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Dealing with moral dilemma raised by adaptive preferences in health technology assessment: The example of growth hormones and bilateral cochlear implants

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ABSTRACT

The aim of this article is to assess dilemma raised by adaptive preferences in the economic evaluation of growth hormone (GH) treatment for non-GH-deficient short children, and of bilateral cochlear implants for deaf children. Early implementation of both technologies and their irreversible consequences increase the potential conflicts faced by the assessors of health-related quality of life (HRQoL) states (on behalf of patients) who could be interviewed (parents, individuals with an experience of the same disability, or representative samples of the general public). Indeed, assessors' preferences may be influenced by their own situation and they are likely to vary according to age and the experience of disability. Three options are put forward which aim to resolve these moral dilemma and help economists make methodological choices that cannot be avoided in order to carry out this assessment. They are grounded on three specific egalitarian theories of social justice. The main contribution of this article is to show that a dialogue between ethics and economics, prior to an assessment, makes it possible to redefine the choice of effectiveness criteria (subjective well-being, capabilities or social outcomes), the choice of perspective (patients or the able-bodied), as well as the scope of assessment (medical and non-medical care).

Introduction

Context

From 2007 to 2011, the French National Authority for Health (HAS) was asked to assess recombinant growth hormone (GH) treatment for non-GH-deficient short children, and bilateral cochlear implants for deaf children, in order to question the relevance of their coverage under French national health insurance. Both health technologies have to be introduced as early as possible in patients' lives to improve their effectiveness (from the first year for cochlear implants and from the age of 4 for GH), and both have irreversible consequences resulting from:

(1) the medicalisation of the child's life induced by daily injections for GH treatment or surgery, and intensive speech therapy for cochlear implants;
(2) their impact on physical appearance, functional capacities, tastes, skills or life projects.

Meanwhile, there are also consequences when deciding not to implement these technologies. Due to social stereotypes, short stature may induce psychological suffering in children and future adults (HAS, 2012). An American study of 166 short children referred for consultation showed that these children have some behavioural disorders, lower educational achievement and lower social integration (Stabler et al., 1994). Studies showed that men with bigger stature are associated with greater qualities related to social and professional success: persons whose jobs are socially best-valued tend to consider themselves taller (Voss, 2006) and marriage is less common among short men, while tall men are less likely to be single (Herpin, 2003). However, the causal relationship between increasing adult height with GH treatment and improvements in quality of life is not really demonstrated. Similar issues arise for bilateral cochlear implants. They provide deaf children with better listening comfort through the ability to hear sounds in stereo. This enhances their capacities to understand speech in noisy conditions and to perceive better where sounds are coming from. But it has no incremental effectiveness on oral language acquisition, compared with unilateral implantation.

Deciding whether or not to reimburse these technologies determines accessibility of children to them, whatever parents' income level. Yet, as the financial resources of national health

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insurance are not unlimited, the needs of children with short size or deafness compete with the needs of other individuals. The total cost per patient of GH treatment, over several years, ranges from €30,000 to €33,200, while the effectiveness is about 2 cm gained in adult height (HAS, 2012). Costs related to unilateral cochlear implants have been evaluated at an average of €35,000 per child for the first year (including the surgical implementation and the cost of the device), while costs of bilateral implantation are about twice as high (HAS, 2007). Therefore, in order to decide whether it is appropriate for national health insurance to cover these two health technologies, it is important to be able to assess whether their benefits are worth the costs.

The issues to be examined

Economists used to measure the outcome of health technologies in terms of their impact on individuals' welfare, through preference elicitation methods. As children cannot be considered as fully rational agents, it could be risky to consult them directly to elicit their preferences, as can be done with any consumer making choices under normal market conditions. Therefore, proxy respondents speaking on children's behalf need to be interviewed. Nevertheless, empirical research conducted to study the shaping of individual's preferences concludes that values assigned to health improvement may vary among individuals, with regard to their age and their experiences in terms of health states. Moreover, using data collected from a large "living with a disability" study, Albrecht and Devlieger have pointed to the existence of a disability: 53.3% of persons experiencing serious disability during the course of their lives reported that they had an excellent or good quality of life (Albrecht & Devlieger, 1999). Therefore, the choice of proxy respondents (parents, individuals with an experience of the same disability, or representative samples of the general public) may generate systematic bias. No data exists which specifically concerns conflicts of preferences relating to short size of deafness. However, as shown in Section 2, the assumption of variations of health related preferences seems particularly relevant in the context of short size and deafness. As the gap between values reported by the different proxy respondents could affect the results of the assessment, methodological choice regarding the selection of proxy respondents raises a moral dilemma for the economists.

