

Consent or Caring? Issues of Autonomy and Paternalism in the Treatment of  
Anorexia Nervosa

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A thesis  
submitted to the Victoria University of Wellington  
in fulfilment of the requirements for the degree of  
Master of Science  
in Psychology

Victoria University of Wellington

2014

**FACULTY OF SCIENCE**  
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**STATEMENT OF AUTHORSHIP**

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## ABSTRACT

Denial is a characteristic feature of anorexia nervosa (AN) that may lead to treatment refusal. If an individual is refusing treatment autonomously, it should be accepted, while a lack of autonomy indicates paternalistic intervention may be justified. AN has the highest mortality rate of any mental disorder, so accepting refusal means accepting the risk of death, so should only be done with the certainty that it is autonomous. The current research is theoretical, reviewing the literature on ethical issues relating to autonomy and paternalism in AN in order to evaluate the evidence base for these assumptions. The aim is to develop a procedural model for establishing autonomy in those with AN. The result is the anorexia nervosa autonomous decision-making model (ANDMM), which provides guidance for responding to autonomous and non-autonomous treatment refusal.

*Key words:* anorexia nervosa, autonomy, paternalism

## ACKNOWLEDGEMENTS

Researching and writing this thesis would not have been possible without the support and encouragement of a handful of individuals who deserve my sincerest thanks.

First and foremost, I would like to thank my supervisor Professor Tony Ward. Your ongoing encouragement and advice helped me grow in confidence and maintain motivation in what was at times a challenging year. Your knowledge on the topic, combined with your genuine interest in my perspective, has led to a thesis I hope does justice to all you have contributed. I feel very lucky to have had the opportunity to work with you.

To Naomi White, my friend and office mate: thank you for all the laughs, especially in those days when we were feeling ‘over’ our research and just needed to have some fun.

Thank you to my family for allowing me to impose my research on many family dinners. I know you are all proud of me, and that means more than I can say. I have to single out Ann-Marie for reading the entire thing to give feedback and editing advice. Your opinion has always been important to me.

Last but not least, I would like to thank my husband, Jason. You have provided more support than should ever be expected of any one person. You have never doubted my ability to reach my goals, and never stopped encouraging me to become the psychologist I want to be. Words will never be enough to express how much your love and support mean to me.

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## CHAPTER ONE - INTRODUCTION

Autonomy, or self-rule, is a fundamental human right. At a minimum, it encompasses the right to follow a self-chosen plan, free from the interference of others (Beauchamp & Childress, 2009). This includes choices relating to physical and mental health care (Giordano, 2005). The right to autonomy is reflected in the New Zealand Code of Health and Disability Services Consumers Rights, which states that all individuals should be viewed as competent to make choices around the treatment they receive for any kind of health condition, unless there are reasonable grounds for the provider to believe individuals lack the competence to make these decisions (Health and Disability Commissioner, n.d.). If a person is found to be lacking autonomy, paternalistic treatment that prioritises individual well-being is deemed justified (Giordano, 2005).

Treatment refusal is a common response of patients with anorexia nervosa. It is unclear whether this refusal is autonomous and should be respected, or if it is a symptom of the disorder that should be overridden. While it is ethically appropriate to respect an individual's autonomous treatment decisions, anorexia has the highest mortality rate of any psychiatric disorder, so every refusal of treatment comes with the possibility of death (American Psychiatric Association [APA], 2000). If those with anorexia are deemed competent, and we accept treatment refusal as a true reflection of an individual's autonomy, we risk losing them to premature death. If we decide an individual is not able to make decisions on their care, we risk violating individual autonomy by forcing people into treatment when they have the ability to refuse (Gans & Gunn, 2003). In an area of mental health where medical certainty is rarely possible, should disagreements over an individual's capacity be resolved in favour of compulsory treatment, at the risk of being overly restrictive, or individual



autonomy, risking neglect and possibly death (Carney, Tait, Touyz, Ingvarson, Saunders & Wakefield, 2006)? The current research aims to answer this question, establishing when the refusal of treatment for anorexia nervosa should be respected, and how this should be determined.

The ability to exercise autonomy is beneficial in the treatment of anorexia nervosa, leading to positive treatment decisions, reduced treatment dropout, and increased treatment compliance (Darcy, Katz, Fitzpatrick, Forsberg, Utzinger & Lock, 2010; Nordbø, Gulliksen, Espeset, Skårderud, Geller & Holte, 2008; Touyz & Carney, 2010; Vandereycken & Vansteenkiste, 2009). There is, however, a lack of consensus in the current literature over whether or not an individual with an eating disorder is able to make autonomous treatment decisions. While some authors have stated that coercive treatment is justified on the grounds that individuals will be grateful when they are returned to an autonomous state (Gardner & Lidz, 2001; Guarda, Pinto, Coughlin, Hussain, Haug, & Heinberg, 2007; Werth, Wright, Archambault & Bardash, 2003), others argue forced treatment in the long term erodes the therapeutic alliance and weakens treatment compliance (Richmond, 2001). There is also no agreement on what it is about suffering from anorexia nervosa that might deprive an individual of autonomy. Some researchers argue that because individuals with anorexia nervosa are in a severely compromised physical state they are unable to make autonomous decisions (Matusek & Wright, 2010; Werth et al., 2003), while others have failed to find any significant cognitive impairment at all (Mathias & Kent, 1998).

These inconsistencies make it difficult to make a judgement on the appropriateness of respecting an individual's refusal of treatment, and it is this problem that has led to the current research.

Authors who have thus far addressed the ethical issues of treatment refusal in anorexia nervosa have included criteria unrelated to ethics, limiting the application of their recommendations. Giordano has written extensively on the ethical issues relating to the treatment of eating disorders, with a focus on autonomy (2005, 2010).

According to Giordano, an individual's ability to refuse treatment for anorexia nervosa is not dependent only on the presence of autonomy. Consideration also needs to be given to whether or not individuals' families support their decision, and whether or not the illness has reached a stage where there is no longer a reasonable chance of recovery. While autonomy is considered important, the emphasis is on the level of suffering experienced by individuals and their families, and how successful treatment will be. Consequently, Giordano argues that both of these factors may justify paternalistic treatment in the face of competent treatment refusal.

Many articles and chapters have been written about the acceptance of treatment refusal in those who are chronically ill with the disorder, concluding that autonomous refusal in the presence of repeated treatment failure and a high probability of death is ethically acceptable (e.g., Draper, 2000; Gans & Gunn, 2003; Fedyszyn & Sullivan, 2007; Matusek & Wright, 2010). Placing this precondition on who can and cannot legitimately refuse treatment means that the vast majority of individuals who are not at the end stage of their life as a result of the disorder are excluded from making autonomous refusals. While these papers provide a starting point for considering the ethical issues, they also place conditions on the ability to refuse treatment that makes it more than an ethical decision. Instead it becomes an issue of autonomy intertwined with illness severity and family opinion.

The current research is theoretical in nature, reviewing the body of literature that currently exists on the ethical issues of autonomy and paternalism in the

treatment of anorexia nervosa. The aim is to pull together the existing literature to establish what the pressing ethical issues are, why these issues arise, what attempts have been made to address them, and where the gaps lie. The focus will be on autonomy: if it is present in those with anorexia nervosa, the role it plays in the treatment of those with the disorder, and how and when it might be impaired. When these areas have been addressed, a framework for establishing whether autonomy and the ability to consent exists will be outlined, providing a process to assist those working with individuals with anorexia nervosa to decide who has the ethical right to refuse treatment.

There are limits to what will be included in this research. Although consent is required to both agree to treatment and refuse it, only treatment refusal will be discussed. This is because ethical issues only become problematic when individuals refuse proposed treatment, while those who consent to it progress with treatment as recommended. There are currently laws relating to who can be legally compelled to accept unwanted treatment for their eating disorder, but a review of this is beyond the scope of this research as these laws include requirements that at times override ethical best practice. It is also only a very limited group of individuals who experience the disorder severely enough to require legal intervention, while the model proposed here can be applied to those at all stages of the disorder. The focus instead will be on what is *ethically obligatory* rather than what is *legally acceptable*. A third limit is the age of the individual that the model developed can be applied to. For those under the age of consent, parents or guardians can make treatment choices on behalf of the minor, overriding their autonomy. This in turn leads to questions of what age an individual gains the competence required to make health based decisions, how this is determined, and the extent to which this ability applies when a child's life is at stake. These

factors complicate the application of ethical practice, and will therefore be excluded in the interest of clarity. Finally, because the incidence of anorexia nervosa is significantly greater in females than males, the pronoun used in this research will be *she*. This is not an indication that this research excludes, or cannot be applied to, males with the disorder.

In the following four chapters, the question of how we decide when we should accept treatment refusal and when paternalism is justified will be addressed. The diagnostic and treatment criteria will be discussed to understand the disorder experienced by those this research applies to. Following this, a review of biomedical ethics will outline and define relevant ethical principles, establishing how they are applied to health in general, and mental health in particular. Next, the question at hand will be placed in context by reviewing the existing literature on the application of ethics to the treatment of anorexia nervosa, highlighting current approaches to autonomy and consent, as well as indicating gaps and difficulties. This will set the scene for introducing the proposed model that has been developed for this piece of research.

## CHAPTER 2 - ANOREXIA NERVOSA: DIAGNOSIS AND TREATMENT

Anorexia nervosa is a psychiatric disorder characterised by three key groups of symptoms: restriction of energy intake leading to a significantly low body weight; intense fear of gaining weight or persistent behaviour that interferes with weight gain, despite being at a significantly low weight; undue influence of body weight or shape on self-evaluation, or failure to realise the seriousness of low body weight (*Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition [DSM-5]*, 2013). A significantly low weight is defined as that which is low in the context of age, sex, developmental trajectory, and physical health. Current criteria utilises Body Mass Index (BMI: individuals' body mass in kilograms divided by their height in metres squared) as a measure of severity. Individuals with a BMI of 17 or less are considered to have mild anorexia, those with a BMI of 16-16.99 are moderate, a BMI of 15-15.99 are severe, and a BMI lower than 15 is considered extreme (*DSM-5*, 2013). Risk of dying increases greatly when an individual has a BMI that is lower than 13 (Touyz & Carney, 2010).

Two subtypes of anorexia have been identified. The restricting type is diagnosed when, over a period of three months, an individual's weight loss is primarily achieved through dieting, fasting, and excessive exercise. The binge-eating/purging type is diagnosed when, over a three-month period, an individual has engaged in recurrent episodes of binge eating or purging behaviour, such as self-induced vomiting or the misuse of laxatives, diuretics, or enemas. Because it is not uncommon for an individual to change subtypes over the course of the illness, a *DSM-5* diagnosis constitutes a description of current symptoms rather than a longitudinal one (*DSM-5*, 2013).

The 12-month prevalence rate of anorexia nervosa is 0.4%, with the most common period of onset in adolescence and young adulthood. Some individuals experience a single episode of anorexia and fully recover, while others have a fluctuating course (*DSM-5*, 2013). It occurs significantly more in females than males, with a 10:1 female-to-male ratio. It is thought that this is due to different gender ideals of beauty. For women there is a cultural focus on low body weight, while for men the emphasis is on a muscular rather than thin build (Keel & McCormick, 2010). The average length of illness is estimated to be 8 years, with 24% of cases persisting for 10 to 15 years. Follow-up studies show that 43% of people recover completely, 36% improve, 20% develop a chronic course, and 5% die. It has the highest mortality rate of any psychiatric illness (National Institute for Health and Care Excellence [NICE], 2004).

Factors that predispose an individual to developing anorexia nervosa include reduced emotional resilience, heightened stress reactivity, and compulsive tendencies (Strober, 2010). Individuals often have histories that show a tendency toward worry and stress, difficulty with self-soothing, inhibited emotional expression, discomfort with change, regimented behaviour, poor self-esteem, extreme perfectionism, and persistence at tasks despite a lack of rewards (Strober, 2010). Added to these features are risk factors such as living in a culture where thinness is valued, working in a profession such as modelling or elite sports in which body image is important, and having first degree relatives with an eating disorder (*DSM-5*, 2013).

A wide range of physical symptoms are associated with anorexia nervosa, although most will reduce as normal eating is restored (APA, 2000). Commonly, individuals will present as emaciated, with low heart rate and blood pressure, and fluid and electrolyte abnormalities. Hair will be dry and brittle, and likely beginning

to fall out. Amenorrhea and a loss of bone mass result from irregular endocrine functions. Slow gastric emptying will leave the individual bloated and constipated, with hypoactive bowel sounds. Less common symptoms include brittle nails, pressure sores, yellow skin from overconsumption of carotenoids in vegetables, fine hair on the face and limbs (lanugo), cold and blue hands and feet, fluid retention in the ankles, heart murmur, eroded dental enamel from purging, osteoporosis, and in rare cases of long-term anorexia, chronic renal disease (*DSM-5*, 2013; Mehler, Birmingham, Crow & Jahraus, 2010). Weight loss can lead to cardiac muscle shrinkage, a reduction in cardiac chamber volumes, and a decrease in cardiac mass and output. This is a significant problem during the initial stages of treatment, as the increased blood volume caused by an increase in caloric intake can lead to metabolic complications that cause cardiovascular collapse, known as refeeding syndrome (Mehler et al., 2010). Lifetime rates of major depression or dysthymia have been reported in up to 50-70% of cases of anorexia, with obsessive-compulsive disorder reported in up to 25% of cases (APA, 2000).

