

Deep Brain Stimulation in Children: Parental Authority Versus Shared Decision-Making

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Abstract This paper discusses the use of deep brain stimulation for the treatment of neurological and psychiatric disorders in children. At present, deep brain stimulation is used to treat movement disorders in children and a few cases of deep brain stimulation for psychiatric disorders in adolescents have been reported. Ethical guidelines on the use of deep brain stimulation in children are therefore urgently needed. This paper focuses on the decision-making process, and provides an ethical framework for (future) treatment decisions in pediatric deep brain stimulation. I defend a shared decision-making model in case of deep brain stimulation for neurological and psychiatric disorders in children. To protect the vulnerable child patient, a dual consent process is needed where parents or parental guardians give their consent, and the child gives his/her assent.

Keywords Deep brain stimulation · Shared decision-making · Informed consent · Assent · Dissent · Psychiatric disorders · Children

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Introduction

Deep brain stimulation (DBS) is the most frequently performed surgical procedure for Parkinson related movement disorders that are refractory to pharmacological therapy [1, 2]. Over 55,000 patients have been treated for movement disorders today, and the FDA recently approved DBS for treatment-refractory obsessive compulsive disorder (OCD) based on a humanitarian exemption. Importantly, this procedure is still experimental in nature with respect to psychiatric disorders. There are long-term successful results for OCD and promising results have been obtained for, among others, Tourette syndrome, major depression, and cluster headache. It is important to mention that this technique targets treatment-resistant disorders, resulting in high success rates and often involving dramatic and durable benefits. Moreover, certain other techniques, such as electroconvulsive therapy, show higher relapse rates compared to stimulation via implanted electrodes [1, 3–6].

A randomized controlled trial of bilateral pallidal stimulation in adults shows that DBS for generalized dystonia is effective in most adult patients [7]. Because of successful treatment in adults, DBS has been used to treat intractable early onset idiopathic generalized dystonia (IGD) in children as young as 7 years [8]. IGD is a progressive and profoundly disabling neurological syndrome that is characterized

by sustained muscle contractions and abnormal posture, involving twisting and repetitive movements. Onset is usually before 10 years of age and typically stabilizes after 5–10 years, resulting in severe disability in most individuals and impaired participation in daily life [9]. Borggraefe and colleagues [10] report on their own findings in 6 children with IGD and 38 children from other studies, and conclude that DBS is an effective treatment for children with IGD. Moreover, because the severity of the disease is a negative prognostic factor for DBS, they argue that DBS should be considered in a timely fashion. Also, two recent studies show that disease duration affects treatment outcome, with >15 years disease duration predicting significantly worse treatment outcomes [11, 12]. Awaiting further confirmatory results, Mehrkens and colleagues [12] suggest that early treatment appears “even more important in pediatric/juvenile patients to prevent irreversible impairment of motor function” (p. 15). Due to the impact of generalized dystonia on the child’s social integration, peer relations and school performance, Clausen [13] urges for early treatment in order to prevent social isolation, which may have long-term negative effects even after successful DBS treatment [14].

There are also reports of DBS for Lesch-Nyhan syndrome, cerebral palsy and hyperkinetic movement disorder in young children [15], although overall few published reports on DBS in young children exist and clinical application is likely limited. There are case reports of DBS for psychiatric disorders in adolescents (e.g., for Tourette syndrome in 16- and 17-year-olds) [16–18]. To my knowledge, no case reports on DBS for psychiatric disorders in very young children exist.

A group of experts recently proposed guidelines for the use of DBS for disorders of mood, behavior and thought [19]. One of their consensus statements holds that, at present, DBS for mood, behavior and thought disorders should be reserved for adults. However, they also mention that “if DBS is found to be safe and effective for adults, then it might be appropriate to investigate its benefits for a younger population with severe, treatment-refractory symptoms” (p. 933). In fact, unless clear scientific criteria exist why children need to be excluded, it can be considered unethical to categorically exclude child and adolescent patients from receiving the only treatment available that could dramatically increase their quality of life. Hence, as soon as treatment success for psychiatric disorders is

established in adults, and provided no clear scientific criteria exist to categorically exclude minors, children and adolescents can be involved in small-scale, early-phase studies provided these are done in research centers. As is the case with movement disorders today, it is not unlikely that DBS for psychiatric disorders will be used in young children as soon as treatment success is established in adults [20]. This paper therefore provides an ethical framework for (future) decision-making in pediatric DBS for neurological and psychiatric disorders.

