

Growth Attenuation Therapy

Views of Parents of Children with Profound Cognitive Impairment

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Abstract: The “Ashley treatment” has provoked much debate and remains ethically controversial. Given that more children are being referred for such treatment, there remains a need to provide advice to clinicians and ethics committees regarding how to respond to such requests. This article contends that there is one particularly important gap in the existing literature about growth attenuation therapy (GAT) (one aspect of the Ashley treatment): the views of parents of children with profound cognitive impairment (PCI) remain significantly underrepresented. The article attempts to redress this balance by analyzing published accounts both from parents of children who have received GAT and from parents who oppose treatment. Using these accounts, important points are illuminated regarding how parents characterize benefits and harms, and their responsibilities as surrogate decisionmakers. This analysis could contribute to decisionmaking about future requests for GAT and might also have wider relevance to healthcare decisionmaking for children with PCI.

Keywords: Ashley treatment; growth attenuation therapy; cognitive impairment; parent; child; decisionmaking

Introduction

The initial report of the “Ashley treatment”¹ provoked much public comment and academic debate.^{2,3} In response to these comments and criticisms, Diekema and Fost usefully catalogued and analyzed 25 discrete objections to the interventions offered to Ashley and her parents, providing a comprehensive map of the discussions that had occurred. Ultimately, these authors concluded that although many of the critiques fail when subject to close scrutiny, others provide strong reasons for proceeding with caution in future cases.⁴ Gillett has revisited some of these objections in his article in this symposium, and in addition has provided two useful principles to assist in reasoning about such cases.

While this academic debate smolders on, it is apparent that more parents of profoundly disabled children are becoming aware of growth attenuation therapy (GAT),⁵ and there have been an increasing number of treatment requests and prescriptions.⁶ Whether and when this form of treatment should be available to children with profound cognitive impairment (PCI) therefore continues to be clinically relevant. At present, requests for such treatment present significant challenges to clinicians and clinical ethics committees; the various clinical practice guidelines and recommendations that exist are divergent,^{7,8,9,10} and thus responses to individual cases have varied.

Given the lack of consensus in the underlying bioethical debate, it is perhaps not surprising that divergent approaches to clinical practice exist. However,

the diversity of responses, at best, is likely to be confusing for families and clinicians and, at worst, may add significantly to the emotional and practical burdens of caring for a profoundly disabled child. The question then is what, if any, further work can be done to address this impasse.

Further work at a philosophical level, such as that described by Gillett, remains valuable. However, it is suggested here that there is considerable scope for empirical data to enhance and inform these principles. In particular, it is contended that there is one especially important gap in the existing academic literature: although families have not been entirely neglected in these discussions, their views are significantly underrepresented. By default, Ashley's parents' narrative viewpoint, although undeniably important, is often the only one considered in relation to GAT. With the exception of a Hastings Center report,¹¹ accounts from other parents similarly involved with the care of an individual with severe disabilities have received much less emphasis. In the light of Bowyer's philosophical analysis of the well-being of the child as a function of a deeply relational situation (see her article in this symposium), it seems that a more inclusive discussion is sorely needed. This article aims to redress this balance, focusing primarily on GAT, rather than addressing the triad of interventions collectively known as the Ashley treatment. In part, this approach relates to Gillett's coverage of the other issues, but, in addition, there is already a significant body of literature concerning hysterectomy, and although some controversy persists, there is established policy in most jurisdictions.¹²

Pediatric Bioethics

Before discussing the various published parental accounts of GAT, the importance of parental views in relation to pediatric healthcare decisionmaking is highlighted. There are several underlying reasons why parents' views should be given considerable weight.^{13,14,15}

- In most cases, a child's parents know the most about him or her, and this is likely to be particularly pertinent in the context of significant disability, in which anyone not directly and intimately involved in caring for such a child may struggle to fully comprehend the impact of any decisions.
- Parents are also cognizant of the way in which medical decisions can affect the wider family, and they can factor family issues and values into medical decisions about their children (just as they do in relation to nonmedical decisions).
- Parents are generally the people who care the most about their child, and these feelings motivate optimal decisionmaking.

