International Journal of Law and Psychiatry 64 (2019) 250–259

Contents lists available at ScienceDirect

International Journal of Law and Psychiatry

journal homepage: www.elsevier.com/locate/ijlawpsy

How should the law determine capacity to refuse treatment for anorexia?

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ARTICLE INFO

Keywords:
Anorexia
Capacity
Mental illness
Treatment refusal

ABSTRACT

This article critically assesses the way a certain court has determined the capacity of a person diagnosed with anorexia to refuse medical treatment. It is shown that when making this determination, the court has adopted a process of circular reasoning, meaning anyone with the diagnosis will be found to lack capacity to refuse its treatment. This circular reasoning means that indicia of capacity that ought to be considered by the court is ignored. The result is a procedure in which the anorexic patient has no voice, and an outcome against which he or she has no effective legal recourse. This problem, it is argued, can be overcome in two ways. Firstly, courts must make sure that the 'functional' test of capacity is properly applied, meaning any finding of incapacity must rest on evidenced deficits in decision-making ability. Secondly, courts must properly engage with the subjective reasoning of the person making the treatment refusal.

1. Introduction

A person diagnosed with anorexia who is refusing treatment is considered a paradigmatic 'hard case' for the law of capacity (Ryan & Callaghan, 2014). In cases where a refusal to eat has led to the point of possible death by starvation, the legal and ethical situation is particularly difficult. Unlike many other potentially fatal illnesses, doctors treating anorexia are able to prevent death at any time by using nasogastric feeding[1] to restore weight. However, an unwilling patient can remove a nasogastric tube, so for it to be effective the patient may have to be chemically or physically restrained during feeding; that is, they must be force-fed (Smolak, 2002). Force-feeding is a controversial medical procedure to perform; it has been described by the World Medical Association as 'inhuman and degrading treatment' (World Medical Association, 2017). In addition, one of the salient features of anorexia for people who have experienced it is the feeling of control it confers (MacLeod, 1981, p. 83). Childhood abuse is a risk factor in developing the illness, and forced treatment may be a traumatic trigger for people with those experiences. Moreover, for the person experiencing the illness, anorexia is often seen as an essential part of his or her personality (Roncero, Belloch, Perpina, & Treasure, 2013). This characteristic of mental illness makes interventions addressed at stopping the behaviours that comprise the illness particularly difficult. It also means that forced intervention is at particular risk of damaging the relationship between a patient with anorexia and doctors, threatening the success of future treatment (Rathner, 1998).

On the other hand, anorexia is a dangerous illness. The effects of starvation on the body are pervasive, and of all recognised mental illnesses, it has the highest death rate (Arcelus, Mitchell, Wales, & Nielsen, 2011). From an ethical perspective, there is a view that giving in to an anorexic patient's request to stop treatment is effectively 'colluding' with the illness, because it is the illness itself that makes the person avoid treatment (Griffiths & Russell, 1998, pp. 132–3). Moreover, given that the option of nasogastric feeding is always available, many find it particularly upsetting not to stop what can be seen as a preventable death (Giordano, 2010).

It is clear that determining whether a person with anorexia has capacity to make decisions about their treatment is both highly difficult and highly important. Not infrequently, it is left to the law to determine whether a person diagnosed with anorexia who does not want treatment has capacity to make that decision. This article will critically assess the way the England and Wales Court of Protection has answered this question, and determine whether the approach being taken is coherent and appropriate. With the assistance of examples from other comparable jurisdictions, it will then provide suggestions as to how this Court and courts applying equivalent law can approach this difficult task.

2. Concepts

2.1. Capacity and competence

This paper considers a person's legal capacity to make medical treatment decisions. In some literature, a contrast is drawn between

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[1] Feeding through a tube inserted through the nose, directly into the stomach (Neiderman, Zarody, Tattersall, and Lask, 2000, p. 270).

https://doi.org/10.1016/j.ijlp.2019.05.001
Received 21 January 2019; Received in revised form 30 April 2019; Accepted 6 May 2019
Available online 15 May 2019

'competence' on one hand, and 'capacity' on the other.[2] In this dichotomy, competence is a legal determination, and capacity (or 'mental capacity') refers to mental abilities that are normally clinically determined. Although there may be merit to distinguishing these concepts with different terms, the law considered in this article does not do so, describing both the legal determination and the underlying mental abilities as 'capacity'. Moreover, this distinction is not widely made in the literature, with the terms 'competence' and 'capacity' being used interchangeably (Appelbaum, 2007; Purser, 2017). This article follows that pattern and uses the term 'capacity', but its focus is on legal determinations, what others might describe as 'legal capacity' or 'competence'.

2.2. Functional test of capacity

There are considered to be three potential bases for assessing capacity: the 'status' approach, where capacity is determined by whether or not someone has a mental disability, the 'outcome' approach, where capacity is determined by the wisdom (or not) of the decision made, and the 'function' approach, where a person's 'functional' decision making is assessed (Law Commission, 1995, p. 33; Wong, Clare, Gunn, & Holland, 1999, pp. 438–40; *R v Cooper* [2009] 4 All ER 1033, p. 1037). The 'functional' approach is favoured in most jurisdictions. Under this approach, *how* the person reaches the decision is determinative; and this means that a person may be found to have capacity, despite having a mental disability, and despite making what is seen to be an unwise decision. This approach, therefore, provides important decision-making freedom to people with mental disabilities (Donnelly, 2010, p. 108; Law Commission, 1995, p. 33). The wording used to define capacity differs across jurisdictions. In England and Wales, the *Mental Capacity Act 2005*, defines capacity as being able:

a) to understand the information relevant to the decision,
b) to retain that information,
c) to use or weigh that information as part of the process of making the decision, and
d) to communicate his decision (whether by talking, using sign language or any other means).[3]

It is added that:

The information relevant to a decision includes information about the reasonably foreseeable consequences of—

a) deciding one way or another, or
b) failing to make the decision.[4]

In Ontario, Canada, the *Health Care Consent Act*, SO 1996 provides:

A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision (c 2 s 4).