Nordbø, Espeset, Gulliksen, Skårderud and Holte (2006) interviewed 18 individuals with anorexia aged between 20 and 34 years to gain insight into the subjective experience of the disorder. Participants had been ill with anorexia nervosa for anywhere from 1 to 20 years, and had been receiving treatment for up to 14 years. Eight themes were identified from semi-open interviews with participants that represented the meaning they found in their disorder. It was reported that anorexia provided individuals with a sense of security through the predictability the illness provided. It was a way of avoiding negative emotions and external pressure, as worrying about food and weight left little time to worry about other things. Anorexia gave individuals a sense of mastery, which then perpetuated the illness. Participants

reported that the disorder helped them to feel confident due to external affirmations on weight loss, generally received in the initial stages when weight loss first begun. They also felt it gave them a sense of identity as different from others. They valued the care it elicited, as they felt concern expressed over their weight loss showed that others were attentive and thoughtful. It was seen as a way of communicating that something was wrong when they did not feel they could verbalise it. Finally, two participants felt their eating disorder was a concrete expression of their wish to disappear through what they viewed as a slow form of suicide. As a result of the meaning individuals find in their illness most are brought to the attention of professionals by concerned family, rather than presenting themselves. Those who do self-present generally do so as a result of somatic complaints or psychiatric difficulties like depression (*DSM-5*, 2013). Legal interventions, such as mental health act legislation, may be required to compel treatment for adults who are at serious medical risk but refusing to accept treatment (Keel & McCormick, 2010).

Interventions are aimed at promoting weight gain and healthy eating, reducing eating disorder related symptoms, weight maintenance, treatment of associated psychiatric conditions, and relapse prevention (APA, 2000; NICE, 2004). A variety of settings are used for the treatment of anorexia nervosa, depending on individuals' needs and what is available in their area. In-patient treatment in either a hospital or a specialist residential facility may be required if there is a rapid or persistent decline in oral intake, a continuing decline in weight despite intensive out-patient treatment, in the presence of comorbid psychiatric symptoms, or where there is strong resistance to treatment (Keel & McCormick, 2010). Day-patient treatment involving a combination of medical monitoring, psychotherapy, and nutritional support is used for those transitioning out of hospital who require ongoing support to continue weight gain, or



for those who have not responded well to out-patient treatment but are medically stable and do not require hospitalisation. A third option is outpatient treatment with a specialist or general community mental health team. Although weight gain is slower than in in-patient settings, outpatient treatment has been shown to achieve similar levels of weight gain, and allows individuals to remain in their normal social environment. Because relapse occurs frequently individuals may transfer between these different treatment settings as the course of the illness fluctuates (Keel & McCormick, 2010).

The NICE guideline *Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa, and related eating disorders* (2004, from this point referred to as the NICE Guidelines) recommend that most adults with anorexia be treated as outpatients, with inpatient treatment considered only for those who have not improved as outpatients. Inpatient treatment becomes more likely for individuals who have already had a number of prior admissions, increased comorbidity, a low BMI, or in the presence of other indications that the person's health is at risk (Carney, Tait, Richardson & Touyz, 2008; Carney et al., 2006; Matussek & Wright, 2010). Feeding clients against their will with a nasogastric tube should be a treatment of last resort (NICE, 2004).

When individuals with anorexia nervosa refuse treatment, the natural response from those working in health professions is to attempt to protect their health by legally compelling them into treatment (Tan, Doll, Fitzpatrick, Stewart & Hope, 2008). This is often justified by the assertion that those with anorexia nervosa are not able to make competent treatment decisions as a result of their compromised physical state (Matussek & Wright, 2010; Richmond, 2001; Tan et al., 2008; Werth et al., 2003). This line of reasoning is not well supported by research, with studies struggling to

demonstrate any evidence of cognitive impairment that undermines decision-making in this way (Mathias & Kent, 1998). This issue will be discussed in depth in chapter 4.

As noted, because individuals with this disorder often do not recognise how physically unwell they are, treatment refusal is common. However, this is not the only reason individuals with anorexia refuse treatment. In a recent paper, Touyz and Carney (2010) identified a number of reasons why individuals may refuse treatment. They suggest that individuals with anorexia are reluctant to give up control, feel humiliated that they are not able to deal with their difficulties themselves, do not believe they will get better from the illness, mistrust the therapeutic relationship, and may be experiencing a mood disorder that adversely affects their motivation to engage in treatment. These findings are similar to those reported by Nordbø, Espeset, Gulliksen, Skårderud, Geller and Holte (2012) in a study looking at the reasons individuals with anorexia give for their reluctance to recover. They interviewed 36 women aged between 18 and 39 years of age treated for anorexia in the past 2 years. Participants had an illness duration of anywhere between 1 and 25 years, and had received treatment for as many as 17 years. They found that individuals were highly sensitive to judgements from others on their illness. This sensitivity to other peoples' evaluations of them had two aspects to it. First, they felt that if people expressed relief at any weight gain, or stopped expressing concern at their low weight, this indicated that there was nothing wrong with them. Another aspect was the (perceived) belief of others that individuals with anorexia lives would be better without the illness. This led to the fear that because they could not live up to these expectations it was better not to try. The participants also reported feeling 'stuck', as if recovery was impossible, which lead to feelings of hopelessness that perpetuated the illness, as did any experiences of distress. Many reported that they felt extremely motivated to recover

until it came time to eat, when their food related fear was stronger. Weight gain was another trigger for their reluctance to recover, although participants were unable to explain why this was the case. They also reported that there were many benefits to having an eating disorder in terms of care and attention received from others, and the buffer it places between them and their emotions. These benefits made them reluctant to give the disorder up.

Robinson (2009) has suggested that the belief of individuals with anorexia nervosa that they are merely following a social norm of healthy living also maintains its behavioural symptoms. There are constant messages aimed at the general public regarding the importance of exercise, decreasing the consumption of sugar and high calorie food, and reducing body fat. Individuals may justify their behaviour as merely following professional advice to maintain a healthy lifestyle, whereas in reality, they are taking to this goal to such an extreme that is causing damage to their health.

Because treatment refusal is a common feature of anorexia nervosa, it is difficult to determine if treatment refusal by those with the disorder is illness driven, or a true reflection of their wishes. If an individual is making decisions driven by the illness, we may be justified in imposing unwanted treatment. However, if treatment refusal is a reflection of other factors, imposing unwanted treatment could be a violation of a person's freedom. In order to explore how this ethical dilemma is currently approached, we first need to establish and define the ethics involved in health care, and how they apply in the treatment of mental disorder. This will be the topic of the next chapter.

## CHAPTER 3 - ETHICAL TOOLS

Before discussing the different ethical issues that arise in the treatment of anorexia nervosa, relevant ethical principles need to be defined. There is a vast amount of literature on biomedical ethics in general, however, because the issue at hand relates to autonomy and paternalism in the treatment of a mental disorder, the current review will be targeted specifically at this area. First, there will be a discussion of the principles of autonomy, nonmaleficence and beneficence, including their practical applications. This will be followed by the introduction of a model that enhances the use of these ethical principles, finishing with a caution on the potential barriers to applying them in a clinical setting.

### **Ethical Principles**

The principles covered here are prima facie obligations that must be fulfilled unless they conflict with a stronger obligation. When there is a conflict between ethical obligations, they need to be balanced up in a way that produces the greatest balance of benefit over risk (Beauchamp & Childress, 2009).

Autonomy is the individual capacity for self-rule, free from the coercion or manipulation by others, in accordance with a self-chosen plan (Beauchamp & Childress, 2009; Heal, 2012). Autonomous decisions weigh up costs and benefits, consider alternatives, show an understanding of the situation, and use all of these to make a choice. The validity of the decision is not based on the outcome, but on the deliberation and reasoning used to make it. This includes decisions that may have a harmful outcome for the individual. Respecting autonomy requires respect for persons' actions and attitudes, and an acknowledgement that they have the right to hold views, make choices and carry out actions based on personal beliefs and values (Beauchamp & Childress, 2009). Autonomy is not an all or nothing ability that an

individual either does or does not possess, but rather exists on a continuum. Because tasks are different and require different abilities, it may be present for some tasks, and not for others. It may also vary over time, with an individual unable to perform a task at one point in time, while later having the ability to perform that same task (Beauchamp & Childress, 2009).

Respecting autonomy is seen as conducive to promoting desirable outcomes for an individual. Persons will endorse choices and actions that are valuable to them, so having these respected increases the chances that desired outcomes will be achieved (Lillehammer, 2012). Promoting autonomy may include building up peoples' capacity to be autonomous by raising their awareness of the options open to them (Beauchamp & Childress, 2009), and may require the assistance from others to follow through (Heal, 2012).

Lillehammer (2012) has identified two types of autonomy: agent autonomy and choice autonomy. Agent autonomy fits the common definition of autonomy. It involves reflecting on and endorsing options, a capacity for planning and executing these options, the ability to consider options in a rational way, and a desire to live a particular kind of lifestyle. Choice autonomy is the ability to choose between available options, free from coercion. While an individual with agent autonomy will necessarily have choice autonomy, choice autonomy can be present without agent autonomy. Someone can fail to meet the criteria for full agent autonomy, but this does not mean they lose the ability to make choices over the options available to them, even if these are limited by their lack of agent autonomy. Lillehammer (2012) suggests that respecting choice autonomy may help individuals regain agent autonomy, prevent the complete loss of agent autonomy, reduce distress for the individual, and respects their agent autonomy, which is very rarely entirely absent.

Autonomy can be threatened by the presence of coercion, where one person intentionally uses a credible threat of harm or force to control another person. Whether or not coercion occurs depends both on the subjective experience of coercion, and if a person changes their intended action as a result of the threat (Beauchamp & Childress, 2009). Actions that override individual freedom and choice without consent in this way are paternalistic which can take strong or weak forms. Strong paternalism restricts a person's autonomy in order to protect their welfare, as defined by the person intervening. In health care, this is generally justified as necessary to protect life and health. Weak paternalism occurs when persons only have their freedom restricted to protect them from non-autonomous actions, or when time is needed to ascertain if autonomy is present. According to Beauchamp and Childress (2009), strong paternalism is only justified when an individual is at a significant risk from preventable harm. In this type of situation, paternalistic action will prevent harm, the benefits of the action outweigh the risks to the individual, there are no other reasonable alternatives, and the autonomy-limiting action is enacted in the least restrictive way possible.

To lessen the chances of coercion occurring in the treatment of physical and mental disorders, informed consent is required before treatment is commenced. Beauchamp and Childress (2009) have outlined the elements required for persons to give informed consent. First, they need to possess the ability to understand the information being provided to them and be able to use it to make a decision. Second, they need to be making a decision voluntarily, free from coercion. The third element is based on the provision of information, and requires health professionals to disclose all the information required to make a decision. This should include the nature and purpose of the intervention, prognosis, risks and benefits, and alternatives. A decision

can be deemed to lack competence if individuals fully understand the information they are given, but do not believe they need the proposed treatment or intervention because they do not believe that they are ill. The fifth and final element involves consent, in the form of deciding in favour of a given plan (either the one recommended by health care professionals, or another selected by the individual), and giving authorisation for the chosen plan to be acted on. It is important to note here that competence is viewed as a collaborative process and does not rely solely on individuals understanding the decisions they are making. It also requires healthcare professionals to provide all the information individuals require in order to make a decision.

It is often believed that individuals with severe mental disorders are unable to act autonomously because their behaviour and choices are often maladaptive; their illness causes them to do things that are abnormal and out of their control. As a result, paternalistic treatment is considered justified. However, Giordano (2005) presents a compelling argument that the presence of a mental disorder alone cannot deprive a person of their autonomy, as a diagnosis is merely a description of events. A person does not have symptoms because he or she has been diagnosed with a mental disorder. They are given a diagnosis because they are experiencing certain psychiatric symptoms. The presence of a diagnostic label does not mean that people suddenly lose the ability to make decisions that they previously could before this label was assigned to them. Therefore, unless there is reason to believe that individuals are acting non-autonomously, those with a diagnosis of a mental disorder should be treated in the same way as those with a diagnosis of a physical illness. That is, the individual with a mental disorder should be able to competently refuse treatment

when this refusal represents autonomous decision-making (Beauchamp & Childress, 2009; Giordano, 2005; Heal, 2012).

