Global Observatory and Database on Donation and Transplantation: World Overview on Transplantation Activities

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ABSTRACT

Introduction. The Global Database on Donation and Transplantation is one of the main areas of the Global Observatory on Donation and Transplantation (GODT), which is the information platform designed to implement some of the requirements of the World Health Assembly Resolution WHA57.18.

Objectives of the Global Database. The objectives are to collect, analyze, and disseminate information on legislative and organizational frameworks and annual aggregated data on donation and transplantation activities of the World Health Organization (WHO) Member States. Another objective is to establish the transplantation network with the national health authorities. The database should provide a working tool that helps to exchange information and be a reference for professionals involved, promoting international cooperation through the website.

Methods. The data collection for the Global Database is done through a specific questionnaire, including questions on legislation, organizational systems, and updated data on organs, tissues and cells donation, and transplantation from each country. For the statistical analysis of activity data, descriptive statistics have been used.

Results. The Global Database has organizational and legislative pieces of information of 94 countries. In 2007 activity data of 97 countries have been analyzed. Reported to the database were 21,489 deceased donors. Currently around 100,000 solid organ transplantations are performed per year worldwide: 68,250 kidney, 19,850 liver, 5179 heart, 3245 lung, and 2797 pancreas transplantations.

Conclusions. This kind of tool is necessary to improve knowledge about the donation and transplantation activities over the world. Close collaboration with countries is crucial to obtain reliable data.

Currently there are almost 100,000 solid organ transplantations performed annually all around the world and the demand is increasing continuously. Although several countries, mainly in the developed world, introduced compulsory registration of donation and transplantation procedures, and some other voluntary registries also existed, there was no comprehensive system to collect donation and transplantation data all over the world.

The mission of the World Health Organization (WHO) in the area of transplantation is to meet the requirements of the WHA 57.18 Resolution on Human Organ and Tissue Transplantation that was adopted in the fifty-seventh World Health Assembly. In this Resolution it was requested to collect global data on the practices, safety, quality, efficacy, and epidemiology of allogeneic transplantation as well as their global availability for all those concerned, including professionals, patients, politicians, and the general public, which is recognized as a prerequisite for global improvement of and better access to transplantations.

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To carry out the objectives of Resolution WHA 57.18, WHO has developed the Global Knowledge Base on Transplantation (GKT).)

The GKT has 4 components:

1. GKT1, Activities and practices in allogeneic donation and transplantation: number of donations and transplantations carried out globally, access, and outcomes of transplantations.
2. GKT2, Legal framework and organizational structures for allogeneic transplantation.
3. GKT3, Threats and responses, reference information, and vigilance and surveillance of risks to safety and ethics in transplantation.
4. GKT4, Xenotransplantation.

GKT1 and GKT2 lead to the Global Observatory on Donation and Transplantation (GODT).

Since the beginning of its activities in the transplantation area, WHO has received the support of different countries, institutions, and some nongovernmental organizations. Due to the extensive experience of the Spanish National Transplant Organization (ONT) in creating and maintaining a database on transplantation, derived from the Newsletter database on behalf of the Council of Europe, and its ongoing extension to the countries of South America through the Alianza Programme, the cooperation between Spain and Latin America and the network of health authorities responsible for transplantations, established by the Pan American Health Organization (PAHO/AMRO) and the cooperation in recent years between ONT and the WHO Essential Health Technologies Department/Clinical Procedures Unit (HTP/EHT/CPR), ONT became a WHO Collaborating Centre. The structure, background, stability, and experience of ONT were offered to the WHO to support the partnership in developing the GODT.

As a WHO Collaborating Centre, Spain provides the necessary technical and budgetary support to carry out and maintain such a program. The main aims can be summarized as follows: (1) creation and maintenance of a Technical Unit covering the following activities: data collection, analysis and validation, production of reports, development, and maintenance of the website platform of information; and (2) creation and maintenance of a Coordinating Unit covering the following activities: administrative link with WHO Headquarters, scientific and advisory board, and planning and implementation of new projects and programs.

Therefore, the GODT is the information platform that ONT has developed in collaboration with WHO to implement some of the requirements of the Resolution WHA 57.18 and the GKT1 and GKT2 components; it has been available since 2007 (www.transplant-observatory.org) (Fig 1).

GODT is intended to be used as a working tool for the exchange of information for the people in charge of transplantations from countries and regions and working groups who are taking part in the Transplant Worldwide Network. It also provides an interface for health authorities and the general public to access data on donation and transplantation practices and on the organizational and legal framework.

The GODT has different kind of access to facilitate the use and management of the information. The general
The public has access to general information, published documents, and activity data on donation and transplantation. Authorized users have a password to access a restricted area with working documents and the questionnaire to be filled in every year.

Apart from the Global Database, the GODT has other areas of information. The General and Public Information section includes the following: general information about the WHO, ONT, and collaboration between these 2 institutions and their common projects; newsroom with information about events of the transplantation area, press releases, and media information; become a donor with videos, media campaigns, and other activities to promote organ donation; library including technical or scientific documents and guidelines classified by means of a specific thesaurus designed for the GODT and a search tool to look for documents in this section; selection of links to websites of national transplant organizations, transplant societies, scientific journals, and other bibliographic resources, education for transplantation and international transplant organizations or projects, transplantation registries, and other; and search tool for people of the Transplant Network.