Ultimately, then, parents are in a privileged position both to understand the unique needs of their child and to make decisions that are in the child's interests. For these reasons parents usually have the responsibility and authority to make medical decisions on behalf of their children. There is, of course, a limit to this ethical authority, but parents' decisions would usually only be overridden if the child were likely to suffer significant harm in relation to the decision.¹⁶ Respecting parental autonomy in this way also places value on the intimate family relationships that are likely to facilitate children's overall physical and emotional development.¹⁷

Whereas these points are familiar to pediatric bioethicists, they would also not come as a surprise to practicing pediatricians: the concept of family-centered care, based on the understanding that the family is the child's primary source of strength and support, is a central tenet of modern pediatrics.¹⁸

Families Represented in This Article

This article therefore reports on the available literature concerning the views about GAT of parents and caregivers responsible for the day-to-day care of individuals with profound cognitive and physical disabilities. The report includes detailed accounts from parents of children with profound disabilities—people who can most accurately claim that they have a deep and nuanced understanding of the issues involved. Given that parents' views are generally considered important in pediatric bioethics, my specific objectives in analyzing these particular parental accounts are threefold: (1) to give these parental voices greater prominence in the debate; (2) to provide direct evidence concerning some of the contested harms and benefits of GAT; and, finally, (3) to reflect on the relevance of some important values underlying these parental viewpoints.

Data for this section have been drawn from parental reports that have emerged over the years since the publication of the "Ashley paper." Although many brief testimonies and comments (both in support of and opposed to GAT) are available, this article concentrates on more detailed and substantial accounts. Superficially, these reports vary: some have been published in academic journals,^{19,20,21} and others in mainstream media, including newspapers, magazines, books, and websites;^{22,23,24,25} some were written by parents themselves, and others by journalists following extended interviews. However, all the reports contain parents' firsthand descriptions of what life is like for them and for their children with profound disabilities; the disabilities in question include quadriplegia, profound cognitive impairment, and significant difficulties with verbal communication. All of the children (including those now adults) require assistance with every aspect of daily living, and some also have other significant issues, such as visual impairment, seizures, scoliosis, and problems with feeding.

The reports include testimonies from Ashley's parents, who run a website and blog²⁶ and have given several interviews to the media.²⁷ However, the article also references accounts from three other parents whose children have undergone GAT²⁸ and from one parent who supports the treatment, although it was not available for her child.²⁹ There are also references to detailed accounts from four parents who oppose such treatment.³⁰ Three of the individuals referred to in these accounts are now adults, and the fourth is a teenager; hence their parents were not actually presented with GAT as a treatment option, but, given their experience of living with their child as he or she develops and grows, their views remain highly relevant.

Family Accounts

These families' views are presented under broad headings similar to those alluded to by Gillett in his article in this issue of the journal. Where possible, points are illustrated with direct quotations from the family accounts.

The Child's Well-Being

This section considers what families say about the benefits and burdens of either pursuing GAT for their child or allowing growth to continue uninterrupted.

Physical effects. The stated aim of GAT is to reduce a child's final height to an extent that permits parents or caregivers to continue lifting and moving the individual more easily. An important empirical question is therefore whether or not treatment with estrogen patches actually achieves this aim. The parents whose children have undergone GAT have provided such outcome data, and, given that this has not been presented elsewhere, their final growth parameters (height and weight) are reported here. Charley (who commenced treatment age four) is 125 cm tall and 23 kg;³¹ Ashley (treated at age six) is 137 cm tall and 34 kg;³² Tom, who was close to completing treatment at the time of parental interview (begun when he was nearly eight), is 134 cm tall and 32 kg;³³ and Erica (treated at age nine) is 145 cm tall and 33 kg.³⁴ These data cannot be assessed against standard pediatric growth charts, as children with cerebral palsy (CP) are known to grow at different rates compared to typically developing children; rather, they should be assessed using a growth chart specific to children with this level of disability. Using these charts, the average height and weight for males and females with quadriplegic CP at age 20 are 150 cm and 38 kg (males) and 144 cm and 34.5 kg (females).³⁵ It therefore appears that GAT with estrogen patches does modestly restrict height (and weight), particularly if commenced at a younger age.