In New Zealand, the *Protection of Personal and Property Rights Act 1988* defines capacity as being able:

(a) to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and
(b) to communicate decisions in respect of those matters (s 5).

In each of these tests, it can be seen that the focus is on the *process* of decision-making; at a minimum requiring the decision-maker to be able to understand information relevant to the decision, and be able to understand the consequences of the decision (or lack of decision). None of the tests rests the conclusion of capacity on whether or not the person has a diagnosed mental illness, nor whether or not those assessing capacity believe the decision reached was wise. These tests established by legislation are closely comparable to that applied in the MacCAT-T, a semi-structured interview developed by Appelbaum and Grisso as a tool for assessing capacity (Appelbaum and Grisso, 1988). It also focusses on the process of decision making, rather than status or outcome. Although not used in judicial decision making, Owen et al. argue that the abilities the MacCAT-T assesses 'map onto' those in the *Mental Capacity Act 2005* test (Owen et al., 2009, p.1391).

The subject of this article is determinations of capacity to refuse medical treatment of people diagnosed with anorexia. It will consider these determinations as made under functional tests of capacity. Owing to the overall similarity between different specific wordings of the functional test of capacity, it is argued that the analysis in this article will be relevant to any circumstances in which a functional test of capacity is used make this determination.

2.3. Capacity: a legitimate gatekeeper of decision-making?

Since the commencement of the Convention on the Rights of Persons with Disabilities (CRPD), the role of capacity in legal systems has been the subject of particularly significant criticism. There is a view that removing capacity on the basis of a mental disability represents discrimination, and thus laws that authorise this are in violation of the CRPD (United Nations Committee on the Rights of Persons with Disabilities, 2014). However, this interpretation of the CRPD is itself a matter of controversy, and it appears that for the foreseeable future, some form of capacity law separating out those who are legally able to make decisions from those who are not will continue to operate (Dawson, 2015).

Whether or not capacity is an appropriate legal mechanism for determining the right to make decisions about oneself is beyond the scope of this article. For the purposes of this analysis, it is simply assumed that the removal of this right is a very weighty outcome for the subject involved. This is so even when, as occurs in some cases considered in this paper,[5] the substitute decision confirms the original decision made by the subject. Substitute decisions may take the person's views and wishes carefully and respectfully into consideration. Yet even when this is so, if a person has been found to lack capacity, ultimate decision-making authority has been removed from that person, and it is within the power of the substitute decision maker to, for example, order that unwanted treatment be given. The person found to lack capacity is always vulnerable to losing her or his right to bodily integrity. Therefore, respectful substitute decision-making alone does not provide a full answer to criticisms of the role of capacity in the legal system. If capacity is to continue to operate, it is vital that it is coherent, fair, and properly understood.

2.4. Anorexia: a special case?

Whether anorexia should be considered a special case with respect to capacity was the subject of a brief but important exchange between Grisso and Appelbaum, leading authorities on capacity, and a group led by Tan and Hope, leading authorities on anorexia and capacity. Their difference of opinion will be considered below. However, there was an

[2] See e.g. Buchanan, Alec, 'Mental Capacity, Legal Competence and Consent to Treatment' (2004) 97 Journal of the Royal Society of Medicine 415

[3] S 3(1) *Mental Capacity Act 2005*.

[4] 3(4).

[5] *The NHS Trust v L and Others* [2012] EWCOP 2741, *A NHS Foundation Trust v Ms X* [2014] EWCOP 35, *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13, and *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56.

important point of agreement between the groups that is relevant here. In a response to Tan and Hope's arguments about capacity in anorexia, Grisso and Appelbaum claimed that capacity should not be altered based on the nature of one illness. They point out that:

> It is not at all clear how the modification might influence findings of competence when applied to other disorders. Using a study of patients with anorexia nervosa as the impetus for changing the competence concept runs this risk (Grisso & Appelbaum, 2006, p. 294).

This appears to be a sound argument. Although anorexia does provide a difficult case for capacity, it is not sui generis (Carney, 2009, p. 42). There are many other recognised mental illnesses that would be associated with similar difficulties for the law of capacity.[6] And importantly, Tan and Hope, in response to Grisso and Appelbaum, agreed with this particular point (Tan, Hope, Stewart, & Fitzpatrick, 2006a). They argued that although anorexia was a difficult case, their investigation into capacity and anorexia was 'studying penguins to understand birds', that is, investigating an unusual member of the group in order to better understand the definitional boundaries of that group.

This paper will adopt the conclusion of this exchange. Thus, the assumption is that the findings of this study will be relevant for capacity in the case of any mental illness.

3. Anorexia and incapacity: under-inclusion or over-inclusion?

Tan, Hope, Stewart and Fitzpatrick developed the argument that the MacCAT-T test of capacity, (which they describe as the 'gold standard' for capacity assessment, p. 268) did not sufficiently capture the autonomy-undermining effects of anorexia. They claimed that an anorexic patient may appear rational, able to understand their situation, and able to explain a refusal of treatment in terms that might seem to indicate capacity. However, they argue, to conclude that the adult had capacity based on these features would be to reckon without the person's 'pathological values', values of thinness and avoidance of food associated with anorexia that are detrimental to autonomy, but are not detected by capacity tests (Tan, Hope, Stewart, & Fitzpatrick, 2006). They argue, therefore, that 'pathological values' was a concept that ought to be relevant to the decision of whether to override patient refusal of treatment, and should be considered when determining capacity.

Tan and Hope are not the only writers to suggest that incapacity will be under-recognised in the case of anorexia. Craigie and Foster have also stated that people with anorexia will often meet the criteria for capacity (Craigie refers to the MacCAT-T criteria, Foster refers to the definition in the *Mental Capacity Act 2005*), but question whether that outcome is appropriate (Craigie, 2011, p.327; Foster, 2013, p.61). These concerns echo those that have been raised in a broader context. It has been stated that the cognitive focus on understanding and using information within the existing tests of capacity does not capture the autonomy-undermining effects of mental illness (Berghmans, Dickenson, & Meulen, 2004; Breden & Vollmann, 2004; Gallagher, 1998; Richardson, 2010) for example, the impact of these illnesses on beliefs and emotions (Charland, 1998; Mackenzie & Rogers, 2013).