DBS is an invasive procedure because it involves brain surgery and the placement of electrodes inside one’s brain. A variety of serious side effects related to the surgery, the technical devices, as well as the stimulation itself may occur [1, 21]. Considering the invasiveness of the procedure, some ethicists and medical experts will argue that the parents should have decision-making authority, and especially so in case of young children [22–25]. Which brings me to the following question: does parental decision-making authority succeed at safeguarding the vulnerable child patient [26]?

What if a child has severe Tourette syndrome that burdens, not only the child, but also (or perhaps even more so) the family? Should the parents decide? What if a child suffers from chronic severe aggression to the point where the child is a danger to himself and society? Should the parents be the sole decision-makers? What if one day DBS becomes a possible treatment for ADHD? Should the parents decide? As we are witnessing today with respect to stimulants as a treatment for ADHD (or what is thought to be ADHD in certain cases); these drugs are heavily overused and many children are taking these without a definite need for them. It is not unthinkable, as DBS becomes more widespread and accessible, that the requirement of medication refractoriness gets loosened. For example, one could consider cases in which medication works to alleviate some or most of the symptoms, but DBS is thought to work better. Again, who should decide?

The debate involves a discussion between ‘child protectionists’ on the one hand, and ‘child liberationists’ on the other hand [27, 28]. ‘Child protectionism’ is the view that children, although they may have rights, are cognitively and emotionally incapable of deciding for themselves, and hence, of exercising their rights. Therefore, either their parents or parental guardians,

in combination with professionals, or legal authorities should decide for them based on their best interests. I use the term child protectionism to refer to any kind of paternalism (be it parents, parental guardians, professional, or legal authorities that are the decision-makers), whereas I use the term ‘child parentalism’ to refer specifically to parental or parental-guardian decision-making authority. Child protectionists argue that too much weight has been placed on child autonomy, and that this might be detrimental for children rather than empowering. In contrast, ‘child liberationists’ argue that children’s rights should be respected, and specifically regarding medical decision-making, they argue that respect for child autonomy should be increased [28]. Child liberationists point to the United Nations Convention on the Rights of the Child, which states that a child that is capable of forming his or her own views has a right to be heard, and that children’s views need to be given due weight in accordance with their age and maturity. Naturally, children’s decision-making capacity differs substantially depending on the context, the child’s age, his or her cognitive abilities and life experience. However, child liberationists Lynn Hagger and Priscilla Alderson argue against age as a cut-off line in medical decision-making because there is no fixed correlation between age and autonomy [29, 30]. Indeed, setting a specific age threshold as a marker for competence versus incompetence raises questions of arbitrariness and unfairness. Moreover, different situations will require different degrees and kinds of competence. Age makes a difference insofar as it correlates with competence and it is competence that qualifies one to have rights [27, 31]. As Alderson [32] puts forward, life experience and cognitive ability can be more salient than age with regard to competency, and especially so in medical decision-making involving serious, chronic conditions: “Children with long-term conditions are frequently involved in treatment and research and are also likely to have experienced limits and failures of healthcare, so that their consent may be highly informed” (p. 2282).

Although DBS is performed in children today, no ethical guidelines have been put forward for its use in children. This paper aims to fill this gap and provide a preliminary ethical framework for decision-making in pediatric DBS. I specifically discuss whether parental decision-making authority succeeds at safeguarding the vulnerable child patient. I argue in favor of shared

decision-making both in case of neurological and psychiatric disorders.

Protectionism Versus Liberationism

‘Child protectionist/parentalist’ Lainie Ross argues that parents may impose healthcare treatments on their mature children because parents have the right and responsibility to “promote their child’s wellbeing” [33, p. 432]. Parents may argue that their children’s decisions are immature, or that they do not promote their best interests (although the child does think this to be the case). Parental decision-making authority is justified according to Ross because (a) parents care deeply about the welfare of their children and know best who they are and what their needs are; (b) parents are the ones that endure the consequences of their children’s healthcare treatment; within limits, (c) because parents have the right to raise their children according to their values and standards; and last but not least, (d) because it promotes family intimacy [34]. In general, the ‘best interests’ doctrine that parentalists defend holds that (a) parental concern is motivated by the best interests of their children, (b) parents have privileged access to and knowledge about their children’s current and future best interests, strengths and weaknesses, and (c) parental support allows for a better treatment outcome [11].