First, it seems consistent to base the assessment on the preferences of individuals who actually have a personal experience with a disability, because the preferences of healthy individuals are more a matter of belief and are not based on any real experience of disability. Nonetheless, able-bodied individuals do enjoy greater autonomy because they do not suffer from a disability. As a consequence, they are offered opportunities which disabled individuals cannot experience. In this respect, able-bodied individuals are better placed to gauge the extra-welfare resulting from those opportunities. Therefore, there is no reason to give priority to the former (patients) or the latter (healthy individuals) in evaluating outcomes of GH treatment and bilateral cochlear implants. Indeed, both groups can claim to report an accurate experience: the experience of the disability *versus* the experience of opportunities provided by health (no disability).

It is usually recommended to base the assessment on the preferences of individuals in the general population. Patients are asked to describe their state of health, but they are not the ones who are asked to evaluate their potential health improvements (Brazier, Ratcliffe, Salomon, & Tsuchiya, 2007). The reasons for this are: i) it is preferable to base the assessment on preferences of taxpayers, and ii) it is better to base the assessment on preferences expressed by individuals behind "the veil of ignorance", who have no knowledge of their future state of health (Gray, Clarke, Wolstenholme, & Wordworth, 2011). The principal argument against these justifications, especially when looking at the two above-mentioned technologies, concerns the reference to the veil of ignorance. Non-GH deficient shortness and deafness at birth are two congenital disabilities. Individuals drawn from a representative sample of the general population are certain they will never be affected by these disabilities. This is obvious for shortness, but it is also true for deafness. The lives of individuals who become deaf are not the same as persons born deaf, as their ability to use oral language varies strongly between these two situations. The specificities of both treatments require renewed debate on the choice of the perspective for assessment. The question raised here is normative, and not positive. It indeed concerns asking which individuals should be sounded in order to estimate the values of changes in patients' health-related quality of life, given that preference adaptation phenomena may occur. This is not a matter of looking at the quality of information about states of health for which individuals have to express their preferences. To be sure, differences in conflicts of preferences could be explained by the weaknesses in the description of a disability provided to individuals who have not experienced the disability when forming their preferences. But this is another question, a positive one which generally arises with regard to methods for assessing health improvements, whatever the health technology assessed.

In this article, it is assumed that the community seeks to apply an egalitarian theory of justice in terms of allocating health resources. Three options have been identified, each of which is based on a different choice in terms of the *equalisandum* (the object whose distribution across the population is to be guaranteed): opportunity of functioning, welfare chances and fundamental social outcomes. This paper shows that each of these options proposes distinct ways of treating preference adaptation phenomena and that they have very different consequences for the methods of evaluating the two technologies.

The following sections of this article review the main studies which have demonstrated the impact of adaptive preferences in evaluating the outcomes of health technology (Section 2). Section 3 identifies several options on the basis of theories of egalitarian justice for resolving the dilemma raised by the conflict of preferences. The main arguments which can be put forward in criticism of these three options are discussed in Section 4.

Adaptive preferences: why they are likely to occur in growth hormone treatment and cochlear implants assessments

Life-long variations of health related preferences

According to Sackett and Torrance, values given to quality of life improvements decrease all along patients' lives, compared to the values given to increased life expectancy, when using the time-trade-off (TTO) elicitation method (Sackett & Torrance, 1978). These findings are challenged by Dolan's study, according to which individuals, until the age of 40, are more and more willing to accept a decrease in quality of life in exchange of increased life expectancy. Then, trade-offs between increased life expectancy and quality of life reverse. Beyond the age of 40, individuals give more and more value to their quality-of-life compared to the value given to their life expectancy (Dolan, Gudex, Kind, & Williams, 1996). Consequently, when groups comprising people with every age are interviewed to value health improvement, preference variation spanning lifetimes cancel out, e.g. health related utility values of the EQ-5D (EuroQol-5 dimensions) scoring function are assessed within a representative sample of the general public over 18 years old. In contrast, if a group of persons interviewed is more homogeneous in terms of age, then health-related, life-long preference