

Genetic Testing of Children for Diseases That Have Onset in Adulthood: The Limits of Family Interests

abstract

Two recent policy statements, one from the American Academy of Pediatrics and one from the American College of Medical Genetics, reach very different conclusions about the question of whether children should be tested for adult-onset genetic conditions. The American Academy of Pediatrics policy begins with the presumption that genetic testing for children should be driven by the best interest of the child. It recognizes the importance of preserving the child's open future, recommending that genetic testing for adult-onset diseases be deferred. The American College of Medical Genetics, by contrast, recommended testing children for at least some adult conditions, although it should be noted they have recently modified this recommendation. They justified this recommendation by arguing that it, in fact, was in the best interests of the child and family to receive this information. In this article, we analyze these 2 different positions and suggest ways that the seeming conflicts between them might be reconciled. *Pediatrics* 2014;134:S104–S110

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KEY WORDS

ethics, genetics, newborns, legal issues, best interests

ABBREVIATIONS

AAP—American Academy of Pediatrics

ACMG—American College of Medical Genetics

WES—whole exome sequencing

WGS—whole genome sequencing

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The role of family interests in medical decision-making has been extensively explored.^{1–4} Although the proper place for family interests in medical decision-making remains unsettled, there is broad recognition that families routinely make decisions that consider communal family interests as well as the individual interests of family members. Physicians believe that families routinely incorporate family interests in medical decision-making for incompetent patients and that family interests should play an important role in medical decision-making.⁵ It has been suggested that physicians should take a greater role in encouraging and supporting family-centered decision-making, or at least avoid discouraging family-centered decision-making.⁶

Applied to pediatrics, Ross⁴ proposed “constrained parental autonomy” as the standard for medical decision-making for children to acknowledge that parents commonly and appropriately consider the interests of other family members and the family as a whole in decisions for their children. There is no bright line for the limits of this autonomy, but general guides have been described that attempt to define clear-cut infringements on the rights of children.^{7,8}

It would seem that a growing consensus holds that the interests of family members count in medical decision-making by families. Now we must move on to sorting out how they should be counted in the medical encounter between physicians, patients, and families. Recently, family interests have been used to justify, at least partially, genetic testing of children for adult-onset diseases. Recommending the disclosure of these findings marks an important shift in policy and has generated significant controversy.

These guidelines further reveal how commonly and seriously family interests are considered in medical decision-making. In this article, we will examine the justification for incorporating family interests in these guidelines and consider

more fundamental questions that emerge from this examination: how these interests should be counted, who counts them, and what interests should be counted?

TWO IMPORTANT POLICY STATEMENTS

Two policy statements, both published in March 2013, provide guidance in an era of rapid advances in genetic and genomic medicine: the American College of Medical Genetics (ACMG) recommendations for reporting of incidental findings in clinical exome and genome sequencing (the ACMG recommendations)⁹ and the American Academy of Pediatrics (AAP) and the ACMG joint statement (the AAP policy) entitled “Ethical and Policy Issues in Genetic Testing and Screening of Children.”¹⁰ The focus of the ACMG recommendations is the reporting of incidental (or secondary) findings in clinical whole exome sequencing (WES) and whole genome sequencing (WGS). WES and WGS are recently developed techniques for rapidly determining an individual's genetic information for nearly all genes. The cost of this testing is falling rapidly, and the availability of the testing is increasing just as quickly. The massive amount of sequence data generated offers extraordinary opportunities to identify potentially treatable and/or preventable genetic diseases, provide diagnostic information to patients with undiagnosed disorders, and optimize the medical management of diseases such as cancer. The focus of the AAP statement is genetic testing, which is typically defined as discrete testing of a single gene or focused set of genes common to a single clinical presentation, as opposed to WES and WGS that gather information indiscriminately on most of our 20 000 genes. Although the focuses of the recommendations are different, they both address the controversial topic of genetic testing of children for conditions that have onset in adult years and for

which there are no medical actions to be taken in children to prevent or ameliorate disease. Before these recommendations, there was broad consensus that genetic testing of children should only be performed if effective interventions were available for the condition in childhood. The primary rationale for deferring testing is to preserve the child's “open future,” which has been defined as their ability to decide for themselves whether they want genetics testing once they reach maturity. The 2 guidelines both challenge this long-standing rule but take different approaches in doing so. We will first describe the policies and then analyze the ethical justifications for the new positions focusing on the incorporation of the interests of the family into the decision-making process.

