Treating anorexia nervosa

Psychiatrists have mixed views on use of terminal care for anorexia nervosa

EDITOR,—We agree with Janice Russell that doctors must constantly review their treatment of patients with anorexia nervosa.¹ Russell refers to a recent case in which a 24 year old patient with anorexia nervosa was given morphine in a terminal care institution, where she died within eight days.² Russell suggests that this raises "disturbing questions for those who battle with this common and tragic illness."

To investigate the attitudes of psychiatrists who treat such patients we sent a short questionnaire plus a copy of the case report by O'Neill *et al* to the 58 founder members of the Royal College of Psychiatrists' special interest group on eating disorders. All 43 respondents (74% response rate) agreed with the principles of the hospice movement. Three quarters (32) also agreed with the use of terminal care facilities for a range of other conditions: end stage respiratory or heart failure and end stage rheumatoid arthritis. There was, however, less support for terminal care in a hospice for anorexia nervosa (median score 23 (interquartile range 7-49) on a visual analogue scale, where 0=disagree and 100=agree). Respondents disagreed that the anorexia nervosa of the patient reported on by O'Neill *et al* was incurable (median score 11 (3-42) on a visual analogue scale). The respondents had differing, strongly held views, ranging from feeling "appalled" and "disgusted" and thinking that such care in anorexia nervosa was "close to euthanasia" to being "generally comfortable with the concept if able to identify truly refractory cases." Several respondents raised specific queries about the management in the particular case, especially the failure to try the full range of treatment options and to involve a specialist treatment service in the patient's care.

We believe that this variety of views on the use of terminal care in anorexia nervosa in general and in this case in particular requires clinicians to discuss further the ethical principles behind their management of such cases. In other cases of terminal illness a desire for death is associated with clinical depression, which is potentially treatable, and may change over time.³ Similarly, in anorexia nervosa a desire for death may be associated with depression and may fluctuate over time and with the course of the illness. On the other hand, acceptance that the illness is incurable will reduce demand for the provision of adequate treatment facilities. We wish to see more debate on this issue.

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1 Russell J. Treating anorexia nervosa. *BMJ* 1995;311:584. (2 September.)

2 O'Neill J, Crowther T, Sampson G. A case study. Anorexia nervosa. Palliative care of terminal psychiatric disease. *American Journal of Hospice and Palliative Care* 1994; Nov/Dec:36-8.

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Patients' beliefs hinder treatment

EDITOR,—Janice Russell clearly describes the good reasons for a multidimensional approach to the treatment of anorexia nervosa.¹ The individual aspects necessary are further affirmed by the Personal View written by an anorexic patient.² An important factor, relevant to treatment, that has received scant attention is the way in which patients with anorexia nervosa imbue thinness with magical properties.

Many patients with anorexia nervosa describe how, through penitence and self denial, they will be rewarded with a complete and permanent happiness that is almost heavenly. The religiosity of this belief is added to by culturally accepted attitudes that describe fasting as good (righteous) and satiety as bad (weak). This belief in such a metamorphosis is held with varying conviction, the level of which seems to bear a relation to the severity of the pursuit of weight loss. Patients who set an ideal weight make an association with a likely reward. Once this weight is attained, however, they realise that they have not undergone any transformation. Rather than challenge the belief, they consider the target to have been wrong and either further weight loss or a remodelling of body shape to be required.

Patients with anorexia nervosa can see how this might be interpreted by others as magical or even silly, but several factors perpetuate their tenacious belief—namely, the boost in self worth that they experienced through achieving early weight loss targets; the fact that, having sacrificed so much, they cannot accept that they were misled and there is no reward; and the media's portrayal of physical perfection as a prerequisite to happiness.

It is essential to focus on the individual factors that lead to the low self esteem and personal dissatisfaction out of which anorexia nervosa arises. However, the belief in a false "quick fix," magical solution to personal problems interferes with the perceived need for gradual resolution of the conflicts that perpetuate the condition.

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1 Russell J. Treating anorexia nervosa. *BMJ* 1995;311:584. (2 September.)

2 What option would you take? *BMJ* 1995;311:635-6. (2 September.)

Neonatal screening

Performance is hard to monitor

EDITOR,—We agree with Allison Streetly and colleagues that any additions to the established neonatal screening programme for phenylketonuria and congenital hypothyroidism should be assessed for effectiveness, including impact on the performance of the overall programme.¹ But we would go further and suggest that such an assessment would prove difficult because of inherent problems with the existing neonatal screening programme, which need to be addressed first.

Streetly and colleagues assume that 99% of babies are tested for phenylketonuria and congenital hypothyroidism, though the figure may be lower, at least in London, where coverage with Guthrie testing varies between health authorities^{2,3} and by ethnic group.⁴ Unlike with other population programmes, such as screening of women for cervical or breast cancer, immunisation, and vaccination, routine statistics on the proportion of the target population tested and a system of following up missed cases are not available.

A local review of neonatal screening highlighted some of the problems of monitoring the performance of neonatal screening. Firstly, the community midwives of the woman's district of residence who carry out the tests (usually on day 7 after birth) and send the Guthrie cards to the laboratory also receive the results. But these arrive after day 10, when the midwife is no longer in touch with the mother. There is no mechanism for transferring the results to the primary health care team (including the health visitor), which by then is clinically responsible. Secondly, there are no arrangements for the results to be entered into the child health information system, which could be accessed by the primary health care team, and for

missing cases to be identified. Instead, the community midwives work from manual registers or log books of women resident in their area who have recently given birth; these are not routinely matched against alternative records, such as the child health information system, to check that all eligible babies are tested. Thirdly, positive results are notified by the laboratory direct to the general practitioner, but no provision is made for follow up of the management and outcome of these cases.

It is unlikely that our findings are peculiar to a single district. The comparative rarity of congenital hypothyroidism and phenylketonuria (about 1 in 10 000) may perhaps explain why we are unaware of any cases that have been missed or not followed up properly. Through district committees (maternity service liaison and child health surveillance) and through the contracting process we are clarifying responsibilities for the neonatal programme and will require a system for monitoring coverage. It would be ironic if the "loss of regional responsibility for overview of programmes"¹ resulted in better organisation of the neonatal screening programme. Equally, unless all districts address these fundamental problems the service may become more fragmented; thus regional guidance on how to establish an appropriate monitoring framework is necessary.

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Pretest counselling and informed consent should be prerequisites

EDITOR,—Neonatal screening is justifiable if the individual screening tests have been assessed against criteria of suitability.¹ For its implementation to be ethical, however, a further component is required: adequate pretest counselling and informed consent.

Neonatal screening has potential for rapid expansion, yet there is little evidence that even those tests recently included in screening programmes have been assessed rigorously to see whether they fulfil criteria for effective screening.² Full assessment is clearly necessary if the costs of further tests are to be justifiable.

The ethics of screening require more than this: the recipients (or in this case their parents) should be able to give informed consent to the tests. The potential seriousness and emotiveness of the conditions tested for (for example, cystic fibrosis, Duchenne muscular dystrophy) are such that specific pretest counselling and consent ought to be prerequisites. This is not evident in current practice, as many professionals are not aware of the scope of screening programmes.

Not everyone will be "reassured" by the results of their tests, so some attention should be paid to the possible outcomes and their implications. This may be analogous to testing in other situations in which the results have enormous implications, such as testing for HIV infection. As screening for more esoteric conditions becomes feasible the ability of professionals (usually midwives) to provide the relevant information to parents may be