Ethics in eating disorders

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Abstract

Eating disorders and their treatment present many ethical dilemmas. These are severe mental illnesses that have considerable consequences on all areas of sufferers' lives. Eating disorders are associated with reduced quality of life, high carer and societal burden and significant mortality. Whilst treatments evolve, it is widely acknowledged that our understanding of these conditions and effective treatment pathways is frustratingly inadequate. Eating disorders are philosophically perplexing in that they are experienced as part of the self and can become highly valued coping mechanisms. As a result, many patients will at some point deny aspects of their condition and avoid or refuse treatment. How should we approach challenging questions such as the following? Should treatment be enforced? Can a patient decide? Is coercion ever acceptable? Should patients be assisted in dying? An exploration of ethical principles can provide a framework, but the complexities of individual circumstances require a comprehensive, compassionate and flexible approach to these most fundamental issues. Ethical considerations must always be kept at the forefront of clinical decision-making.

Keywords: eating disorders, ethics, autonomy, capacity, decision-making

What is ethics?

Ethics is a branch of philosophy that is concerned with the question, "what is the morally right course of action in this particular situation?", and underpins every clinical decision. Medical ethics aims to assist in finding a solution to these problems. This is achieved through guiding an impartial, informed approach that considers the relative merits of the available options in the search to determine the best course of action. Medical ethics does not offer absolute or definitive answers but should guide a coherent and rational approach to clinical decision-making.

Principlism, as set out by Beauchamp and Childress, is the most widely adopted ethical approach applied in current clinical practice (1). It outlines four universal basic principles that define the moral obligations of clinicians; these are beneficence, non-maleficence, respect for autonomy and justice. Beneficence is the obligation of a clinician to act for the benefit of the patient and promote their welfare. Non-maleficence is the duty of a clinician not to harm the patient. The practical consideration of non-maleficence lies in weighing the benefits against burdens of possible interventions. The principle of autonomy recognises individuality, in that we all have intrinsic and unconditional worth. We have the right to make decisions and exercise self-determination. Autonomous decisions are contingent on one's capacity to make that choice. Justice is generally interpreted as fair, equitable and appropriate treatment.

Beneficence and non-maleficence can be traced back to the time of Hippocrates and would generally be regarded as fundamental, inarguable doctrines in clinical practice. Respect for autonomy has gained primacy in contemporary medicine, which is congruent with societal and cultural shifts towards personal freedom. Most notable is the steady shift from medical paternalism to a patient-centred approach that relies on determination of capacity and the use of informed consent. Whilst these principles are singularly uncontentious, dilemmas arise when they conflict.

Ethics based on principles incorporates a deontological or "rules-based" approach with a focus on the nature of the action and a utilitarian stance that is reliant on the outcome. In the healthcare setting, virtue ethics also has something to add. This highlights the importance of the character of the clinician and seeks to answer, "what would a kind, honest, benevolent, caring person do in these circumstances?", which places the actor (clinician) under the spotlight and emphasises the importance of self-knowledge and self-reflection. This seems key, as the process of balancing conflicting principles is recognised to be highly subjective.

Clinicians should therefore have a good understanding of ethical principles and experience in systematically evaluating them from each of these viewpoints. Embedding this approach within clinical teams will enable sound ethical decision-making in clinical practice.

What is it about eating disorders that makes them ethically challenging?

There are a number of features of these illnesses and current treatment approaches that are uniquely perplexing for clinicians. We must first attempt to understand why patients commonly deny the severity of illness, lack insight and resist treatments.

Identity and values

Conflict is commonly encountered in the treatment of eating disorders because overvalued ideas about weight and shape are core symptoms that drive eating disordered behaviours to prevent weight restoration. Treatment aims to challenge these behaviours in order to regulate eating and weight (2). Eating disordered psychopathology is by definition ego-syntonic, or in other words, experienced as part of the self and congruent with one's values and life goals (3). Treatment may be viewed as inherently incongruent with, or even threatening to, the sense of self (4). Additionally, an eating disorder can be experienced as a solution to wider difficulties, particularly in terms of emotional regulation. It becomes a strongly valued coping mechanism.