The presence of a mental disorder may become a threat to autonomy when it induces a state of mind that interferes with the individual's ability to form and follow a constant and cohesive life narrative (Bolton & Banner, 2012). To be able to make a decision on mental health care, individuals need to recognise that they are experiencing symptoms that are problematic and indicate the presence of a disorder. Without this, persons will not accept treatment, as they do not consider themselves to be ill (Holroyd, 2012). Autonomy can also be compromised if they understand the information provided, but refuse treatment based on the belief that they are not ill. This is not competent refusal as the decision is based on a false belief (Beauchamp & Childress, 2009). It is not a violation of autonomy to impose treatment on individuals to protect them from making decisions based on inappropriate knowledge or false beliefs, particularly when they pose a risk to the individual or others (Bolton & Banner, 2012; Giordano, 2005). In these cases, it is believed that unwanted treatment is protecting the autonomous self from the current disorder driven state (Bolton & Banner, 2012).

The autonomy of those with mental disorders can be compromised by the actions of others. Information relevant to the decision can be manipulated in order to alter the individuals understanding of the situation and encourage them to do what the influencing agent intends. Relevant facts can be withheld or exaggerated to alter persons understanding of a situation, motivating them to make the decision the influencing agent intends. Information can also be framed in either overly positive or negative terms, delivered in a tone of voice that implies a particular outcome is likely, or even stated as an out right lie (Beauchamp & Childress, 2009). Autonomy may also



be limited by the social stigma and exclusion that some people with mental illness may experience, leading to self doubt and a lack of confidence to follow through on autonomous choices (Bolton & Banner, 2012).

Autonomy needs to be considered alongside other ethical values. It may be justifiable to override autonomy in order to promote other values, or to promote autonomy in the long run (Lillehammer, 2012). Of particular importance in biomedical ethics are nonmaleficence and beneficence. Autonomy does not trump these principles, and all three should be given equal consideration in situations where they apply, especially if they clash in some way (Beauchamp & Childress, 2009).

Nonmaleficence is the obligation to avoid causing harm to others, either deliberately or inadvertently. Harm includes both physical harm and setbacks to individuals' interests by either inflicting harm or by putting them in situations where they are at risk of harm. There are instances when this obligation can be legitimately overridden. When an individual autonomously refuses treatment, the obligation to provide treatment does not apply. There is no obligation to provide treatment that is deemed to be futile and has an improbable likelihood of success due to a physicians inability to perform it, a slim chance of producing the desired physiological effect, a lack of efficacy for that treatment, the likelihood that it will only produce a low-grade or insignificant effect, or treatment that is untested. However, depending on what is at stake in a particular situation, it may be ethically justifiable to use methods lacking in conclusive scientific evidence to prevent harm. In cases of treatment futility, there is no requirement to treat simply because an individual autonomously wishes (chooses) to receive it. That is, the decision to withdraw futile treatment does not exclusively apply to situations where an individual is refusing it. There is also no obligation to

provide treatment where the burden outweighs the benefit, taking into consideration a person's suffering and quality of life (Beauchamp & Childress, 2009).

Beneficent actions are those that are intended to help another persons or promote their welfare. This includes protecting and defending the rights of others, preventing harm from occurring to others, removing conditions that will cause harm, and rescuing those in danger. This does not mean that we are required to perform all possible beneficent acts towards all people, which would be both impractical and impossible. Instead, we have a specific obligation to help those at significant risk, when we have the ability to prevent the harm in a way that has a high probability of success, while at the same time not placing ourselves at significant risk. There are also special relationships that require a higher obligation of beneficence. For example, those working in health care are obligated in that context to actively promote the welfare of their patients (Beauchamp & Childress, 2009). When carrying out beneficent actions, it is important to be aware of the preferences of the individual to ensure that the desire to prevent her or him from harm does not cross over into paternalism.

### **Values-Based Decision-Making**

Fulford, Peile and Carroll (2012) have developed a ten-step process for values-based decision-making, that they argue is capable of bridging ethical gaps that occur when the application of the ethical principles is unsuccessful. Ethical dilemmas arise in a situation when two or more of the prima facie obligations highlighted by Beauchamp and Childress (2009) come into conflict with each other. However, knowing the principles and recognising them as creating an ethical dilemma does not on its own lead to a resolution. While they can highlight issues to focus on from a clinical perspective, they do not show what issues are of most concern from the

client's perspective. The values-based decision-making framework is designed to assist clinical judgement when working with an individual, ensuring the final decision is a balanced one that takes both of these perspectives into account. Values are defined as positive or negative aspects of experience, persons or situations, that function as guides in decision-making. These values sit alongside other evidence individuals use to inform their decisions, and contribute to how much weight an individual assigns to the various sources of information.

The first four elements of values-based decision making are grouped together under a sub-heading of *clinical skills*. The first of these is an awareness of values, where all the different values regarding a particular decision are accurately identified. This includes the different values of practitioners within the clinical team, the individual client or patient, and friends, family and other supports. Each person involved should make her or his values clear, and appreciate the values held by others. The next element is closely linked. It is reasoning about values, and involves identifying which values are applicable to a given situation, and the impact they may have. The third element is knowledge about values. This element requires acknowledgement that, although research and experience can point to the values that may be important in a given situation, each individual is different and will present with different values. The final element is communication skills. Health based interactions between a medical professional and an individual often involve looking at what is wrong with a person. Instead, this process encourages professionals to look at what is going right for the person; his or her strengths, aspirations, and resources. This provides the context in which values are set, and how they relate to their relationships and lifestyle. As a whole, this first sub-set of elements is intended to allow for a

strong understanding of all the values that come in to play when making a decision, and how these fit into an individual's life.

The next sub-group is made up of two relationship centred elements. Both of these elements emphasise the two-way nature of the relationship between clinician and patient, where both share knowledge and values. The first is person-values-centred practice, which is based on mutual-respect. Instead of focusing on either "patient knows best" or "doctor knows best", both are seen as bringing their own expertise to the interaction. The patient brings his or her own values and experiential knowledge, while the doctor brings their evidence-based knowledge. Decisions are made collaboratively, balancing values and evidence according to the circumstances. The next element, the extended multi-disciplinary team, involves gathering diverse value perspectives from the multi-disciplinary team. From this perspective it is anticipated that the availability of multiple perspectives will increase the chance that a balanced and considered decision will eventually be made. Both of these elements are consistent with the practice of informed consent.

The next three elements come together as science-based principles. These are viewed by Fulford et al. (2012) as *red flags* that draw attention to areas that may be overlooked in the decision-making process. The two feet principle and the squeaky-wheel principle both remind us that any given situation needs to take into account *both* values and evidence. If a decision appears to be purely factually based, extra effort should be given to explore values. At the same time, if a situation seems particularly value laden, it is important to examine the relevant evidence. Finally, the science-driven element specifies that as scientific advancement increases, so should the inclusion of values to allow for the greater range of choices available to an individual.

The final subcategory, entitled partnership and disagreements, contains a single element that underpins the entire process. This element is *partnership in decision-making*, and stipulates that a primary aim of values based decision-making is not to reach a consensus, but rather to instead find a balance of values that fit in the given circumstance. Rather than excluding certain values, parties agree to disagree on some points. Following this process ensures a greater likelihood that the resulting decision is made on the basis of evidence and values, rather than in response to immediate symptoms or coercion.

Values-based decision-making is especially important in mental health where conditions are accompanied by a wide variety of values. As apposed to health, where there are generally accepted standards of what constitutes ill health, different people hold diverse values about what is considered ‘good’ and ‘bad’ with respect to their mental health. In mental disorders distress is caused by more than physical signs that something is wrong with a person and involves emotions, values, and other less tangible factors. As a result, values need to be considered in treatment decisions to ensure care is not based solely on clinical judgement and paternalism. Instead, values-based decision-making brings together science-based and person-centred treatment (Fulford & Van Staden, 2013).

### **Rationality and Decision Making**

Caution is warranted even when using the most robust decision making-models. Rogerson, Gottlieb, Handelsman, Knapp and Younggren (2011) point out that decision making models are developed with the assumption that those who are using them are making a purely rational decision, uncoloured by emotion or past experience. However, research has shown that, when given a hypothetical scenario involving health care decisions, clinicians will choose a different outcome when they

are the subject of the scenario than when they are making the decision for someone else: “decisions are not based on the objective state of the world but rather on our subjective experience of it” (p. 616). They have developed a list of factors that influence the way clinicians engage in a decision-making process involving patients. The first group of factors involve intuition and reasoning. Clinicians will look at previous similar decisions through the lens of hindsight, which can lead to inaction due to a desire to avoid repeating mistakes. Heuristics and biases can also influence how a situation is approached. For example, where thinking is biased by availability and representative heuristics, confirmation bias, the presence of negative and positive stereotypes, or when clinicians fail to recognise bias in themselves. There is also an affect heuristic, where a clinician will act on their emotions rather than more objective, evidence based factors.

The purpose of discussing research on decision-making in this chapter is to highlight potential factors that may unconsciously influence how practitioners approach important clinical decisions. Bringing these factors into awareness may help clinicians recognise them, and by doing so, increase the chances that such factors will not distort the ethical decision making process.

### **Conclusion**

The different perspectives on ethical clinical practice outlined in this chapter collectively provide a *conceptual tool kit* to guide the decision making process for professionals working in health care. The principles of autonomy, nonmaleficence and beneficence provide basic prima facie obligations to ensure individuals are provided with the opportunity to make their own decisions according to their own life plans, while also preventing harm and promoting welfare. Because the focus is on process rather than outcomes, the way an individual has come to a decision needs to

be explored to ensure that it is autonomous. The values-based decision-making model breaks down the thinking behind individual's decisions, complementing the 'big four' bioethics ethical principles. It also ties in with the cautions of Rogerson et al. (2011), concerning the requirement that clinician should understand their own values and ensure that these do not negatively impact the final outcome. The next chapter will review the literature to explore how these ethical principles are applied in the treatment of anorexia nervosa.

## CHAPTER 4 - ETHICAL PRINCIPLES APPLIED TO ANOREXIA NERVOSA

Now that the ethical principles have been defined and applied to the mental health field, the focus can shift to their application in the treatment of anorexia nervosa. The issues will be grouped into four categories: autonomy, competence, coercive treatment, and issues relating to severe and enduring eating disorders. Each of these will be covered individually.

Throughout this review, treatment that is provided to individuals with anorexia against their wishes will be referred to as “coerced”, “forced”, or “involuntary”. Each of these terms refers to actions or influence that persuade subjects to change their intended and desired courses of action. This can range from verbal pressure intended to influence the person’s decision-making process, to treatment that is physically imposed, such as forced hospitalisation and tube feeding.

### **Autonomy**

Various studies have supported the benefits of respecting autonomy in those diagnosed with anorexia nervosa, finding that it promotes both the intention to change, as well as facilitating the change process itself.

Nordbø et al. (2008) interviewed 18 individuals with a diagnosis of anorexia, at various stages of the illness (BMI ranging from 14.2 to 21.7; length of illness ranging from 2.5 to 25 years; treatment length ranging from 1 to 12 years) to discover what motivated them to recover. One of the four themes that emerged was a sense of autonomy. Participants cited that choosing to recover without the pressure from others gave them the responsibility of being persons who are in control of their own life. It gave them feelings of strength, will power, and mastery, with a right to control their own lives.



Vandereycken and Vansteenkiste (2009) compared 87 individuals diagnosed with anorexia nervosa treated in a low autonomy treatment programme with 87 individuals treated in a treatment programme that optimised choice and autonomy. In the low autonomy programme, staff made treatment decisions, and families were asked to put pressure on individuals to seek and stay in treatment using guilt relating to the emotional burden the illness placed on the family. If they refused to comply with treatment, they were required to sign a document stating they were refusing treatment against medical advice. In the autonomous programme, family were asked not to engage in battles around treatment, and the individuals were free to continue to engaging in anorexic behaviour (restriction of caloric intake, laxative use, purging) while in a five-day trial to decide if they would like to take part in the programme. If individuals decided to commit to inpatient treatment, they were required to adhere to a minimum weight and stop compensatory behaviour. If they felt the programme was too difficult, they were able to leave in the first four-months, even if this went against family wishes, with an open invitation to return to treatment at any point in the future should they wish to fully engage. The study found that there was a significantly higher dropout rate between those in the coercive treatment programme (higher) and those in the less restrictive one. It was also found, although only anecdotally, that individuals who dropped out from the less restrictive programme were *more* likely to return to treatment at a later stage than those who dropped out from the more coercive programme. The outcomes for those who continued in either treatment programme were the same in terms of weight gain. These findings suggest that providing opportunities for those requiring treatment for anorexia nervosa with autonomy around how, if and when to engage in treatment increased the chances that they will do so, without compromising outcomes.