However, if underestimation of incapacity in the case of anorexia were a problem in legal decision-making, it might be thought that there would be some judgments in which a person with anorexia was found to have capacity in circumstances where there was a genuine question about their autonomy. Yet there are no decisions of which this researcher is aware in England and Wales, Australia, Canada or New Zealand in which a person with anorexia was found to have capacity to refuse food-related treatment.[7] Moreover, as Richardson notes, assessment of the case law on capacity involving other mental illnesses shows that courts have not considered purely cognitive deficits in ability. People with mental illnesses seen to be autonomy-undermining are frequently, perhaps routinely, found to lack capacity by courts (2010, p. 71).

Assessments of capacity most often occur outside of the courtroom (Appelbaum, 2007, p. 1834), and it is possible that the problem Tan, Hope and others identified may occur in the clinical determinations of capacity in the case of anorexia.[8] Nevertheless, from the published cases on anorexia, it would easier to conclude that the exact opposite was the problem in judicial decision-making: not that incapacity is undetected, but that incapacity is inevitable. This concern was voiced in critical reaction[9] to the Court of Protection case *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639. This case involved a 32 year old woman with anorexia, who had been receiving treatment for the illness since she was 15 years old. E had decided that she no longer wanted treatment for the illness, and instead wanted palliative care. E's health care team, with the support of her parents, agreed to cooperate with E's request. The seriousness of E's condition meant the withdrawal of treatment for anorexia would most likely result in her death. However, after the palliative care regime had commenced, the government authority overseeing the health care team made an application to the Court of Protection to determine the legality of this course of action. In his ruling, Jackson J found that, firstly, E did not have legal capacity to make decisions about food at the time of hearing, nor when she made an advance directive requesting no further treatment for the illness. This meant that E's treatment refusal was not legally effective, and therefore a substitute decision needed to be made on her behalf on the basis of her 'best interests'.[10] Secondly, His Honour found that it was in E's best interests to be transferred to a specialist unit for the treatment of anorexia (an option that had not previously been available), where she would be treated, whether or not she consented.

Memorably, the parents of E were quoted in the case:

> It seems strange to us that the only people who don't seem to have the right to die when there is no further appropriate treatment available are those with an eating disorder. *This is based on the assumption that they can never have capacity around any issues connected to food.* There is a logic to this, but not from the perspective of the sufferer who is not extended the same rights as any other person (para 52)(emphasis added).

As will be seen in this paper, the reasoning used by the Court of Protection means that underestimation of incapacity in the case of anorexia, as feared by Hope and Tan, has not come to pass in its legal decision making.

4. Current approach to capacity and anorexia in the Court of Protection

4.1. Why study the Court of Protection?

The Court of Protection was chosen as the target of analysis of this

[6] Grisso and Appelbaum (2006), point out:

> ..anorexia is one of a class of mental disorders that is characterized by a failure to abstain from behavior (here, limiting food intake and other behaviours designed to reduce weight) that has negative consequences for the person. Other conditions in this category might include substance abuse disorders and impulse control disorders (e.g., pathological gambling), (p. 294).

[7] Only one unreported case from the USA, does not fit this trend, Schmidt (2016), discussed in Cave & Tan (2017, p. 16).

[8] See Elzakkers, Danner, Grisso, Hoek, and van Elburg (2018) for a recent study on clinical assessment of capacity in the case of anorexia.

[9] See Whiteman (2012); Saul (2012); Hewson (2012); Coggon (2013); Mackenzie (2015); and Welman (2017).

[10] *Mental Capacity Act 2005*, ss 2–4.

article for three reasons. Firstly, this Court is notable as one that is specifically tasked with determining capacity to make decisions in cases of disability (Keen, Kane, Kim, & Owen, 2019). Secondly, there is a series of relatively recent cases, which form the basis of the analysis in this article, in which capacity in the case of a person with anorexia who is refusing treatment is directly addressed. Finally, when addressing that question, the Court is applying the *Mental Capacity Act 2005*, which has a functional definition of capacity. Therefore, the critique of these decisions provided in this article, and the suggestions given for how to improve its decision making, will be relevant to the large number of other jurisdictions making this same determination under a functional definition of capacity.

4.2. Legal decisions on capacity and anorexia in the Court of Protection

Since 2012, there have been five cases that determine whether a person with anorexia has capacity to refuse medical treatment for anorexia in the Court of Protection. All five cases involved a person who had been treated for anorexia for a number of years without success, and who wanted the treatment to cease. Although not always identified as such, each subject of the cases would probably meet the criteria for 'severe and enduring anorexia'.[11] Each of the five was found by the court to lack capacity to make the decision to refuse treatment for anorexia. The first of these cases was *Re E (Medical Treatment: Anorexia*). There followed:

- *The NHS Trust v L and Others* [2012] EWCOP 2741
- *A NHS Foundation Trust v Ms X* [2014] EWCOP 35
- *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13
- *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56

The adult in each case was very sick, and was not present in any of the hearings. In *Re W (Medical Treatment: Anorexia)*, Jackson J did speak to W via video-link, but did not appear to consider the impression gained by this in his determination of capacity. In fact, the question that the Court gives most effort to determining is not whether the adult has capacity, but what substitute decision should be made on their behalf. Each case used evidence from the same psychiatrist, Dr. Tyrone Glover, a specialist in eating disorders, and his evidence played a prominent role in the determination of capacity, which was usually stated in a single paragraph.

The precise reasoning on the question of capacity in the five Court of Protection cases differs, but the general reasoning is very similar. In each case, anorexia, or a diagnostic symptom of anorexia, was presented as the *cause* of the patient's incapacity to make the decision to refuse treatment for anorexia. At this level, the reasoning used resembles that of Lord Donaldson in the *parens patriae* jurisdiction, who in *Re W (A Minor)(Medical Treatment: Court's Jurisdiction)* [1992] 3 WLR 758 stated:

> [i]t is a feature of anorexia nervosa that it is capable of destroying the ability to make an informed choice. It creates a compulsion to refuse treatment or only to accept treatment which is likely to be ineffective. This attitude is part and parcel of the disease and the more advanced the illness, the more compelling it may become (p. 769).