Developmental process

The incidence of eating disorders is highest during the adolescent period and there is some evidence of impact in increasingly younger children (5). This is a critical developmental stage, with the process of identity formation a key task (6). Retreat into an eating disorder can feel like a safer option at this time and the illness then hijacks or halts the process; an "anorexic identity" is adopted. Because a stable sense of identity has not formed prior to developing the illness, a tangible alternative option to the eating disordered self, an "authentic self", can be elusive (7). The natural process of individuation and progression towards independence is interrupted. Addressing this interplay between the development of a stable sense of self and the eating disorder is a critical part of many therapeutic approaches.

Severity

Eating disorders considerably impair physical health and disrupt psychosocial functioning. Psychiatric comorbidity is the norm and medical risk associated with being underweight, malnutrition and purging can be life-threatening (8). Mortality associated with all eating disorders is significant and for anorexia nervosa widely reported to be among the highest of all psychiatric disorders. Death results from complications associated with malnutrition or electrolyte disturbance through purging. Suicide accounts for 1 in 5 patients who die with anorexia nervosa (8-10).

Evidence for effective treatment

Eating disorders are notoriously under-researched, resulting in uncertainty as to their pathophysiology and effective management strategies. This is particularly the case for anorexia nervosa. The National Institute for Health and Care Excellence (NICE) acknowledges the "low-to-very-low" quality of evidence for psychological treatments for adult anorexia nervosa (2). Randomised controlled trials are underpowered to show superiority for any specific therapy and even the best current treatments bring about significant improvement in only 50% of patients, with 20% remaining severely ill (11, 12). However, early intervention appears to improve outcomes (13, 14), which may provide ethical justification for a tipping of the balance towards a more proactive/coercive approach. There are clearly significant gaps in our understanding of the effectiveness and acceptability of current interventions (15) and further research is urgently needed.

Treatment approach

Due to the complexity of both psychiatric and physical symptoms, treatment often requires a coordinated approach between the patient, family members, general practitioner, general psychiatric teams, eating disorder services and physicians (16). Discontinuity and disruption of care has a significant impact on the establishment of a therapeutic alliance and thus how beneficial treatment will be.

The most common ethical dilemmas require a determination of risk versus benefit (beneficence and non-maleficence), particularly in the face of treatment refusal when respect for autonomy may conflict with our duty to protect. We must therefore consider the nature of these illnesses and evidence for the effectiveness of the treatments we currently provide.

Misunderstanding and stigma

Misunderstanding and stigma regarding eating disorders is endemic. Compared with other mental illnesses, eating disorders are more commonly viewed as less severe, self-inflicted and under an individual's control (17). Crucially, studies have shown that these beliefs are held by professionals as well as the public (18). Stigma is a barrier to help-seeking and accessing treatment in a group who already feel substantial shame and guilt. Our understanding and theoretical view of an illness fundamentally informs our approach. The danger of stigma must be recognised as it affects all aspects of care from families, employers, health professionals and policymakers. Stigma has a pernicious impact on investment in research and clinical services. It is vitally important that clinicians recognise and reflect on their own prejudices in this respect, as engagement in treatment and perception of care is heavily influenced by the therapeutic alliance and level of trust a patient has in their clinician.

Ethical dilemmas

Treatment refusal

We have an understanding of why patients with eating disorders may struggle to accept, or even refuse, treatment.

Enforced treatment is considered when there is significant medical or psychiatric risk, when such treatment is life-saving. Severe underweight, rapid weight loss, medical risk associated with purging or risk of severe self-harm are the most common indicators (2, 19, 20). From an ethical standpoint, the controversial decision of whether to embark on compulsory treatment hinges on a judgement of risk versus benefit (maleficence versus beneficence), where the autonomy of the patient is juxtaposed with the obligation of the clinicians to save lives.

