Comment

On p 799, Decruyenaere *et al* report on adolescents' opinions about genetic risk information, prenatal diagnosis, and termination of pregnancy. This is a topic that should be of interest to us all, since people of this age group are the potential parents of the future. So what can this study tell us?

Psychology has two main potential roles in this area. There is "effects of" psychology, which looks at existing situations and describes the effects that these have on people, for example, anxiety associated with prenatal screening, depression following predictive testing, and so on. The other role for psychology is in attempting to explain what people do. One of the benefits of this is that it allows us to be predictive and to anticipate people's behaviour and reactions. Such predictions can be made on the basis of theories developed from "effects of" psychology or from pre-existing psychological theory: for example, psychological work on decision making is increasingly being applied to genetic testing situations. A third approach to prediction, as in this case, is to ask people questions about how they think that they would react in some hypothetical scenario.

The latter course may have an intuitive appeal, but, unfortunately, does not have a very good track record of getting it right. The demand for predictive testing for Huntington's disease is one classic example, demand for CF carrier testing another. In both cases demand was severely overestimated. (What the CF carrier testing studies have shown is that willingness to accept testing (as opposed to actively seeking it) is highly dependent on the context in which it is offered. So high rates of uptake can be achieved, but that is not the same as demand.) One reason for this may be that until faced with a real situation one simply cannot know what all the factors contributing to decision making will be. Another is that those for whom the questions are only hypothetical are likely to be poorly informed. Certainly this is true for these Flemish adolescents; the list of disorders volunteered makes it clear that they have little first hand experience of serious genetic disorders, and also that they do not necessarily know which disorders are genetic and which are not. In this respect they are probably typical of adolescents elsewhere. Thus, unfortunately, we really do not know what they understood by a "severe genetic disorder" when answering these questions.

The study asked two questions about society's role that students were invited to agree or disagree with: "Society has to try to prevent the birth of seriously handicapped children by giving information to the general population" and "Society has to try to prevent the birth of seriously handicapped children by stimulating young couples to ask

a doctor for information before having children". These were endorsed by 77% and 66% respectively. Unfortunately, the form of these questions does not allow us to know whether it is the goal of prevention that is being endorsed or the responsibilities of society to provide information, or both. However, whichever interpretations respondents had in mind, there is certainly a strong suggestion of much greater enthusiasm for these points of view than appears from questions concerning their own, hypothetical, behaviour. Even though the data were obtained in a context in which students will have wanted to give the "right" answer, only 17% said that they would "definitely" seek information and another 39% "probably". More striking still (but many were Catholics), only 13% said that they would "decide to terminate a pregnancy of a child with a serious genetic disease" and 57% were sure that they would not. Eleven percent explicitly stated that they would not want information because they would not want to act on it. So, considering what we know about the typical overestimates of hypothetical exercises, this would seem to be evidence of a considerable lack of interest among these adolescents in using genetic information.

It can be argued that these results would not apply in countries where fewer people have religious objections to abortion. Nevertheless, the apparent lack of interest in either having information or acting on it does raise more general questions, especially given the apparent public apathy with regard to cystic fibrosis carrier testing. It is frequently stated that the role of education campaigns associated with genetic testing is to allow people to make informed choices. This is a good aim, but what do we do if people apparently do not want to make those choices? To what extent do we have a responsibility to provide information that people will not want to act on? Is there, in fact, a responsibility to give people at least a minimum amount of information (even if they think that they do not want it), so that they can be making an *informed* decision not to have more information? To answer these questions, we need to give deeper thought to the motivation for genetic information campaigns and the ethics of information giving.

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The authors of the original paper have responded to this commentary on p 836.