Ross argues that respect for children not only entails respect for their current autonomy, but also respect for their future autonomy and the person they are becoming [34]. Unlike children themselves, parents are able to take into account the impact of their children’s current experiences on their short-term and long-term autonomy and their future in general. According to Ross, parents respect their children by deciding for them, by deciding “what are the appropriate activities in which a child might participate” [34, p. 351]. However, doesn’t respect for a child’s so-called life-time autonomy necessitate respect for the child’s choices? Or at the very least, involvement of the child in the decision-making process? In reality, involvement of the child is rarely observed during the medical decision-making process. According to Tates and colleagues [35], medical interviews are “the prototype of a paternalistic interview in which adults dominate the interaction and treat the child as a passive by-stander” (p. 8).

They analyzed 105 video-taped medical interviews and found that about 72% involved non-supportive behavior instead of supportive behavior (e.g., asking the child to explain the medical problem, directing medical questions to the child, involving the child in the discussion) on behalf of the adults (i.e., both the parents and doctor). They found that doctors are more inclined to facilitate child participations, while parents tend to advocate and enforce a passive role for their children. Hence, if we look at the situation today, we find that child patients are not being heard and that parental decision-making authority and the ‘best interests’ doctrine prevails.

However, do parents always know what’s in their children’s best interests? Or anyone for that matter? The SPARCLE study investigated self-reported quality of life in 500 children with cerebral palsy aged 8–12 years from several European countries. Cerebral palsy is a chronic motor condition that causes physical disability, affecting a person’s ability to move and maintain balance and posture. The children with cerebral palsy that were able to self-complete the KIDSCREEN quality of life measure “reported that their quality of life was similar to that of children without functional limitations” [36, p.100]. Hence, in these ‘disabled’ children, being ‘disabled’ does not equate with having a lesser quality of life. Hart and Chesson [37] warn us that one should not assume that parents’ perception of their child’s illness is an accurate reflection of the child’s actual state of mind, especially as children become more independent. Case studies and research has shown that children tend to protect their parents, that adults project their own experience of the child’s illness onto their children, and that divergent opinions exist between parents and medical staff about the child’s situation. Indeed, various studies find that self-report quality of life often differs from proxy report, both when considering adult patients and child patients [38]. These findings show us that we need to be careful when deliberating about the physical, emotional and social consequences that a chronic disease might or might not entail for children. Moreover, because increasing evidence exists that “children below 8 years are able to use rating scales, can use common response terms and can understand and interpret underlying concepts” [38, p. 896], children’s self-reported quality of life should be taken into account whenever possible.

Also, do parents always act in their children’s best interests? Child maltreatment data clearly show that this is not the case. Gilbert and colleagues [39] describe child maltreatment (e.g., physical abuse, sexual abuse, psychological abuse, neglect) as a *common* phenomenon in high-income countries. In fact, they report that, except for sexual abuse, “80% or more of maltreatment is perpetrated by parents or parental guardians” (p. 69). Self-report and parental report measures range between 3.7–29% for experiencing physical abuse during childhood, 4–33.3% for psychological abuse, and 1.4–15.4% for neglect in high-income countries (countries in the UK, USA and Europe) [39]. We have child abuse and neglect laws for a reason. Based upon the child maltreatment incidence data, I’m inclined to claim that parents and parental guardians *more* than “sometimes breach their obligations toward their children” [40, p. 315].

In sum, the ‘best interests’ doctrine does not sufficiently protect child patients because parents do not always know what’s in their children’s best interests and do not always act in their children’s best interests. Adherence to this doctrine is especially questionable in case of extremely vulnerable child patients, because we run the risk of exposing children to negative life-events, including serious adverse and potentially life-long consequences.