The infringement of a patient's right to self-determination is deemed by some to be fundamentally wrong (21). There are also clinical concerns regarding this approach which see it as counterproductive. An oppositional patient who is forced to gain weight may "eat his/her way out of hospital" with no psychological benefit. Enforced weight gain can increase the risk of developing additional eating problems, such as the use of covert compensatory behaviours. The result may be a worsening of illness with an increased likelihood of rapid relapse on discharge. Worryingly, compulsory treatment risks damaging the trust in clinicians and eroding the therapeutic relationship, which may undermine the likelihood of future engagement in treatment (22).

Unfortunately, empirical data on the effectiveness of compulsory treatment is sparce, and with differing criteria it is difficult to draw firm conclusions (23). The potential benefits of compulsory treatment are most evident in the short-term when intervention can certainly be life-saving. Long-term outcomes appear to be similar to those who are treated voluntarily, with no significant difference in mortality rates (24, 25). Given that those treated compulsorily arguably have more severe illness at baseline and would not have engaged with treatment otherwise, this suggests that compulsory treatment may not be detrimental and may be beneficial in the long-term. In practice, compulsory treatment is used as a life-saving measure and the question is when to treat rather than whether to treat.

Qualitative studies of patient and parent views offer valuable perspectives (26-28). As expected, a wide range of views emerge from these studies. It is recognised that enforced feeding can relieve feelings of guilt about accepting nutrition and treatment, and as such give some patients the "permission to eat". There is also evidence that some patients retrospectively agree that compulsory treatment was the right course of action (26), and that the degree of satisfaction after discharge is similar for voluntary and involuntary admissions (27). However, Rienecke et al. highlight the diversity of experiences. They report that involuntary treatment is recognised in retrospect as beneficial by those who were doing well; however, those who continue to struggle with their eating disorder report negative consequences (28).

What is clear is that the nature of the relationship between the patient and the clinical team is key and can be the most important determinant of whether any aspect of treatment is experienced as coercive or as an act of compassion (26, 28, 29). We will return to this later in the discussion about the futility of treatment.

The legal mechanism for compulsory treatment in England and Wales is outlined in the Mental Health Act (1983) (30). It provides legal justification for treatment of a mental disorder without consent when criteria relating to the nature, severity and risk associated with the illness are met. Most jurisdictions have some form of mental health legislation recognising the special vulnerability of those with severe mental illness and the need for protection and treatment in the case of treatment refusal (21, 31, 32). From an ethical standpoint, a utilitarian/paternalistic approach has taken precedence over a more libertarian stance in these circumstances. With clear sociocultural shifts away from paternalism since the latter half of the last century, the right to self-determination in healthcare decisions has gained prominence. There is a corresponding move towards a heavier reliance on an assessment of mental capacity in all clinical decision-making, and parity between decisions regarding physical and mental health. Whilst this may have face value, it necessitates a close and careful look at how capacity is conceptualised and determined in different patient populations.

Decisional capacity

Mental capacity is a prerequisite for self-determination in relation to healthcare decision-making. The Mental Capacity Act (2005) (33) outlines the process of assessment of capacity and how to approach treatment in those deemed not to have capacity in relation to a particular decision. In cases involving adults there is an assumption of capacity, and all practicable steps must be taken to enhance the patient's ability to make an autonomous choice. Unwise decisions should not be regarded as evidence of a lack of capacity, and the least restrictive course should always be taken. Minors can consent if they have sufficient understanding and intelligence to understand fully what is

Box 1. Format for the assessment of capacity in eating disorders (adapted from Tan and Richards (41))

- Ability to understand and retain information
- Ability to use information
- Appreciation of information and facts of the decision
- Presence of compulsions
- Changes in values due to the eating disorder
- Changes in identity due to the eating disorder
- Presence of depressive features, loss of hope and affective elements
- Presence of neuropsychological deficits
- Mentalisation ability

involved in a proposed treatment, including its purpose, nature, likely effects and risks, chances of success and the availability of other options. There is a determination of "Gillick competence" (34). In the absence of Gillick competence, consent must be provided by someone with parental responsibility or the court.

Capacity in anorexia nervosa

The legal test of capacity is largely intellectual. It relies on an ability to understand relevant information, have an appreciation for the consequences and undertake a process of reasoning in order to make and communicate a decision. When standardised instruments such as the MacArthur Competence Assessment Tool for Treatment (MacCAT-T) (35) are used, even patients with severe anorexia nervosa can be judged to have decisional capacity regarding treatment, with low concordance with clinical judgements of capacity (36, 37).