SPECIFIC OBJECTIVES OF THE GLOBAL DATABASE ON DONATION AND TRANSPLANTATION

Specific objectives are as follows: to collect, analyze, and disseminate information on legislative and organizational aspects, in addition to the annual aggregated data on donation and transplantation activities of the WHO Member States; to facilitate the establishment and maintenance of the network of focal persons in the field of transplantation; and to provide a working tool for the exchange of information, a reference for the professionals involved, and promotion of international cooperation through the website.

WORK METHODOLOGY FOR THE GLOBAL DATABASE ON DONATION AND TRANSPLANTATION

The field for this project includes all WHO Member States. The data collection of the Global Database is done through a questionnaire specifically designed by and approved for this project by the ONT-WHO working group. The questionnaire is available on the website for every country (Fig 2) and includes questions on legislation, organizational aspects for donation and transplantation on organs, tissues, and cells, and updated aggregated activity data on organs, tissues, and cells (Table 1).

Most of the questions about legislation and organizational system are qualitative with yes/no answers, nevertheless there are others designed to include comments and brief explanations. A user guide has been prepared to make completion of the questionnaire easier. It is essential to avoid different interpretations of the questions depending on the cultural aspects, languages, or organizational frameworks in the countries.

The data available at this moment in the Global Database come from 2 sources. The first source is the Newsletter Transplant International database. It has provided aggregated activity data since 2000 to 2007 from most of the European countries, United States of America, Canada, New Zealand, Australia, and Latin America countries. The
second source is the Global Database questionnaire, which is currently available online, although it was distributed by e-mail at the beginning of the Project. At present the health authorities have designated a focal point or focal person in each country who is responsible for updating the activity, legislative, and organizational information of the database on a yearly basis.

The general public can look up all the data and obtain basic statistics, by means of tables or graphics, using the website software. In addition, the ONT/WHO working group provides reports with more complete analysis of the data.

RESULTS

At present the Global Database compiles information on the organizational and legislative frameworks from 94 countries. We know that 74% of these countries have an official body responsible for overseeing and coordinating donation and transplantation activities about organs at a national level and 82% have specific legislation for organ procurement and transplantation.

Activity data have been analyzed for 97 countries in 2007; they represent nearly 80% of the worldwide population (4 countries are from the Africa Region, 20 countries are from the Region of Americas, 14 countries are from the Eastern Mediterranean Region, 40 countries are from the European Region, 6 countries are from the South East Asia Region, and 13 countries are from the Western Pacific Region). They also represent most of the countries with donation and transplantation programs. Although some countries do not provide complete data of deceased donation, information from 21,489 deceased donors was reported to the Global Database.

Around 100,000 solid organ transplantations are performed per year worldwide: 68,250 are kidney transplantations (45% from living donors), 19,850 are liver transplantations (14% from living donors), 5179 are heart transplantations, 3245 are lung transplantations, and 2797 are pancreas transplantations.

Table 2 includes detailed data about transplantation activity depending on WHO region.

CONCLUSIONS

This kind of tool is necessary to improve knowledge about the donation and transplantation process over the world. Cooperation of countries is crucial to obtain reliable and high-quality data and to use them to know the differences between regions and countries on legislation, organizational systems, and possible relationships between these factors and the donation and transplantation activities.

The Global Observatory and Database is a dynamic and creative project in continuous development. Its design and implementation have needed the close cooperation be-

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**Table 1. Main Items of the Global Database Questionnaire**

<table>
<thead>
<tr>
<th>Organizational system</th>
<th>Legislative system</th>
<th>Activity data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Official body or specific organization responsible for overseeing and coordinating donation and transplantation activities about organs, tissues, and cells. Activities, report, and funding of this organization.</td>
<td>Specific legislation for donation and transplantation activities. Role of the national health authorities in the regulation and oversight of the donation and transplantation activities, including authorization and licence for transplantation. Legal requirements for quality, efficacy, and safety of the donation and transplantation procedures. Legal requirement for consent to donation from deceased and living donors. Legal requirements and restrictions for living donation. Penalties in the event of commerce with donated organs, cells, and tissues. Explicit prohibition of organ trafficking in the legal framework. Distribution and allocation criteria for organs, tissues, and cells. Confidentiality and traceability specified by law. Import and export of organs, cells, and tissues controlled by law.</td>
<td>Number of transplantation centers. Organ donation activity. Organ transplantation activity (kidney, liver, heart, lung, pancreas, small bowel, and multivisceral). Donation and transplantation activity on tissues and cells.</td>
</tr>
</tbody>
</table>

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**Table 2. Transplantation Activity: Year 2007**

<table>
<thead>
<tr>
<th>Region</th>
<th>2007 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa Region</td>
<td>378</td>
</tr>
<tr>
<td>Region of Americas</td>
<td>26,086</td>
</tr>
<tr>
<td>Eastern Mediterranean Region</td>
<td>6296</td>
</tr>
<tr>
<td>European Region</td>
<td>19,523</td>
</tr>
<tr>
<td>South East Asia Region</td>
<td>5490</td>
</tr>
<tr>
<td>Western Pacific Region</td>
<td>10,477</td>
</tr>
<tr>
<td>Total</td>
<td>68,250</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Region</th>
<th>2007 Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney transplantations</td>
<td>378</td>
</tr>
<tr>
<td>Liver transplantations</td>
<td>36</td>
</tr>
<tr>
<td>Heart transplantations</td>
<td>26</td>
</tr>
<tr>
<td>Lung transplantations</td>
<td>7</td>
</tr>
<tr>
<td>Pancreas transplantions</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>457</td>
</tr>
</tbody>
</table>
tween the ONT, the WHO HTP/EHT/CPR, and the focal points in the participant countries.

REFERENCES


