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Infodemiology of renal diseases: a novel opportunity to investigate public global interest

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Abstract. – OBJECTIVE: The aim of this study was to investigate the global community interest about renal diseases through relative search volumes (RSVs) of Google Trends (GT).

MATERIALS AND METHODS: The online interest for the search terms hematuria (H), proteinuria (P), chronic kidney disease (CKD) and dialysis (D) was measured by evaluating RSVs from 2010 to 2019. All countries listed in GT were analysed and those presenting RSVs related to all search terms were considered following geographical position.

RESULTS: Mean values of RSVs for D, CKD, H and P were 80±9%, 11±2%, 17±2% and 11±1%, respectively. D is the search term most frequently typed in English-speaking countries. On the other hand, in Latin Countries, the interest for P and H was higher than D. Searching for D, CKD and H are highly correlated whilst correlation coefficients between RSVs for D, CKD, and H with P are lower. Since 2010, the interest for renal diseases maintained stable.

CONCLUSIONS: GT is a reliable tool in evaluating global interest for renal diseases in different geographical areas and temporal patterns. Although infodemiology represents a method for investigating the dissemination of information at a global level, our results suggest the need for increasing general population's interest for renal diseases especially, and move from simple interest to global awareness in the view of prevention strategies.

Key Words:
Infodemiology, Google Trends, Renal disease, Relative search volumes.

Introduction

Global awareness about renal disease is highly recommended and international societies of nephrology organize every year the World Kidney Day (WKD), a global campaign aimed at raising consciousness about kidney diseases. Raising awareness about risk factors for chronic kidney disease (CKD), encouraging systematic screening for CKD and preventive behavior, educating all medical professionals about their key role in detecting and reducing the risk of CKD, especially in high risk populations, stressing the important role of local and national health authorities in controlling the CKD epidemic, encouraging to take action and invest in further kidney screening and stimulating transplantation as a best-outcome option for kidney failure are the aims of the WKD [1]. In 2011 and 2013, our group analyzed data collected locally during WKD[2,3], but after a few years, we could not detect an increasing level of consciousness in the population. In 2019, the theme of the WKD was "Kidney Health for Everyone Everywhere". WKD wanted to raise awareness of the high and increasing burden of kidney diseases worldwide and the need for strategies for kidney diseases prevention and management[4]. In February 2019, a new journal entitled Kidney Medicine published its first inaugural issue, joining other journals from the United States National Kidney Foundation. One of the focus of this journal is

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art of nephrology, meaning that individual and social barriers to application of scientific data should be considered together with understanding how individuals approach medical decisions based on evidence-based medicine. One of the aims of the journal is to ensure that the knowledge could be included in the art of medicine and it could be understood and accepted by individuals and their family[5]. All these ideas suggest the need to evaluate what people know and understand about renal diseases around the world, however, authorities do not know if such a plan reaches the global population. Googling can be considered as the first step, available to all, to collect information. Googling commonly refers to searching for information in the World Wide Web, and the term suggests the act of looking something up on an internet search engine to include any people or background search to find out anything significant not previously known. Fast growing Internet use by patients in order to acquire more health information and changing in health care system towards a patient-centered approach should be considered by clinical researchers[6]. Google has become a very important tool for improving patients' knowledge, and health care professionals' should be conscious of these fast changes, in order to help individuals in understanding and evaluating information. Infodemiology has been accepted as a new science able to evaluate distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy[7]. As a wider application, infodemiology has also become an appreciated and useful tool for medical research, as an easy source to describe general population interest on various topics. In particular, Google Trends (GT), a popular tool used for describing information on human behavior, public health and medicine, represents an excellent platform for evaluating information seeking activities, and a popular source for big data research as well[8-10]. We have previous experience with infodemiology for other specific topics, such as medication errors, risk management, shift work[11] and solid organ transplantation[12].

Aim of this study was to conduct a descriptive analysis of the global community's interest about renal diseases through GT use. To do that, we compared relative search volumes (RSVs) of different countries worldwide by analyzing the search terms hematuria, proteinuria, CKD and dialysis.

