Bioethical Inquiry (2011) 8:215–216
DOI 10.1007/s11673-011-9296-0

Response

Henry Kilham · David Isaacs

Received: 9 February 2011 / Accepted: 24 February 2011 / Published online: 24 March 2011
© Springer Science+Business Media B.V. 2011

Oral feeding in individuals with Rett syndrome is notoriously difficult and time-consuming, as is often the case in conditions involving severe neurological disability and disordered swallowing, and may lead to poor nutrition and episodes of pulmonary aspiration.

For complex reasons, families often resist percutaneous entero-gastrostomy (PEG) for artificial feeding. If performed, however, a PEG usually offers substantial benefits. For example, the patient may be more settled due to not being constantly hungry. His or her access to nutrition—and thus overall improved condition—allows carers more time to attend to the patient's other needs as well as those of family members and themselves. Inserting a PEG is a relatively safe procedure, even where there is poor nutrition, and it does not preclude giving small amounts of food orally for enjoyment.

Miss K's poor state when first seen by Dr Lukin would have been due primarily to a lack of nutrition, which a PEG and good artificial feeding probably would have reversed. PEGs require good routine care, can become infected, and may require periodic revision, but are generally well tolerated. Even with the benefits from a PEG, Miss K would still have a very low quality of life because of the nature of her underlying condition.

Miss K clearly reacted to noxious stimuli (e.g., a nasogastric tube) and appeared to enjoy chocolate mousse; thus, she was capable of experiencing general senses such as pleasure, discomfort, pain, and other suffering. However, we are dubious about her mother's stated belief that Miss K had *wishes*, including not wanting to live, as this implies a much higher level of mental functioning.

The plan to continue without artificial feeding effectively equated to allowing Miss K to starve to death, albeit with some palliative care to make the process easier. Such plans occasionally have been agreed to concerning people in "chronic vegetative states," at times with approval from the law (e.g., the case of Mr Anthony Bland, discussed in Kerridge et al. 2009). In such instances, assumed best interests of individuals have been prioritized over the sanctity of life doctrine—opposing approaches that simply cannot be reconciled. Ultimately, such difficult decisions have

H. Kilham (✉)
General Medicine and Clinical Ethics, The Children's
Hospital at Westmead,
Westmead, NSW, Australia 2063
e-mail: henrykilham@gmail.com

H. Kilham · D. Isaacs
The Centre for Values Ethics and the Law in Medicine,
University of Sydney,
Sydney, NSW, Australia 2006

D. Isaacs
e-mail: davidi@chw.edu.au

D. Isaacs
Infectious Diseases and Clinical Ethics,
The Children's Hospital at Westmead,
Westmead, NSW, Australia 2063

to be made *for* the patient, by his or her legal guardian, ideally after full and frank discussion with appropriate professionals.

In view of Miss K's extremely poor quality of life, with or without a PEG, we don't believe the actions taken can be roundly and fully condemned as morally wrong. However, we are concerned about some of the decision-making processes in this case, including the need for wider discussion and consideration of alternatives. Dr Lukin had met Miss K in the context of assessing her for a medical procedure. It was good he was prepared to "take on" discussion of some of the larger issues, including, in effect, ethics and end-of-life care. That said, he does not claim to have had much experience with people with conditions as severe as Rett syndrome, and it does not appear that he discussed the plan of action with other doctors who must have been involved in Miss K's care, nor with professionals with substantial experience with similar people, including the long-term use of PEGs. Such broader discussion, possibly involving the care facility staff and Miss K's brother, might have led to a different course of action; for example, an agreed trial period with a PEG and some oral comfort feeding may have helped all of those involved, particularly with regard to accepting any final course of action.

Reference

Kerridge, I., M. Lowe, and C. Stewart. 2009. *Ethics and law for the health professions*, 3rd ed. Annandale: Federation.