The AAP Policy Statement

In their policy on the genetic testing of children, the AAP begins by reaffirming the established position that predictive genetic testing for adult-onset conditions should be deferred until the patient is able to consent to the testing. Having done so, they then support exceptions for families who desire the testing to resolve disabling parental anxiety and/or to provide potential psychosocial benefits to the extended family. They base this approach on accumulating empirical data that suggest less harm related to disclosure of genetic findings than anticipated, as well as a fuller empirical understanding of the psychosocial benefits of disclosure. These include a reduction in uncertainty and anxiety, the opportunity for psychological adjustment, and the ability to make realistic life plans and share the information with family members.

The AAP Guidelines and the Interests of the Family

The moral framework of the AAP policy supports the incorporation of family interests into medical decision-making. The policy begins with the presumption

that genetic testing for children should be driven by the best interest of the child. It recognizes the importance of preserving the child's open future, recommending that genetic testing for adult-onset diseases be deferred. But it then goes on to specify these rules on the basis of family factors. Recognizing that the family has instrumental value to the child, for example, the fact that members of cohesive and supportive families tend to have better health outcomes than those without similar resources,^{11–13} the policy states that it is ethically acceptable to test children to resolve disabling parental anxiety or support life planning decisions if they are in the child's best interest. Recognizing that society allows parents great discretion in determining what is in a child's best interest, for example, including the inculcation of deeply held and long-standing values of the family in the best interest calculation, it allows that the best interest of the child cannot be limited to a narrow medical best interest. Therefore, it appeals to a broader best interest incorporating important family factors as determined by the parents. Having broadened the concept of best interest, no explicit limits are identified in the policy for this expanded definition. Having reaffirmed the right and duty of parents to determine what is in their child's best interest, clarity is not provided regarding the role of the physician in the process.

Opening the door for the incorporation of parental interests into decisions regarding the genetic testing of children is a significant policy change¹⁴; as with any policy change, unanticipated problems may arise. For example, it is conceivable that improperly motivated families will take inappropriate advantage of the expanded range of options available to them. Another possibility is that, without explicit limits, there may be excessive variability in practitioners' interpretation of the policy, leading to questions of

fairness in application of the policy. With regard to the lack of clarity regarding the role of the physician, it is possible that the rights and interests of the pediatric patient may not be adequately safeguarded by the physician. The policy does attempt to at least partially mitigate these potential problems by including language intended to moderate the consideration of family interests, limiting it to situations involving significant psychosocial burden and disabling parental anxiety and to be most appropriate in situations in which the patient is an adolescent who wishes to be tested. Time will tell whether any of these theoretical concerns will become a reality, or whether, as some have suggested, this policy change did not go far enough in incorporating parental interests.¹⁴ Empirical study of the effect of this policy change would be valuable.

The ACMG Statement*

In the same month, the ACMG released recommendations for the reporting of incidental (or secondary) findings from WES and WGS. Because there is potential for recognizing and reporting incidental findings unrelated to the primary indication for the testing, the ACMG Working Group developed a panel of 57 genes deemed highly likely to cause diseases for which preventative measures and/or treatments were available. They recommend that laboratories actively search for mutations in this panel of genes and report them when either WES or WGS testing is performed on all patients, including children. Seven of the genes on the panel, associated with 3 different genetic conditions (hereditary breast and ovarian cancer, Lynch syndrome, and the polyposis associated with a mutation

*The ACMG has subsequently modified their statement to allow for patients and families to opt out of testing for secondary medically actionable findings. This paper, however, analyzes the original statement because that statement reflects a coherent view of one approach to the return of genetic results.¹⁶

in the MYH gene), cause life-threatening diseases that do not have onset until adult years, and several of the other genes have age-dependent penetrance and rarely manifest in children.¹⁵ This recommendation represents a major change in policy, because these recommendations functionally require testing of children for these conditions whenever WES or WGS is performed. The ACMG justifies this approach in a number of ways: (1) the best interests of the child, because the child may not be tested for these adult-onset conditions again, even as an adult; (2) the obligation to inform families of incidental findings that have significant implications for the parents and extended family because most of these conditions are autosomal dominant and inherited from a parent and because the child would benefit from lifesaving treatment of a parent; and (3) the net benefit to the child, parents, and family of disclosing this information. Related to this third justification, they cite the cost-effectiveness and expeditiousness of such testing. The working group writes:

