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Do physicians have a duty to disclose the child's diagnosis to them against the will of their parents in the case of CAIS?

Physicians have a professional duty to protect patient welfare— this includes fully disclosing diagnoses¹ to maximise patient autonomy. Complete Androgen Insensitivity Syndrome (CAIS) renders XY individuals intersex (female external appearance and genitalia but abdominal testis is present) due to unresponsiveness to testosterone². Policies and ethical arguments allowing parents to request for physicians to hide diagnoses their child are premised on the child's inability to exercise their autonomy before the age of 16³ and the perceived psychosocial harms that disclosure would bring to the child. This essay argues that physicians have a duty to disclose CAIS diagnoses to patients because CAIS is diagnosed in early adolescence⁴, when patients are cognitively competent to exercise their autonomy. Additionally, psychosocial harms are greater with nondisclosure.

The physician's duty to disclose can be interpreted through specific legal directives and broader professional obligations to adhere to normative ethical principles. First, I examine current legal guidance on CAIS disclosure and the treatment of children, leading into a discussion of autonomy, as these policies are undergirded by respect for patient autonomy. I argue that because CAIS patients have autonomy, medical proxies are redundant and physician disclosure is necessary. Second, I mitigate concerns that medical proxies are important to protect the child's future autonomy by claiming disclosure cannot significantly harm future autonomy. Third, I argue that disclosure is in keeping with the normative principle of nonmaleficence, which physicians are duty-bound to uphold, as it leads to comparatively fewer psychological and societal harms. Following this, I counter the argument that parents can more accurately assess the magnitude of these harms than physicians, by arguing that Gillick Competent CAIS patients are best able to assess this. Finally, I conclude that on both principle-based and consequentialist moral frameworks physicians have an ethical duty to disclose even if they do not have a legal one.

This essay discusses CAIS cases where the following is true: (1) Disclosure requires parental permission. This is common practice as parental proxy decision-making power encompasses the decision for the child not to know about the condition⁵ (2) Disagreements about disclosure are cases of "good intent vs good intent" as described by Waz⁶, with parents and physicians disagreeing about what is best for the child. This is the only scenario where nondisclosure is morally dubious as when either party does not act solely in the interests of the child, they are morally and legally culpable under status quo^{5,7 (See 22(3))} (3) Physicians have an obligation to protect the patient's needs and rights over parental rights. The Children Act 1989⁸ (Section 3(1)) specifically reframed parental rights over the child as responsibilities to the child's "physical, emotional" needs. (4) Due to lack of awareness, the CAIS patient has not expressed an interest to know about their diagnosis. If they had, disclosure is generally ethical and recommended^{5,6} and parental refusal is grounds for mediation⁹. This is because parents can act in 'substitute' capacity to realise their child's wishes in these cases⁹.

Disclosure and legal guidance under the status quo

Physicians in the UK are only legally obliged to disclose CAIS details such as genetic basis, genital anatomy, fertility, and treatment options to parents, as legal proxies for the young patients¹⁰. By medical consensus, patient participation in decision-making is merely “encouraged commensurate with changing cognitive and psychological development”¹⁰ but there is no stipulated course of action when parents request for children to not be told. Hence, it is logical for physicians to interpret their legal duties based on general laws around treatment of children and the justifications underpinning them. This section argues that disclosure is an implicit duty in spirit of these laws.

The legal use of medical proxies is designed to respect patient autonomy¹¹. Beauchamp describes autonomy as the right to a “self-chosen plan” for our future^{12, p.99}. Physicians have a professional responsibility to respect patient autonomy as they must protect the “best interests”¹³ of and “value of life”^{12, p.140} for their patients, which can be best determined by the patient themselves. In healthcare, autonomy is formally respected by ‘consent’, as a treatment affecting your future only respects your “self-chosen plan” if you permit it. Beauchamp argues autonomy requires adequate understanding for meaningful choice^{p.99}, so patient who cannot understand “risks, probable benefits and prognoses”^{p.127} cannot freely consent¹². Children are less cognitively competent so cannot rationally deliberate decisions in a “sufficiently autonomous manner”^{12, p.105} warranting parents, temporary custodians of their autonomy, to consent for them after “weighing harms and benefits of treatment”⁵.

