

Infodemiology of solid organ transplantation: relationship to the Global Observatory on Donation and Transplantation data

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Abstract. – OBJECTIVE: Although transplantation medicine has been continuously improving, its impact on the general population needs to be evaluated. This study describes the global community interest in solid organ transplantation (SOT) using Google Trends, comparing relative search volumes (RSVs) and data from the World Health Organization (WHO) Global Observatory on Donation and Transplantation (GODT) regarding SOT activity all around the world.

MATERIALS AND METHODS: The online interest for the search terms “kidney transplantation”, “liver transplantation”, “heart transplantation” and “lung transplantation” was measured, evaluating RSVs and the number of worldwide SOT recorded in the GODT website from 2008 to 2018.

RESULTS: The mean values of RSVs were 51.7 ± 16.8 for liver transplantation, 39.8 ± 9.6 for kidney transplantation, 22.4 ± 7.4 for heart transplantation and 15.4 ± 5.2 for lung transplantation, and these values gradually reduced during the study period. Anglo Saxon countries had the highest interest for SOT, and the mean values of RSVs per year and annual numbers of SOT were inversely correlated.

CONCLUSIONS: Despite the apparent interest and awareness, we found that public interest in SOT is decreasing. Access to information is crucial for improving understanding of transplantation and motivation to donate. Health care professionals could take advantage by using the internet, and evaluation of RSVs could represent valuable feedback.

Key Words:

Google trends, Infodemiology, Relative search volumes, Solid organ transplantation.

Introduction

Transplantation medicine has been continuously improving. Patients feel better due to a balance between function of the graft and psychological and physical well-being; therefore, a well-functioning transplant increases the quality of life¹. However, comorbidity increases the risk of death and hospitalization²⁻⁴, resulting in rising costs⁵.

Internet searches are constantly developing, and we are now in the era of information overload. Data produced by searches constitute big data, a source of information characterized by exponentially rising volumes and a wide range of datasets, veracity, value, variability, volatility and validity⁶. Google Trends (GT) is a popular tool used to assess information on human behaviour, public health and medicine. A decade ago, Ginsberg et al⁷ evaluated the predictive power of GT on the spread of influenza. By analysing Google search queries to track influenza-like illness, such as influenza-like symptoms, they suggested that it is possible to estimate influenza activity in different geographical areas. Such a method makes it possible to use search queries to detect influenza epidemics⁷. A series of characteristics, such as being an excellent platform for evaluating information seeking activities, immediate adaptability to users' needs, friendly use and its options for comparison, make GT a popular source for big data research⁸. Currently, searching for information in the World Wide Web is very common. Google represents one of

the most popular search engines, and the word “googling” has come to mean the act of looking up something new on an internet search engine regarding a specific item. Recently, researchers have begun performing epidemiological investigations based on internet-derived information. GT generates data on geographical and temporal patterns according to specific keywords. On the other hand, people affected by different diseases also use the internet to acquire more health information. Health care professionals should be aware of this change, and in fact, modern health care systems are adjusting to a patient-centred approach⁹. We previously described GT patterns regarding interest in medication errors, risk management and shift work¹⁰. The aims of this study were i) to calculate mean relative search volumes (RSVs) for solid organ transplantation (SOT) from January 2008 to December 2018 to describe global community interest in transplantation; ii) to evaluate temporal patterns of RSVs for liver, kidney, heart and lung transplantation, relating them to data from the World Health Organization (WHO) Global Observatory on Donation and Transplantation (GODT)¹¹; iii) to evaluate the global distribution of RSVs for solid organ transplantation (SOT); and iv) to plot annual RSVs and annual numbers of liver, kidney, heart and lung transplantations to assess the type of relationship.

Materials and Methods

Infodemiology has become a popular area of research focusing on general interest in health related content¹². Google Trends (GT) is a free publicly available, internet-based, popular tool aimed at describing information on human behaviour, public health and medicine, representing a platform for evaluating information seeking activities. It has been established that studies utilizing GT for health care research could be classified into 4 topic domains: infectious disease, mental health and substance use, other non-communicable diseases, general population behaviour. Data from GT could be analysed for causal inference, description, and surveillance¹³. GT allows searching limited to a well-established period of time (weeks, months, or years), and RSVs for given search terms with a value between 0 and 100 are obtained. If during the selected period of time, no significant searches were performed, RSV is equal to 0. If during the selected period of time