Patients with eating disorders are often highly articulate and persuasive in their reasoning (20, 38). Research has shown, however, that there may be more subtle impairments related to the specific psychological aspects of the illness. The previous discussion regarding values, identity and valued nature of the illness again come into focus. A determination of what is an authentic desire and what is illness-driven or a "pathological value" is crucial (4, 38, 39).

Neuropsychological difficulties, such as inefficient set-shifting and poor central coherence are a feature of eating disorders and considered to be important maintaining factors. They appear to be trait characteristics, but this cognitive inflexibility is also exacerbated by underweight. The bias towards local, as opposed to global, functioning is highly likely to affect the reasoning and appreciation aspects of decision-making (40). In other words, the focus on detail clouds the bigger-picture considerations, for example, the current meal as opposed to the broader impact of illness.

An explorative study on this issue concluded that diminished mental capacity occurs in a third of patients with severe anorexia nervosa and is associated with a low BMI (although not exclusively), less appreciation of illness and treatment, previous treatment for anorexia nervosa, low social functioning and poor set-shifting. This study also highlights the importance of considering the emotional state of the patient and mentalisation ability (36).

Aside from the complex clinical picture, the determination of capacity is highly subjective and considerably impacted by the experience, beliefs and attitude of the assessor. Takimoto uncovered vastly differing views and outcomes in a survey of physicians in Japan, the UK and the USA (37). Determining consensus and guidance on the treacherous task of capacity assessment in those with eating disorders is of the highest priority.

Coercive treatment approaches

It is important to acknowledge that restrictive treatment is not confined to enforced feeding. The use of leverage is fairly commonplace in the treatment of eating disorders. Leverage in mental health treatment can be exercised in a multitude of ways, ranging from persuasion to inducements and "threats of coercion" (42). Practices such as supervision at mealtimes, monitoring bathroom use, exercise restriction and routine weighing and physical health monitoring could be perceived as coercive. Clinicians must recognise that whilst these approaches have clear clinical benefits they are not without risk. We have a duty to review the relative merits of such approaches and explain the rationale for all aspects of treatment in order to justify their use in particular circumstances.

Palliative care and medical aid in dying

The question of whether it is ever ethically justifiable to withdraw life-saving treatment or to assist in the death of someone with anorexia nervosa is one of the most troubling and controversial issues. In patients with severe and enduring illness who persistently refuse treatment, the determination of the relative risk and benefit of further intervention can be particularly problematic. The legal and ethical concerns surrounding this issue have received growing attention (23, 43, 44). In the UK, since 2012 there have been a number of appeals to the Court of Protection (45) to determine a legal route. A judgement of incapacity has, in most cases, led to a "best interests" decision not to compel life-saving treatment (46-51).

In Canada, a new category of "terminal anorexia nervosa" has been proposed as an expansion of the country's criteria for medically assisted dying to those suffering with a mental disorder (52, 53). The debate surrounding this is clinically and philosophically challenging.

Proponents of the withdrawal of treatment in certain circumstances offer a number of arguments. It is proposed that for some people who persistently resist treatment, the benefits are outweighed by the burden/harm of such intervention. It is not difficult to argue that enforced feeding, for example, whilst life-preserving is highly traumatic. Respect for patient autonomy and the right to exert personal values of a life worth living may be the most compassionate approach, affording someone the right to determine when "enough is enough". In these extreme circumstances it is proposed that palliative care to ameliorate suffering, as opposed to continued treatment attempts, is ethically imperative. It is suggested that consensus in this area would allow the development of clinical and policy guidelines and validate the experience of this limited but significant group of patients.

The proposed criteria for "terminal anorexia nervosa" are as follows. (1) diagnosis of anorexia nervosa; (2) age 30 years or over; (3) prior persistent engagement with high-quality, multi-disciplinary, eating disorders care; and (4) consistent,

clear expression by an individual who possesses decision-making capacity that they understand that treatment is futile, choose to stop prolonging their lives and accept that death will be the natural outcome. A prognosis of less than six months is suggested, using evidence of duration of life in hunger strikers, and it is concluded that this is congruent with current practice in determining a terminal diagnosis (52).