On a similar note, a small study by Darcy et al. (2010) found that treatment that increased autonomy led to better outcomes post-treatment. Twenty-four women with a history of anorexia nervosa completed a variety of qualitative and quantitative measures of their eating disorder symptoms and reasons for engaging in treatment. They found that having more autonomy in treatment decisions was positively associated to scoring within one standard deviation of a normal population on a measure of eating disorder symptoms following treatment.

Collectively these studies support the importance of autonomy in increasing positive treatment decisions, reducing treatment dropout, and increasing treatment compliance. This suggests that autonomy has importance not only as an ethical right, but also as a positive enhancement to the treatment of anorexia nervosa. It has practical utility as well as ethical import. Despite this, respect for autonomy is inconsistently applied in the treatment of anorexia due to uncertainty over the presence of it in those with the disorder.

As stated earlier, autonomous actions are those that are based on an understanding and application of all relevant information pertaining to a given situation. Individuals with anorexia have been shown to have an excellent grasp of their nutritional needs and the impact starvation can have on a person (Tan, Stewart, Fitzpatrick, & Hope, 2006). However, they do not believe that these rules of nutrition apply to them, and in fact use their knowledge to further restrict their diet (Holroyd, 2012). They also display a range of thinking errors that adversely impact on their ability to make autonomous decisions. Their thinking becomes “black and white” and overgeneralised, as evident in beliefs such as “I was happy when I was thin and am unhappy now that I am fat”. Small weight gain is exaggerated in magnitude, and decision-making is based around maintaining a low weight without taking into

account the impact this will have on other aspects of their life (Giordano, 2005). Because their decisions and actions are based on these distortions that represent false beliefs, they are arguably not autonomous (Giordano, 2005).

Although there is no requirement for an autonomous decision to be rational or in agreement with professional recommendations (Lillehammer, 2012), it does need to appropriately weigh all the information equally without overvaluing some aspects over others (Holroyd, 2012). A primary value evident in individuals diagnosed with anorexia is the importance of achieving a low weight, reflected in the diagnostic importance of deliberate weight loss (Giordano, 2005). Tan et al. (2006) interviewed 10 women with a diagnosis of anorexia nervosa about their values in relation to their eating disorder. The women reported that their values changed as a result of having the disorder, saying that they felt gaining weight was a reflection of laziness and a lack of self-control, which made them unlovable failures. Being thin was valued over family, friends, health, and academic achievement. It was so highly valued that it decreased the motivation to recover. Giordano (2005) has elaborated on this finding, arguing that body fat symbolises laziness, indulgence, and lack of will power, self-control, and self-respect. This judgement is a negative judgement on the value of the person. They value thinness highly, and judge that they lack value if unable to attain the ideal of thinness. Food restriction indicates discipline and control. Fasting is seen as detoxing the system; so being empty of food is being clean. In the case of anorexia nervosa, it is argued that individuals place more value on maintaining a low weight than protecting their physical health, even risking death (Holroyd, 2012). This would suggest that they are not making autonomous decisions when rejecting treatment. This is then used as justification for violating individuals' autonomy and imposing

unwanted treatment on them (Holroyd, 2012). However, violating autonomy based only on the content of values may not be justification enough.

The argument that undervaluing life is an indicator in itself that autonomy is absent is not convincing when we consider that there are other situations where a person refuses potentially life saving health interventions that we do not question. A clear case of this is when a Jehovah's Witness refuses a blood transfusion because they value religious doctrine more than preserving their life. This suggests that undervaluing death in general is not enough justification for overriding autonomy, as many people see religious values as equally distorted as weight based values, yet one is accepted while the other is not. There must then be more to values than their basis that leads them to distort individual thinking patterns in a way that removes - or significantly erodes - decision-making ability (Holroyd, 2010).

So how do we decide if a value is autonomous and should be respected, or if it is illness driven and should be overridden? Tan et al. (2006) has suggested that a value that comes about as a *result of the illness* adversely affects the ability to make an autonomous decision, because it is derived from (or may even be partly constitutive of) the disorder rather than the individual. If a value is exerting an influence on treatment decisions, it should be tracked back to its origin, and only be given priority if it predates the illness. This allows us to look at the process used to make the decision when judging autonomy, rather than on the outcome of the process. This is similar to the idea put forward by Heal (2012), who stated that a decision made by an individual who is currently experiencing a mental disorder can be seen to be autonomous if the chosen action represents a continuation of that person's life story, linking actions across time. It also means that an individual can hold values that

deviate from the norm without immediately being seen as dysfunctional and lacking in autonomy.

## **Competence**

As already outlined, the fact that individuals *have a mental disorder* does not automatically mean they are unable to make reasonable decisions about treatment, unless they are found to lack the competence to do so.

To make a competent decision individuals need to possess the ability to understand relevant information and apply it to their own situation, appreciate the likely consequences of the chosen outcome, rationally weigh up the costs and benefits associated with the various outcomes, and be able to communicate their choice to others. As with autonomy, competence is task specific and independent of outcome (Appelbaum & Grisso, 1995). Determining competence in individuals with anorexia nervosa poses some difficulty, as they appear to be globally competent while at the same time lacking competence in specific areas. This is seen in the discrepancy between their deep understanding of anorexia nervosa, and their ability or willingness to apply such knowledge to themselves. Such individuals can be very knowledgeable about what constitutes a healthy diet and how many calories a person needs in a day to remain healthy. Furthermore, they appear to have good understanding of the facts and risks of their disorder, however, they do not believe that these facts apply to them. In their mind, they are different from others, and do not require the same caloric intake to maintain their health. As a result, they do not feel they would benefit from treatment because they do not believe that they have a disorder that requires it (*DSM-5*, 2013; Matussek & Wright, 2010, Tan, Hope, Stewart & Fitzpatrick, 2003; Tan et al., 2006).

Illustrating the above difficulty, a standard measure of competence, the MacArthur Competence Assessment Tool - Treatment (MacCAT-T) test, was administered to 10 women with anorexia. All participants were found to have excellent understanding of their disorder, its consequences, and the treatment being offered. MacCAT-T scores reflected this, with performance on par with that of a healthy and competent population (Tan et al., 2006). However, interviews showed that although they understood their disorder, most did not believe that they were ill, and valued low body weight over family, friends, health and academic achievement. For some, being thin was important enough to risk death pursuing it.

It is frequently stated in literature that individuals with anorexia nervosa are compromised in their ability to make competent decisions as a result of the physical impact of their disorder. It is believed that when a person is 75% below their ideal body weight they lack the ability to reason rationally and weigh up information (Matussek & Wright, 2010). Cognitive deficits resulting from anorexia are thought to impair a person's ability to make realistic judgements related to their need for treatment (Werth et al., 2003). Malnutrition and starvation are believed to impair cerebral functioning, cognition, judgement and insight (Richmond, 2001). However, research into the cognitive functioning of individuals with anorexia nervosa has struggled to support these beliefs.

This lack of consensus is reflected in the literature on neuropsychological impairment in the cognitive functioning of those with anorexia nervosa (Zakzanis, Campbell & Polsinelli, 2010). A meta-analysis of the magnitude of cognitive impairment of individuals diagnosed with anorexia nervosa found that there were some deficits in verbal recall and working memory, concluding that learning tasks may need to be more repetitive to ensure information is retained (Zakzanis et al.,

2010). This is a difficulty that can be overcome through the provision of information in a way that compensates for these deficits. Thus, it should not necessarily result in a judgement that the individual concerned lacks the competence to *make decisions* about treatment (i.e., treatment refusal).

The belief that low body weight adversely affects the ability to make competent decisions by those with anorexia is also challenged by available research. A small study compared individuals diagnosed with anorexia nervosa ( $n = 32$ ) to matched healthy controls ( $n = 26$ ) on a variety of neuropsychological measures, as well as examining medical markers of malnutrition in those with anorexia. Medical testing found that although individuals with anorexia had lower than optimal blood results, actual malnourishment was infrequently found. Despite exhibiting nutritional levels that were less than what was believed to be required for maximising cognitive performance, this study found that there were few differences between the two groups on cognitive ability, suggesting that there is little evidence of a relationship between biochemical indications or poor health and cognitive performance (Mathias & Kent, 1998).

It has been hypothesised that the rigidity characteristic of individuals with anorexia nervosa results in poor decision making abilities, which should be evident in poor set-shifting (the ability to switch between tasks and mental states). Danner et al. (2012), however, found that there was no significant difference between set-shifting performances in individuals with anorexia nervosa compared to a control group, indicating that cognitive rigidity does not interfere with decision-making ability.

Other than these specific findings, it is unclear what impact anorexia nervosa has on cognitive functioning. It is unknown how large a role comorbid conditions, such as depression, anxiety and personality disorders play in levels of impairment, or

the exact nature of impairment caused by very low weight. It is also worth noting that many studies of competence use tests that are only loosely related to the skills needed to make a competent decision, such as standard IQ measures; such measures tap different skills than those required to make a competent decision (Appelbaum & Grisso, 1995).

Two final points are worth highlighting before closing the discussion on competent decision-making ability in individuals diagnosed with anorexia nervosa. First, the NICE guidelines state that only “a small number of patients with anorexia nervosa do not have the capacity to make decisions about their own health and safety” (NICE, 2004, p. 80). Secondly, a large-scale project on competence in the treatment of mental disorder, the MacArthur Treatment Competence Study, found that individuals who were unable to understand information presented to them initially, were subsequently able to understand it when it was presented a second time part by part (element disclosure). This is important to keep in mind whenever competence is in question, as those who may initially appear to lack competence may in fact be competent when information is re-presented (Appelbaum & Grisso, 1995a). These points are an important reminder that competence is not necessarily absent, and that it may be something that can be returned easily or compensated for. A comprehensive assessment of the individual is always required to establish competence.

### **Coercive Treatment**

An autonomous decision is one that is made free from coercion; however, coercion is a frequent feature in the treatment of anorexia nervosa (MacDonald, 2002). There are a variety of coercive techniques used in the treatment of anorexia cited in the literature. Many involve dietary controls; nasogastric feeding, enforced nutritional replacements, supplementary feeding, restriction of food related rituals,



removal of diet pills, and measuring food and calories consumed. Behavioural techniques include surveillance at meals and in the bathroom, bed rest, exercise restriction, and behavioural contracts. Other types of coercion are the use of medication that aids in weight gain, restriction of visits and activities contingent on treatment progress, and legal coercion such as involuntary hospitalisation (Matusek & Wright, 2010). Coercion exists on a continuum, from informal pressure to get help from friends and family, to legal and formal coercion by the mental health system (Rathner, 1998). Views on the appropriateness of coercion range from the belief that it is required to return a person to a weight that allows therapy to be meaningful, to those who see it as meaningless at best, and counterproductive at worst (Giordano, 2005; Matusek & Wright, 2010).

Clinicians who support the use of coercive treatment justify it by highlighting the need to protect an individual's well being by restoring weight, which will reduce symptoms, increase mood, and preserve their life (NICE, 2004). Others have stated that the imposition of a structured environment and close monitoring are needed to break the dysfunctional eating and diet related habits associated with individuals diagnosed with anorexia nervosa in order to create new, healthy habits (Matusek & Wright, 2010). It is also reported that, for some individuals, involuntary treatment provides independent validation that they have a serious illness, and this gives them "permission" to eat. For others, it is hypothesised that while their thinking may not change in terms of their beliefs about their illness, stringent interventions can at least restore physical health so that they are in a position to further engage in treatment (Carney et al., 2006).

Restoring autonomy is seen by some health professionals as a valid reason to impose unwanted treatment, returning individual to a state in which they are then able

to make their own treatment decisions (Richmond, 2001; Touyz & Carney, 2010). Others go further, stating that restoring autonomy is the only reason to coerce treatment in an individual who is not currently autonomous (Sjöstrand & Helgesson, 2008). This assumes that treatment will return autonomy, and that we know what the individual would want if they were in a position to make an autonomous decision. However, knowing what decision to make for another person is not simple. Research has found that an individual's wish when looking hypothetically at having an illness differs radically from the wishes of those who actually have the illness (Sjöstrand & Helgesson, 2008). It may be the case that autonomy is violated by the very act designed to return the person to that state.

Similar to the argument that autonomy can be restored through treatment is the justification of treatment based on a belief that individuals will give retrospective consent once they return to health (Carney et al., 2006; Touyz & Carney, 2010). That is, treatment is initially provided against individuals express wishes, however, when the treatment begins to take effect, they are expected to agree with the need for it and endorse its initial use against their will. This is problematic for two reasons. First, it is based on the assumption that the person will eventually be grateful for their treatment. Second, there is no guarantee that treatment for anorexia nervosa will be successful due to the weak evidence base for this area of mental health care (outlined in more detail below). Research by Gardner & Lidz (2001) found that even in those who later agreed that their involuntarily psychiatric treatment was justified and necessary, very few were then grateful. In fact, individuals who felt coerced at initial admission felt the same way at follow-up. As several authors have pointed out, you cannot forcibly place persons in a treatment setting and make them cooperate. In the end, it is up to

individuals to decide to engage in treatment and allow others to help them; it is never guaranteed (Matusek & Wright, 2010; Rathner, 1998).