half as many searches are executed, RSV is equal to 50 and if matched with the highest volume of searches, it means that RSV is equal to 100. Data on temporal patterns of relative interest between different areas are adjusted for population size. Each data point is tailored considering the total searches of the geographical area and the time interval that it represents for comparison of relative frequency and for standardizing data between different countries¹⁴. We investigated the search terms “kidney transplantation”, “liver transplantation”, “heart transplantation” and “lung transplantation”. To avoid possible confounding results, the search was performed only in the category “Health” to limit non-health related queries. GT was analysed from January 2008 to December 2018 to obtain results related to the same time interval that was used for obtaining data from the WHO GODT website on kidney, liver, heart, and lung transplantation. Data about kidney, liver, heart and lung transplantations, starting in 2008 and ending in 2018, were obtained by accessing the WHO GODT website¹¹. We calculated mean RSVs and yearly mean RSV values during the study period, analysing their global distribution and temporal patterns, comparing results with the numbers of SOT performed worldwide each year. The results were plotted in graphs, and a descriptive analysis was performed.

Results

Mean values of RSVs during the study period were 51.7 ± 16.8 for liver transplantation, 39.8 ± 9.6 for kidney transplantation, 22.4 ± 7.4 for heart transplantation and 15.4 ± 5.2 for lung transplantation. The values of RSVs during the study period are shown in Figure 1. General population interest for SOT gradually decreased from 2008 to 2018.

Annual mean RSV values and numbers of kidney, liver, heart, and lung transplantation are reported in Table I. The worldwide distribution of the highest RSVs is reported in Figure 2. The United States of America, Canada, the United Kingdom, and India appear as countries where the interest of the population is higher for SOT.

The relationship between the annual numbers of SOT and annual mean RSV values is illustrated in Figure 3. While the number of SOT gradually increased during the study period, general interest for such procedures decreased, suggesting an inverse relationship.

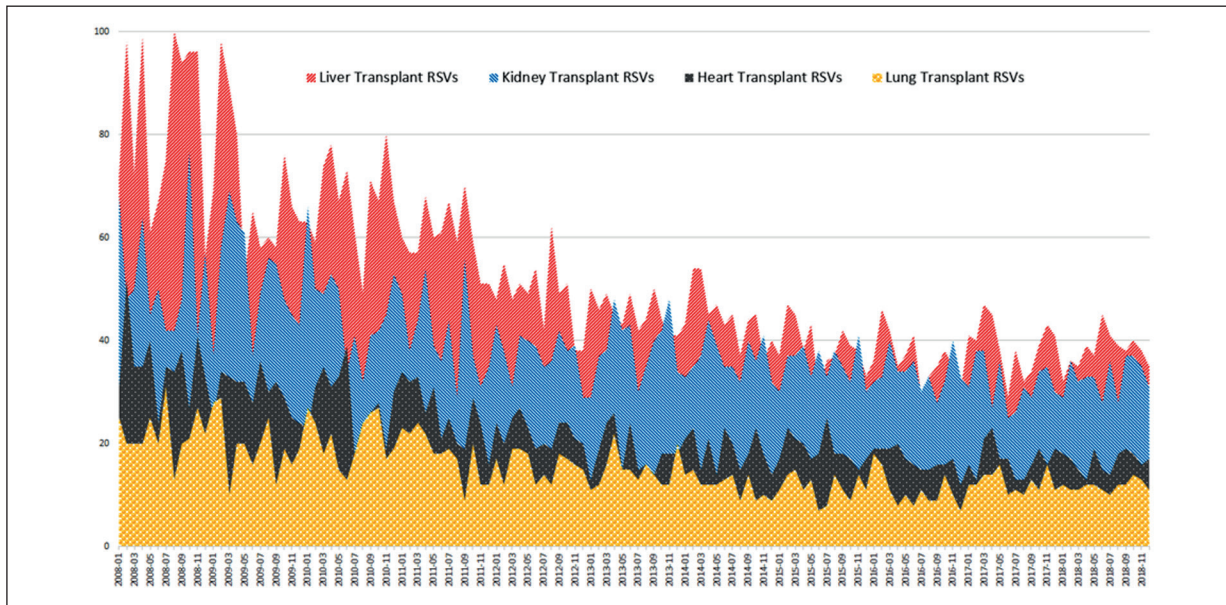


Figure 1. Relative search volumes (RSVs) for liver transplantation, kidney transplantation, heart transplantation, and lung transplantation, from 2008 to 2018.

Discussion

We found that public interest in SOT is decreasing. This observation confirmed results from a recent paper adopting a similar study design using GT data that showed during a period of 15 years, worldwide RSVs related to kidney transplantation decreased by 66.7%¹⁵. Our results underline that the inverse relationship between SOT numbers per year and mean annual RSVs is

confirmed for kidney transplantation, but it also exists for liver, heart and lung transplantation. Moreover, the Anglo Saxon populations seems to show the highest interest in SOT.