Jackson J's reasoning in *Re E (Medical Treatment: Anorexia)* is comparable:

> ..E's obsessive fear of weight gain makes her incapable of weighing the advantages and disadvantages of eating in any meaningful way. For E, the compulsion to prevent calories entering her system has become the card that trumps all others. The need not to gain weight overpowers all other thoughts (para 49).

Both extracts mention a 'compulsion' to refuse treatment; the cause was stated in *Re W (A Minor)(Medical Treatment: Court's Jurisdiction)* to be anorexia, in *Re E (Medical Treatment: Anorexia)* it was a 'fear of weight gain', one of the diagnostic symptoms of anorexia (American Psychiatric Association, 2013, p 338–9). This compulsion, it was held, meant that the subjects lacked capacity to make decisions about food.

In *Re E (Medical Treatment: Anorexia)*, Dr. Glover told the court that 'anyone with severe anorexia' would lack capacity to make decisions about its treatment (para 51). Jackson J did not find it necessary to reach a conclusion on this general point, but does not disagree with it.

In the other Court of Protection cases, direct causal links were made between anorexia and incapacity, reflecting the views of Dr. Glover. In *The NHS Trust v L and Others*, King J stated: '[t]he illness, [Dr Glover] explained, *causes a deficit in capacity* specific to issues relating to food and weight gain' (para 54) and on this basis her Honour was 'entirely satisfied' L lacked capacity (para 56) (emphasis added). Similar reasoning was used in *A NHS Foundation Trust v Ms X* (para 28) *Re W (Medical Treatment: Anorexia)* (para 26) and *Cheshire & Wirral Partnership NHS Foundation Trust v Z* (para 5).

The specific connection between anorexia and incapacity for decisions about food found in these cases is highlighted by the fact that three cases identify other types of decision for which the adult retains capacity. X was found to retain capacity to make decisions about drinking alcohol, despite being diagnosed with alcohol dependence syndrome (para 30). L was found to have capacity to make other health decisions, including whether to take antibiotics for pneumonia (as the antibiotics are not calorific), pain relief and treatment for bed sores (para 54). W was found to have capacity to make other relevant decisions, like those about physical health (para 26).

The causal connection between anorexia and incapacity to make decisions about treatment for the anorexia in these cases is not surprising. Firstly, Section 2(1) of the *Mental Capacity Act 2005* appears to require this reasoning be applied. It states that:

> For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter *because of* an impairment of, or a disturbance in the functioning of, the mind or brain (emphasis added).[12]

Moreover, the view of there being a causal relationship between anorexia and incapacity in this way has wider support. Baroness Hale uses 'the kind of compulsion which drives a person with anorexia to refuse food' as an example of something that would 'rob [a person] of the ability to make an autonomous choice' (*R v Cooper* [2009] UKHL 42, para 25). The Mental Capacity Act 2005 Code of Practice, when discussing the ability to 'use or weigh' information, states that:

> a person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore (Department of Constitutional Affairs, 2007, p. 48).

The UK Law Commission (1995), para 3.17) uses anorexia as an example of a 'compulsive condition' that could cause people to be unable to use information, despite being able to understand it.

Furthermore, the notion of anorexia being a cause of incapacity is not a legal construct; it reflects a widely held view in medicine also. As

[11] There is a subset of people with anorexia whose experience of the illness is acute, treatment resistant and long lasting; recently this collection of characteristics has been described as 'severe and enduring anorexia'. See (Ciao, Accurso, & Wonderlich, 2016).

[12] This part of the *Mental Capacity Act 2005* is known as the 'diagnostic threshold' (Law Commission, 1995). It means that there is an element of 'status' in the capacity test being applied, because for someone to be found to lack capacity, it is necessary that an 'impairment of the mind' is first identified.

noted, these decisions essentially repeat the views of the psychiatrist who presented evidence on capacity.[13]

However, despite support for this reasoning, the following will show that it is problematic when used to determine a person's legal capacity to make a decision.

4.3. Problems with reasoning

4.3.1. Circularity

It is illogical to describe a mental illness as a cause of the patterns of thoughts and behaviours that comprise that illness. The diagnostic symptoms of anorexia are:

- Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, and developmental trajectory, and physical health …;
- Intense fear or gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight;
- Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight (American Psychiatric Association, 2013, p. 338–9).

The second and third of those symptoms have implications for decision making; they will manifest in decisions that avoid gaining weight. Therefore, to say that anorexia is the causal agent of a person's decision to avoid gaining weight is both incoherent and without content (Giordano, 2005, p. 70). It might be possible to *associate* certain decision making with anorexia. One could distinguish the actions of a person diagnosed with anorexia from that of a person on hunger strike by saying that one set of behaviours was associated with a mental illness and the other was not, but to treat anorexia as a cause of its own diagnostic symptoms is circular. And yet, as shown above, this is the reasoning followed in Court of Protection capacity cases involving anorexia.

In *Re E (Medical Treatment: Anorexia)* and *Re W (A Minor)(Medical Treatment: Court's Jurisdiction)*, the court purports to identify a compulsion to avoid food that either causes or comprises (the judgments are not entirely clear) incapacity. It is true that some who have experienced anorexia describe a compulsion,[14] and if that were the case, it would be legitimate to consider the compulsion a barrier to decision-making capacity. However, the subjects in *Re E (Medical Treatment: Anorexia)* and *Re W (A Minor)(Medical Treatment: Court's Jurisdiction)* did not state that they were compelled to act as they did, so this compulsion was not directly evidenced, and could only be assumed. Moreover, it is not possible to separate the putative compulsion from the diagnostic criteria of anorexia itself; they amount to the same thing: a pattern of thoughts and behaviours involving a high value put on thinness and avoidance of food. Therefore, the reasoning followed in these cases is entirely circular. As will be seen, this logical problem is associated with deficiencies in the decision-making process used by courts in the case of anorexia.