According to ‘child liberationist’ Lynn Hagger [29], if we wish to maximize children’s autonomy, “we must avoid arbitrary cut-off points where possible and make assessments about their ability to make decisions on a case-by-case basis where there is disagreement” (p. 23). Hagger argues that parents have the duty to gradually diminish their proxy decision-making and allow their maturing children to make their own choices. By providing opportunities to choose for themselves, children can develop and learn the necessary skills to become competent adults. It prepares children for adult life. In stark contrast, Ross [41] argues that precisely because children have only limited world experience, we need to protect them from their own “impetuosity” (p. 43). This way children can ‘safely’ learn about the world and acquire the necessary background knowledge and capacities that will enable them to make decisions that promote their life plans once they are adults. However, if children cannot make their own choices because they lack the necessary experience to make sensible choices, then denying them all opportunities

to choose basically prevents them from ever obtaining sufficient experience. For example, it is well-known that children with severe chronic illnesses are typically more mature compared to their healthy peers precisely because of their experience. Experience matters. I agree with Hagger [29] when she mentions that “parents do not fulfill their duties if they do not gradually relinquish their proxy decision-making role so that their maturing offspring are given opportunities to make their own decisions, thus developing their skills to become competent adults” (p., 70).

Arguing against children’s autonomy, ‘parentalist’ Ross [33, 41] further claims that allowing ‘older adolescents’ to decide on healthcare treatments would necessitate decision-making rights in other areas of life (e.g., driving a car, investing in the stock market) for reasons of consistency. I disagree. Competency is not an all or nothing concept. The criteria for competency in decision-making vary from task to task and are therefore relative to the particular decision to be made. Whereas minors with serious chronic diseases might be found competent to give their consent or assent/dissent regarding particular medical decisions, this does not imply that they are competent to decide in all other areas of life. Moreover, the examples that Ross refers to are extremely different from decisions regarding healthcare treatment. Driving a car doesn’t only bear possible risks for the mature minor, it also involves possible risks for anyone else on the road. Hence, the risks necessitate that a cutoff line is drawn that ensures that all individuals are deemed competent to drive a car at that specific age. Investing in the stock market is also a different kind of example. Paternalism can be justified in case of stock market decisions because research has shown that risk-taking behavior, in particular the kind without much room for deliberation, is higher in minors due to developmental brain differences. Guaranteed time for deliberation, which is an essential part of medical decision-making, allows one to overcome these developmental differences [42, 43]. Hence, in medical decision-making, strong paternalism is not justifiable on those grounds. In fact, as mentioned above, we have good reasons to respect the child’s developing autonomy. Also, for the minors in question, the stakes are not as high as with healthcare treatments. Not being able to make choices regarding certain healthcare treatments (e.g., DBS) may have a far greater impact on

the minor’s future compared to not being able to drive before a certain age, or not being able to invest in the stock market before a certain age. Differences also exist between various healthcare treatments as to whether or not the child should be involved in the decision-making process (e.g., in terms of risks, life-time consequences, ...). Rather than enforcing child autonomy, weak ‘child liberationists’ argue for adequate respect for children’s rights where appropriate (i.e., depending on the context and the child’s life experience and cognitive abilities). It does not entail that children should receive decision-making rights in all areas of life.

Decision-Making in Pediatric Deep Brain Stimulation

(a) Against exclusive parental authority:

It may be argued that a combination of the ‘best interests’ doctrine and medical expertise sufficiently protects the vulnerable child. However, even if this would be the case, a shared decision-making model is nevertheless to be preferred because this creates the kind of environment in which (1) the child’s developing autonomy is respected, and (2) the child’s decision-making skills are nurtured [30]. Moreover, (3) benefits in terms of better treatment outcomes and coping behavior have been reported [44]. In fact, the Italian DBS group treating Tourette syndrome has ‘patient compliance’ as one of their patient selection requirements, precisely because patient cooperating is essential to establish good results [45]. Also, (4) research has shown that children with severe, chronic diseases are more mature compared to their peers. We therefore have good reasons to respect their (developing) decision-making competency. As Hagger [29] argues: “The boundaries of determining best interests become more contentious when establishing whether a child’s experience of life justifies significant medical interventions and the extent to which they should be involved in the decision-making process” (p. 74).

