



Ethical dilemmas

Genetic testing – balancing the pros and cons

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About this series

This is the fourth piece in a short series looking at real-life ethical dilemmas concerning people with diabetes and their primary care health professionals.

The authors' objective is to raise awareness in this important and complex part of person-centred care, where the boundaries are grey and the answers are varied and depend on who you talk to. This can cause misunderstanding for all concerned; therefore, some important ethical principles that underlie clinical decision-making are outlined.

The case scenarios have been anonymised so that they bear no resemblance to the original person with diabetes.

The authors recognise that there are wide-ranging opinions and possible ways forward in all of the ethical cases in this series. They are not trying to highlight expert clinical management, but instead wish to demonstrate the contrasting ethical viewpoints that contribute to decision-making processes.

Authors

Juliette Mathie is a Practice Nurse with an interest in diabetes, Poole. Chris Elfes is a Part-time GP and GP Educator, Bournemouth, and an Honorary Lecturer in Ethics to the Wessex MRCPG courses.

Scenario

by Juliette Mathie, Practice Nurse

The parents of a 14-year-old boy with maturity-onset diabetes of the young (MODY) brought him in recently as his glucose meter was broken. They also asked me about genetic testing for his 2-year-old sister.

They have read about his GCK genetic mutation MODY and they showed me information implying that his sister has a one in two chance of inheritance with a 95% lifetime risk of developing diabetes.

Their biggest concern is that her brother was immediately started on insulin against their wishes when his diabetes was initially diagnosed as being type 1.

He was subsequently withdrawn successfully from insulin, although he is still being carefully monitored with blood glucose testing and hospital follow-up.

Ethical principles covered

Autonomy ● Beneficence
Best interests ● Non-maleficence
Virtue-based ethics

Aristotle helped define “virtue-based ethics”, and we can simply ask “what would a virtuous clinician do?” This encompasses compassion, wisdom, competence, trust, honesty and hope – to name but a few.

The fears of the parents and the possible future wishes of a currently 2-year-old girl all need consideration and understanding. We do well if we “do no harm”.

Best interests have been defined in the House of Lords as actions taken to “preserve life, health or well-being” (including the well-being of relatives), and decisions on behalf of a third party should be justifiable, proportionate and the least restrictive of the available options.

Ethical discussion of the scenario

by Chris Elfes, GP

I would update my knowledge of MODY and verify the information we have been given. I am intrigued why primary care is being asked about this when, presumably, paediatric diabetologists are also involved in the care. However, “assuming” is unwise and, anyway, the distinction between testing in primary and secondary care is of little relevance to the parents!

Clearly, *they* have the right to ask and *we* to say “no” or “we are not sure.” However, the daughter does not yet have the capacity to make her own autonomous decision.

We are being asked to make a “best interests” decision and have to consider the harm done to her by having a blood test, the parental anxiety of “not knowing” and the potential for her to be given insulin in the future.

If the ability of the parents to care for her were significantly compromised by their anxiety (unlikely) then it *might* be deemed reasonable

to test her at an early age, but a virtue-based decision has wider considerations. Firstly, there is no *immediate* need to test her, and, secondly, what difference would it make *now*?

Regardless of whether a test is positive, negative or declined, her parents should be encouraged to look at family-wide lifestyle issues. The consequences of all options should be discussed and it should be explained that, even in the knowledge of a sibling having MODY, if the girl did develop glycosuria, paediatric diabetes experts might still recommend insulin – dependent on her well-being at the time.

I would aim to support the parents in reviewing lifestyle issues and ensure they test the girl’s urine at regular intervals and know when to promptly seek professional advice, as well as enabling the parents to further discuss their very reasonable request with the paediatrician, a genetic counsellor or both.

Being honest about a lack of expertise while being able to listen, explain and signpost appropriately is core to being a good primary care health professional.