But the impact of GAT on final height represents only part of the picture: further important questions include what impact (if any) this degree of height restriction has on the parents' ability to move their child, and what impact this has on the child's quality of life (QoL). To my knowledge, there has not been an attempt to quantify frequency of movement or transfers in this situation. However, all of the accounts reviewed in this article from parents who had accessed GAT for their children include details of frequent lifting during routine care, and all the parents believed that restricting their child's final size had prevented future difficulties for both themselves and the child. These parents reported a wide variety of benefits accruing to their children in relation to this ease and frequency of movement. For example, Ashley's Dad says, "We move her frequently throughout the day, repositioning her to prevent bedsores and to aid circulation."³⁶ Other reported benefits include their children's ability to access a wide variety of different experiences, often with other family members, outside the house. For Charley this included floating on an inflatable in the family pool and riding on a Jet Ski,³⁷ and, for Ashley, going out for walks with her family to get fresh air.³⁸ Some families also attribute less expected benefits to the treatment: for example, Charley's parents report that she has experienced fewer seizures, her muscle tone has relaxed, and, much to her father's delight, she began to smile.³⁹ There were no parental reports of adverse effects associated with the use of estrogen patches.

These accounts contrast starkly with that given by Jessica's mother, who writes in support of GAT, which had not been available when her daughter was younger.⁴⁰ At 15 years Jessica weighs 39 kg and is 155 cm tall, and her mother believes that her recent growth spurt has "greatly limited her life experiences." She explains that routine care, such as changing Jessica's diapers, has become much more difficult, and their ability to access recreational activities has diminished. Jessica's mother

believes that those who argue that more resources would solve these problems do not fully understand the needs of such children or the desire of parents to not only make sure their children are comfortable but also prevent boredom and seclusion.⁴¹

Conversely, the parents of children with PCI who oppose GAT argue that issues related to their child's size can indeed be addressed by resources. Their opinions are highly relevant, as three of their children (Sesha, Charklie, and Pearlsky) are adults (in their twenties to forties) and the fourth (Sophie) is a teenager. For example, Kittay, commenting on Ashley's case, states:

That we have to hire help or rely on equipment to do what parents' hands and arms can do is a loss, but although the ability to care for Ashley without such assistance may be lost, the ability to care for Ashley, and even to provide that care at home is not. Learning what services and resources are available, advocating for more services, and adjusting to new people and equipment all take time and energy, but GAT is not an appropriate shortcut through these difficulties.⁴²

Swenson echoes these thoughts when she talks about being taught how to position her (now adult) son to enable his participation in a broad range of activities, how to transfer him without lifting, how to support his mobility and find useful equipment, how to include him in everything, and how to think about his rights.⁴³ Similarly, Roy articulately describes how her daughter Sophie has been provided with "as much physical and intellectual stimulation as possible," including "daily educational programs, arts and crafts, physical therapy and outings in the community, through engaged parenting and the many support services available."⁴⁴ Finally, Single Dad (a *nom de plume*) suggests that his daughter's QoL is at least as good as Ashley's: "Pearlsky is a young woman, well cared for, has a good quality of life from her point of view, and her body is intact. Ashley is in a modified body, ... and to what end? Is she better off than Pearlsky?"⁴⁵

Psychosocial effects. In addition to the arguments concerning ease of movement, parents in favor of GAT also highlight how small size enables them to continue to hold and cuddle their child frequently, as if they were an infant. This benefit appears to be very important to these parents and is frequently discussed in some detail. For example, Erica's mother stated that her daughter "loves being in our laps" and is "sometimes fussy around me like a baby if I'm not holding her. She lies in our laps and sucks her thumb."⁴⁶ Similarly, Tom is reportedly happiest among his family when he is being cuddled.⁴⁷ Commenting on a common objection to this type of view, Erica's mother says that these viewpoints do not mean that families focus on infantilizing their child; rather, they are simply a means to an end: "I don't want to keep her a baby, I just want to keep her happy."⁴⁸