[We] recognized that this is a transitional moment in the adaptation of genomic medicine where the parents of children undergoing sequencing do not have ready access to inexpensive, readily interpretable exome or genome sequencing in order to obtain personal risk information for the conditions on our minimum list. In the future, where parents might all have such access, the identification of an adult-onset disease variant in their children could be restricted. But at this moment in the evolution of clinical sequencing, an incidental finding relevant to adult disease that is discovered and reported through clinical sequencing of a child may be the only way in which that variant will come to light for the parent.⁹

The ACMG Recommendations and the Interests of the Family

The ACMG recommendations address the genomic testing of adult and pediatric patients and have relevance for the families of those adults and children alike, but a discussion of genomic testing of adult patients is beyond the scope of

this article. With regard to the testing of children for adult-onset genetic conditions, the ACMG recommendations take the family very seriously but approach it very differently than the AAP. Similar to the AAP, they appeal to the best interest of the child, in several ways. They claim that testing is in the child's medical best interest because they may not be tested for these conditions ever again and would therefore be at risk of and unprepared for disease in adulthood. They claim the instrumental value of the family to the patient, because children clearly benefit from lifesaving treatment of the parents. But deviating substantially from the AAP policy, which presumes that the family is responsible for determining the child's best interest, the ACMG arrogates the authority to make this determination by mandatorily including these tests whenever genomic testing is performed. This usurpation of parental authority is problematic, considering the highly variable contexts in which decisions such as this are made. If, for example, the family placed a particularly high value on their child's open future, it is quite plausible that they may refuse testing for adult-onset conditions, but this is not an option according to the ACMG recommendations. This situation is a particular concern for families who are already aware that such a disease or mutation exists in their family and are already aware of these risks and intentionally want to preserve the child's open future. With regard to the ACMG claim of a professional obligation to inform parents and children of incidental findings that have significant implications for the family, critics argue that this misses the point and have noted that the mandatory nature of these tests violates patient (and parent) autonomy. With regard to the third justification, the claim of a net benefit to patients and families of testing (note that critics disagree that there is net benefit^{15,17,18}), it would be erroneous to conclude that this claim shows respect

for the interests of the family as a social unit. Instead, the benefits to the "family" accrue to them because they happen to be the individuals (other than the patient) likely to benefit most from the testing by virtue of being genetically related to the patient. Consider a case of an adopted child, in which a number of genetically related individuals with substantial interests in the testing results are completely unknown to the index patient; these "strangers" could still tip the net benefit calculus in favor of testing the child. The ACMG Working Group, through the net benefit justification, implicitly concludes that the medical benefits to patient and genetically related individuals outweigh the potential psychosocial harms to the child as well as any obligation to allow him or her to decide about testing when he or she comes of age.

A key area of disagreement between proponents and opponents of reporting the 57 genes is whether there is a morally important act involved in the generation of incidental findings. Proponents argue that WGS and WES, properly conducted with informed consent, generate incidental findings as an integral part of the test, so that to conduct the primary analysis is also to generate the incidental laboratory test results; therefore, no moral act is connected to the generation of the data. The moral act, in their view, comes later when the physician or the laboratory decides how to handle the data.¹⁹ Opponents claim that a moral act is performed when the genomic testing of the 57 genes is ordered, as well as when it is analyzed and reported. They liken the proponents' position to requiring a laboratory to test every vial of blood, obtained for a primary indication, for 57 other tests (eg, cholesterol, glycosylated hemoglobin) for which early treatment is potentially beneficial.¹⁸ Although proponents may be technically correct that WGS and WES "constitute a single

comprehensive assessment"¹⁹ that makes incidental findings readily available for analysis and reporting, the fact that a decision is made to perform a deliberate and systematic analysis of the data, which would not otherwise routinely be performed, makes the generation of incidental findings a morally significant act. This analysis is time consuming and expensive for laboratories, as well as potentially inaccurate given some laboratories' limited experience with these genes and the lack of well-curated mutation databases for these genes. The claim that these 57 tests must be performed whenever genomic testing is performed lacks credibility, and reasonable alternatives to their approach should be explored. For example, 1 possible alternative would be to have 2 panels of mandatory incidental tests, 1 that includes adult-onset conditions and 1 that excludes them. After thorough genetic counseling, the ordering physician and the family, using the criteria established in the AAP policy, could decide which panel, if any, serves the best interest of the child.

