

The Challenge of Managing Severely Ill Patients with Anorexia Nervosa in Ireland

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Abstract

Anorexia Nervosa (AN) has the highest rates of morbidity and mortality of any psychiatric disorder. Psychiatrists in Ireland have reported difficulties in managing patients with AN, particularly those with severe levels of illness. This paper explores these management difficulties, including the financial and organisational impediments to service provision, and the legal and ethical dilemmas involved in dealing with those patients who refuse treatment.

Key words: Anorexia Nervosa, legal and ethical difficulties, coercive feeding

Introduction

A session at the inaugural conference of the new College of Psychiatry in Ireland (March 2009) highlighted the paucity of Government-provided services for the management of patients with eating disorders in Ireland, particularly those who are severely ill with AN. Several psychiatrists reported difficult experiences while trying to treat such patients on general medical wards in environments that were both physically and psychologically unsuitable. Others commented on the problem of accessing appropriate specialist care for eating disorder patients, especially for those with severe illness. This paper seeks to explore some of the issues that currently make caring for such patients so challenging, and to consider the service developments that need to be implemented in order to address the needs of this group of patients.

Although facilities to treat Bulimia Nervosa (BN) are equally deficient in Ireland, we have chosen to focus on AN in this paper. Patients with AN present the added challenge of low body weight with the attendant risk of significant physical consequences and serious medical events, although the risk of death may be similar in both groups.^{1,2} There is also the problem of how and where to manage patients with severe AN, especially those who refuse treatment. The possible need for coercive feeding of these patients creates legal and ethical complications that remain without clarification from Irish legislative or regulatory bodies. In attempting to outline the barriers to the provision of efficient and effective care to patients with severe AN in Ireland we will briefly consider three issues: (1) the absence of reliable data on the scale of the problem; (2) impediments to service development; and (3) the legal/ethical dilemma of coercive treatment.

Quantifying the scale of the problem

The only study looking at incidence or prevalence rates for eating disorders in Ireland was reported by Shinkwin & Standen in 2001.³ Their research identified an incidence rate of 4 per 100,000 for AN, although the authors reported significant methodological difficulties with data collection. However, their findings were broadly comparable to studies from the rest of Europe, although the reported incidence rates vary widely between 0.1 and 12 per 100,000.⁴ The European prevalence rate appears to be approximately 0.3%.⁵ It is estimated that 200,000 people suffer from an eating disorder in Ireland, with 400 new cases and approximately 80 deaths per year.⁶

In attempting to quantify the numbers of patients with more severe levels of illness, we looked at data from the National Psychiatric In-Patient Reporting System (NPIRS) and the Hospital In-Patient Enquiry (HIPE) that show psychiatric and medical admissions respectively.

Number of admissions per year

Year	NPIRS (Psychiatric)*	HIPE (Medical)**
2004	175	152
2005	182	168
2006	178	154
2007	147	163

* NPIRS includes public and private admissions, but does not distinguish between AN and BN.

** HIPE data is for AN alone, but only includes public admissions.

In their study, Shinkwin and Standen identified data retrieval as a significant problem. There is certainly a marked lack of accessible, accurate information on patients with AN. For example, the NPIRS does not distinguish between AN and BN, whilst HIPE does. Thus, there remains considerable uncertainty with regard to how many patients with AN are treated annually, in what facilities, and at what financial cost. The problem of data access is highlighted further by a recent Freedom of Information enquiry. A request was made to elicit information on how many patients with AN have received publicly funded specialist treatment in either public or private facilities in Ireland between 2004 and 2009, and at what cost. The response to the request was that this information would be almost impossible to deliver, as there is no department, or specified person, with the responsibility of tracking this data.⁷ Service planning clearly becomes very difficult if appropriate data is unavailable.

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Developing services to manage patients with eating disorders

When *A Vision for Change* set out the plan to provide comprehensive services to treat patients with eating disorders nationally, it was agreed that adults, adolescents and children would initially all be managed at primary care level. Those patients who required more intensive treatment would be referred to their local general Community Mental Health Teams. For more complex cases, adults would be referred for specialist treatment to one of four six-bedded units, attached to a general hospital mental health unit. These would be placed in each of the four HSE regions (six beds per million population, with 24 in total), and staffed by a Multi-Disciplinary Team (MDT). Children and adolescents would have access to a National Centre for Eating Disorders based at a main children's hospital and also staffed by a MDT.

However, there has been effectively no progress on national service provision in the intervening period.⁸ From the HIPE and NPIRS data (above) it is clear that, given that there are only three designated adult eating disorder public beds, the majority of patients with AN are managed in general medical or general psychiatric hospitals, mostly without access to specialist involvement. There are a number of reasons for this lack of progress. Firstly, there has been a shortage of available funding for the development of services for the treatment of eating disorders. Secondly, an equally significant barrier to the provision of a coherent and comprehensive national service appears to be a lack of strategy on how, and where, to spend any available funds. In 2007, Minister Brendan Smith pledged €750,000 of funding for the development of designated eating disorder services in the Dublin and South areas.⁹ This pledge was subsequently withdrawn. However, it is apparent that some funding was made available, but on a piecemeal basis. For example, since 2006, €699,519.35 has been spent on fourteen patients who were sent abroad for treatment.¹⁰ There have also been monies provided to fund treatment of individual patients in privately owned specialist eating disorder facilities in Ireland, although the amount is uncertain.⁷ It is arguable that such monies might have been more efficiently used if invested in the development of the national strategy that is outlined in *A Vision for Change*.

