Genetic counselling

SIR

The question of what counts as success in genetic counselling is discussed by Chadwick (1) and Clarke (2). They agree that measuring the effectiveness of genetic counselling by number of termination of pregnancies is inappropriate.

Clarke suggests an alternative outcome measure of workload, but Chadwick regards this as inadequate. She also considers the 'right to choose' (or autonomy) to be an inadequate outcome measure. Autonomy is a process rather than an outcome. It is a means to an end. But what end?

She says that one cannot avoid the question of 'what is the objective of genetic counselling'? It is, she suggests, to give options that may improve the genetic health of individuals, thereby improving the genetic health of the population. This is not eugenics, in that the population result is a by-product of giving choice, albeit a restricted choice, to individuals, rather than a government policy. In order to avoid any possibility of hidden coercion, Chadwick suggests that the objective of genetic health be explicitly stated.

Giving choice is not a neutral activity. It involves giving information, and giving information is of necessity selective. What information is given, and how it is presented, is influenced by certain factors, for example, counsellors' beliefs about the objectives of counselling and how to achieve 'non-directiveness'.

So talk of autonomy or workload does not answer the question of what genetic counselling is aiming to achieve, or what counts as success. These questions need to be answered if patients are to be better informed about the service they are being provided with, as advocated by Chadwick.

Clarke tries to deal with the problem by broadening the remit of genetic counselling beyond information relevant to reproductive choice to diagnosis and support for those with genetic disease, and by broadening the measure of effectiveness beyond workload to include patient and referrer satisfaction. Both are steps in the right direction, but they are not sufficient. First, I will deal with the process of counselling; second, with the outcome, and third with the input.

Effective counselling requires effective communication: giving information that is relevant to patients' concerns in a way that is easily understood. We know something about what issues genetic counsellors address, but less about whether these are the issues of most concern to patients (3). We have little information about the extent to which patients' views are elicited or the extent to which counselling style is 'non-directive'.

In terms of outcome, we know something about what patients recall of what they have been told, but less about what they understand and value of what they have been told (4). We know little about the extent to which counsellors have accurately judged patient concerns or met their needs.

Neither patient nor counsellor comes to the consultation as a blank sheet. Each brings their experience, expectations and beliefs. These will shape the process of the consultation and may be important in understanding the outcome and how it is achieved.

In conclusion, there appears to be a lack of clarity about what counts as success in principle. Despite this, we can make progress in answering the question of what counts as success in practice. The empirical study of the processes of counselling, and how they relate to a variety of outcome measures, can inform us as to what the active ingredients of counselling are. Once this is known, the discussion of which of the active ingredients count as effective will be easier. Any discussion of effectiveness, evaluation or success inevitably raises the question of objectives, which include value systems. The discussion between Chadwick and Clarke is useful in helping to make this explicit amongst health professionals, as a first step to enabling it to be made explicit to patients. The debate about 'what counts as success in genetic counselling?' would be strengthened by:

* more evidence about the input to, the processes and outcomes of counselling, and the relationships between them, and
* the inclusion of purchasers and users of the service.

References

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