Global Data On Solid Organ Transplantation

The only treatment for end-stage organ failure, such as liver, heart and lung, is transplantation. Although the organ that is transplanted derives

Table I. Mean yearly relative search volumes (RSVs) for solid organ transplantation (SOT) and yearly numbers of SOT.

Year	Kidney transplant RSVs	Liver transplant RSVs	Heart transplant RSV	Lung transplant RSVs	Total kidney transplants	Total liver transplants	Total heart transplants	Total lung transplants
2008	52.7	82.2	35.4	22.0	69,312	20,280	5,327	3,329
2009	52.2	69.5	30.0	19.5	71,418	21,027	5,403	3,649
2010	46.3	67.4	27.4	20.8	72,975	21,610	5,582	3,927
2011	41.0	60.0	25.8	18.0	76,447	23,727	5,741	4,279
2012	37.6	48.8	22.2	15.8	77,788	23,986	5,935	4,359
2013	38.8	45.3	18.3	14.8	78,567	25,078	6,285	4,857
2014	36.6	44.4	18.8	11.9	79,110	26,337	6,580	4,704
2015	35.3	38.8	18.8	11.5	84,436	28,200	7,138	5,100
2016	33.8	36.4	16.8	10.9	85,508	28,972	7,673	5,505
2017	31.7	38.9	16.9	12.5	90,306	32,348	7,881	6,084
2018	32.9	37.9	16.6	11.8	91,465	32,162	8,071	6,266

Data are derived from the World Health Organization (WHO) Global Observatory on Donation and Transplantation (GODT)¹¹.

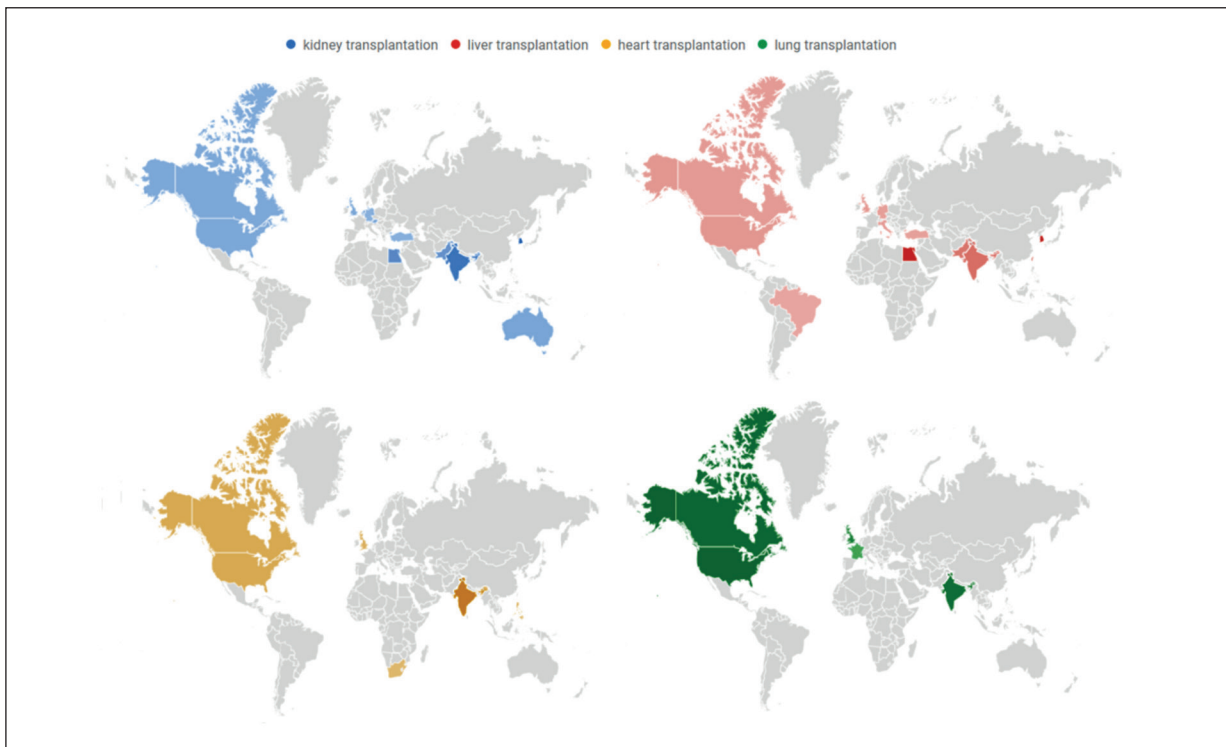


Figure 2. Distribution of the highest relative search volumes for solid organ transplantation all around the world (image captured from Google Trends).