A number of factors make it more likely that an individual with anorexia nervosa will be forced against their will into hospital-based treatment. Number of previous hospitalisations, low BMI, the presence of comorbid medical and psychological conditions, and a history of developing refeeding syndrome contribute significantly to the decision to hospitalise an individual against their will. Those with a BMI of 12 or less have been found to require more invasive forms of involuntary treatment when admitted to hospital than those with a BMI of 14 or greater. In fact, for every BMI point a person drops, the odds that they will be coerced into treatment increases (Carney et al., 2008; Matusek & Wright, 2010; Touyz & Carney, 2010). An Australian study into the outcome of hospital admissions for those treated involuntarily found that by discharge, little weight gain had been achieved, indicating that admission was for life preservation rather than significant weight gain (Carney et al., 2006). A survey on psychiatrists in the United Kingdom by Tan et al. (2008) found that 72% of psychiatrists working in a variety of mental health settings felt that treatment refusal by those with anorexia was not a true reflection of the individuals wishes. However, despite this, the decision to treat involuntarily was most often made when a person was at greater risk from the severity of their illness, rather than because a person was not believed to be competent to make treatment decisions, making it a health and safety based decision.

Those who argue against the use of coercion point to the negative impact it may have on autonomy, relationships, and long-term well-being. Autonomy is important to people with anorexia, and overriding personal choice by forcing unwanted treatment, risks making individuals worse by compromising the therapeutic

relationship and potentially making them more resolved to persist in their problematic behaviour (Giordano, 2005; Matusek & Wright, 2010).

A problem with such arguments is that they are based on ideals that, while commendable for their focus on the importance of therapeutic relationships and long-term individual well-being, are not supported by evidence. For example, it is frequently stated that using coercive treatment for those with anorexia will damage the therapeutic alliance through a violation of trust, making the individual less likely to seek help in the future (Matusek & Wright, 2010; Richmond, 2001; Tan et al., 2003). However, there is currently little evidence to support this belief. In a recent study, Sheehan and Burns (2011) found that although psychiatric inpatients admitted under coercive conditions reported a poor therapeutic relationship, the conclusions that could be made from this were unclear. Individuals were asked to rate their relationship with the clinician they felt was most responsible for their admission. This was not necessarily be their primary clinician, and also does not take into account other sources of coercion, such as pressure from other members of the care team, and from family and friends. It was also unclear if feeling coerced led to a bad evaluation of the relationship, or if a bad therapeutic relationship existed prior to the admission.

Studies looking at the use of coercion from the client's perspective have also found that it is not the use of coercion per se that is a problem for clients, but how it is implemented. Carney et al. (2006) reported that it was the more subtle informal coercion that individuals with anorexia criticised rather than legal coercion. For example, being told to either voluntarily enter into treatment or be subjected to legal coercion, having their possessions removed and their return contingent on progress in treatment, and having decisions made about them without their involvement. Individuals in a study by Tan et al. (2003) stated that the more people tried to take

control away from them, the stronger the illness became. Instead of fighting the illness, they were fighting the treatment team. Conversely, being given some choice in the type of treatment they received helped to motivate individuals to engage in treatment, and work with the treatment team to fight the eating disorder. Participants, however, did acknowledge that there were times when control needed to be taken from them in the very early stages of acute treatment if they were at risk of dying, but that this should be returned when out of the danger zone. These individual perspectives are consistent with best practice for involuntary treatment, which should be for the shortest time possible, in the least restrictive environment (Touyz & Carney, 2010). It should also be discontinued if the individual engages in treatment (Giordano, 2005; Rathner, 1998).

Another example of a reason for avoiding coercion that is not backed up by evidence is the widely cited belief that individuals with severe anorexia nervosa forced into unwanted treatment have a higher rate of suicide as a result. A study by Ramsay, Ward, Treasure and Russell (1999) found that although the rate of suicide was greater at follow-up for a group of involuntary compared to voluntary patients, this was as a result of treatment refusal and intractable illness, rather than due to a damaged therapeutic alliance. This finding was supported by Franko et al. (2004), who discovered that increased suicide risk in those with anorexia was due to the presence of psychological symptoms such as depression and substance abuse.

Some claims over the necessity of coercion in treating anorexia are ethically questionable. A study of 139 people admitted voluntarily to hospital for anorexia nervosa looked at perceptions of coercion at the time of admission compared to 2 weeks later. At follow up, half of those who had not endorsed the hospitalisation at admission had changed their mind and acknowledged the necessity of it. However,

the perception of coercion did not change between the two time points (Guarda et al., 2007). The authors concluded that this later endorsement of the need for hospitalisation illustrates that coercion is a necessary part of treatment for anorexia, with an outcome that is superior to voluntary treatment. This is an interesting interpretation considering all of the participants in this group were voluntary patients so did not require any coercion. It is also difficult to see how coerced treatment in those who are already willing to engage is going to be more effective, especially considering evidence suggesting there is little difference between treatment that is provided voluntarily compared to that which is involuntary (NICE, 2004). Similarly dubious, Watson, Bowers & Andersen (2000) support the use of involuntary treatment for individuals with anorexia based on the finding that, of 66 patients admitted involuntarily to an inpatient eating disorder facility over a 7-year period, no legal or official complaints were made regarding the inappropriateness of the admission or treatment.

When an individual is at a critically low weight and treatment is required as a life saving measure due to a very real risk of death, coercion is generally a less contentious issue than it is with individuals who are experiencing symptoms that may lead to death, but who are currently in no immediate danger (Carney et al., 2006). In general, coercion is used in the treatment of mental disorders when someone is a risk to themselves or others, and it is believed that providing treatment will reduce this risk. Because violence is rare in people with a mental disorder, the main reason for coercion is to protect individuals from the harm they pose to their own health and safety. However, if a person is making autonomous choices, risk to the self is not enough to justify coercive treatment. If it were, then the use of coercion would also apply to individuals who refuse treatment for physical health problems that may result

in deterioration or even death (Sjöstrand & Helgesson, 2008). In the case of anorexia nervosa, it is ethically difficult to justify unwanted, autonomously refused treatment in individuals who, while existing at suboptimal levels of health, are not at any immediate risk of death. Carney et al. (2006) suggest that coercion should be restricted to the times it is required as a life-saving intervention, and should exist on a sliding scale, where less certainty in outcomes justify only small amounts of coercion, with greater certainty in treatment outcomes allowing for greater levels of coercion. This is the same principle Beauchamp and Childress (2009) advocate when judging if individuals are competent: the higher the risk to persons autonomy should they be deemed incompetent, the greater the evidence required to decide on competence.

### **Treatment Evidence Base**

Although there is an obligation in healthcare to promote an individual's welfare, the actions performed should also have a high probability of preventing harm (Beauchamp & Childress, 2009). However, a successful outcome is not guaranteed in anorexia nervosa, with up to 25% of those with the illness developing a chronic course or dying (NICE, 2004), and a lack of evidence for effective treatments.

NICE (2004) has evaluated the evidence base for the treatment of adults with anorexia and given it a C-grade, meaning that directly applicable studies of good quality are absent or not readily available. It is noted that the body of research is small and methodology is inconsistent, and only limited conclusions can be drawn due to a lack of follow-up data and statistical power. Most studies are 6-12 week trials, assessing only short-term treatment effects. Many are unclear about characterising the illness stage at which individuals began treatment. Most studies only looked at the efficacy of the treatment on the eating disorder and not other comorbid conditions (APA, 2000; NICE, 2004). Research is hampered by the fact that anorexia nervosa is

a low prevalence illness, limiting the number of potential subjects, compounded by individuals lack of awareness of the need for treatment which makes them unlikely to participate in research. Attrition rates from research are high, there is no clear consensus on what constitutes different stages of illness and recovery, and sample sizes are generally small (on average  $n = 23$ ) and based on mostly single site studies (Bulik, Berkman, Brownley, Sedway & Lohr, 2007; Le Grange & Lock, 2005). As a result, there is no uniform approach to the psychological treatment or management of anorexia nervosa in adults in terms of what should be offered, intensity, duration, or treatment setting (APA, 2000; NICE, 2004).

Many adults with anorexia nervosa struggle to gain weight outside a hospital setting (Keel & McCormick, 2010), yet evidence for restrictive, hospital-based treatment has failed to find any long-term advantage to hospitalisation when treating anorexia except as a short-term life-saving intervention for high-risk patients (NICE, 2004; Carney et al., 2006). Further, individuals admitted to hospital for treatment have lower remission rates than those who are treated outside of a hospital setting (DSM-5, 2013). Of course, this may indicate that hospitalised individuals have more severe forms of the illness.

Treasure, Crane, McKnight, Buchanan and Wolfe (2011) looked at how treatment may maintain anorexia nervosa, and found four domains of treatment that had the potential to do so. The first domain was interpersonal factors, specifically a tendency for treatment to be overprotective. This provides the individual with little opportunity to practice new skills outside of the treatment setting, which makes it less likely that any changes will be maintained at discharge. A second domain pertains to the type of treatment setting. Inpatient settings specifically for people with eating disorders can result in individuals learning new skills from other patients that will



help them to become a “better” anorexic. It also serves to segregate those with anorexia nervosa from others, leaving them in a setting where they need to maintain their illness in order to fit in with their current social circle. This can provide ongoing pressure to hold on to at least some aspects of the illness. Another aspect of this domain identified in the study was treatment that supported pro-anorexia beliefs. The authors suggested that treatment that used coercive feeding practices could enhance a fear of food, strengthening food avoidance. A third domain was therapeutic conditions that maintained high levels of emotional avoidance and anxiety, keeping away from topics that may increase these emotions, such as food intake or weight gain, meaning nutritional issues are never addressed. The final domain was treatment that reinforced the rigid behaviour and thinking styles characteristic of the illness through a highly structured routine in inpatient settings. These types of settings left individuals unprepared for the unpredictable and unstructured environment they would face when back in the everyday world, making it less likely that treatment gains would be maintained at discharge.

Looking at the current literature on the evidence base for effective treatment for individuals with anorexia nervosa, it seems that the argument to accept treatment refusal is ethically strengthened in some cases by the lack of certainty of achieving a successful outcome. However Beauchamp and Childress (2009) state that, while the obligation to treat may be terminated if treatment is unlikely to be successful, they also feel that it may be ethically justifiable to take steps to prevent harm “in the absence of conclusive scientific evidence, to avoid hazard where the harm is both serious and irreversible” (p. 229). For the 5% that are predicted to die from the disorder, the hazard is certainly irreversible.

## **Severe and Enduring Eating Disorders**

As already mentioned, roughly 20% of individuals with anorexia exhibit a chronic form of the disorder (NICE, 2004). Members of this group are considered to have severe and enduring eating disorders (SEED), of at least 10-years continuous duration or with a course requiring repeated and prolonged hospitalisation for life-threatening clinical problems (Robinson, 2009). The physiological risk evident in individuals with SEED are the same as those seen in more acute eating disorders, however, the symptoms pose a greater risk as they have been present for a longer duration, leading to an increasingly fragile physical state and a greater risk of death (Robinson, 2009, Strober, 2010). As with other individuals with anorexia, those who have a long-term chronic course deny that they are sick, yet also understand how the illness has reduced their quality of life (Strober, 2010).

There is no consensus on how to approach individuals who have a long-term history of anorexia nervosa that has not responded to repeated treatment (Strober, 2010). The current recommendation is to focus on improving quality of life for the individuals concerned and maintaining a stable weight, rather than seeking a full recovery (NICE, 2004). Many people with anorexia manage to live a relatively productive and satisfactory life despite their condition, and, arguably, their quality of life would be diminished if they were forced into treatment that had a full recovery focus (Fedyszyn & Sullivan, 2007).

A small minority of individuals with SEED make a decision to refuse treatment for their disorder because they feel treatment is no longer of benefit to them, and that the associated side effects are potentially worse than living with the disorder (Giordano, 2005). Although the anorexic behaviour may not be autonomous, the decision to refuse further treatment can be, if it is based on quality of life rather than

fear of treatment (Giordano, 2005). It is an individual's right to make decisions that may pose real risk as long as the process used to make these decisions meets the criteria for competence and autonomy (see above). Respecting the right of individuals to make this decision is in line with the principles of non-maleficence and beneficence, where the obligation to treat is overridden if the treatment is more likely to cause a burden than a benefit taking into account the pain and suffering of the individual concerned (Beauchamp & Childress, 2009). If the chances of a successful, even partial recovery are futile, respecting treatment refusal may actually be the most compassionate and ethical course of action. Beauchamp and Childress (2009) define medically futile treatment as that where the chance of a successful outcome is improbable, and the costs of continuing with the treatment far outweigh the benefits. In these cases, it is acceptable for a patient to refuse medical treatment, even if this is likely to result in their death, provided they are making a valid and autonomous decision.