4.3.2. Functional capacity assessment bypassed, and relevant information ignored

Due to the circularity of the reasoning used in these cases, the decision by the person with anorexia to refuse treatment is simultaneously taken to be evidence of the cause (anorexia) and of the effect (incapacity), a logical problem warned of by Beumont and Carney (2003, p. 591). The problem is admitted in *Re E (Medical Treatment: Anorexia)*:

> I acknowledge that a person with severe anorexia may be in a Catch 22 situation regarding capacity: namely, that by deciding not to eat, she proves that she lacks capacity to decide at all (para 53).

The Superior Court of Ontario makes a similar admission (without noting the 'Catch 22') in *L.`C. v. Pinhas* 2002 CanLII 2843.[15] Reviewing a number of Capacity and Consent Board (Ontario) cases on capacity in the case of anorexia, the court states without criticism:

> The very fact that the patient declined to follow the recommendations for treatment was considered a manifestation of the inability to appreciate the reasonably foreseeable consequences of a decision or lack of decision and contributed to the finding of a lack of capacity (para 37).

As noted, the test of capacity being applied in England and Wales, and Ontario, is a functional test, not one decided on status or outcome, and this feature of the test is seen to be important for ensuring appropriate decision-making freedom for people with disabilities.[16] However, as acknowledged by Jackson J, people with anorexia face a 'Catch 22' in which their capacity will be determined by the combination of 'status': the person is diagnosed with anorexia, and 'outcome': the person refuses treatment. This approach means the functional assessment of capacity, supposedly the central feature of the test of capacity, is completely bypassed (Wang, 2015), and the law is thus not being applied properly. Of itself, this is a problem.

There is another serious issue with the reasoning used in the Court of Protection cases. In the judgments, capacity is dealt with in a short passage, usually only containing reference to evidence from the psychiatrists. The issue is that the judgments themselves actually record indicia of understanding held by these adults in sections not relating to capacity. For example, in *Re W (Medical Treatment: Anorexia)*, W provided the judge with two documents about her position, which the judge described as 'remarkable for their clarity and analytical nature' (para 29). The judge, having spoken to W through video-link, noted that W was able to give an 'insightful response' to questions about her anorexia, (para 31) and was able to talk about her treatment options, saying that her current unit was problematic because 'she feels that she has failed and that nobody believes that she can succeed' (para 30). In *An NHS Foundation Trust v Ms X*, X wrote a letter to the judge stating that the 'pressure of mental health staff and services' associated with her treatment over the last 14 years was making things worse, rather than helping (para 51). In *Re E (Medical Treatment: Anorexia)*, in comments related by the Official Solicitor's representative, E stated that her life was a 'torment', and that all the treatment she has received involved 'a lot of pain with very little benefit' (para 76). E knew that without treatment she would die, but wanted to 'live for the remainder of her life as she chooses' (para 76).

These comments include understandable reasons for refusing further treatment, and indicate a seemingly accurate understanding of the situations in which the decision makers found themselves. They do not prove that these people had capacity, but given the functional test of capacity involves consideration of a person's understanding of information relevant to the decision at hand, these comments should be considered directly relevant to the determination of capacity. The fact that relevant comments like these are ignored when deciding capacity can be associated with the circular reasoning used by the courts. Anorexia, or the compulsion it creates, is seen as the cause of the treatment refusal. Therefore, even impressive reasons made in support of the refusal can simply be treated as more persuasive emanations from

[13] See also Geppert (2015, p.34), a psychiatrist who argues that 'decisional capacity impairment in [anorexia] is *an intrinsic part* of the pathology of the disorder' (emphasis added).

[14] E.g. in *H. (Re),* 2005 CanLII 57,849, the anorexic patient describes the anorexia as a 'tyrant in her head against which she could not fight', (para 7).

[15] 2002 CanLII 2843.

[16] See above, Section 2.2.

the illness.[17] This means that the person's specific reasoning will not change the determination in any way, and as a result, it is irrelevant.

It is true that deceit, whether conscious or not, is a known feature of anorexia (Norris, Boydell, & Pinhas, 2006). Therefore, reasons given for avoiding weight gain may be a post-hoc justification for a decision taken due to a compulsion. Thus, it may not be good practice for a doctor to take the reasons given by a person diagnosed with anorexia for their avoidance of food entirely at face value. However, to ignore stated reasons for a treatment refusal when making a determination on whether a person has a legal right to make that refusal is entirely different.

For people experiencing anorexia, it means that the right to decide what others do to their body is removed simply by their classification as anorexic; without a voice in the process, and without any recourse to legally challenge this determination. As Jackson J admits, as long as they are refusing treatment, they will be taken to lack capacity to refuse this treatment,[18] and so anything they say about it will be considered to have no relevance.

As well as anorexia, any mental illness, for example, depression, in which a disturbance in decision making is one of the diagnostic symptoms of the illness, is similarly at risk of incapacity by diagnosis if this reasoning is followed. This pattern of decision making is a therefore a significant problem for the legal system.

5. How should capacity in the case of anorexia be determined?

5.1. Ensure functional capacity assessment is performed

The above analysis shows that capacity in the case of anorexia cannot simply amount to determining whether the decision to refuse treatment was caused by the illness, or symptoms of the illness, without being circular, and without leading to incapacity by diagnosis. Therefore, the immediate imperative is to ensure that this causal reasoning be avoided, so that cases can be decided by a functional test.

A concern might be raised that abandoning the causal reasoning criticised here might lead to a different problem. Anorexia primarily manifests in goals and values, rather than problems with cognition to which the functional test of capacity is directed. Insisting on a functional assessment that avoided consideration of causation, therefore, might lead to an underestimation of incapacity in the case of anorexia.[19] It will be recalled that this was the reason behind Tan et al. (2006) suggestion that 'pathological values' be included in the test of capacity. However, there is good reason to think that such a move is not necessary.

