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.)

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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"⁵ 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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1 Streetly A, Grant C, Pollitt RJ, Addison GM. Survey of scope of neonatal screening in the United Kingdom. *BMJ* 1995;311:726. (16 September.)

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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

overtaken and training requirements will become important.

If pretest counselling were more complete and informed consent required then the public acceptance and uptake of genetic tests might not be as great as figures from the current neonatal screening programmes suggest.

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- 1 Wilson JMG, Junger YG. *Principles and practice of screening for disease*. Geneva: WHO, 1968. (Public health papers No 34.)
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Pitfalls in the interpretation of tumour markers

EDITOR,—We do not agree with H S Pandha and colleagues that poor sensitivity and specificity of assays cause a major problem in the measurement of α fetoprotein concentrations.¹ Measurements of α fetoprotein are used in several clinical situations, including to diagnose and monitor neoplastic disorders (such as germ cell tumours and hepatomas) and in antenatal screening for Down's syndrome and neural tube defects. Modern immunoassays for α fetoprotein have adequate sensitivity, and it is important for clinical laboratories to use an assay that is specific for α fetoprotein but that adequately detects all its molecular forms in view of the variety of clinical settings in which α fetoprotein is measured. In specific cases, identification of the particular form of α fetoprotein secreted may be valuable, but this is not generally required.

Although concentrations of both α fetoprotein and human chorionic gonadotrophin were initially raised in the case reported, the authors do not comment on the absence of any increase in the concentration of human chorionic gonadotrophin concomitant with the second increase in α fetoprotein concentration. This might have suggested that this increase in α fetoprotein concentration was not due to recurrence of the primary tumour. However, recurrent tumour deposits or metastases may not secrete the same tumour markers (or may not secrete them in the same proportions) as the primary tumour, and this may cause particular difficulty with heterogeneous tumours such as teratomas.

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Risk factors for acanthamoeba keratitis

EDITOR,—We wish to respond to the letters¹ about our case-control study of risk factors for acanthamoeba keratitis in people who use contact lenses.² We undertook the study to determine the reasons for the increase in the number of cases of acanthamoeba keratitis seen at Moorfields Eye Hospital. Aware of the multiplicity of risk factors for the disease, we performed multivariable analysis and commented on factors identified as significant. David V Seal and John Hay do not

identify the "sweeping generalisations" or "misleading comments" they say that we made, and we are not aware of having made any.

We did not claim that frequent replacement of the lens case alone would prevent growth and replication of acanthamoeba when chlorine based disinfectants are used, but we suggested that monthly replacement of the case, which we have promoted since the data were collected, "may reduce the prevalence of contamination of storage cases." Since cases containing acanthamoeba usually have bacterial or fungal co-contamination, or both,³ we reasoned that a general reduction in the rate of microbial contamination, as occurs with regular replacement of cases,⁴ may reduce the likelihood of acanthamoeba contamination. Obviously, the use of disinfectant with a cysticidal effect is preferable.

With regard to the crude minimum relative risk of 2.63 ($P=0.004$) calculated for Acuvue compared with other brands of daily wear disposable lenses, we accept that the introduction of five (not 47) brands of disposable lenses (according to our definition²) by the time that the controls were collected may have led to a slight overestimate. Given the high proportion (84%) of Vistakon lenses used by the controls using disposable lenses, however, this is unlikely to have been appreciable. To confirm this we have recalculated the crude relative risk for patients presenting in the final year of the study: among users of daily wear disposable lenses ($n=46$) Acuvue lenses were still associated with a significant excess risk (crude minimum relative risk 1.16 ($P=0.044$)).

Our epidemiological data suggest that there may be a causal relation between certain disposable lenses and acanthamoeba keratitis. Although there is no laboratory evidence of this, available data are limited. We agree that further investigation is required, both in the laboratory and in a nationwide population based incidence study.

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Placebo controlled trials of ondansetron for postoperative nausea and vomiting

EDITOR,—Rebecca L Aspinall and Neville W Goodman conclude that patients who participated in placebo controlled studies investigating the role of ondansetron in the management of postoperative nausea and vomiting were denied access to effective treatment.¹ This is not correct: no patient was denied access to effective treatment, and the health and wellbeing of patients are of overriding importance in the design of all studies sponsored by GlaxoWellcome. Any patient who developed nausea and vomiting could request and receive rescue treatment at any time. In addition, all of the studies discussed were subject to local ethical approval by independent review boards or

ethics committees, and all the patients were fully informed about the implications of the studies and volunteered to participate.

Aspinall and Goodman concede that the use of antiemetics for prophylaxis against postoperative nausea and vomiting is not accepted by all anaesthetists. There are many causes of postoperative nausea and vomiting, and placebo controlled studies can provide valuable information on the relative influence that the various factors may have on its occurrence.² In the studies to investigate the efficacy of ondansetron in established postoperative nausea and vomiting the number of patients who received placebo was kept to a minimum. Indeed, the true number of patients included in the studies cited by Aspinall and Goodman was 313 and not "over 400" as the quoted figures contain some duplicate reports.

There will always be debate about the need for and desirability of placebo controlled studies irrespective of the disease or treatment under investigation. GlaxoWellcome, however, will continue to work to high clinical standards to ensure the development of safe and effective medicines that meet the needs of patients, clinicians, and regulators.

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Deprivation payments should be based on enumeration districts

EDITOR,—In 1981 the Saffron estate, a district of council housing afflicted by poverty, made up one half of an electoral ward. The other half of the ward was a comfortable suburb outside the Saffron Group Practice's area. The Jarman index for the ward was 22. Although nearly 5000 of our patients lived in enumeration districts with Jarman indices over 30 or 40, the practice received no deprivation payments until July 1995. In 1983 the ward boundaries were redrawn. The estate now forms part of a new ward, and the Jarman score is no longer heavily diluted by the prosperous suburb.

It is ironic that, although deprivation on the Saffron estate, as measured by the Jarman index, has improved, the family health services authority now makes deprivation payments to the practice worth £29 000 a year. Decisions made by the Electoral Boundary Commission result in the allocation or denial of huge resources to primary care. A further revision of boundaries or small demographic changes could suddenly deprive our practice of over 15% of its capitation income. We cannot make long term financial plans in the face of such uncertainty.

I welcome the conclusion by Tim Crayford and colleagues that deprivation payments should be based on enumeration districts in future.¹ The practice would then be able to decide how to use these extra resources. As well as asking the Department of Health to make this change now I would like the philosophy behind these payments to be clarified. I believe that they should be regarded as a supplementary capitation fee to allow practices in deprived areas with high workloads to maintain