THE POLICIES AND THE DEBATE OVER THE PROPER ROLE OF FAMILY INTERESTS IN MEDICAL DECISION-MAKING

These policies reflect the growing consensus that physicians and the medical establishment should incorporate the interests of family members into the clinical care of patients. They, and policies like them, offer answers (albeit incomplete and imperfect answers) to the questions raised by the tension between the seemingly incompatible ethical frameworks of the "communal" family and the patient-centered medical profession. But, if the message of these policies is seen only to lie in the break with the "deficient" medical tradition of single-mindedly focusing on the patient's interests, then there is a danger that we will lose sight of what is valuable with

the patient-centered medical model. After all, even if the traditional medical model oversimplifies medical decision-making by focusing exclusively on patients, it does so for important reasons. Physicians would be unable to perform their healing duties effectively without the confidence and trust of the patient, particularly given the vulnerable status of the patient and the highly personal nature of what must be revealed (both historically and physically) to the physician in the healing relationship. The fiduciary nature of the physician-patient relationship is therefore essential to the healing telos of the medical profession.

In this section, we will explore what we can learn from these policies about how physicians can honor the ways in which families make decisions while maintaining their effectiveness as healers of vulnerable patients.

The Role of Society and the Medical Profession in Deciding Whose Interests Count

Although families, especially parents, enjoy rights to decide for incompetent family members, these rights are not absolute. Most clearly, there are many examples of society intervening and deciding whose interests count, based on the state's *parens patriae* powers. Car seat laws enacted to protect the health and lives of children often dictate to parents what types of car they can drive, child abuse/neglect reporting laws compel health care workers to protect children's interests without consideration for family wishes, and mandatory newborn screening greatly reduces the morbidity and mortality of many childhood diseases. These intrusions by the state into family life represent the most socially and legally accepted mechanism for limiting the freedom from interference presumptively enjoyed by families.

In contrast, the role of the physician in deciding whether the interests of

others should count is not well elucidated and is ethically problematic: should the physician retain his fiduciary relationship to the patient or should he seek to balance the interests of all involved?¹ Should the physician following the AAP policy seek to resolve parental anxiety by forfeiting the patient's interest in an open future? This dilemma dissolves if the physician determines that the treatment of parental anxiety is truly in the child's best interest, but what if it isn't clear that the attempt to relieve the psychosocial burden will benefit the child? Is the physician justified in compromising the patient's interest for the sake of the parents'? Although some might defend this approach on the basis of utilitarian grounds, this seems to go too far. Members of the medical profession hold no special qualification or authority to make decisions such as these, and acting in the family's interest (and potentially against the child's interests) would serve to weaken the trust that is so central to an effective healing relationship between the medical professions and patients.

Family Interests in the Medical Encounter: Exclusion, Encouragement, Recommendations, and Mandates

Historically, the institutions of medicine have systematically excluded the consideration of family interests from medical decision-making.² Although family-centered care initiatives have created more welcoming hospitals that are more physically and emotionally supportive of patients and their families, and more supportive of the cultural and family context of the patient, the basic structure of medical decision-making taught to medical students today is just as patient-centered and antagonistic to families now as it was a generation ago. Looked at in this light, the AAP policy is an exception, and can serve as an example for the medical community of how to prudently incorporate family interests.

By explicitly including family interests in the policy, physicians are given permission to encourage the family to engage in family-centered decision-making. By extension, the policy should also serve as a deterrent to those who would actively discourage any consideration of family interests on the basis of the potential for conflict of interest. Yet, the policy stops short of asking physicians to promote or recommend the incorporation of family interests (or mandate their incorporation as in the case of the ACMG recommendations) by using language to encourage careful balancing of the child and family's interests. In effect, the policy asks physicians to actively and transparently assist parents in determining the child's broad best interest that considers family factors and the family's values, but to avoid advocating for the interests of anyone but the patient's.