Materials and Methods

We chose GT, a free, publicly available, internet-based application to search by using appropriate keywords. Searching could be limited to a well-established period of time (weeks, months, or years), and, for given search terms, RSVs with a value ranging between 0 and 100 are displayed. RSVs do not represent an absolute number, but a percentage calculated by GT. When RSV is equal to 0, it means that no significant searches were carried out. RSV equal to 50 suggests that half as many searches were carried out in that given time period, compared to the highest volume of searches, represented by RSV equal to 100. Also, RSVs may compare temporal pattern of relative interest between different areas, also adjusting data for population size, so allowing appropriate comparison between more or less populated areas. In order to compare relative frequency, and to standardize data between different countries, each data point is divided by the total searches of a given geographical area and the time interval that it represents. As a first step, we explored GT data in English, with the following search terms: hematuria, proteinuria, CKD and dialysis. Search query volume was filtered by the category "Health" in order to avoid non-health related queries, therefore avoiding confusing results. We decided to analyze GT from January 2010 to December 2019 in order to obtain results related to a decade. All countries listed in GT were analyzed, and those presenting RSVs related to all four search terms were considered and divided following the geographical position in the five continents. Data analysis was directed to show RSVs variations during the study period, comparing different world areas, and assessing correlations between RSVs related to hematuria, proteinuria, CKD and dialysis.

As a second separate step, we explored GT data also in Spanish language, using the search terms: "Diálisis", "Enfermedad renal crónica", "Proteinuria", and "Hematuria", filtering by the category "Health" during the study period. Due to differences in common terminology, we decided to investigate GT by using more popular Spanish terms, as "Diálisis", "Enfermedad renal crónica", "Proteína en la orina", and "Sangre en la orina", trying to assess a less scientific language.

Results were plotted in graphs, and descriptive analysis was performed, only for the English language analysis. We tested the association by

means of calculation of Pearson correlation, after RSVs logarithmic transformation. Statistical Package for Social Science (SPSS®; IBM Copr., Armonk, NY, USA) was used. A two-side $p<0.05$ was considered statistically significant. Results from the Spanish language are reported in the Discussion section of the manuscript.

Results

Mean values of RSVs for dialysis, CKD, hematuria and proteinuria during the study period were 80±9%, 11±2%, 17±2%, and 11±1%, respectively. RSVs for dialysis, CKD, hematuria and proteinuria all around the world are shown in Figure 1. Dialysis appears to be the search term most frequently typed. This finding is confirmed by temporal pattern analysis of the logarithm of RSVs during the considered decade (Figure 2). Figure 3 displays the world distribution of RSVs related to every single search term. Mean RSVs for the four-search term related to countries where they were all tracked and classified on the basis of their geographical position in the five continents, are reported in Table I. Table II shows RSVs in the five continents, Africa, America, Asia, Europe, and Oceania, respectively. Although, searching for dialysis attracts the majority of internet users in the world, population in Italy, Spain, Portugal and different Countries of South America are particularly interested in proteinuria and hematuria, as shown by high RSVs. Searching for dialysis, CKD and hematuria are highly correlated whilst correlation coefficients between RSVs for dialysis, CKD, and hematuria with proteinuria are lower (Table III).

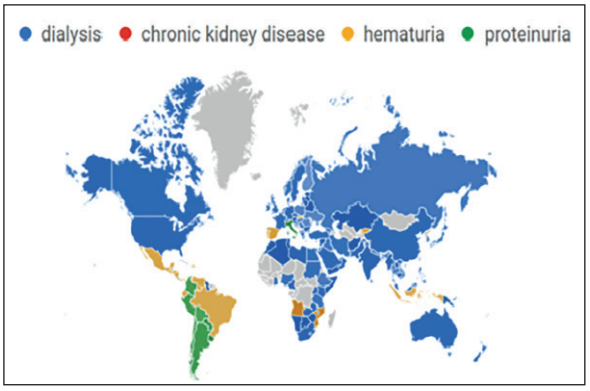

Figure 1. Relative Search Volumes for dialysis, chronic kidney disease, hematuria and proteinuria all around the world (the figure was captured from Google Trends).

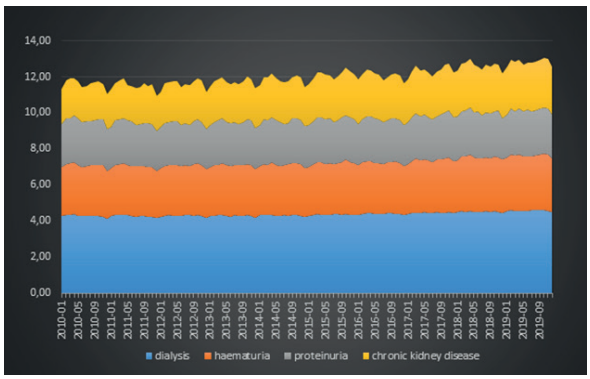

Figure 2. Temporal pattern analysis of the logarithm of Relative Search Volumes for dialysis, chronic kidney disease, hematuria and proteinuria during the decade 2010-2019.

