Strategy. They provided in-kind support to the development of the Australian and New Zealand Cerebral Palsy Strategy.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study

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