Moreover, granting parental decision-making authority without children’s assent, doesn’t protect those children that feel that they do not need DBS surgery, that despite their disorder (e.g., Tourette), they are happy and experience a good, possibly even high quality of life. Disorders like Tourette

syndrome are extremely difficult for the surrounding family, and could possibly motivate parents, more so than the children themselves, to reach for more invasive treatment options. One can imagine cases in which a child/adolescent with Tourette syndrome might not find his/her disease unbearable in itself, but rather because of the effects it has on his/her family, friends etc., feels pressured into considering certain kinds of treatment. Moreover, there may be cases where parents unduly pressure their children in considering certain kinds of treatment because of the difficulties they themselves experience due to their child's disease (e.g., ADHD, Tourette). Caregiver burden has been observed in parents of children with Tourette syndrome, "including major parental burden stemming from the stigma-prone and socially distressing symptoms of GTS [Gilles de la Tourette syndrome] as well as adverse effects on parental psychology" [45, p. 586].

(b) Against exclusive liberationism:

Granting the child/adolescent the right to decide on DBS treatment without parental approval, (1) does not ensure that the child/adolescent receives the best possible care and support during the treatment process. Research shows that children/adolescents that have a strong support network fare better in terms of treatment outcome [e.g., 46]. In fact, (2) exclusive liberationism may function as a negative factor from a relational point of view and undermine family intimacy. Children with severe psychiatric and neurological disorders are already dependent on their parents or parental guardians and their medical team in their day-to-day lives. Hence, from a relational point of view, shared decision-making can only benefit the child and family in question. Also, (3) the child may benefit a great deal from discussing the potential treatment options and their short and long-term consequences with their parents and their medical experts whom have the child's long-term interests in mind, both in terms of their current choices and because this fosters the development of their decision-making skills. One could argue that parents and/or medical experts, even more so than competent children, take their children's life-time experiences and development into account. This is specifically important in those disorders that may spontaneously remit or become subclinical with time and/or become manageable by learning new coping

strategies (e.g., Tourette syndrome, depression, eating disorders, aggression, ...).

(c) Shared-decision making:

In sum, pediatric DBS is ideally decided in a context of shared decision-making between the medical expert, the parents and the child. The defining elements of a shared decision-making account typically include (1) an information exchange between medical experts and patients, and (2) the involvement of both medical experts and patients in the treatment decision that is made [see, 47]. Moulton and King [48] define shared decision-making as a "process in which the physician shares with the patient all relevant risk and benefit information on all treatment alternatives and the patient shares with the physician all relevant personal information that might make one treatment or side effect more or less tolerable than others. Then, both parties use this information to come to a mutual medical decision" (p. 431).

In case of pediatric healthcare treatment, shared decision-making similarly involves a shared process of information exchange and decision-making between the medical experts, the child patient and the parents or parental guardians, resulting in a dual consent procedure (i.e., the parents or parental guardians give their consent and the child patient his/her assent). Questions back and forth between the medical team, the child patient, and parents or parental guardians are essential. Moreover, the medical team should ensure that all relevant information is given in a manner that is understandable to the child patient to promote an active role on behalf of the child patient. To give assent/dissent, children need to understand the nature of their illness, the proposed treatment and the risks entailed, why treatment is necessary and how it may affect their lives. Finally, to ensure that the child does not feel pressured into choosing a particular treatment option, a private meeting with a psychologist or medical expert trained in assessing coercion is required before treatment can take place. In case of disagreement between the child patient and the parents, a case-by-case assessment of a child's competency to give assent/dissent is needed, either by a psychologist trained in assessing competence, or by a member of the medical team with such expertise. If the child dissents for reasons that can be considered 'irrational' from a third-person perspective, then the medical team and parents can try to change this by pointing out the

irrational nature of the child's reasons and by answering any questions the child may have, thus providing the child with additional and accurate information. For example, if a child patient with treatment-refractory early-onset dystonia might greatly benefit from receiving DBS treatment, and if the child acknowledges this and wants to receive treatment but nevertheless dissents because of a disproportionate irrational fear of the surgical procedure, then the medical team and parents can discuss this with the child in the hope of alleviating his/her disproportionate worries.

