Patient perspective is becoming increasingly important in healthcare decision making. Patients should be involved as ‘end-users’ in the health technology assessment (HTA) processes to broaden the perspectives of the assessors and advice provided to decision makers. Patients can provide information on their daily experience with disease, treatments, and their needs, provide views on aspects not measured in studies, or state their preferences for various therapy aspects and treatment endpoints.

Health technology assessment (HTA) agencies include patient views in their processes in different ways and to different extents (Figure 1). Patient views and preferences can be captured either by engaging patient organisations, the patients themselves, or informal carers in the healthcare setting (as is done for example in the UK or Canada and some other countries). Such patient aspects can also be explored in qualitative and quantitative studies which are considered as part of evidence documentation by the assessment committees.

Clinical studies often feature patient-reported outcomes, such as quality of life, which report the patients’ status in several dimensions (e.g. physical, mental, functional, social and emotional). These outcomes are focused on the health state the patient is in, rather than trying to identify or value how patients feel about being in that state of health. On the other hand, patient preferences regard measuring the patient’s value for a specific component or attribute. By exploring how patients trade between various components the relative value of each component can be determined. It has been documented in literature that patient preference methods are more grounded in economic theory and are more patient-centred than the quality of life measure1. It is also important to note that patient preference methods are very flexible and adaptable to practically any health-related question. For example, they offer the option to quantify trade-offs between health outcomes and other treatment features, the risk/benefit trade-offs, or monetary valuation related to treatment options.

OBJECTIVES

To explore the inclusion and evaluation of patient preference data in AMNÖG early benefit assessments.

METHODS

We reviewed value dossiers and the corresponding benefit assessments in Germany from 1st January 2011 to 31st March 2014. Types of patient preference data included in the value dossiers, and their consideration in the assessments, were collected and summarised.

RESULTS

A total of 68 dossiers were analysed. 18 dossiers (26%) included data on patient preferences. As shown in Table 1, patient preference data related to:

- relevance of different treatment endpoints from the patient’s perspective in oncology, hepatitis C, diabetes, or HIV infection,
- patient preference for a specific drug administration route (e.g. oral vs. injections), administration system (e.g. different inhalation systems), or administration frequency
- patient preference for therapy duration or type of therapy.

In none of the assessment reports did the evaluating committee specifically address the evidence presented on patient preferences. A comment on patient preference data was given in one assessment report only (for aciclovir). The manufacturer stated that patient preference for their drug delivery system positively impacts patients’ quality of life. The committee, however, noted that patient preference for the administration system is not a measure of quality of life which itself relates to the physical, mental and social well-being of a person.

CONCLUSIONS

About a quarter of the value dossiers referred to data on patient preference. Surprisingly, it appears that the evidence on patient preference was not considered in the AMNÖG benefit assessments, despite the fact that benefit to the patient is the central criterion of the AMNÖG early benefit assessment.

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