Addressing the new teen trend of “diabulimia”: Moral quandaries of a pediatric endocrinologist

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The management of diabetes mellitus in adolescents has grown increasingly nuanced as insulin resistance appears at ever-younger ages and technology advances into hitherto unattainable realms. Hence, it is in the midst of an already complex milieu that a new syndrome has managed to emerge largely unnoticed. This rarely researched and thus largely mysterious condition has been dubbed “diabulimia” by the media; the scientific community has yet to name it. Diabulimia refers to the practice of withholding insulin in order to lose weight.¹ It typically co-exists with other disordered eating behaviour (DEB; e.g., extreme restriction, use of laxatives, etc.) or full-scale eating disorders.² DEB is particularly worrisome in the context of pediatric diabetes for two reasons:

(a) It is dangerous. Eating disorders in diabetics are associated with poor metabolic control, greater need for hospitalization, a higher rate of microvascular complications (in particular retinopathy and nephropathy), and premature mortality.³ ³ ⁴ ⁵ ⁶ The root of this rather extraordinarily high prevalence is unknown, but there have been postulations: diabetic children are encouraged to pay a great deal of attention to their diets and also tend to have higher BMIs than their peers, which may increase anxiety about weight.⁷ The problem seems to increase with age: deliberate insulin omission is reported by roughly 2% of preteens, 15% of mid-teens, and 30-39% of older teens.¹ ³

(b) It is common. A startling 51% of adolescents in a Toronto study reported DEB, and over 10% met diagnostic criteria for an eating disorder.² The root of this rather extraordinarily high prevalence is unknown, but there have been postulations: diabetic children are encouraged to pay a great deal of attention to their diets and also tend to have higher BMIs than their peers, which may increase anxiety about weight.⁷ The problem seems to increase with age: deliberate insulin omission is reported by roughly 2% of preteens, 15% of mid-teens, and 30-39% of older teens.¹ ³

The remainder of this paper will focus on ethical concerns that may arise in the care of these patients. As Carney insightfully notes, “Behavioural disorders accompanied by questionable beliefs... expose the frailties of medico-legal knowledge.”⁸ If we attempt to understand these frailties and grapple with those issues for which “there is no ‘right’ decision, only a decision that is thoughtfully made and perhaps ‘more right’ than the alternatives,” we will gradually strengthen the ethical foundations on which medicine relies.⁹

Case 1

You receive an urgent page informing you that Erica, a 15-year-old patient of yours, is in diabetic ketoacidosis at the hospital. You go to see her and discover that she has been skipping many of her insulin doses for months and does not wish to be treated for her ketoacidosis with insulin. She is terrified at the prospect of gaining weight and equates taking insulin with weight gain and loss of control. What should you do?

Though literature on diabulimia is scant, much has been written on the ethics of compulsory treatment for anorexia nervosa, and the essential difficulty in both circumstances is the same. It lies in balancing two of the most sacredly held principles of bioethics: beneficence and autonomy.⁸ ¹⁰ ¹¹ Put in another fashion, this is a tension between positive rights (i.e., the right to health) and negative rights (i.e., the right not to be hospitalized or treated against one’s will).⁸

Before moving on any further, it is crucial to get the question straight. In this case, there is in fact more than one question. The first is this: should a clinician respect a competent patient’s autonomy if his or her own vision of the patient’s best interests differs from the patient’s (assuming that what the patient desires the clinician to do lies within ethical bounds)? That question has been considered in depth and resolved.¹² It is not a very difficult one when well-being is considered from a holistic point of view, since “a respect for autonomy clearly emerges from a beneficence-based ethic”.¹³ In the case of eating disorders, however, we have a cluster of more complicated questions, ones in which beneficence and autonomy truly do conflict: they are questions regarding the nature of competence, how mental illness can affect it, and what to do when it is fragile or absent.

Competence requires the ability to understand and remember information about treatment options, appreciate the personal reality of relevant benefits and risks, weigh and consider various possibilities, and express a choice.¹¹ ¹⁴ ¹⁵ While an eating disorder certainly does not automatically remove a patient’s capacity to make medical decisions, concern is valid and needs to be explored on a person-by-person and task-by-task basis. Anorexia, the most studied of the eating disorders, has variable and unpredictable effects on concentration, beliefs, and information processing.¹¹ ¹⁶ ¹⁷ Patients frequently express contradictory convictions: for example, they usually do not want to die, yet they also do not want to eat enough to live.¹⁸ Whether these difficulties are of a nature that can be adequately captured on standard tests of competence (e.g., the MacCAT-T) is a matter of debate.¹⁸ ¹⁹ ²¹ Some propose that pathological values derived from the eating disorder may cause a cognitive impairment greater than that detected by current tests.¹⁸ ²¹