from the body of a deceased person or from a well-selected living donor, transplantation procedures have to respect precise and well-defined

legal requirements, including adequate information. Data from the WHO GODT website shows that the numbers of SOT performed worldwide up

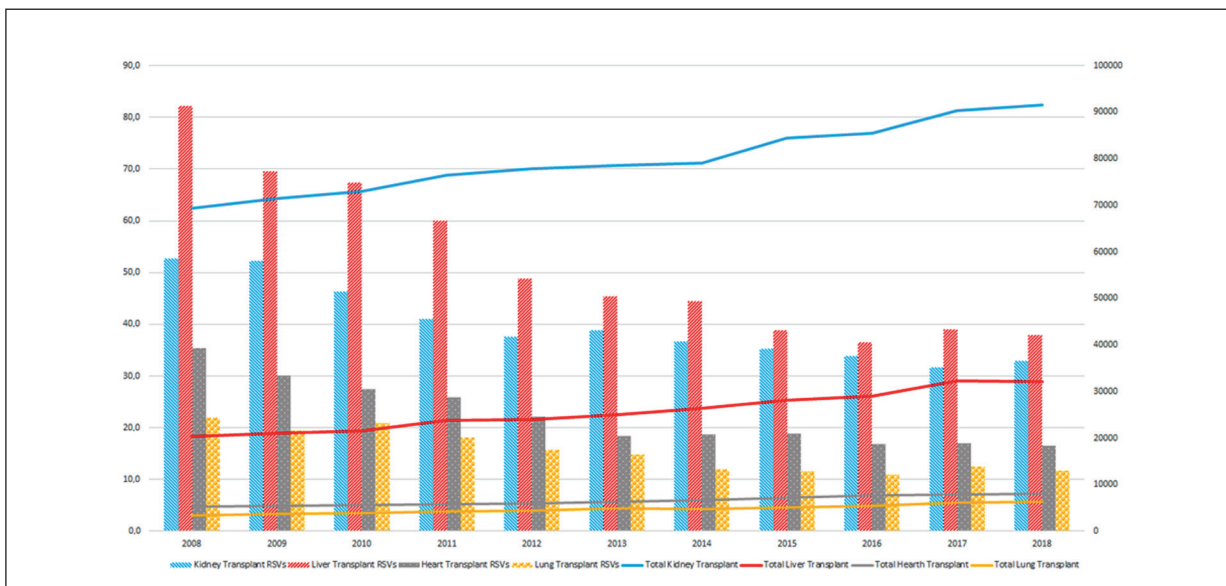


Figure 3. Relationship between annual mean relative search volumes (bars) and annual number of solid organ transplantations (lines). The latter data are derived from the World Health Organization (WHO) Global Observatory on Donation and Transplantation (GODT) [11].

to 2017 were 139,024, although this number represents less than 10% of the international need¹⁶. In their 2016 annual report, the European Renal Association-European Dialysis and Transplant Association (ERA-EDTA) registry stated that renal transplantations were 22,046, with large variations among countries/regions. The overall unadjusted transplant rate was 32 pmp, and the rate of deceased donor kidney transplant was much higher than the rate of living donor transplant (70% vs. 30%)¹⁷.

Googling of Solid Organ Transplantation and Neurocognitive Performance

In solid organ transplantation, psychological factors impact everyday activities, and depression and cognitive function are considered risk factors affecting long-term clinical outcomes, quality of life and neurocognitive performance¹⁸. Neurocognitive performance should be taken into consideration in subjects searching definite items on the internet, and subjective feelings, such as fear, could influence internet searching volume. The outbreak of an acute disease inducing a pandemic increases RSVs as in the case of influenza⁷. A well-functioning transplant improves quality of life, although the benefits of transplantation across organ type on quality of life do not reach the level of healthy controls due to the persistence of symptoms and side effects of immunosuppression¹⁹. On the other hand, Holster et al²⁰ assessed differences in preoperative expectations and postoperative quality of life in liver transplant patients. They found that patients' preoperative expectations of a normal lifestyle post-transplantation were predominantly optimistic (60%), while postoperatively, only 40% thought that their expectations were realized. The authors suggested that therapeutic measures, such as professional pre-transplant counselling, could be useful²⁰. However, all reported data partially explain our results, i.e., the decreasing interest in SOT, even if the finding that the numbers of SOT are increasing globally, suggesting a communication problem between the general population and management of SOT. On the other hand, this relationship could also mean that patients trust their health care professionals, since transplantation medicine is a very complex topic.