Discussion

To the best of our knowledge, this is the first study describing infodemiology of renal disease at a global level. Very recently, another group of scientists specifically focused a similar analysis on renal transplantation, showing a decreased public interest in kidney transplantation[13]. We found that temporal variation in percentage of RSVs for dialysis, chronic kidney disease, hematuria and proteinuria during the decade 2010-2019 was negligible. Moreover, if dialysis appears to be the most frequently typed search term, searching for CKD, hematuria and proteinuria was similar. Although English ranks first among the largest languages in the world (https://www.ethnologue.com/guides/how-many-languages, accessed on 21st April 2020), and also represents the main global word language for economy, finance, and health, we decided to perform also a secondary analysis for Spanish language (ranking fourth world place, after Mandarin Chinese and Hindi). As expected, we found a change related to dialysis and CKD, since the search terms were different, however, as expected, RSVs for proteinuria and hematuria were the same. Besides, a further try with Spanish more popular, even if less scientific, search terms: "Diálisis", "Enfermedad renal crónica", "Proteína en la orina", and "Sangre en la orina", showed mean RSVs of 21%, 4%, 1%, and 73%, respectively. On the other hand, international scientific language is English, that should be adopted worldwide by health care professionals.

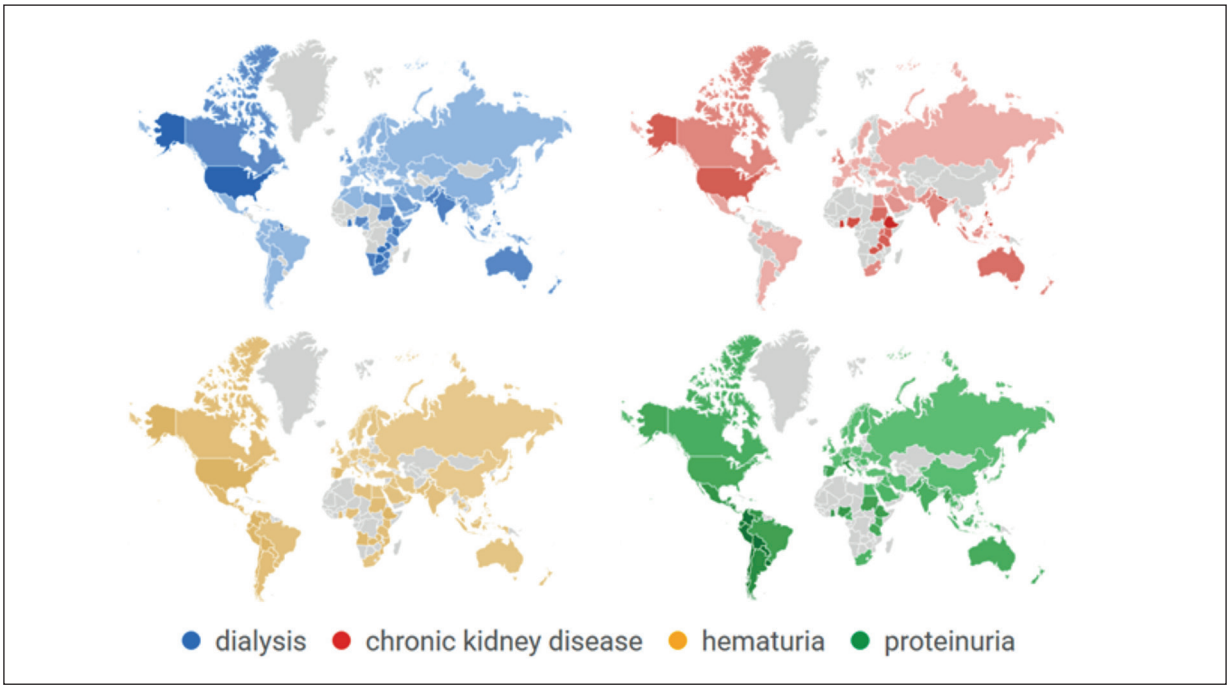

Figure 3. World distribution of Relative Search Volumes for dialysis, chronic kidney disease, hematuria and proteinuria considering every single search term (the figure was captured from Google Trends).