Generally, physicians respect parental nondisclosure requests because parents represent patient autonomy. Patients can ordinarily decide if they want to learn about their diagnosis¹⁴ so their parents are now entitled to this choice. The right not to know is even legally recognised in genetic medicine in a UNESCO declaration that every individual is entitled to decide whether or not to be informed of the results of genetic examination”¹⁵ (Article 5c). However, this argument is inapplicable to CAIS because adolescent patients are usually ‘Gillick Competent’ with “sufficient understanding and intelligence”¹⁴ to exercise their autonomy so proxy decision makers are unnecessary. The NHS currently permits patients under 16 to consent if they demonstrate “enough intelligence, competence and understanding to fully appreciate what’s involved”³.

It may be argued that the role of parents as proxy-decision makers extends beyond substituting for the child’s cognitive incompetence. Ross claims that parents are more able to protect a child’s “future autonomy” than the child who has “limited world experience”, hindering formation of a “well-conceived life plan”⁹. Therefore, decisions autonomously made today must be assigned less importance. To draw on an example from CAIS medical treatment, if a CAIS patient decided not to undergo estrogen replacement therapy, physicians should not allow this because it will further reduce their bone density¹⁵. The reason why this counterargument is mitigated when disclosure is in question is because disclosure itself does not significantly compromise future autonomy. As patients are still minors, most decisions made following disclosure (eg: genital surgery²) still legally require parental consent so parents can still prohibit actions harmful to their future autonomy.

Is disclosure consistent with obligations to uphold consequentialist principles?

The duties of physicians extend beyond their legal obligations. Under the Hippocratic Oath, physicians swear to “use treatment to help the sick...never to injure or wrong them”¹⁴. They have an additional duty to uphold consequentialist ethical principles of beneficence (“to help”) and nonmaleficence (to never injure) when deciding on disclosure. Due to limited scope, this section only considers the harmful consequences of disclosure and nondisclosure, concluding disclosure is required to practice nonmaleficence.

Physicians’ duty of nonmaleficence forbids “inflict(ing) evil or harm” to patients^{12, p.151} as this is prima facie in direct contradiction with the role of caring for the sick. Beauchamp argues that ‘harm’ does not only include “physical and psychological...health and survival” but broader factors such as reputation as well^{12, p.152}. This broad definition also applies legally, after a Supreme Court ruling¹⁹ considered harm to a mentally incapacitated man. As there is no substantive evidence that early medical intervention is necessary to prevent tumours resulting from CAIS¹⁹ nondisclosure cannot be said to increase physical harms. Hence, only psychological and social harms are discussed here.

Psychological harm

Parents make nondisclosure requests to protect children from threats to self-image²⁰, “fear, sadness or stigma”¹⁵. Knowledge of CAIS is known to cause “psychological distress in the teen”². A study of 66 women with CAIS or gonadal dysgenesis found 33% suffered psychological illness such as anxiety or depression and there were four suicide attempts²². While it remains unclear if this was caused by early disclosure of diagnosis as the median age of interviewees was 32, the study proves that psychological distress can result from a CAIS diagnosis. Intersex advocacy movements stress that psychological harm also comes from societal stigmatisation³. Should physicians, respect nondisclosure requests to protect the psychological wellbeing of CAIS patients?

Disclosure is still ethically justified because nondisclosure brings greater psychological harms. Accounts from CAIS patients reveal an “awareness of the silence surrounding them” resulting in “a childhood of uncertainty and sense of being imperfect”, even if parents were accepting of them, because they did not know the reason for it¹⁴. Learning about their condition in an unprotected environment without physician disclosure is also distressing. An intersex patient recalls her mother “screaming and running from the room” after disclosing her condition long after diagnosis, reinforcing that intersexuality was “inherently unspeakable”. Physician disclosure is collaborative and involving multidisciplinary team¹⁰, which includes parents, to ease patients into diagnoses and to destigmatise CAIS. Nondisclosure here is harder to reconcile with nonmaleficence because in aiming to temporarily delay psychological distress from CAIS knowledge, nondisclosure creates stigma within families which otherwise would not exist.