Unsurprisingly, there is considerable opposition to this proposal. Some reject euthanasia and other forms of assistance in dying on the fundamental principle of the sanctity of life, emphasising the view that all human life has inherent value and should be preserved regardless of suffering or illness. Clinicians and patients have expressed multiple concerns highlighting the damaging and potentially dangerous effect of the debate itself, in addition to criticism of the validity of the suggested criteria (54-58).

Box 2. Ethical considerations in clinical practice

- Reflect on own attitudes and beliefs as these will influence decision-making
- Develop a therapeutic alliance as this is key
- Use motivational approaches
- Identify reasons for treatment refusals
- Provide careful explanations of treatment options
- Weigh the risks and the benefits of interventions
- Involve important others, for example, family members
- Negotiate where possible and use the least restrictive approach
- Avoid conflict
- Carry out thorough capacity assessments
- Enhance autonomy and aim for collaborative decision-making
- Team discussion and regular review of all aspects of care
- Consider legal means of enforcing treatment when refusal is judged to constitute a serious risk
- Consider different treatment focus in those with longstanding illness where standard treatment has not been helpful

The current lack of knowledge regarding underlying mechanisms, effective treatments and predictors of outcome are key clinical objections to the concept of futility (54-56). Anorexia nervosa is a potentially treatable condition and recovery is possible at any stage, even after decades of illness (59, 60). Whilst there have been attempts at developing a staging model for anorexia nervosa, we simply do not understand enough about the course of the illness to define clear prognostic indicators. In other words, we cannot currently be confident about which treatment is likely to be more effective for whom, or who is more or less likely to recover even after years of illness.

The widespread scarcity of resources and lack of standardisation in treatment approaches across services brings the determination of the third criterion, previous "high-quality care", into question (15, 61). Consideration of the impact of comorbid conditions, particularly obsessive-compulsive disorder, depression, personality disorder and neurodevelopmental conditions such as autism, also requires considerable attention due to the additive impact on hope for recovery.

The determination of capacity again becomes key. When we consider the wide variability of opinion and practice it seems clear that we are not currently in a position to feel confident about how this criterion will be assessed, particularly concerning such high-stakes decisions (36, 37).

What this debate highlights is the devastating impact of severe illness and repeated attempts at treatment on patients, family members and clinicians. This can inevitably lead to pessimism and a loss of hope. However, resources should be directed at exploring how we can "give sufferers the right to *truly* live - not just exist, survive, or wait to die" (55). A harm-reduction approach is infinitely more ethically justifiable (62, 63). An explicit shift of focus, from full recovery and weight restoration to one that aims to improve quality of life while minimising harm, also enhances personal autonomy and, most importantly, protects future autonomy.

Conclusion

Eating disorders are clinically and philosophically complex conditions. This is due, in part, to the unique nature of these illnesses and limitations in the current understanding of the underlying mechanisms and the most effective interventions. Clinical decision-making is highly subjective and there is currently no consensus, particularly in guiding treatment for the most severely unwell. In addition to a worldwide lack of resources in the field, this results in inadequate or inappropriate care for many sufferers.

Determining the balance between the safeguarding of autonomy and treating severe illness or the withdrawal of treatment should be approached with caution and after careful consideration. It is imperative that the ethical aspects of treatment are addressed alongside clinical parameters. Further research and the development of evidence-based treatment pathways for complex cases should alleviate some of the controversy regarding the most challenging treatment decisions.

On an individual basis, all clinicians must strive to practice to the highest ethical standards. This can be achieved through self-reflection and the development of skills in applying core ethical principles to clinical practice. Compe-

tence in collaboratively exploring the most thorny issues with patients, families and within teams should ensure the provision of compassionate, timely, patient-centred care. Treating patients in this way is also likely to be more effective.

Declaration of interest

The author declares that they have no conflicts of interest.

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