Grisso and Appelbaum (2006) argued in their response to Hope and Tan that the differences in thinking associated with anorexia will tend to find expression in some kind of distortion of reality, which in turn will be identifiable in a functional capacity assessment. Whether courts are in fact able to identify legitimate factors on which to base a finding of incapacity in the case of anorexia is an important issue. Grisso and Appelbaum's arguments were not based on actual legal decision-making. Moreover, the analysis of the Court of Protection's reasoning critiqued above may cast doubt on whether this a realistic possibility for judicial decision-making. However, this article will show that there is case law from other jurisdictions that does lend support to Grisso and Appelbaum's position. There are a number of cases on capacity to refuse treatment for anorexia from Ontario, Canada and one from New Zealand that include examples of specific problems in decision making that can be legitimately linked to a functional capacity assessment. The cases mentioned in this section involve hospital patients who were diagnosed with anorexia, and were refusing treatment for the anorexia.[20,21]

Three common problems in decision making that have been identified in these reported cases will be described.

5.1.1. Reasons anorexia may be 'detected' on a functional assessment

5.1.1.1. False beliefs about quality of available food. In some cases, a person refusing to eat was doing so for the stated reason that their diet at the hospital was inadequate.[22] This belief about the nature of the food provided in the hospital was found by the court or tribunal to be factually incorrect, and thus evidence of a lack of understanding of information pertaining to the decision. In *Re RM* 2012 CanLII 7685, the patient stated that the hospital food was 'unnatural' compared to the 'holistic' and 'natural' food she ate at home (para 8). This was held by the Capacity and Consent Board of Ontario to constitute 'delusional thinking around food' (para 11), caused by anorexia which, along with other manifestations of the disorder, prevented RM from being able to understand and appreciate information relevant to the treatment decision.

In the New Zealand guardianship case of *Re CMC* [1995] NZFLR 538, evidence was presented that CMC had been provided with 'an abundance of food and variety of food' (p. 542) at the hospital, but still argued that she was given an inadequate diet. His Honour stated that in fact 'she wished to be so selective that she effectively prevented herself from being able to have a full and balanced diet' (p. 542).

If a belief that is relevant to the decision being made is unequivocally untrue, then it is reasonable to conclude that this negatively affects capacity to make that decision. This informed the reasoning in *Norfolk & Norwich Healthcare (NHS) Trust v W* [1996] 2 FLR 613, in which W, who refused an emergency caesarean section on the basis that she believed she was not pregnant, was found to lack capacity to make this decision.

5.1.1.2. Unable to apply information about nutrition to oneself. Anorexia is not normally associated with broader cognitive problems (National Institute for Health and Care Excellence, 2016).[23] It is likely that most people with anorexia would be able to understand the medical fact that people require a certain intake of food to be healthy. One pattern observed in anorexic patients is that they will at some level understand the information given to them about weight and nutrition, but not fully believe that it applies to them. Tan et al. (2006) quote the following statements by subjects in their study that evidence this feature of anorexia:

> Participant B: Your bones can be weak, your heart slows down, you can be infertile, stuff like that.
> Interviewer: Has the risk of death been mentioned?
> Participant B: Yeah.

[17] In Foster's words, the Courts are effectively treating the refusal as being made 'by the parasite' (Foster, 2013 p. 61).

[18] Cave and Tan (2017, p. 16) argue that this approaches a presumption of incapacity, in opposition to the presumption of capacity in the law; Whiteman (2012, p. 151) believes it may be discriminatory against people with anorexia; Wang (2015) and Whiteman (2012, p.152) both argue that incapacity by diagnosis offends the *Convention on the Rights of Persons with Disabilities*.

[19] Section 3 above.

[20] In Ontario, Canada, children are also dealt with by the same law as adults, merging 'Gillick competency' and capacity (Geist, Katzman, & Colangelo, 1996). Case law from this jurisdiction, including cases relating to minors, is therefore directly relevant to the issue of capacity in that jurisdiction. Some cases mentioned here involved patients who were under 18.

[21] The decisions from Ontario and New Zealand discussed here were taken under equivalent tests of capacity to that in the *Mental Capacity Act 2005* and the MacCAT-T. See above Section 2.2.

[22] *RM (Re)*, 2012 CanLII 7685, *JQ (Re)*, 2011 CanLII 84,618 and *Re CMC* [1995] NZFLR 538.

[23] National Institute for Health and Care Excellence, *Eating Disorders: Recognition and Treatment: Full Guideline* (Draft for Consultation) (National Institute for Health and Care Excellence, 2016).

Interviewer: Do you believe these things you've been told?
Participant B: No.
Interviewer: About the risk of death, do you think it could happen?
Participant B: Not to me.
Interviewer: That's the opinion of doctors, and I wonder why you don't think it can happen to you.
Participant B: Because you have to be really thin to die, and I'm fat, so it won't happen to me. (p. 274)

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Interviewer: Why do you think you don't believe these things could happen to you?
Participant H: Because although logic tells me I'm underweight, but I don't feel it. When I'm just going around doing whatever in the day, then I don't feel that I've got a problem. But I know I am underweight because I stand on the scales.
Interviewer: So it sounds like logic tells you you're underweight. But the way you feel is that you're normal weight?
Participant H: Yeah, I just feel that I'm – I don't feel ill, if you know what I mean. I just feel – I guess I've got used to the feeling. But my hands are often cold and so – but I'm used to it so to me it's normal (p. 275).

This problem in decision-making formed part of the evidence heard in one of the Court of Protection cases, *A NHS Foundation Trust v Ms X*. There, X's clinician stated:

> [Ms X] is able to understand the information provided and on my assessment of her cognitive state on the 28th August 2014 she was able to retain and feedback to me the information provided to her about the same evidencing both retention and understanding due to ongoing severe body dysmorphia, false beliefs about her weight shape and nutritional state and absolute fear of weight gain from her anorexia, she was and is unable to apply the information to herself or believe in the need for it. In addition the absolute fear of weight gain and anxiety induced around the same over rides any loose connection she might have to the information pertaining to herself. *The reality and importance of the associated risks including death of her malnourished state are therefore not truly appraised which means she is unable to weigh up the information provided in the decision making process* (para 53) (emphasis in original).