Conversely, when the silence was broken MacKenzie reports “empowerment” as “a positive sense of self is more likely to be achieved”¹⁴. Growing up in a narrative of CAIS knowledge and discourse reduces the psychological distress of CAIS, whereas learning of it only in adulthood through “recurring medical exams with others present” is shameful¹⁴. Disclosure enabled patients to seek support from communities of “others born with different bodies” which they found to be critical for empowerment¹⁴. MacKenzie’s accounts are based on interviews with the few New Zealanders

who finally felt empowered to speak out about their intersexuality— it is possible that nondisclosure created a lasting shame for many more. Nondisclosure yields similar psychological distress as disclosure, but with additional psychological harms to a patient's self-identity. These heighten the physician's duty to disclose CAIS to their patients who are Gillick Competent— perhaps even to those who are not.

Social harms

Finally, as Beauchamp argues, it is necessary to interrogate ethical duties via a bottom-up approach of considering the practical outcomes of disclosure. Weinstock proposes that doctors have secondary duties to meet “societal and professional expectations of protecting the public”²⁰, including building trust between patients and the healthcare system, so patients seek medical help when they require it. This obligation is an extension of nonmaleficence.

Intersex patients wished “to have nothing to do with the medical profession because of their negative experiences” as even if nondisclosure requests had come from their parents, they felt a betrayal of trust when physicians agreed to withhold information¹⁴. Dreger describes a CAIS patient who avoided “medical care for 18 years” until “she developed severe osteoporosis”¹⁵. As nondisclosure is capable of undermining patient trust in physicians and the healthcare system, doctors have a secondary duty to disclose CAIS to patients, even if parents disagree. Going against parental wishes by taking such cases to court might “breakdown the (physician-parent) relationship”¹⁵, but this is a palatable loss given physicians have a primary obligation to patients before their secondary obligation to society.

There is no legally enforceable duty but in general, physicians have an ethical duty to disclose CAIS. CAIS patients are Gillick Competent and therefore do not need medical proxies to exercise their autonomy even if they are legally provided. This means (1) physicians have an ethical duty to maximise CAIS patient autonomy by making her aware of her medical condition (2) physicians have a greater obligation to respect their wishes over their parents'. While parental decision-making is also important to protect the child's future autonomy, widening the child's autonomy by disclosure does not significantly comprise this future autonomy, so disclosure is still justified. On top of this, CAIS disclosure is in line with the physician's wider duty to protect patients from psychological harm as the harms of nondisclosure are greater. Because the magnitude of harms to an individual can vary depending on contextual features such as the child's psychological maturity and family support, the lack of legal duty enables physicians to actively deliberate their duty to disclosure individual cases. Physicians can protect society at large when patients trust them and seek medical help when they need it. This trust is built from young— when your physician is not legally obliged to disclose your childhood condition, but they tell you anyway.