It is evident that this kind of web-based information needs to be matched with what is stated by traditional renal epidemiologists. Renal disease represents one of the most important non-communicable disease[14], and the global prevalence of CKD has been estimated to be between 11 to 13% with the majority of individuals belonging to stage 3. However, the burden of kidney disease changes substantially worldwide[15]. Crews et al[16] reported that geographic and racial disparities in CKD prevalence subsist, and racial and ethnic minority groups progress quickly towards end-stage renal disease compared with whites. The reasons could be either due to genetic factors and socioeconomic disparities. At the same way, disparities in accessing to living kidney donation could derive from socioeconomic status of the donor, as opposed to recipient factors[15]. Global age-standardized mortality rates for CKD increased significantly (36·9%) between 1990 and 2013[17]. Liyanage et al[18] systematically searched for observational studies and renal registries and analyzed renal replacement therapy (RRT) prevalence data. They found that in 2010, more than 2.5 million people were on RRT worldwide. They estimated that more than 2 million people might have died because RRT was not available, they reported the largest treatment gaps in low-income countries, particularly Asia and Africa. Worldwide use of RRT is projected to more than double, especially in Asia[18]. Due to limited or insubstantial collection of figures and supervision

Table I. Mean Relative Search Volumes detected in the five continents related to the search terms dialysis, chronic kidney disease, hematuria and proteinuria.

Continent	Dialysis	CKD	Hematuria	Proteinuria
Africa (%)	64.2	15.1	12	8.6
America (%)	30	5.4	34.5	30.1
Asia (%)	60.3	12.2	16.6	10.7
Europe (%)	51.6	11.7	17	19.6
Oceania (%)	73	12	6.5	8.5

CKD = chronic kidney disease.

Table II. Relative Search Volumes related to the different countries of the five continents in which the terms dialysis, chronic kidney disease, hematuria and proteinuria were searched.

Continent and countries	Dialysis	CKD	Hematuria	Proteinuria
Africa				
Ghana (%)	64	18	9	9
Kenya (%)	73	12	9	6
South Africa	79	8	8	5
Nigeria (%)	60	18	11	11
Ethiopia (%)	52	22	17	9
Sudan (%)	63	13	15	9
Tanzania (%)	61	16	13	10
Egypt (%)	62	14	14	10
America				
United States (%)	75	9	12	4
Jamaica (%)	68	11	14	7
Canada (%)	69	9	16	6
Puerto Rico (%)	30	12	36	22
Chile (%)	5	1	46	49
Colombia (%)	4	2	46	48
Mexico (%)	8	3	52	37
Argentine (%)	4	1	43	53
Brazil (%)	7	2	46	45
Asia				
Nepal (%)	64	15	13	8
Malaysia (%)	71	10	11	8
India (%)	78	8	8	6
Pakistan (%)	75	7	11	7
Emirates (%)	71	8	14	7
Sri Lanka (%)	58	23	9	10
Bangladesh (%)	67	12	10	11
Saudi Arabia (%)	72	8	13	7
Hong Kong (%)	63	10	13	14
Jordan (%)	53	12	22	13
South Korea (%)	47	15	22	16
Taiwan (%)	47	18	21	14
Iraq (%)	53	13	24	10
Thailand (%)	46	18	25	11
Indonesia (%)	20	21	43	16
Iran (%)	62	10	17	11
China (%)	73	1	12	15
Japan (%)	66	13	12	9
Europe				
United Kingdom (%)	69	17	6	8
Spain (%)	7	2	57	34
Italy (%)	14	3	1	82
Portugal (%)	25	9	36	30
Sweden (%)	71	9	11	9
Belgium (%)	70	11	10	9
Romania (%)	41	13	27	19
Netherlands (%)	67	12	11	10
Germany (%)	74	10	8	8
France (%)	68	11	10	11
Poland (%)	46	14	21	19
Ukraine (%)	42	23	19	16
Russia (%)	55	19	13	13
Ireland (%)	74	11	8	7
Oceania				
Australia (%)	73	14	6	7
New Zeland (%)	73	10	7	10

CKD = chronic kidney disease.

Table III. Correlation coefficients between logarithm Relative Search Volumes (RSVs) related to the search terms dialysis, chronic kidney disease, hematuria and proteinuria registered during the study period.