Quantitatively, medical futility is considered to be present when there is less than a 5% chance of recovery (Beauchamp & Childress, 2009). In general medical care, individuals who have suffered a long duration of illness, repeated treatment failure, have a poor quality of life and are competent to make decisions on their treatment, often decide to refuse further treatment. This is especially the case if the outcomes are likely to be unsuccessful and impose great burdens on the persons concerned. This possibility is generally not considered in psychiatry because in most cases chronic conditions can be effectively managed and/or reversed. However, cases of chronic anorexia nervosa may meet the criteria to be considered futile. A longer duration of illness, greater number of hospitalisations, low psychological functioning,

comorbid psychiatric conditions, and purging through vomiting and laxatives, all result in significantly lower chances of recovery (Lopez, Yager & Feinstein, 2010).

Understandably, it is difficult to accept this type of decision, and frequently the argument against doing so is that the patient's decision is not rational, and therefore not competent. However Gans and Gunn (2003) have formulated a few questions that help to bring the decision into perspective: is it irrational to refuse treatment that is more of a burden than the illness itself? Is it irrational to refuse treatment that will not be of benefit to an individual? Is it irrational to refuse treatment that will reduce quality of life?

When a chronic case of anorexia nervosa limits any possible recovery for that individual, a *palliative* approach has been suggested as appropriate in order to prevent the disorder from getting worse, or to reduce the chances of the disorder resulting in the individual's death (Strober, 2010). Palliative care *does not* mean the withdrawal of all treatment, but rather stipulates that aggressive treatment should be withdrawn unless the individual chooses otherwise. Instead supportive treatment is offered, aimed at symptom control and improving psychological wellbeing (Lopez et al., 2010), and improved functioning (Strober, 2010).

Draper (2000) has set the following criteria for allowing an individual with anorexia nervosa to withdraw from treatment: those who have been unwell for longer than the natural cycle of the illness (more than 8 years), those who have unsuccessfully been forced into treatment previously, those with insight into the impact the illness is having on their life, and those who are not currently at risk of imminent death. Alongside this is the requirement that the individual is able to make an autonomous decision. The final decision is not based on the medical view that the individual would be better off if treatment were withdrawn, but rather is based on

what the individual believes to be best for them (similar recommendations have been proposed by Gans & Gunn, 2003).

Because anorexia nervosa can be effectively treated (i.e., resulting in a complete and permanent removal of symptoms), some clinicians have argued that it should be treated exclusively with a curative approach (Fedyszyn & Sullivan, 2007). This has led to reluctance to consider treatment alternatives that do not have full recovery as the ultimate goal and outcome. The decision to treat a patient is based on the presupposition that the quality of life of an individual following the implementation of therapy will be greater than before. Using any life-prolonging measure rests on the judgement that it will improve the quality of life of the recipient (Beauchamp & Childress, 2009). For individuals with SEED, the disorder and associated behaviours may be so long standing and deep rooted that changing the person's habits may not be possible, and instead the focus should arguably be on improved functioning rather than full recovery (Strober, 2010). An acceptance of this ethical argument is needed in order for research to move forward on alternative treatments and end of life options for this subgroup of individuals suffering from anorexia nervosa.

### **Conclusion**

Although there are still many uncertainties in the treatment of anorexia nervosa, it is clear at least some individuals with the disorder are capable of making autonomous decisions about their treatment options. If the presence of autonomy is the key criteria in the ability to make treatment decisions, the decisions of such (autonomous) individuals should be respected. The question that flows from this position is: how do we determine if an individual with anorexia nervosa is autonomous? This is a difficult task as an individual with this disorder can present as

competent in some respects while lacking this ability in relation to other specific tasks. To further muddy the waters, autonomy needs to be considered alongside nonmalificence and beneficence. Again, establishing where these obligations fit is difficult when there is no consensus on the impact treatment will have on the course of the disorder. The following chapter outlines a proposed model for working with individuals with anorexia to establish if their decisions are autonomous, and that specifies what actions should be taken for the different potential outcomes if they are.

## CHAPTER 5 - ANOREXIA NERVOSA DECISION MAKING MODEL

The literature reviewed thus far has illustrated that most individuals with anorexia nervosa maintain the ability to make decisions relating to treatment. The conclusion from this review is that, if we are following ethical best practice, we should respect decisions refusing treatment that are made autonomously. Establishing the presence of autonomy in individuals with anorexia can be difficult. Because treatment refusal is a characteristic of the disorder, it cannot simply be assumed that these refusals should be respected. Further information is required on the process the individual is using when arriving at treatment decisions to establish whether or not autonomy is present. The aim of this chapter is to describe a set of guidelines that will assist in this process. First, the proposed decision making model, the ANDMM, will be outlined, followed by a discussion of further considerations, possible outcomes, and how to work with the different outcomes.

### **Decision Making Model**

The proposed model is the anorexia nervosa decision-making model (ANDMM), and is summarised in table 1. The ANDMM incorporates a number of ethical ideas and practices from the bioethics and broader ethical domains. When applied to particular cases the ANDMM can ensure that a thorough assessment of an individual's autonomy is conducted. Such an assessment is structured around the three stages of the shared decision making model (SDM) formulated by Elwyn et al. (2012). In the SDM individuals are introduced to their choices, options are described, and they are supported in the process of exploring their preferences in order to make a decision. The SDM has been selected due to its consistency with the principle of autonomy, particularly collaborative autonomy, where shared information supports an individual to make meaningful decisions (Widdershoven & Abma, 2012). The SDM

has been found to result in decisions that are better understood by the patient in terms of positive and negative consequences, and more conservative treatment decisions.

Table 1

*Anorexia Nervosa Decision Making Model (ANDMM)*

Stage	Task
Choice talk	Consulting the multidisciplinary team
Option talk	Informed choice
	Element disclosure
	Weighing costs and benefits of each outcome
Decision talk	Identify values
	Identify how values are being used
	Provide time for decision making
	Consider autonomy, treatment outcome, risk, quality of life

Autonomy is a key feature of the ANDMM, as literature has shown that for individuals with anorexia nervosa, autonomy is associated with positive treatment decisions, reduced dropout, and increased treatment compliance (Darcy et al., 2010; Nordbø et al., 2008; Touyz & Carney, 2010; Vandereycken & Vansteenkiste, 2009). This is not to suggest that the purpose of the shared decision-making process is to persuade those with anorexia nervosa to engage in treatment. Rather, the process is intended to ensure individuals are making autonomous treatment decisions that result in their desired outcome with reduced likelihood of paternalism.

The three stages of the SDM are referred to as *choice talk*, *option talk*, and *decision talk*. In the integrated decision making model developed in this thesis, these



three stages remain but are made more robust by adding conceptual elements identified in the ethical literature as important for making autonomous decisions. Informed consent, as discussed by Beauchamp and Childress (2009) is an important factor, as an individual needs all relevant available information to make a truly autonomous decision. Aspects of values based decision making (Fulford et al., 2012) are also included, as a shared understanding of the different values an individual brings to the decision making process places highlights the process individuals are engaging in when making decisions. The values based decision making perspective also allows clinicians to understand their own values when assisting patients in the decision making process, ensuring these do not inappropriately influence the outcome. Health based interactions between a medical professional and an individual often involve examining what is *wrong* with a person. Instead, this process encourages professionals to look at what is going right for the person; their strengths, aspirations and resources. It allows for a view of the context in which values are set, and an understanding of how they relate to relationships and lifestyles (Fulford et al., 2012). If decision-making has followed this process, it is more likely that it is one that has been made on the basis of evidence and values, and is thus more likely to be autonomous.

I will now describe each phase of the ANDMM.

### **Choice Talk**

The first stage of the ANDMM is referred to as *choice talk*, and involves making sure individuals know that they have options, that these options differ from each other, and each leads to a different outcome. In the case of eating disorders, the options are total treatment compliance, partial treatment compliance, non-autonomous treatment refusal, and autonomous treatment refusal. The aim at this stage in the

decision making process is to show individuals that it is a collaborative decision making process, and that their ideas on the final outcome are important. It also raises their awareness to all options available to them, preparing them for the next stage, when these options will be discussed in more depth.

To gain a variety of perspectives and maximise the options that can be provided to the individual, a values based decision making perspective recommends discussing individual cases with a multi-disciplinary team. Having multiple perspectives available increases the chances that a balanced and considered decision will eventually be made (Fulford et al., 2012). In the case of individuals with anorexia nervosa, there are often a wide variety of professionals involved, particularly for those who have had the illness for many years. General practitioners, community nurses, psychiatrists, psychologists, psychotherapists, social workers, and occupational therapists involved in both cases and the treatment of eating disorders in general should be all consulted in order to acquire a variety of perspectives and interventions options to present to patients.

Hopefully, the presentation of a range of possibilities and viewpoints will encourage individuals to begin to consider the options available to them; which is the second stage, referred to as option talk.

### **Option Talk**

*Option talk* involves exploring a variety of options available in practical terms, looking at the costs and benefits of each, ascertaining whether they are similar or different (and in what ways), and deciding which options will have reversible outcomes, and which will not (Elwyn et al., 2012). This stage requires that health care professionals are fully informed about the evidence base for eating disorder treatment so that they can present this information to individuals, in order for them to make an

informed choice. This data is likely to include the provision of relevant facts and information related to the refusal of or consent to treatment, professional recommendations, and the limits and nature of the consent being sought (Beauchamp & Childress, 2009).

It is through the provision of information that health professionals are able to significantly foster autonomy in individuals with eating disorders. If a decision is important, such as whether to engage in treatment for an eating disorder, care professionals should support people in making these decisions in a way that goes beyond the mere provision of the information required. As well as setting out the various different options they should help persons understand the consequences of each option. Widdershoven and Abma (2012) have developed set guidelines for clinicians wanting to support individual's autonomy. They suggest working with them to evaluate and negotiate over *concrete* outcomes, rather than abstract ideas. They also state that both the clinician and the client need to be open to the ideas of each other, as both are experts: clinicians are the expert on the medical aspects of the treatment, while clients are the experts on their own experience. By listening carefully to each other, each is able to understand what is at stake for the other person based on each different outcome. If, in the end, an individual still decides to refuse treatment, at least this is done based on an understanding of all the available knowledge, and an awareness of the consequences of this decision. It also ensures the process meets the criteria for autonomy in that the person is weighing up the costs and benefits of each outcome, has considered alternatives, and understands the situation.

Because the provision of information plays such an important role in increasing an individual's ability to make an autonomous choice, health professionals need to be careful how they present information in order to avoid coercion. Managing

information in a way that alters persons understanding of it in order to motivate them to choose what the professional considers the “right” choice is coercive. It is, therefore, important to ensure that information is not withheld or exaggerated in any way. When options are delivered to patients, tone of voice, gesture and the framing of information in terms of success and failure need to be neutral (Beauchamp & Childress, 2009). If any subtle forms of manipulation are present, the individual is being denied the right to make a truly autonomous decision.

Because there are vast amounts of information pertaining to every medical decision a person is making, and making every piece of this information available to the individual would be both prohibitively time consuming and lead to the disclosure of great quantities of information that is not pertinent to any possible outcome, there needs to be a limit on the information required to give informed consent. A simple, although admittedly far from perfect, way of making this determination is to consider what information a reasonable person would consider to be pertinent when deciding to accept an intervention. An individual can then be deemed adequately informed if her understanding of the outcome of a decision matches the professionals understanding. This includes having a shared understanding of the meaning of any medical terms or procedures before proceeding. If individuals are unable to comprehend the precise nature of what an intervention involves, their understanding can be enhanced by making analogies to more familiar situations, stating risks and benefits in terms of percentages, and relating the situation to equivalent risks from every day life (Beauchamp & Childress, 2009). As individuals may struggle to understand the available information when it is given in one clump, compromising their ability to make an informed decision (Appelbaum & Grisso, 1995a), each option

should be presented in smaller chunks, frequently checking that the information is understood.

### **Decision Talk**

The final stage is *decision talk*, where individuals are supported in the process of considering their preferences and deciding what to do. Recognising the values individuals use to make a final decision provides an opportunity to hear what is important to them, their understanding of the information they have been given about the situation they are currently in, and how this information is being weighed. Three elements of Fulford et al. (2012) values based decision-making model provide an outline of the different areas that need to be explored to ensure all relevant values are considered. This task is encompassed by three elements: awareness of values, reasoning about values, and knowledge about values. All the values an individual holds regarding the particular decision need to be recognised, as do those of the clinical team, their friends, family and other supports. Each person involved should make their values clear, and understand the values held by others. Next, how the values impact on the decision should be explored. Throughout, there needs to be understanding and acknowledgement that each individual has different values, and these may be drastically different to others with the same disorder.