References

- 1 Gmc-uk.org. 2020. *Disclosures For The Protection Of Patients And Others*. [online] Available at: <<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/disclosures-for-the-protection-of-patients-and-others>> [Accessed 8 December 2020].
- 2 Oakes, M., Eyvazzadeh, A., Quint, E. and Smith, Y., 2008. Complete Androgen Insensitivity Syndrome—A Review. *Journal of Pediatric and Adolescent Gynecology*, 21(6), pp.305-310.
- 3 NHS.uk. 2020. *Consent To Treatment - Children And Young People*. [online] Available at: <<https://www.nhs.uk/conditions/consent-to-treatment/children/#:~:text=People%20aged%2016%20or%20over,significant%20evidence%20to%20suggest%20otherwise>> [Accessed 8 December 2020].
- 4 Viner, R., Teoh, Y., Williams, D., Patterson, M. and Hughes, I., 1997. Androgen insensitivity syndrome: a survey of diagnostic procedures and management in the UK. *Archives of Disease in Childhood*, 77(4), pp.305-309.
- 5 *Paediatrics & Child Health*, 2004. Treatment decisions regarding infants, children and adolescents. 9(2), pp.99-103.
- 6 Waz, W., 2010. The Need to Know: Disclosure of Information to Paediatric Patients. *Ethics & Medicine*, 26(2), pp.75-79,67.
- 7 *F v. F* [2013] ALL ER (EWHC), p.149.
- 8 Children Act 1989. 3(1).
- 9 Ross, L., 1997. Health Care Decisionmaking by Children Is It in Their Best Interest?. *The Hastings Center Report*, 27(6), p.41.
- 10 Lee, P., Houk, C., Ahmed, S. and Hughes, I., 2006. Consensus Statement on Management of Intersex Disorders. *PEDIATRICS*, 118(2), pp.e488-e500.
- 11 Varadan, S., 2020. Article 5: The Role of Parents in the Proxy Informed Consent Process in Medical Research involving Children. *International Journal of Children's Rights*, 28(3), pp.521-546.
- 12 Beauchamp, T. and Childress, J., 2009. *Principles Of Biomedical Ethics*. 6th ed. New York: Oxford University Press, p.99, 103, 105, 127, 140, 151, 152, 227, 382
- 13 Wancata, L. and Hinshaw, D., 2016. Rethinking autonomy: decision making between patient and surgeon in advanced illnesses. *Annals of Translational Medicine*, [online] 4(4), p.77. Available at: <[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779776/#:~:text=While%20one%20does%20not%20take,of%20those%20interests%20\(1\).>](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779776/#:~:text=While%20one%20does%20not%20take,of%20those%20interests%20(1).>) [Accessed 9 December 2020].
- 14 Laurie, G., 2014. Recognizing the Right Not to Know: Conceptual, Professional, and Legal Implications. *The Journal of Law, Medicine & Ethics*, 42(1), pp.53-63.
- 15 UNESCO, 1997. *Universal Declaration On The Human Genome And Human Rights*. [online] Paris: UNESCO, p.43. Available at: <<http://portal.unesco.org/en/ev.php>>

URL_ID=13177&URL_DO=DO_TOPIC&URL_SECTION=201.html> [Accessed 9 December 2020].

- 16 Gillick v West Norfolk and Wisbech AHA [1986] Hall ER 533 (CA), p.536.
- 17 Bertelloni, S., Meriggiola, M., Dati, E., Balsamo, A. and Baroncelli, G., 2017. Bone Mineral Density in Women Living with Complete Androgen Insensitivity Syndrome and Intact Testes or Removed Gonads. *Sexual Development*, 11(4), pp.182-189.
- 18 *British Medical Journal*, 1998. The hippocratic oath. 317(7166), p.1110.
- 19 Aintree University Hospitals NHS Foundation Trust v. James [2013] ICLR (EWCA).
- 20 Conn, J., Gillam, L. and Conway, G., 2005. Revealing the diagnosis of androgen insensitivity syndrome in adulthood. *BMJ*, 331(7517), p.628.
- 21 Limb, R., 2019. Non-disclosure requests by parents: Who should decide? A legal and ethical framework. *Medical Law International*, 19(1), pp.62-77.
- 22 Engberg, H., Strandqvist, A., Nordenström, A., Butwicka, A., Nordenskjöld, A., Hirschberg, A. and Frisé, L., 2017. Increased psychiatric morbidity in women with complete androgen insensitivity syndrome or complete gonadal dysgenesis. *Journal of Psychosomatic Research*, 101, pp.122-127.
- 23 Chase, C., 2003. What is the agenda of the intersex patient advocacy movement?. *The Endocrinologist*, 13(3), pp.240-242.

- 24 MacKenzie, D., Huntington, A. and Gilmour, J., 2009. The experiences of people with an intersex condition: a journey from silence to voice. *Journal of Clinical Nursing*, 18(12), pp.1775-1783.
- 25 Chaudhry, S., Tadokoro-Cuccaro, R., Hannema, S., Acerini, C. and Hughes, I., 2017. Frequency of gonadal tumours in complete androgen insensitivity syndrome (CAIS): A retrospective case-series analysis. *Journal of Pediatric Urology*, 13(5), pp.498.e1-498.e6.

- 26 Weinstock, R., 2015. Dialectical Principlism: An Approach to Finding the Most Ethical Action. *Journal of the American Academy of Psychiatry and the Law*, 43(1), pp.10-20.
- 27 Dreger, A., 1998. "Ambiguous Sex": Or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality. *The Hastings Center Report*, 28(3), p.24.