This delicate balance may be achievable if family interests are welcomed into discussions, even as physicians hold firmly to fidelity to the patient. Families allowed to freely engage with health care providers in decisional constructs that weigh the interests of all family members' interests will likely be better informed in their decisions, and opportunities for health care providers to recommend or offer treatment options that reduce family burdens and harms may be more easily identified.

What Interests Should Count and What Interests Should Not Count?

The best interest standard remains the prevailing standard in defining the limits of parental authority,^{8,20} despite the shortcomings recognized in its theory and application.^{4,21,22} One important consequence of explicitly incorporating family interests into the best interest calculation is that an already difficult and subjective determination of the limits of parental authority will unavoidably become messier and more difficult. For example, how does one address the

commensurability of the parents' interest in avoiding disabling anxiety and the child's interest in an open future in a best interest calculation? This is the background and the context for the AAP's reasonable attempt to define a broad definition of best interest as the guiding standard for incorporating family interests into decisions regarding genetic testing of children for adult-onset conditions. But although this policy may regulate and guide professional behavior regarding testing, parents would not be bound by it and would almost certainly be able to request and obtain testing under the law.²² There are situations, even if controversial, in which family interests are known to drive medical decisions, even if they are not in the best interest of the pediatric patient.²⁴ These considerations make it unlikely that the AAP's "solution" will completely resolve the difficulties related to the consideration of family interests.

Instead of focusing on best interest, some have identified the quality of the family interest as a limit, albeit a vague one, on the incorporation of family interests.²⁵ How do we make judgments about the quality of interests? In deciding whether a newborn with life-threatening heart disease should have potentially lifesaving surgery, parents may invoke family interests such as caregiver burden. In a financially struggling family in which both parents work and have other medically complicated children at home, caregiver burden may well be worthy of consideration. For a couple with bountiful financial, emotional, and social resources who simply

does not wish to raise a disabled child, such consideration may seem undue. Likewise, some financial interests may seem appropriate, such as the impact on the quality of the schools the family can afford for their other children, and some may not, for example, if the money at stake is to go to designer clothes or new cars for the parents. Using the AAP approach as an example, the policy qualifies the allowable types of family interests by using measures of degree: "significant" psychosocial burden, "disabling" parental anxiety. These determinations are highly context-sensitive, and will be subject to interpretation, but as the AAP policy shows, some qualitative limits on the interests worthy of consideration will be essential to fair and morally sound policies. On the basis of these considerations, for a family interest to be worthy of consideration in a medical treatment decision for a child, it should be an interest in avoiding substantial harm and burdens to other family members and/or the family as a whole.

CONCLUSIONS

These 2 policies represent significant changes in policy toward the incorporation of family interests in medical decision-making. The AAP policy explicitly recommends the consideration of important family interests provided that serving these interests also serves the child's broader interest. The ACMG recommendations invoke the language of family interests, but essentially the recommendations are intended to maximize the utility of genomic testing, at

the expense of individual and family autonomy.

These policies allow for reflection on the role of family, society, and physicians in medical decision-making. Families are given great discretion under the law to make decisions regarding medical treatment of their children, even to make decisions that sacrifice important interests of the child for the sake of the family, constrained only by society's duty to protect the well-being and rights of children. The role of the physician is complex. Their professional obligations to patients can conflict with any consideration of the interests of the family. This situation is where the agent-specific roles of parents (to care for each member of the family and the family as a whole) and physicians (to heal sick patients) lead to different obligations. Given the critical nature of the medical duty to act in the vulnerable patient's interest, physicians should advocate for family interests if they are in the patient's interest but refrain from advocating for family interests beyond that.

Review of these policies reveals a number of key concepts instructive for future policies and practices that involve family interests: respect for the authority of families to determine best interests, active support for the proper incorporation of family interests in decision-making, guidance to physicians in their duty to assess the quality and the proportionality of the interests under consideration, and reaffirmation of the fiduciary duty of physicians to be guided by the patient's best interest.

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