	RSVs for dialysis	RSVs for CKD	RSVs for hematuria	RSVs for proteinuria
RSVs for dialysis	1	0.875*	0.861*	0.467*
RSVs for CKD	0.875*	1	0.815*	0.372*
RSVs for hematuria	0.861*	0.815*	1	0.673*
RSVs for proteinuria	0.467*	0.372*	0.673*	1

CKD = chronic kidney disease. *$p < 0.001$.

in many countries all around the world, availability of prevalence data on the true burden of renal disease varies significantly. Registries produce organized and standardized data that could be collected in order to be analyzed for improving routine clinical practice. However, the maintenance of efficient registries requires considerable amount of resources, not often available in low and middle-income countries.

"Infodemiology" and infoveillance" are useful tools to improve the approach for public health[7,19]. Infodemiology is recognized by the scientific community as a new opportunity for collecting public health and public policy information and evaluating its distribution and determinants in internet[7]. Internet data represent a powerful tool to understand human behavior, and they are being increasingly integrated into health informatics research[20]. The relationship between epidemiology and infodemiology could be explained on the basis of general population's knowledge about a given condition. When population knowledge is poor, GT underestimates the real epidemiologic burden. Of course, being a science dealing with information at the population level, media coverage is a major determinant of search volumes[21]. The risk is that media may overestimate benefits, exaggerate claims, and avoid disclosing risk and conflicts of interest[21]. Our data are consequently exposed to this limitation.

Natural history, epidemiology, prevalence, incidence, treatment, and outcomes of renal disease are data regularly stored in Regional or National Registries. Liu et al[22] identified and assessed worldwide renal registries reporting on RRT and evaluated those most suitable for use by researchers. A systematic literature review and internet research were performed, based on the evaluation of information on dialysis, number of records, and evidence of activity between June 2007 and June 2012[22]. Moreover, public information on dialysis treatment, outcomes, and individual characteristics, as well as accessibility of patient-level data for external research, were analyzed. Of 144 identified renal registries, 48 met inclusion criteria, 23 of which were from Europe. Public accessibility to annual reports, publications, or basic data was good for 17 registries and moderate for 22. Also, the Italian dialysis and transplant registry (RIDT) was included in this analysis (https://ridt.sinitaly.org). Authors concluded that there is a lack of data in emerging economies, information gaps about health care and outcomes[22]. Our study design could, at least in part, overcome these limitations, since we explored searching volumes at a global level, in order to compare interest for diagnosed CKD with risk factors. This could represent an initial stage in order to compare GT finding looking for the temporal change in the general population's interest. We could not discriminate who was searching for, but only global interest for possible different manifestations of renal disease.

Improved focus on early intervention, innovating later-stage care and improving the evidence base facing policy makers, are the ambitious priority action areas for kidney disease research, policy-making, and clinical community necessary to reach the universal health coverage[23]. Patients' knowledge has improved by the use of internet, health care professionals' should be prepared to data derived from this platform, and should help patients in understanding and evaluating such amount of information. Internet data sources are very heterogeneous, due to the fact that they include business transaction, customer databases, medical records, internet clickstream logs, mobile applications, social networks, scientific experiment results, machine-generated data, and real-time data sensors. Infodemiology data can be collected and evaluated in near real time, could predict disease outbreaks, monitor populations' status updates on specific diseases, detect difference in health information availabil-

ity, identify importance and measure information diffusion and knowledge on specific public health items, and track the effectiveness of health campaigns. Also, health-related behavior of populations could be derived, analyzing what is being published on the Internet, and by the use of demand-based methods. On these premises, infodemiology could help understanding renal diseases, and, by exploring GT, we could suggest what the world is searching for. At the same time, health care professionals could take advantage and increase their knowledge. Nuti et al[8] analyzed published papers utilizing GT for health care research; out of seventy studies, infectious diseases were evaluated in 27% of articles, mental health and substance conditions in 24%, other non-communicable diseases in 16%, general population behavior in 33%. GT was investigated in 27% of articles for casual inference, in 39% for description, and in 34% for surveillance. Only 7% of articles could be reproducible based on complete search strategy documentation[8]. In this study, we limited to general population's interest for renal diseases. In a systematic review, Mavragani et al[9] reported different approaches to GT: in 23% of studies seasonality was analyzed, in 39% correlations were performed, in 33% modelling and in 8.7% predictions and forecasting were evaluated in health-related items validity[9]. In our study we evaluated correlations between RSVs in order to understand general population's attitude towards searching, and we found that RSVs for dialysis, CKD and hematuria are highly correlated, meaning that they are probably searched together. To the best of our knowledge, no previous study has analyzed Internet data on renal diseases, and GT could be taken into consideration as a non-specific search engine that could be used to test general sensibility to a specific query.