The extent to which the cognitive distortions of
anorexia are present in diabulimia is unknown and difficult to surmise, since both severe malnutrition (which may or may not be present in diabulimia) and the mental illness itself contribute to them. The latter should not be underestimated, for “the types and range of relationships that patients may have with the eating disorder are similar to the relationships they may have with people.” Thus, establishing the competency of a patient with any eating disorder requires a careful and thoughtful evaluation. In Ontario, a hearing before the Consent and Capacity Review Board is sometimes necessary, though this is impractical when urgent care is required.22

If it is determined that a patient is not competent to refuse a specific medical intervention, the treatment team must then discuss the issue with a substitute decision maker (in pediatrics, usually the parents) and offer appropriate counsel. For patients who do not have an advance directive, the guiding standard generally applied is that of “best interests”,8,10,21 This raises a new question: even with legal permission, is it good judgment to treat Erica against her will? Forced treatments are highly psychologically distressing and may jeopardize recovery if used excessively.20,24 All costs must be counted and the patient’s wishes should be respected whenever possible, even if he or she is not competent.25

Nonetheless, in Erica’s case, we suggest that the standard of best interests would involve administering insulin. There is good rationale, indeed probably better rationale than for forced feeding in anorexia: she is in an acutely life-threatening situation, the intervention is of known medical benefit, there are no viable alternatives, and her true wishes cannot be reliably ascertained due to the cognitive effects of her illness.8,10,11,14,20,25 Further, because an eating disorder is normally an expression of emotional distress rather than a genuine attempt at a slow suicide, there is a particularly strong “duty to protect”.8,10,11 This scenario is not akin to withdrawing care at end-of-life; patients with eating disorders do recover and frequently go on to lead full, happy lives.11,14,15

It goes without saying that Erica will need other care. Her ability to consent to (or refuse) each intervention should be considered independently by a clinician attuned to possible changes over time.14,24 The process of evaluating competence can be given more thought and time once she is stable. Fortunately, compulsory treatment given sensitively does not seem to negatively affect the therapeutic relationship.10,14

Conceptually, perhaps the most important point here is that the underlying rationale is not a lack of respect for autonomy but a belief that true autonomy is occasionally impossible. Hence, the goal is not to privilege the clinician’s view over the patient’s, but to give what the patient’s genuine self, rather than her mentally ill self, would want, with the ever-present hope that in the future she will regain the ability to choose freely and even healthfully. Clinicians should strive for the model achieved in a British Columbia eating disorders program in which “the team is always working towards empowering the patient to achieve her own agency and at the same time must remain cognizant of the power of the anorexia, which may mask the authentic wishes of the patient to seek wellness.”24 A blind and unconsidered adherence to the wishes of a patient who is in severe psychiatric distress and desperate medical need helps no one.

Case 2

You head back to your office. Laura, a 12-year-old with Type I diabetes, is coming to see you for a routine check-up. Upon reviewing her chart, you discover that her sugar levels are rather high and she has lost about 10 pounds. What is your approach?

This particular scenario is not ethically complex, yet it is important, because if you were to discover that Laura has a full-scale eating disorder, you would have a window of opportunity to simultaneously avert suffering and avoid the ethical complexities of the previous case. Call it “preventative ethics”, if you will. You might accomplish these goals by (a) treating her early, and (b) working with Laura, her family, and an interdisciplinary team to prepare an “advance directive” that could be used to guide treatment if she should lack decision-making capacity in the future.14 Evidence suggests that DEB persists for at least five years in over 90% of cases; a “wait-and-see” approach is not wise.1

Unfortunately, physicians feel that they lack training in caring for adolescents with these difficulties, and routine care is likely inadequate.5 Recommendations for those hoping to achieve successful early intervention include yearly screening questions beginning in the preteen years, attempts to normalize eating behaviour and bolster self esteem early in the course of illness, and a low threshold for referral to specialized eating disorder services.1,15 Last but never least, according to patients, the “key to a meaningful intervention is to be recognised by the therapist as a person”.26

In sum, “diabulimia” illuminates the ethical importance of early intervention in mental illness and raises important moral issues that the field of pediatric endocrinology will need to address in coming years. Such discussion is an integral part of the rapid evolution of society and medicine, for as Macdonald so aptly put it, “Ethics – the making of value judgments, of weighing our actions against shared standards – is a task inherent to clinical life.”25

References


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