Legal and ethical issues in treating severely ill patients with AN

In patients with severe AN, cooperation with treatment can diminish to the extent that their life becomes seriously threatened. In such cases the question of the introduction of forced naso-gastric feeding may be raised, a scenario that is medically, ethically and legally contentious.¹¹

Legal provisions for the use of coercive approaches in the treatment of AN differ considerably across jurisdictions.¹² Pertinent issues leading to this variance include: (1) disparities in the conceptualisation of AN as a mental disorder,^{13,14} (2) a lack of clarity apropos the medico-legal concepts of competence and capacity in patients with AN;¹⁵ and (3) socio-cultural differences which influence the legislative provisions for the use of coercive approaches in the treatment of AN.¹⁶ These differences tend to be influenced by the views and attitudes of medical professionals, legal experts, the lay public and media regarding AN.

Despite this, there appears to be an emerging international trend with regard to the use of coercive re-feeding, although this is not universal. In England and Wales, the courts have held that AN is a mental disorder, and that patient consent is "not required for any medical treatment administered by a responsible medical officer for a mental disorder under the Mental Health Act 1983 s.63". Naso-gastric feeding is regarded as a "medicine and an integral part of the treatment for anorexia nervosa".¹⁷ Thus, English common law recognises forced feeding as a psychiatric treatment in the context of severe and life threatening AN. Similarly, in 1999 in Australia, following the Mental Health Tribunal hearing of a case concerning a 19 year-old severely-ill patient, New South Wales legislation recognised AN as a mental disorder thereby bringing NSW into line with other Australian states. Prior to this, clinicians had resorted to certain provisions under the Guardianship Act 1997 to treat patients with AN, a process that was described as being fraught with many practical difficulties.¹⁸ In Germany, where there is evidence of direct and imminent danger to the patient's life, detention and involuntary treatment are permitted under federal state law or by invoking civil law guardianship. In 2004, doctors treating a patient with AN were fined for accepting her refusal of any kind of feeding or intravenous drip.¹⁹ In Israel, under the Mental Health Act 1991, theoretically it is not possible to involuntarily hospitalise a patient with a diagnosis of AN. However, involuntary detention and treatment does take place, usually through the mechanism of appointing a legal guardian for the patient's body.¹²

The situation in Ireland is rather complex. Uncertainty exists as to whether re-feeding can be considered a psychiatric treatment under the Mental Health Act (Ireland) 2001. The problems encountered by psychiatrists in the treatment of severe AN, made more difficult through the shortage of treatment facilities, are further compounded by a lack of clarity on the legal status of coercive treatment. *A Vision for Change*, whilst setting out the plan as to how to develop services for patients with eating disorders, is silent on the legal and ethical challenges posed by the management of AN. The Mental Health Act (MHA) although not specifically excluding AN as a mental disorder, does not address whether admitting such a patient under the Act for re-feeding is an acceptable psychiatric treatment. Legal opinion has indicated that this issue needs to be clarified by the courts before it can be assumed. Should re-feeding not be accepted as an appropriate psychiatric treatment, it will not be possible to invoke the MHA to detain and coercively feed patients with AN. Alternatively, should forced re-feeding be permissible, the lack of appropriate facilities where this could take place could limit the implementation of the Act.

Moreover, there remains the question of whether a patient who refuses re-feeding in a clinically appropriate context should always be coercively fed. This raises issues of competence and capacity. The effect of AN on competence in particular, and the decision-making process in general, remains poorly understood and problematic.^{14,20} It is to be hoped that the Mental Capacity Bill currently passing through due legislative process in Ireland will clarify some of these uncertainties when finally enacted.

Conclusions

In conclusion, the significant levels of morbidity and mortality in patients with eating disorders are well reported,^{21, 22} as are the benefits of early and effective intervention.²³ It is clear that there

is a compelling need to implement the recommendations of *A Vision for Change* to equip clinicians with the appropriate facilities to treat all eating disorder patients, and particularly those with severe levels of illness. However, without a detailed plan on how this would be achieved, it is difficult to see how meaningful progress can be made. In addition, the legal uncertainties surrounding the management of patients who refuse treatment need to be clarified, both in relation to the MHA, and the new Mental Capacity Bill. Finally, our ability to record and collate data must be improved as, without this, appropriate service provision cannot effectively be achieved.

Conflict of interest

None

Addendum

Since this paper was written, the provision of eating disorder services in Ireland has been included as one of the priorities of the HSE Clinical Care Programmes in Mental Health. In addition, there is a review of the Mental Health Act 2001 being conducted by the Mental Health Commission. These initiatives are very welcome, and it is hoped that they will adequately deal with the issues raised in this paper, and address the challenges of caring for these patients.

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