(d) Dissent:

Depending on the nature of the disease and the long-term consequences of treatment versus no treatment, specific cases may exist where the child's enduring dissent may be overridden. A difference needs to be made between those disorders that may spontaneously remit or become subclinical with time, and those disorders that will remain the same or aggravate with time. For example, movement disorders such as childhood dystonia typically worsen with time (or remain the same), may benefit substantially from timely intervention in terms of treatment outcome, may result in irreversible damage in motor function, as well as have long-lasting negative effects due to social isolation [13]. Pediatric DBS for dystonia aims to alleviate dysfunctional motor symptoms, prevent irreversible damage and restore participation in daily life. In those cases, successful DBS treatment can only benefit the child, whereas refraining from treatment can be seen as harming the child due to the inevitable (long-term) negative consequences of this disease if left untreated. If successful, timely DBS treatment for dystonia benefits both the child patient and the caregiver. Hence, we have strong reasons to consider DBS treatment in a timely fashion, even in those cases where the child patient dissents.

The situation is entirely different for those disorders that may (or may not) spontaneously remit or become subclinical with time and for which we do not possess sound prognostic factors that allow us to predict who will spontaneously get better and who will not. According to a recent review study, by early adulthood, approximately three quarters of children with Tourette syndrome will have greatly diminished tics and more than one-third will be tic free [49]. The finding that tic severity typically declines in adolescence is hugely important with regard to potential

pediatric DBS treatment. In fact, according to the authors, it strongly argues against invasive treatment options: "invasive interventions for TS such as DBS and neurosurgery are strongly discouraged until well into adulthood, even for patients with impairing tics" (p. 499). However, as Mink et al. [50] put forward: "Remission of tics may occur in the third decade of life in up to 50% of patients, but to date, there are no prognostic features that predict which patients will have a remission in their symptoms" (p. 1832). As long as we do not possess sound prognostic factors, child patients should not be categorically excluded from receiving the only treatment available that could dramatically improve their quality of life [51].

In line with previous studies [52, 53], a recent follow-up study on childhood and adolescent OCD ($n=142$; mean length of follow-up=5.1 years; mean age at follow-up=18.6 years) found that 60% of children and adolescents did not have a full clinical disorder at follow-up, and two-thirds of participants rated themselves as much improved regarding their OCD [54]. Although some previous studies found that severity of initial OCD symptoms affected adult outcomes, severity at baseline did not predict persistence of OCD in this study. However, duration of illness at baseline was found to be the primary predictor for persistent OCD in this group. Moreover, approximately 70% of the participants had comorbid mental disorders at follow-up, mainly involving anxiety disorders, depressive disorder and tic disorder. At the same time, about 70% of the participants were in full-time or part-time education or work, with only mild to moderate functional impairment across work and social life regardless of persistence of OCD at follow-up. According to the authors, this suggests that "many young people can adapt to their illness and lead a fairly normal life despite being symptomatic" (p. 133). Again, no clear prognostic factors exist that may predict which children will spontaneously become better or able to adapt to their illness and which children will not.

If DBS treatment is performed for childhood Tourette syndrome or OCD that would have spontaneously remitted or become subclinical with time, then the dissenting child patient can be considered harmed because an unnecessary invasive procedure was forced upon him/her, and the only real benefit that occurred is a third-party benefit (i.e., caregiver relief). Unless clear scientific data can show that a

child patient would benefit by receiving DBS treatment and would be harmed if not given treatment (e.g., in case of childhood dystonia), DBS should not be performed if the child patient dissents. Moreover, if children/adolescents are considered incompetent to give assent/dissent because of developmental immaturity, treatment should be postponed unless clear scientific data can show that the child would benefit from DBS treatment and would be harmed if not given treatment.

Final Conclusion

Ethical guidelines regarding the use of pediatric DBS for neurological and psychiatric disorders are urgently needed. In order to protect vulnerable child patients, I defend a shared decision-making model in which parents or parental guardians should give their consent and the child his/her assent before treatment can take place. To give assent/dissent, children need to understand the nature of their illness, the proposed treatment and the risks entailed, why treatment is necessary and how it may affect their lives. If the child is found incompetent to give his/her assent/dissent due to developmental immaturity, then treatment should be postponed unless we can accurately predict that the child would benefit from treatment and would be harmed if left untreated. A difference therefore needs to be made between those disorders for which we can predict that they will remain the same or aggravate with time, and those disorders that may (or may not) spontaneously remit or become subclinical with time. If the child patient and parents disagree, then the competent child's decision should be upheld except in those cases where we can predict that the child would benefit from treatment and would be harmed if left untreated.

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