Reliability of online health information is a very actual problem that health care professionals need to consider. This is due to the fact that there are thousands of medical websites and choosing which websites to trust is an essential step. Usually, health websites sponsored by government agencies, professional organizations, medical schools and well-recognized hospitals are good sources of information. Funding, authors and contributors, timing, purpose, privacy policy and possible solutions offered should be clearly stated by health websites[24]. It has been reported that patients' interest and ability to use patient portals is strongly influenced by personal factors, such as age, ethnicity, education level, health literacy, health status, and role as a caregiver[25]. The usability and acceptability of web portals for patients with limited health literacy should be improved, including enhancements in the design of the portals, patient and provider education and training, and engagement of proxies, such as caregivers and close family members[26]. Oloidi et al[27] assessed the quality and readability of internet-based information related to selected Angiotensin Receptor Blockers and found that patient information on the websites was of moderate quality and suboptimal readability. In the same way Roughead et al[28] described the characteristics and recommendations of Internet resources on preoperative fasting and assess the quality and readability of these websites. They concluded that online fasting recommendations are frequently inconsistent with current guidelines, and the poor quality and readability of Internet resources on preoperative fasting may confuse patients[28]. Jayasinghe et al[29] analyzed the quality of information included in websites aimed at the public on COVID-19, concluding that the majority of websites on COVID-19 for the public had moderate to low scores with regards to readability, usability, reliability and quality. Finally, it has been reported that it is possible to look for suicide methods looking for websites aiming at preventing it[30].

Media could have an important impact on health literature and health seeking behaviors, but health care professionals need to check the quality of information. Authors and contributors should be clearly stated, and it is necessary to interpret information. Internet has become a formidable rival to the more traditional scientific form of information and heath care professional should be involved in such a process. Our findings could be a first step towards consciousness of what all around the world is looking for about medicine.

Limitations

We are aware of the limitations of the study. First, the study design. We limited to describe GT data for English search terms and reported data of this search. Second, we did not focus on an area but described the entire world. We limited to the most used English language and did not perform individual searches in the other languages of different countries. However, we made a supplementary search in the Spanish language (ranking four among the largest language of the world), by using also more popular and easy terms. Third, we could not define the profile of the different

searching populations, since it is not possible to find any association between individuals and queries in the Google database, in fact, the latter does not record information about the identity, internet protocol address or specific physical location of any user. Finally, technology used in this study is web 1.0, and analysis of web 2.0 like twitter or other social media needs to be implemented due to the growing use.

Conclusions

Our results show that people around the world mainly look for increasing their knowledge on dialysis. This is not a secondary observation, since it sounds like to close the stable door when the horse has bolted. This could not be true in "Latin" countries, where it seems that people from that areas realize that uremia could be prevented. These findings suggest that nephrologists should increase their educational performance, since 'an ounce of prevention is worth a pound of cure'. The increasing volume of search performed by users on web-based sources provides the opportunity to evaluate trends and interests on medical items. Thus, researchers in different branches of science are showing increasingly interest on infodemiology, and availability of huge amount of data creates new challenges and offers new opportunities[31]. Internet information is characterized by volume, variety, velocity, veracity, value, variability, volatility, and validity. Social costs of renal diseases are high and are associated with frequent hospitalizations and in-hospital mortality[32-40]. It has been reported that the interaction between patients and healthcare workers could be better evaluated by analysis of web-based behavior and behavioral changes[41]. Our results suggest that GT is a reliable tool in evaluating RSVs related to different temporal patterns, geographical areas, and also using specific languages, therefore GT appears a valuable source of information in the field of health Internet data. Moreover, our findings suggest a need for more accurate data, higher level of general population's interest for renal diseases, better access to diagnostic test for prevention and diagnosis, better understanding of preventive treatments, and more investments to develop effective care. Based on our results, new ideas could be developed based on infodemiology, in such a way dissemination of information aiming at improving patient care could be monitored. Infodemiology makes possible to obtain data that could be interpreted as a feedback of general population's interest towards medical items.

Conflict of Interest

The Authors declare that they have no conflict of interests.

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Statement of Ethics

Since this study did not investigate patients, but rather the interest for renal diseases derived from internet search, any kind of informed consent or Ethical Committee approval was not necessary.

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