When the relevant values have been established, they should be weighed up alongside other evidence to allow for autonomy to be balanced with beneficence and non-maleficence. To decide how much weight values should be given when looking at treatment refusal, Tan et al. (2006) suggest tracking values back to their origin. If the value is one that changed because of the illness, like those cited in the previous chapter, then it is likely derived from the disorder rather than reflecting individuals deep commitments and priorities, and so should be discounted. This strategy is

supported by Widdershoven and Abma (2012) who assert that preventing choices that conflict with individuals' life plans is not obstructing autonomy, but rather protecting it.

If it appears a decision only requires consideration be given to the empirical evidence base for treatment, extra effort should be made to explore any associated values. At the same time, if a situation seems particularly value laden, clinicians are advised to also carefully examine the empirical evidence associated with the various options on the table (Fulford et al., 2012). This is especially important in the case of anorexia nervosa, where as stated above, the evidence for any given treatment is slim and the risk of violating individual autonomy is high. In a disorder where decisions around treatment more often than not fall into a grey area, extra effort ought to be made to balance values and available evidence.

Individuals may require time to consider their options, and may also want to discuss them with others. Time for them to do so should be given. Finally, when a decision has been made, the person should know that this can be reviewed should she change her mind. Although this opportunity may be limited if the decision made is one that cannot be reversed once put in motion (Elwyn et al., 2012).

### **Considerations**

Several areas deserve extra consideration when assessing autonomy and treatment refusal in those individuals suffering from anorexia nervosa. Autonomy needs to be considered in relation to more than dietary intake and weight gain, and the risks and benefits should be explored to ensure paternalistic treatment is only utilised when risk is high and the treatment will reduce it.

## **Autonomy**

The current literature identifies two problems in the decision-making process by those with anorexia that may indicate a lack of autonomy. Specifically, the inability to recognise they are experiencing the symptoms of an illness, and the inability to apply relevant information to the self in order to make treatment decisions.

Lack of insight is a characteristic of individuals with anorexia nervosa (*DSM-5*, 2013). Individuals need to recognise that they are experiencing an illness in order to have insight into what is required to recover from it. If they do not believe that they are experiencing an illness, they will not apply information about treatment to themselves, as they do not recognise that it is required (Holroyd, 2012). Individuals with anorexia typically deny that they are unwell, and more often than not come to the attention of health services due to pressure from family members, or when presenting for medical input for another health issue (*DSM-5*). This lack of insight leads to an inability to correctly weigh up the costs and benefits of engaging in treatment, compromising the ability to make an autonomous decision.

Giordano (2005) has reported that autonomy may be compromised by the way in which individuals apply information about food and nutrition to themselves. As stated earlier, those with anorexia do not lack the knowledge of what is required to maintain a healthy lifestyle, but they do not believe these rules apply to them. A false belief about a rigid dietary regime that is not supported by available evidence indicates a lack of autonomy as it fails to meet the requirement that an individual should be able to relate information about a given situation to themselves. Of course, not all false beliefs point to a lack of autonomy. Many decisions are made every day that are not based on all of the possible information. However, as people find new information they typically adjust their decisions to take it into account, and may

change their initial course of action as a result. However, even in the face of indisputable scientific evidence proving that their beliefs are incorrect, individuals with an eating disorder typically regard their beliefs relating to food as indisputable. Autonomy is compromised by an inability to understand all the relevant information required to make a decision. Thus individuals with anorexia nervosa often selectively apply their knowledge to others but not themselves.

While these two examples indicate compromised decision making ability in individuals with anorexia nervosa, autonomy exists on a continuum and is very rarely completely absent. It is also task specific, so it may be present for some tasks and not for others (Beauchamp & Childress, 2009). Furthermore, the NICE guidelines on the treatment of eating disorders state that only “a small number of patients with anorexia nervosa do not have the capacity to make decisions about their own health and safety” (NICE, 2004, p. 80). So although these thinking errors may be present, it is not guaranteed they will compromise all aspects of autonomy, or that autonomy will permanently be compromised by them. Denial of illness, and an inability to apply information to the self are only two reasons a person may refuse treatment. As already discussed, individuals refuse treatment for a multitude of reasons, including a lack of motivation, a belief that treatment will not work, and valuing the positive aspects of the illness. A belief that treatment will not be effective may be made after looking at and understanding all the relevant information, and weighing up the costs and benefits of the treatment options available. This would particularly be the case in an individual who has been ill for many years and has been through a range of treatment options that have not had long-term benefit. Having this experience, she may have come to the decision that the available options will present her with greater



costs and be more burdensome than remaining ill. This decision would meet the criteria of an autonomous decision and should therefore be respected.

When determining the presence or absence of autonomy in individuals with anorexia nervosa who are engaged in making treatment decisions, it is important to look at the decision they are making, and to grasp whether or not autonomy issues are salient in the situation. Although individuals may have thinking patterns that compromise their autonomy in relation to dietary choices, this may not be relevant to the decision at hand if treatment refusal is based on other factors. It can never be assumed that autonomy is compromised purely based on the nature of the illness, so the reasons for treatment refusal should always be further explored.

### **Predicted Treatment Outcomes**

Balancing beneficence with nonmaleficence requires a focus on both promoting well-being while at the same time taking care not to prolong an individual's suffering. Just because treatment will be of some benefit to a person with anorexia nervosa, is not a sufficient reason to impose it. Short-term and long-term benefits should be weighed up against the individual's right to make autonomous decisions (Matusek & Wright, 2010). The obligation to treat is overridden in cases where an individual competently refuses treatment, when treatment is considered to be futile or pointless, or when the burden of treatment will outweigh the expected benefits (Beauchamp & Childress, 2009).

The evidence base and effectiveness of treatment for anorexia has already been discussed. There are various factors cited in the literature that contribute to the probability that treatment will be ineffective. Poor treatment outcomes are associated with low BMI, binge-eating/purge type, physical deterioration prior to the initiation of treatment, personality or interpersonal problems, family difficulties, and first

presentation for treatment occurring after the individual is aged 20 years old (NICE, 2004). In a 21-year follow-up study of 84 individuals with anorexia nervosa, a long duration of illness prior to hospitalisation, low BMI, inadequate weight-gain at first hospitalisation, binge-eating/purge type, and severe psychological or social problems predicted a poor outcome (Löwe et al., 2001). High trait anxiety has also been found to predict a poor prognosis in anorexia nervosa, with food restriction and exercise used as an anxiety reduction mechanism, increasing the reluctance to relinquish these behaviours (Zerwas et al., 2013).

This consideration of factors that are indicative of treatment effectiveness is not intended to suggest that treatment should be withheld from an individual because the course of the illness suggests that it will not have a favourable outcome. What it does do is support an individual's autonomous refusal of treatment. If a person with anorexia nervosa is refusing treatment based on the argument that it will be more of a burden to her than a benefit, and believes that it will not be successful, information concerning prognosis ought to be explicitly considered and weighted by clinicians.

## **Risk**

We need to be realistic about how at risk an individual is when considering imposing large amounts of involuntary treatment. Coercion should be limited to those occasions where an individual is at risk to harm either themselves or others. Because individuals with anorexia nervosa are generally not a risk to others, and are very rarely at risk of suicide, the risk to self is directly related to the symptoms of their eating disorder (Giordano, 2005; Matusek & Wright, 2010). As stated earlier, risk of death increases in those who have a BMI of less than 13, sharply increasing in those with a BMI less than 11, especially when this is accompanied by over-exercise and self-induced vomiting (NICE, 2004). Urgent action is required for those with a

serious cardiac arrhythmia or an acute abdominal problem. However, both of these conditions are very uncommon. Other conditions associated with anorexia build up over time and are able to persist for many years without posing a serious short-term risk to the individual. They may only require weekly outpatient monitoring until it is established that the individual has adapted to the physical change and is not at immediate risk (Robinson, 2009).

When there is a high risk of death, there needs to be a correspondingly high certainty of autonomy. That is, when the stakes are extremely high, we need to ensure that the evidence that autonomy is either present or absent is compelling before making a decision concerning treatment (Beauchamp & Childress, 2009).

### **Quality of Life**

Individuals with anorexia may make an autonomous choice to refuse further treatment based on not wanting to live with the quality of life available to them should they accept treatment. That is, treatment is viewed as a greater burden than living with the illness (Draper, 2000; Giordano, 2005). Some people manage to live a relatively normal life despite their illness, and would potentially be in a worse situation were they forced into treatment (Fedyszyn & Sullivan, 2007). When considering quality of life, the only concern should be the quality of the individual's life, not the value or quality of the person's life to others, even if this conflicts with family or other societal burdens or costs (Beauchamp & Childress, 2009).

### **Outcomes**

Having followed the process of determining autonomy, there are four possible outcomes: autonomous treatment acceptance, non-autonomous treatment refusal, autonomous treatment refusal, and autonomous refusal of life-saving treatment. The first option does not require discussion as from that point treatment is commenced.

The other potential outcomes will be discussed individually to determine how to proceed.

### **Non-Autonomous Treatment Refusal**

If a person is found to be lacking in autonomy, paternalistic treatment is only justified if the individual is at risk of a significant and preventable harm, there is no other reasonable alternative to paternalism, and the paternalistic action has a high likelihood of preventing this harm. The chosen intervention should be in the least restrictive setting required for reducing these risks, and only for as long as required to return individuals to a state where they are again able to make autonomous decisions (Beauchamp & Childress, 2009). As autonomy exists on a continuum, and is very rarely completely absent, an individual should still be given choice autonomy. That is, even if the only options available to an individual are unwanted and chosen by others, the individual should still be given the power to choose between these options (Lillehammer, 2012).

### **Autonomous Treatment Refusal**

Gans and Gunn (2003) have developed criteria for who should be “allowed” to refuse treatment for anorexia. They included patients in the end stages of life, who had a long and chronic history of anorexia that had never been in remission for a significant length of time, experience of multiple treatment providers and interventions, a significant history of non-compliance, irreversible medical problems, who’s subjective assessment that their quality of life is poor is shared by their family and treatment team, and met the criteria for competence at the time of evaluation. Although this list is a useful starting point for considering when to accept treatment refusal, it also places many pre-conditions on the criteria for treatment refusal that go over and above the presence of autonomy. As stated by Giordano (2005) “coercive

treatment represents a failure to respect competent refusal of therapy...every time competent refusal of therapy is not respected” (p. 247). It also limits the refusal of treatment to those who are at a stage where death will result, even if treatment were implemented. Although anorexia does have the highest mortality rate of all psychiatric conditions, this is the outcome for only 5%. These criteria exclude the 20% of individuals who develop a chronic course that arguably diminishes their quality of life to an equal extent, but under these conditions they would not be eligible to refuse treatment because they are not in the end stages of life.

In my view the criteria for accepting treatment refusal should be based on autonomy, explored through the process outlined above, with particular care given to ensuring the individual understands all of the treatment options, and the reality of the consequences. As refusal of treatment rarely means refusal of all aspects of treatment (Rathner, 1998), it should be established if there are aspects that the person does find acceptable that she would be willing to engage in, and how she can be supported to do so. It is also important to remember that treatment refusal now may not mean treatment refusal forever, so a willingness to engage in treatment should be regularly explored, ensuring the individual is clear that treatment is always open to her should she want to engage in the future.

Strober (2012) has formulated useful guidelines for practitioners working with individuals who have a severe and enduring case of anorexia nervosa, and who refuse treatment. I suggest that these guidelines can be applied to anyone who is refusing treatment of this disorder. Strober proposes that individuals should be reassured that weight gain is not the goal unless that is what they want. Despite their detailed knowledge of food and nutrition, most individuals with anorexia do not know how many calories they can consume without gaining weight. This information should be

conveyed to the individual, although it is better to wait until there is trust in the therapeutic relationship, as any food related suggestions will most likely be viewed with suspicion. Support for family is important at this stage. If individuals are willing, their family should be informed of the current goals and their purpose, and discouraged from alienating their family member through disparaging comments or pressure to engage in more intensive treatment. Both family and clinicians should also avoid showing relief or excitement over any weight gain if the individuals do increase their caloric intake, as this can be misinterpreted to mean that they are getting “fat”. To improve quality of life, individuals should be supported to reduce their isolation through support groups, time with supportive friends and family, and social or church groups. This social interaction needs to be balanced with the need of family and friends to have time away from the individual and their disorder. The aim of this approach is to improve functioning and quality of life while at least maintaining a safe or stable weight. If the individual will agree to it, ongoing medical monitoring is also important to see if their health is at immediate risk and requires urgent attention.