The same feature is identified in the Capacity and Consent Board (Ontario) case of *In the Matter of R.B., a Patient at the Hospital for Sick Children*[24]:

> [a]lthough R.B. superficially understood the need for food and fluid to remain medically stable she was unable to apply this information to her own condition (para 54).[25]

Understanding whether a general medical fact that applies to all humans also applies to that individual is a relevant piece of information regarding the decision. Failure to understand this may legitimately lead a capacity assessor to question someone's capacity.[26]

5.1.1.3. Dissonance between goals and decisions. Another aspect of decision making in anorexia that may influence a legitimate functional assessment of capacity is the inconsistency between a person's stated goals and their individual decisions. This does not demonstrate a lack of capacity; however, it is an alerting aspect of decision-making, and one which might legitimately be put to the decision maker. Grisso and Appelbaum note the following inconsistency in Hope and Tan's subject's discussion, in which Patient I at one point says: 'I wasn't really bothered about dying, as long as I died thin', but later says: 'I do think that being thinner for me will make me happy.' (Grisso & Appelbaum, 2006, p. 296).

This reasoning can be seen in *In The Matter of L.W.*,[27] where the Capacity and Consent Board of Ontario found: 'Although L.W. states she does not want to die, she is unable to take steps to prevent herself from dying' (para 54). Similarly, in *L. C. v. Pinhas*:

> L.C. wants to move on with her life. The fact is, however, that, over the past almost four years, she has consistently conducted herself in a manner that takes herself further and further from her goal of recovery (para 40).

This dissonance was seen by the Board as caused by the anorexia, and assisted it to conclude that the patient in those cases lacked capacity to make decisions about food. *Re CMC* also includes this reasoning:

> Whilst she stated that she wished to survive and wished to have a future quality relationship with her children – indeed, wished to attain an optimum weight for her own wellbeing, she could not see what was necessary in order for this to be achieved (p. 542).

Inconsistencies like this, as Grisso and Appelbaum (2006) argue, are not constitutive of incapacity, but with further inquiry might be seen as evidence of a lack of ability to use or weigh information pertaining to the decision.

5.2. Engage with decision maker's subjective reasons

A proper capacity assessment requires the assessor to understand the specific reasoning behind the decision made. As noted, the Court of Protection cases on anorexia do the precise opposite; the 'Catch 22' identified by Jackson J rendering their subjective views irrelevant. Addressing the Catch 22 will need to involve close and careful engagement with the decision maker, to understand the decision from his or her perspective (Banner, 2013, p 84), and to avoid the circular reasoning noted above.

This process must engage with and elucidate the subjects' understanding and opinions as individuals, not as sufferers of anorexia. As was shown above, this direct discussion with the adult may reveal understanding of the situation, and reasons for the decision to refuse treatment that a court may be able to understand.

Direct engagement with the decision-maker is also made more important by the process of seeking to identify deficits in functional decision-making capacity as advocated above. If the adult is left out of the legal proceedings, he or she does not have the opportunity to respond to the evidence upon which his or her rights will be decided. Three observed features of decision making in anorexia that could underpin a finding of incapacity were presented. One of these features was that the subjects reported perceiving the provision of food to be inadequate, when this was not, in fact, the case. If a court infers a deficit in capacity from this aspect of a patient's decision making, that features, and the associated inference, should be put to the adult so that he or she has the chance to respond. The court can say: 'You say X, but the reality is Y. This tends to indicate you lack capacity to make this decision. Would you like to say something about that?'. Responses may not reveal anything to displace the initial views of the court. But this cannot be known in advance, and as a matter of natural justice the subject must at least have a chance to answer this question.

As well as these policy reasons, the Court of Protection is arguably under a legal obligation to actively take its own evidence on capacity. In *Cheshire West and Chester Council v P and M* [2011] EWCOP 1330 Baker J stated:

[24] Unreported decision described. in *L. C. v. Pinhas* 2002 CanLII 2843.

[25] For another decision using this reasoning see Board of Capacity and Consent (Ontario) decision in *LC*, cited in *L. C. v. Pinhas* 2002 CanLII 2843, para 40.

[26] This point is made in *Neto v. Klukach* [2004] O.J. No. 394.

[27] Cited in*L. C. v. Pinhas* 2002 CanLII 2843.

> the function of the court is not to determine in a disinterested way a dispute brought to it by the parties, but rather, to engage in a process of assessing whether an adult is lacking in capacity (para 52).

Case law from the European Court of Human Rights (ECtHR) has also held that it was necessary for judges to make their own determinations an adult's capacity, and not just rest the decision on medical evidence. In *X and Y v. Croatia* (2012) App No 5193/09 the ECtHR held that capacity was a matter for the judge, not a psychiatrist or other medical expert, to decide (p. 84). Moreover, this ought to be done having had direct contact with the person whose capacity is being assessed (p. 84).[28]

Considering the cases discussed in this article, it is not surprising that a recent study by Keen et al. (2019) showed that the Court of Protection frequently does not follow this advice.[29] Although the court was more likely to actively engage with a person on the issue of capacity when that person was party to proceedings (p. 67), the judge spoke directly to the adult in less than a third of cases overall (p. 69).

Engaging directly with the decision maker in the ways advocated here may be very difficult. People at the severe end of the illness may be very medically unwell, and too weak to attend a hearing, complicating the court's ability to directly question the adult. It also may be difficult for the person whose capacity is questioned to be directly confronted with what the court sees as their distortions of reality. Nevertheless, despite these difficulties, direct and open engagement with the adult on the issue of capacity is essential for proper decision making. Without it, for people with anorexia who are refusing treatment, there is a serious ongoing risk of their capacity being decided on their diagnosis alone, something capacity law is supposed to avoid. Moreover, without this engagement, authorised invasion of the subjects' bodily integrity may occur without their having any voice in the process.