Infodemiology Of Solid Organ Transplantation

Eysenbach defined the concepts of "infodemiology" and infoveillance" as aiming to improve

the approach for public health^{21,22}. The scientific community recognizes infodemiology as a new science aiming to collect public health and policy information to evaluate its distribution and determinants on the internet²¹. Internet data represent a powerful tool for understanding human behaviour, and they are being increasingly integrated into health informatics research²³. Infodemiology might allow health care professionals to measure general population interest in different conditions, and GT is an easy way of doing this. On the other hand, infodemiology might suggest that health care professionals should help individuals in understanding and evaluating electronic health information, as in the case of very complex items, such as transplantation.

If knowledge of the general population regarding a given condition is poor, GT underestimates the real epidemiological burden. Media coverage is a major determinant of search volumes; however, the media overestimate benefits and exaggerate claims and may avoid disclosing risks and conflicts of interest²⁴, raising the question of the real role of the media when dealing with health²⁵.

Pre-existing knowledge plays an important role on the process of searching. When knowledge increases, in the same way, search activity rises but only up to a certain point. In fact, when knowledge is considered sufficient, search activity decreases. Thus, an inverse U-shape relationship with the peak at an intermediate level of knowledge is shown²⁶. However, likely does not explain our results because understanding transplantation medicine takes great effort and requires many time. In addition, it is necessary to consider that searching activity increases when the level of risk is high or when information is lacking²⁷. GT does not measure clinical data, but it deals with the need of information. Therefore, it takes into consideration the reactivity of global or different populations to an item that could be related to health, as recently shown by the statistically significant correlations between online interest and COVID-19 cases and deaths²⁸.

Limitations

This study has several limitations. First, we merely described an association between RSVs and SOT. Second, we analyzed the entire world; however, all searches were performed in English, not taking into account individual searches in other languages of different countries. On the other hand, the majority of transplant literature is written in English. Third, we could not dis-

tinguish living SOT from deceased; similarly, we could not detect who was searching for this information. Any particular individual might be associated with any of the queries in the Google database. The latter does not maintain information about the identity, internet protocol address or specific physical location of any user. In addition, the relationship between infodemiology and epidemiology is still a matter of debate. In 2017, the reliability of GT was tested in different clinical settings, including both common diseases with lower media coverage and less common diseases attracting major media coverage. The authors evaluated GT results using the keywords “renal colic”, “epistaxis”, and “mushroom poisoning”, “meningitis”, “*Legionella pneumophila pneumonia*”, and “Ebola fever”. The authors stated that no relationship existed between GT results and the epidemiology of renal colic, epistaxis and mushroom poisoning. In contrast, searching the term “mushroom” generated a seasonal pattern that almost overlapped with the epidemiological profile. GT results were not related to geographical or temporary patterns of disease for meningitis, *Legionella pneumophila pneumonia* or Ebola fever, suggesting that GT is not associated with the epidemiology of relatively common diseases, depending more so on minor media coverage. RSVs appeared to be more influenced by media clamour²⁹. Moreover, we did not examine the visibility of SOT websites. Visibility in search engines depends on the number of keywords, position of the website and URL³⁰. However, evaluation of health and medical websites was not one of our aims. Of note, only 7% of studies based on GT data could be reproduced¹³. Finally, in this study, we used web 1.0 technology, and we do not know whether investigating web 2.0, such as twitter, could result in different findings.

Conclusions

Recently, Luyckx et al³¹ wrote a review highlighting that management of end stage renal disease needs to include discussion of several ethical items, such as treatment. The authors stated that, in order to implement the development of ethics, health care professionals should first be educated. In the same way, all transplant programs require engagement with multiple stakeholders, including health care professionals, as well as patients and the general community³². We suggest that, such education should also involve patients and their

caregivers, and the results of this action could be measured using internet resources. Social media continues to increase in popularity; therefore they are powerful and important tools for health education, promotion and communication activities³³. The WHO stated that access to information is crucial if we aim to improve understanding of transplantation and motivation to donate³⁴. Health care professionals could improve understanding by using the internet, and evaluation of search volumes could represent valuable feedback.

Conflict of Interest

The Authors declare that they have no conflict of interests.

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Authors' Contribution

All authors have read and agreed to the published version of the manuscript.

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