These parents use this analogy with babies both to further explain their impressions of their child's likely subjective experience of life and to guide them in how best to care for their child. For example, Ashley's parents acknowledge that "every child should get the stimulation, education and love that helps them grow, develop, and reach full potential." They talk frankly about the vast difference in the way they achieve this for their son and younger daughter versus for Ashley. For their typically developing children, they achieve this through a wide variety of means that would be familiar to most parents, including books, sports activities, and

education. But they also feel that they do the same for Ashley, by recognizing that her needs are very special and different: "What is meaningful for Ashley is being able to enjoy those things she can enjoy: being with family, hearing music, cuddling." They describe how, although some people might consider these "activities" to be trivial, they can be profoundly meaningful for individuals with PCI: Ashley "kicks her legs and orchestrates her arms, she makes little happy sounds, her face radiates with smiles."⁴⁹

Charley's parents echo this thought, commenting on how seemingly "tiny pleasures" such as "the taste of chocolate cake, the soft blow of air onto her face, a new sound, a tap on the nose or bounce on the knee" may be important in their daughter's QoL.⁵⁰ The corollary of this is that what may be thought of as minor or inconsequential harms to typical children (such as sitting too long in one place) can be very distressing and disruptive for children like Tom,⁵¹ and families feel these situations may be more easily avoided if the child is easier to move.

But, again, parents of children with PCI who oppose GAT do see these approaches as patronizing and infantilizing. They reject the idea that their children are "perpetual babies," and that they are best served by being cared for in a "baby-like" manner. Their arguments highlight how difficult it is for parents to be certain about their child's developmental potential and the best way to care for him or her, particularly in the early years: "Having a severely disabled child changes one's life. In almost all cases, the situation is a complete unknown. You find yourself in a situation where you know nothing. This is a child like you have never encountered. Your own child is not like you, nor anyone or anything you know."⁵² They also highlight the impossibility of accessing the subjective life of people with PCI, even later in life, suggesting that although individuals with PCI may not be able to function beyond the level of an infant, their understanding and lived experience far exceed any such age limitations. Kittay explains this position by noting that the brain, no matter how impaired, remains a dynamic organ, not a static one. She has direct experience of watching her daughter change over the years and describes how her tastes in music have evolved and how she has developed "emotional maturity."⁵³ Swenson, who has also watched her son grow to adulthood, suggests that it remains possible that individuals with PCI may develop a much greater "sense of themselves" than we imagine, and that we risk making them feel we are "dissatisfied with them just as they are" if we try to change them, rather than adapting the environment to suit their needs.⁵⁴

Peace and Roy also articulate this viewpoint, commenting on the unrelenting focus on what individuals with PCI cannot do instead of on what is possible. They further contend that the idea that there exists a group of individuals with limited cognitive and physical ability that are so fundamentally different from others as to make GAT ethically permissible is false. Here Roy points to aspects of Ashley's story, as well as the experience she has with her own child Sophie, to suggest that people with PCI still have distinct preferences that they can communicate, and that they do progress and change over their lifespan, albeit not in a typical fashion.⁵⁵ Finally, this sentiment is echoed more forcefully by Single Dad, who objects to the attitude that "if you are not 'us,' not like us, you are the Other. We are able-bodied, you are the Other. We can communicate, you are the Other." He believes that children who have undergone the Ashley treatment have been victimized, "their undiagnosed potentials ... modified if not destroyed" and that this has (wrongly) been justified purely by virtue of their differences.⁵⁶

Decisionmaking for Children with PCI

Caring for a severely disabled child inevitably involves parents participating in a wide array of sometimes difficult and complex healthcare decisions, the majority of which impact on ease of care in addition to having direct effects on the child. All of the parents who chose GAT for their children feel strongly that they are best placed to make these decisions (including those in relation to GAT). For example, Tom's parents say, "Somebody has to make decisions for them and who better ... than the parents who love the child?"⁵⁷ Similarly, Erica's mother says that although she respects other people's right to their opinions, she "knows what is right for her daughter."⁵⁸ Walker, who writes in support of GAT but was not able to access it for her own child, feels that the opposition to the Ashley treatment has taken society a "step backward." She continues by commenting on the "positive attempt in recent years by the medical community to allow parents to make some of the difficult decisions regarding their children's care."⁵⁹