While an individual may place weight gain into a “no-go zone” in terms of treatment acceptability, other symptoms can be a target for intervention. For example, antidepressant medication can be used to reduce depressive symptoms; cognitive behaviour therapy can target obsessive and compulsive symptoms; nutritional supplements for nutritional deficits; and support provided to maintain employment and social interactions with others. Again the aim is to improve the individual’s quality of life and reduce overall disability (Robinson, 2009). Psychotherapy is also recommended for those with severe anorexia who refuse treatment, to motivate change, or to ease the burden of the illness (APA, 2000; Fedyszyn & Sullivan, 2007).

## **Autonomous Refusal of Life-Saving Treatment**

Although the symptoms of anorexia are reversible, for a minority of individuals there is no realistic chance of recovering to a meaningful standard. This is particularly the case for those who are suffering extreme pain, and receiving treatment that is only prolonging their suffering (Giordano, 2010). The longer the disorder progresses, and the more ineffective treatment an individual receives, the lower the chances of attaining a positive treatment response. Despite this, in all areas of mental health care, individuals with a long-term treatment resistant mental disorder are more likely to be subject to experimental, off-label, high dose treatment that comes with higher risks and reduced chances of effectiveness (Berk et al., 2013). The risk of ignoring autonomous treatment refusal by those with anorexia in the final stages of their lives is that we increase pain and suffering by persisting with an ultimately futile treatment.

Some of the previously mentioned guidelines on accepting treatment refusal developed by Draper (2000) and Gans and Gunn (2003) have clinical utility when considering autonomy in the context of life-saving treatment refusal. A consistent wish to refuse treatment over time leading to repeated treatment failures, and a subjective assessment that quality of life is poor both support the autonomy of the decision to refuse treatment. The former shows the decision is one that is long standing rather than made on impulse when under great physical and mental strain, while the latter shows the decision is based on considerations other than the desire to remain thin. The presence of significant and irreversible medical problems and an objective assessment by mental health professionals and family that the individual's quality of life is poor further supports that an individual is able to apply information

to themselves in a way consistent with the available evidence, although neither should be a necessary factor.

Giordano (2010) asserts that two factors are required for an individual to be able to competently refuse life-saving treatment: the illness is causing intractable suffering, and there is involvement by the family in the decision-making process. She believes family opinion is important in this decision because of the high degree of family support provided to an individual who is being treated for anorexia, and the need to apply autonomy with concern for others. Although I agree that family play an important role in the support of their loved one, I endorse Beauchamp and Childress (2009) assertion that quality of life in end of life treatment decisions should only consider the individuals subjective quality of life judgement. I do, however, believe that family should have the opportunity for involvement in the process. In the interests of informed consent and understanding the consequences of their chosen outcome, an individual needs to hear the impact their decision to refuse life-saving treatment will have on their family. This is in line with values-based decision-making and the element of awareness of values recommended earlier. The family should also be supported to come to terms with the loss or impending loss of their loved one from this disorder.

Over and above what has already be outlined, it is not appropriate to develop a set of criteria for accepting who should be able to refuse life-saving treatment. As mentioned in the previous paragraphs, this adds preconditions that take the decision beyond an individuals right to make autonomous choices. Although in most cases the complications of anorexia are reversible, and death is avoidable, “everybody is entitled to exercise their autonomy, not only ‘in the middle’ of their life, but also at the end of it, or when their own life is at stake” (Giordano, 2005, p. 246).



## CHAPTER SIX – CONCLUSIONS

The current research has looked at the ethical dilemma surrounding treatment refusal by individuals diagnosed with anorexia nervosa revolving around autonomy versus wellbeing considerations. The aim of the thesis was to establish when these refusals should be accepted, and how to make this determination. Treatment refusal is a common feature in those with anorexia, and it is difficult to ascertain in any one individual whether refusal is due to denial of illness, or if it is related to a valid belief that treatment will provide greater burden than benefit (Giordano, 2005). In order to be functioning autonomously in a given domain individuals ought to demonstrate an ability to weigh up costs and benefits of any decision, with an understanding of the specific situation they are in (Giordano, 2005; Heal, 2012; Holroyd, 2012).

The literature on anorexia nervosa lacks consensus over the presence of this ability in those diagnosed with the disorder. It is also unclear what it is about the disorder that may result in individuals losing the ability to function autonomously, or what procedures to follow to determine if this is in fact the case. Finally, there is ongoing debate on the impact, either positive or negative, of imposing unwanted treatment on someone with the disorder (Richmond, 2001). The literature on these issues was reviewed in order to provide a theoretical base for a model designed to establish the presence of autonomy in those with anorexia nervosa. It is important to do this, as an assumption that autonomy is absent can lead to the imposition of treatment that an individual has the right to refuse. While accepting all refusals may allow individuals to continue with life threatening behaviour that does not reflect their true intentions.

The literature has clearly illustrated that most individuals with anorexia nervosa maintain their ability to make autonomous decisions about to accept or refuse

treatment (Giordano, 2005; NICE, 2004). The conditions under which autonomy is compromised are very specific. If individuals hold a false belief that they are not ill or are unable to apply the information required to make a decision on treatment to themselves as a result of this illness, then autonomy is absent (Beauchamp & Childress, 2009; Holroyd, 2012). If they are making the decision based on values that have developed as a result of the illness, such as valuing a low body weight over other aspects of their life, even life itself, then autonomy is absent (Holroyd, 2012; Tan et al., 2006). Therefore, if an individual is able to accept and relate information about their condition to themselves, and are refusing treatment based on a wider view of life beyond illness driven values, then treatment refusal should be accepted.

Although there is no support for the view that paternalism in the face of treatment refusal damages therapeutic relationships (Sheehan & Burns, 2011) or leads to an increased suicide rate in those with anorexia nervosa (Ramsay et al., 1999), overriding treatment refusal should be limited to high-risk situations where an individual's life is at immediate risk (Beauchamp & Childress, 2009). Paternalistic treatment should also be enacted in the least restrictive setting required, and only for as long as is required to remove the risk (Beauchamp & Childress, 2009; Rathner, 1998; Touyz & Carney, 2010).

The implications of these findings are significant. Current approaches to the treatment of anorexia nervosa are largely coercive (MacDonald, 2002). They are based on the assumption that individuals with the disorder lack autonomous decision making ability, and are impaired by the effects low body weight has on cognitive ability. What has instead been shown is that respecting autonomy in those with the disorder leads to greater engagement in treatment (Darcy et al., 2010), reduced treatment drop out (Vandereycken & Vansteenkiste, 2009), and motivation to recover

from the disorder (Nordbø et al., 2008). There is insufficient evidence to suggest that the low body weight that accompanies anorexia nervosa results in cognitive impairment of the type that threatens individual's capacity to function autonomously (Mathias & Kent, 1998). Furthermore, even if individuals lack the ability to make autonomous decisions in relation to health and nutritional needs, they may still be refusing treatment autonomously (Giordano, 2005). As a result, clinical interactions with those who are refusing treatment for anorexia nervosa should focus on establishing if an individual is making this decision autonomously, based on all relevant information, before considering the use of informal or formal coercion.

Significant work has been undertaken by a number of authors on who is able to refuse treatment for anorexia nervosa. Draper (2000), Gans and Gunn (2003), and Giordano (2005, 2010) have developed criteria for accepting treatment refusal. All researchers have argued that treatment refusal should be accepted when it is made autonomously, through a process of informed consent, by an individual who has repeatedly failed to respond to treatment, is chronically unwell with the disorder, has little chance of regaining a better quality of life through treatment, and is supported by clinical staff and family.

The recognition that those with anorexia nervosa possess the ability to reasonably refuse treatment is a welcome start to changing practice. However, these authors have limited the acceptability of this option to those suffering from the most severe form of the illness. The problem with this position is the literature has shown that the key to making valid treatment decisions is autonomy, and these authors have placed extra conditions beyond this capacity. They have also provided limited guidance on establishing whether or not individuals are autonomous and refer only to the basic criteria: an ability to apply information to the self, weighing costs and

benefits, and making a decision based on this. However, because there is a high risk to persons autonomy should they be incorrectly deemed lacking in it, the level of evidence required to establish this should be correspondingly high (Beauchamp & Childress, 2009). The current study has attempted to address these gaps by developing the anorexia nervosa autonomous decision-making model (ANDMM).

While previous models have included autonomy as a *precondition* for legitimate treatment refusal, the ANDMM has placed autonomy at its core. Because autonomy is established via understanding the thought processes an individual has used to make a decision, this process needs to be adequately explored. The ANDMM allows this to be done by structuring the process around a shared decision making model (Elwyn et al., 2012). The ANDMM supports an individual to explore all of the options, weighing them against her own preferences, before making a treatment decision.

In order to reasonably consider all the options open to them individuals need to know what they are, and to have a good idea of the possible consequences associated with each. To ensure this happens, the ANDMM explicitly outlines the importance of gaining informed consent when proposing treatment for individuals with anorexia nervosa. To ensure a full range of options is presented to the client, clinicians are encouraged to consult with other disciplines and treatment providers to ensure a full range of options has been established prior to presenting them to the client.

Unlike the other recommended processes for accepting treatment refusal, the ANDMM provides guidance on working with those individuals who do not understand the information being provided to them. Rather than taking this as a sign that autonomy is absent, the ANDMM suggests first disclosing information in smaller

chunks (Appelbaum & Grisso, 1995a), and then relating the risks and benefits to other common life experiences to see if this brings their level of understanding up to the required level (Beauchamp & Childress, 2009). This strategy maximises the chances that persons will understand the information and be able to make an autonomous decision.

The way individuals weigh personal values when making a decision to either accept or refuse treatment can compromise their autonomy (Giordano, 2005; Holroyd, 2012; Tan et al., 2006). Because of this, the ANDMM includes aspects of values-based decision-making (Fulford et al., 2012) to help establish what values are important to individuals in the given situation, and what role they play in the decision making process. This is similar to earlier models, and assumes that values that are illness driven indicate an absence of autonomy. Including an exploration of values acknowledges that evidenced based practice needs to be balanced against individuals values to ensure that the result is the best outcome for that individual (Fulford et al., 2012). What the ANDMM provides that the previous models do not is an exploration of clinicians' values, and the impact they may have on the decision-making process (Rogerson et al., 2011). This allows professionals to critically look at how they are responding to treatment refusals to ensure they are not evaluating their validity entirely based on their personal (rather than professional) values.

The final step in the ANDMM is ensuring that explicit consideration is given to autonomy, treatment outcomes, risk, and quality of life. These areas balance autonomy with the clinical obligation to act with nonmaleficence and beneficence.

While the ANDMM is designed to remedy the gaps in previous models, it has its own weaknesses. Because the current research is theoretical in nature, the ANDMM has not yet been applied in a real world setting. This is also the case for the

models (and its processes) proposed by Draper (2000) and Giordano (2005, 2010). In the case of Gans and Gunn (2003), the criteria they have set are illustrated using a single case, but this is as far as application to a real setting has been taken. Some of the issues that hamper research into treatment likely contribute to this, such as the low prevalence of the illness compounded by the reluctance of those with anorexia to engage in research (Bulik et al., 2007). Any future research into the application of the ANDMM will need to be conducted over a period of time that takes these limits into account.

Another factor is the current treatment approach, which focuses almost exclusively on full recovery in those with the disorder (Fedyszyn & Sullivan, 2007), which is incompatible with the current proposition that treatment refusal and weight maintenance also be acceptable treatment (and ethical) options. As a result, the focus of treatment is a recommended area for future research. While a maintenance rather than curative approach currently appears to be accepted for those with a severe and enduring course of the disorder (Robinson, 2009; Strober, 2010), future research should explore the use of this approach in all individuals autonomously refusing treatment, regardless of the stage of the illness. This will allow clinicians to respect individual autonomy through treatment refusal, while at the same time preventing harm and promoting well-being.

Finally, the ANDMM is an ethical decision making model, so it does not take into account the role current mental health legislation plays in overriding treatment refusal when an individual is a risk to him or herself. Although the proposed model advises a realistic assessment of risk to ensure compulsory treatment is only applied in cases where harm is immanent, it is still superseded by mental health law.

The questions that led to the current research asked if individuals with anorexia nervosa were able to make autonomous treatment decisions, when these types of decisions should be accepted, and how to make this determination. Findings indicate that most individuals with anorexia nervosa maintain the ability to make autonomous decisions, and that their autonomous treatment refusals should be respected. While previous literature has highlighted the factors that may impair the ability to make these types of decisions, it has not been able tell us if these factors are present in a particular individual. Every case of treatment refusal should be assessed to ascertain if it is being made autonomously, with a focus not on the decision the person is making, but on the process they are following to make it. The ANDMM has been developed to guide these assessments.

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