5.3. *Full functional assessment in the case of serious mental illness: an example*

Properly applying the functional approach to capacity as advocated here requires courts to make an exceptionally difficult balance, weighing very different considerations together. A person diagnosed with anorexia may experience distortions of reality. They may exhibit serious internal inconsistency between their life goals and individual decisions. On the other hand, they may provide compelling reasons why treatment is particularly troubling for them. They may make accurate statements about the futility of the treatment. Bringing these different factors together in the determination of capacity is a very challenging task. Indeed, it might be considered an unrealistic one. However, this is not the case. Cave and Tan (2017) have identified a Court of Protection case that provides an example of how proper engagement with the decision maker can allow him or her to have a voice in the decision, and avoid the question of capacity being determined in advance by their diagnosis. *Re SB (A Patient: Capacity to Consent to Termination)* [2013] EWCOP 1417 involved a woman who had a diagnosis of bipolar disorder, and was being compulsorily detained under the *Mental Health Act 1983*, who was seeking a termination of her pregnancy. Her capacity to make this decision was assessed by the Court.

Holman J was presented with unanimous medical opinion that SB lacked capacity to make this decision, owing to the fact that the psychiatrists believed the decision was based on 'paranoid ideas about her husband or mother' (para 42). This opinion was supported by SB's family. His Honour noted that SB's views about her husband and family may have been influenced by 'delusion or paranoia'. Nevertheless, Holman J balanced this against the evidence that SB presented herself when questioned in Court. His Honour found that SB provided 'a range of rational reasons for her decision' (para 44). Importantly, SB told the court that having a baby as a compulsorily detained patient was 'crazy'; stating 'I am extremely unhappy where I am. Imagine being unhappy and being pregnant?' (para 42). In fact, the idea of carrying the baby to term made her feel suicidal, and she believed that it was preferable to have a termination than to commit suicide (para 43). Holman J found SB's views on this to be understandable, and did demonstrate an understanding of the situation in which SB found herself. Therefore, Holman J held that these reasons needed to be considered in the determination of capacity, and they weighed against the psychiatrist's and family's views of SB's delusions. Ultimately, SB was found to have capacity to make the decision on termination.

As Cave and Tan (2017) point out, this case has great significance for decisions on capacity in the case of anorexia. In it, the Court was faced with thoughts and beliefs associated with a mental illness that were found to be inaccurate, and could legitimately inform a finding of incapacity under a functional assessment. Against this, there were other reasons from the adult, given a chance to speak and explain her decision, which indicated capacity. These subjective reasons were ultimately found to be more convincing. There is no reason why a comparable type of balancing could not have taken place in the Court of Protection cases on anorexia.

This case is significant for a second reason. Despite his Honour's positive engagement with the person subject to the proceedings before him, Holman J reveals a lack of appreciation of the situation in which others who appear before the Court find themselves. In his judgment, Holman J made the following comment:

> In most cases that come before the Court of Protection, at any rate in my experience, the assessment of capacity by one or more psychiatrists is regarded as determinative. But those are generally cases in which the patient himself or herself is not positively and strongly asserting, and actually giving evidence, that he or she has the required capacity (para 36).

This is an accurate characterisation of the process of capacity assessment in Court of Protection anorexia cases. In each, capacity was decided on the medical evidence alone, without speaking to the adult themselves. However, to draw the distinction between SB's situation and that of other people with matters before the Court of Protection that SB was 'positively and strongly asserting' her capacity is highly questionable. As has been shown in this article, certain others whose matters are heard by the Court have had their capacity effectively determined before they go to Court, just by the fact of their diagnosis and their refusal of the treatment. In fact, for the subjects of the five anorexia cases, their capacity to refuse treatment for their illness had most likely never been considered possible, evidenced by the fact that they had all been in and out of compulsory treatment for the duration of their illness. Certainly, they were not given the chance to 'strongly and positively assert' their capacity before the Court; the judges did not think it even necessary to engage with them on the issue of capacity. The finding in *Re SB (A Patient: Capacity to Consent to Termination)* compellingly shows the different outcomes that were possible had this engagement occurred.

6. Conclusion

This paper has analysed problems that are evident in the reasoning of cases deciding capacity to refuse treatment for anorexia. Two conclusions have been reached following that analysis. Firstly, courts should avoid reasoning that directly links the treatment refusal to incapacity, or anorexia to incapacity. Deficits in decision-making ability relating to a functional assessment of capacity must be identified. Secondly, if courts infer a deficit in capacity from features of a patient's decision making, those features, and that inference, should be put to the adult so that he or she has the chance to respond.

Whether an application of these recommendations would have

[28] See discussion of other cases in Series (2014).

[29] See also Lindsey (2018).

resulted in a different finding in any of the cases considered in this article is not possible to determine. Capacity is a judgment that must be made on the specific evidence presented. Nevertheless, by involving the subject in the legal determination of their capacity, and thereby broadening the evidence upon which the judgment is made, the decision making will improve. Anorexia is the specific focus of this paper, however, the assumption that the law should not be adjusted to fit this particular mental illness has not been displaced. Accordingly, the recommendations made here ought to apply to any person whose capacity is being assessed by a court or tribunal, not just those diagnosed with anorexia.

In *Cheshire & Wirral Partnership NHS Foundation Trust v Z*, after ruling that Z lacked capacity to make her own decisions owing to her anorexia, Hayden J determined that continued forced treatment would not be in Z's best interests, and therefore she should be discharged home to her parents. His Honour found that this was 'the only proposal which carries any vestige of hope and most effectively preserves Z's dignity and autonomy' (para 19). This statement indicates that for Z, her autonomy only came into calculation *after* she had been found to lack capacity. This must change.

Re SB (A Patient: Capacity to Consent to Termination) presents an example of how the conclusions of this article could be implemented in the case of anorexia. It ought to be held as a positive example for courts to follow in the future. People with anorexia may still have an uphill battle to convince a court that they have capacity to refuse treatment. Nevertheless, if this approach is followed, they will at least have a voice in the decision, and a realistic possibility of a finding of capacity. This will have a positive effect on the legal system, for anorexia, and for other mental illnesses.

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