Again, though, parents who oppose GAT reflect on the limitations and potential biases (such as parental pride or ego) of parental decisionmaking and ponder exactly where the limits of their authority should lie. For example, Swenson says, "The human rights of the child as a person with disability should limit parental rights." She further questions the degree to which a parent can know what his or her severely impaired child wants (or will want), stating that it is important to question "if there is a supported decision making process that gives me more to go on than my own interpretations? Decisions that are made behind a parental privacy shield can be too easy for our own good."⁶⁰ Similarly, Kittay, looking through the lens of an ethic of care, notes the asymmetry in power and dependency of the various parties involved in decisionmaking for children with PCI. She states that parents are dependent on medical personnel (with their presumably medical conceptions of disability) for expertise in making the best choice for their child and that the parents themselves (unless disabled or already the parent of a disabled child) bring with them their own "ableist" biases. Acknowledging how difficult such decisionmaking may be, she continues, "Parents have to tread a delicate line between refusing resignation and accepting a child as she is and will become. When there is no way to normalcy or increased function a change in perspective is more than just settling, it is positively transformative."⁶¹ In this regard she is echoed by Peace and Roy, who focus on the ways in which parents themselves can change and adapt, without "altering their child."⁶² Single Dad appears to be more sure of his own ability to make decisions on behalf of his daughter: "I continually demand she be treated with respect, as the young lady she is, that others see her from her point of view, whatever that may be. ... Why can I not substitute my voice for hers, even though hers is silent?" What he does object to are other parents who make decisions on the basis that their own children ("the Other") are fundamentally different from other children.⁶³

Disability Rights, Including the Rights of the Individual Child with the Disability

The individual child. Parents in favor of GAT believe that this means of treatment not only does not limit their child's rights but also actually enhances such rights. For example, Erica's mother, describing what she sees as the positive impact of

GAT on her child's QoL, states that her daughter "has a right to a happy life."⁶⁴ These parents also talk about the respect they have for their children: "I don't think they can accuse us of disrespecting our children. It's the opposite. ... This is to do with respecting a human being who needs help."⁶⁵ Similarly, Ashley's father uses another term frequently employed in these discussions when he states that "we care a great deal about our daughter's human dignity and feel that the treatment makes Ashley more dignified by providing her with a better QoL."⁶⁶

Conversely, parents opposing GAT think about their child's rights and the concept of dignity very differently. The basis of their position appears to be that people with disabilities possess the same set of fundamental rights as typically functioning individuals: individuals with PCI "deserve the same legal, ethical and civil rights as everyone else."⁶⁷ Kittay explains this further, referring to growth: "we value our children growing because growth is normally a sign of thriving, and such thriving is part of a flourishing life" and sexuality: "having breasts is not just to attract a male. They are part of what it is to be female and a being with sexuality." She proposes then that these rights relate to goods that are of intrinsic, rather than just instrumental, value.⁶⁸ To reinforce this notion she states, "we stand Sessa up and love that she is just a tad taller than me. Why? Why does anyone enjoy noting how tall one's child has become? We take pleasure and pride in our bodies as they grow and mature because ... we do. Full stop. It needs no further justification."⁶⁹ For Kittay (a philosopher whose research has focused on feminist philosophy), this viewpoint is informed by the "embodied ethics" of an ethic of care. From this perspective "we cannot attend to the body without attending to the person, and we cannot care for a person without attention to their bodily integrity and well being."⁷⁰

Disability rights. Those parents who oppose GAT therefore believe that the treatment reflects a lack of respect for and understanding of children with PCI. Much of their concern relates to the specific individuals involved, but it is also tied to the history of abusive treatment (such as involuntary sterilization) to which people with disabilities have been subjected, purportedly for both societal and individual benefits.⁷¹ Such concerns mean that these parents believe that the impact of individual decisions concerning GAT on the broader group of people with disabilities should be taken very seriously, as "targeting an already stigmatized group runs the risk of their further stigmatization and maltreatment."⁷² In this regard they are also concerned about slippery slopes:

The Ashley treatment is the only medical intervention for which PCI is the sole and necessary indication even though there are many populations who make similar demands on care givers. The most plausible explanation for this is that this is the only population who will never know the difference ... what else can we do to this population because they will never know the difference anyway?⁷³

Similarly, Peace and Roy are critical of this (often implicit) line of reasoning, as it may lead one to conclude that "it would be acceptable to provide minimal care in unattractive surroundings and devoid of privacy because they have no sense of what is going on."⁷⁴

Parents in favor of GAT, however, take issue with these criticisms from the disability community: “Those people who reacted most harshly were [self-aware] disabled people. They are aware of their rights. Tom isn’t. Ashley isn’t. Somebody has to make decisions for them and who better to make that decision than the parents who love the child?”⁷⁵ These parents do not consider that disability groups are in a good position to comment on such issues; they even consider them misinformed: “People don’t understand that we are talking about a small percentage—just one percent of the disabled population with disabilities like Erica’s—who would be candidates for this treatment. It’s not for everyone. There are grey areas. But for her it’s black and white.”⁷⁶ This sentiment is echoed by Ashley’s father: “From reviewing the reaction of the disabled community in detail, it is clear to us that not enough attention was given to Ashley’s unique condition and needs, and how the treatment brings her significant and direct benefits.”⁷⁷ Some parents felt wounded by such criticism: “They spoke of the ‘perspective of the disability community,’ as though Ashley and her family were not a part of it. I felt disenfranchised by the very organizations and individuals that were put into place to protect Jessica and our family.”⁷⁸ And Ashley’s father felt that a collective policy to block the Ashley treatment from children, independent of their individual needs, was itself similar to past eugenic practices (such as sterilization) in that both could be construed as misguided collective policies that harm the individual.⁷⁹

Discussion: What Can We Learn from These Accounts?

Acknowledging the importance of parents in pediatric healthcare decisionmaking, this article has described a range of available reports from parents of children with PCI, including both those in favor of and those opposed to GAT. We now turn to a discussion of these results.

Limitations

Before summarizing the two main parental viewpoints, some limitations of this article should be acknowledged. First, it is likely that the parents represented here form a particularly articulate, well-educated, and opinionated group: they may not be representative of the broader group of parents of children with PCI. There have been more occurrences of GAT than those documented here,⁸⁰ and there are also other parents who oppose GAT, but their views have generally not been published in an accessible form.

Second, the parents reported here who oppose GAT have not actually been in the position of considering it, as their children are older, and GAT was not available during their early years. This does not negate the importance of their comments; in fact, it may enhance their relevance, as these parents are living with the consequences of unaltered growth. However, it would be useful to also include the perspectives of parents who have actively considered but ultimately rejected GAT. Finally, although these parental accounts are rich and detailed, the author’s own biases and assumptions are likely to have influenced this article. Without direct access to the parents involved, it has not been possible to check the authors’ interpretations of their accounts. All of these limitations could be addressed through a formal qualitative study involving a larger number of parents.

Similarities and Differences

At first glance there appears to be little similarity between the views of families in favor of GAT and those opposed. However, it is important to recognize that, underlying their accounts, all of the parents share some quite fundamental opinions or wishes for their children. The terminology used by different parents varies, but their views are consistent with Kittay's description of what parents generally want for their children:

- That they live and stay as healthy as possible
- That they have a chance for happiness and joy and that malevolent forces do not disturb their lives
- That they contribute in some way to the lives of others⁸¹

Summary of Parental Findings

Beyond these similarities, perhaps the most important contribution these accounts can make to the debate is a better understanding of the areas in which there is deep disagreement. The predominant focus of parents in favor of GAT is the lived experience of their child. They believe that their child's best interests are served by maximizing pleasurable experiences and minimizing those that are negative: if this can best be achieved by caring for their child in a similar manner to a young infant, then that is entirely appropriate. They argue that they know their children best and are therefore best placed to make these decisions. Although they prioritize these practical aspects of QoL, they are also cognizant of issues such as dignity, rights, and respect but feel that these more abstract concepts are best acknowledged and respected through attending to the practical QoL issues. Recognizing that this predominant focus on experiences is different from the way in which they parent their other children, these families argue that their child's level of cognitive impairment makes such a different approach ethically preferable, and in turn makes GAT ethically acceptable for their child.

Parents who oppose GAT also acknowledge the importance of experiences and a positive QoL for their child and believe that they have a significant role in attending to these issues. However, they have reservations about the degree of parental discretion that should exist in relation to healthcare decisions for children with PCI because of the potential for bias and entanglement of interests and because people with disabilities may require special protection in the context of previous abuses. Similarly, although they are concerned about their child's subjective experiences, they do not consider that attempts to maximize QoL should subjugate other important elements of their child's life, such as their rights or dignity. This attitude relates in part to concerns that we may be underestimating the abilities of those with PCI but also to a belief that there are some aspects of life that are intrinsically valuable to everyone. For them there is no point on a scale of cognitive impairment at which it is permissible to treat a child in a fundamentally different way; hence GAT is always inappropriate. They argue that to define such a point is to devalue not only the life of their individual child but also the lives of others with disabilities.

Although philosophical analysis of these positions is not the aim of this article and is indeed beyond its scope, it appears that the crux of this deep disagreement between parents relates to how the best interests of children with PCI should be

interpreted. One set of parents favors a focus on pragmatic issues related to QoL, whereas the other points toward the importance of more abstract, higher-order interests. This difference in parental emphasis is reminiscent of Dworkin's differentiation between experiential and critical interests,⁸² and subsequent arguments concerning the way in which the relative importance of these two distinct types of interest may be altered in the context of PCI.⁸³ Further normative analysis in this area may inform not only decisions concerning GAT but also decisionmaking more generally for children with PCI. This normative analysis should, however, be supplemented by the qualitative work alluded to earlier: there is existing evidence within the social science literature that parents' "agency" in relation to their children may vary by time and context. For example, parents have been described as both "nomad and settler" between more pragmatic and more conceptual approaches to their child. In this way, people's lives may not necessarily fit into neat academic divisions.⁸⁴

Conclusion

At a fundamental level, all of the parents represented here have the same goals for their children. But they disagree on more precise conceptions of best interests, how they should be achieved, and who should decide. Having argued that views such as these should be privileged in pediatric healthcare decisionmaking, the question that follows concerns how we should incorporate such divergent opinion into clinical practice. In the face of such deep disagreement, no single recommendation concerning policy or guidelines for GAT can be acceptable to all. However, established arguments support the view that in situations in which true moral uncertainty exists, (as it does for many of the commentators here, including bioethicists, pediatricians, and parents), parental views should be given greater weight.⁸⁵ In practice, that means that parents should be supported in making decisions about GAT based on their own assessments of the interests and needs of their children and families. Ultimately, then, depending on their conception of their child's best interests, a parental decision in either direction may be ethically justified.

This does not mean that parental requests for GAT (or other controversial interventions) should proceed without question. The decision to undertake such treatment is complex and sensitive; it is deeply personal and at the same time has significant ramifications for others. For other medical decisions with similar features (such as genetic testing for Huntington's disease) a consultative and counseling process is proscribed before the decision can be made. A similar process could be developed for GAT, with a period of time set aside for provision of information (including plain English accounts detailing the varied views of parents of children with PCI) and repeated discussions and deliberations with families. Snelling's article in this symposium argues for a taxonomy of reasoning, or a road map for judicial reasoning, to ensure that best-interests assessments are extensively informed (by medical, familial and social evidence) and robust. The process referred to previously, in conjunction with a clinical ethics committee opinion that explicitly identifies and tests potential assumptions regarding the lived experience of the individual, could also arguably achieve this aim without the need for court approval. Although such a conclusion will not please all, it does attempt to acknowledge both the parents who believe strongly that GAT is in their child's best interests and those who believe it to be ethically problematic.

Notes

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65. See note 24, McVeigh 2012.
66. See note 22, Pilkington 2012.
67. See note 30, Single Dad 2012.
68. See note 21, Kittay 2013.
69. See note 20, Kittay 2011, at 621.
70. See note 20, Kittay 2011, at 616.
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72. See note 20, Kittay 2011, at 616.
73. See note 21, Kittay 2013.
74. See note 19, Peace, Roy 2014, at 44.
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