

FOREWORD

Does open data tell us everything?

Leopoldo Sarli, Federico Monaco

University of Parma, Department of Medicine and Surgery, Italy

The community of the entire planet is still grappling with the management of the Sars-CoV-19 pandemic and in some countries the spread of the infection is as serious as it was in Italy in the first months of 2020. In this issue of the magazine Kalli M et al. describe the situation in Chad. The containment measures and above all the mass vaccination have allowed today in Italy to contain the consequences of the pandemic and to face them with greater tranquillity so that many health activities not related to Covid-9 have resumed regularly. Scientific research, unlike many other activities that have slowed down due to containment measures decrease the march of Covid-19, has had a significant boost in the last two years. The number of articles published in scientific journals has increased considerably (1), even if only high impact journals are taken into consideration.

However, the increase in the number of scientific articles did not concern topics not related to Covid-19, the number of which has even decreased (1). In these pages, however, numerous articles concern topics different from pandemic management: Albanesi B et al. are dedicated to a validation in Italian of scales already validated in English as regards the Nursing Decision Making Instruments, Guasconi M et al. deal with the Behavioral Pain Scale in sedated, intubated, and mechanically ventilated pediatric patients. Moreover, they are dedicated to the Adaptation and Validation of the Ethical Conflict Nursing Questionnaire-Critical Care Version. The paper by Menichini D et al. documents how there are critical aspects in the counselling of foreign women for prenatal screening tests; Giannetta N et al. describe several strength points of using Clinical-Trials.gov to monitor intervention in order to improve the drug safety process; Camedda C et al. analyse the

skills necessary for family and community nurses in Italy and in Europe; Paduret G et al. report how the nursing management of the tourniquet does not avoid the risk of contamination; Cosentino C et al. report the effects of Expressing Writing on Palliative Care healthcare professionals, and finally Gerlando F et al. evaluate intraosseous access as an alternative to venous catheterization in emergency conditions.

The number of publications on Covid-19 has increased dramatically and this is the reason for the overall increase in scientific publications. A quarter of the articles published here relate to the ongoing pandemic. In addition to the aforementioned article by Kalli M. et al., Rossi S et al. describe the difficulties encountered by emergency psychologists, Foà C et al. which report the representation that the media have given of citizens' perception of frontline nurses, Annaloro C et al. performed a systematic review of the literature on nurse burnout and Vitale E et al. show that even in the case of Covid-19 patients, the quality of end-of-life care benefits has a positive correlation with the awareness of a good death and attitudes towards end-of-life care.

The interest of researchers in finding scientifically valid solutions to the problems created by the pandemic is a possible explanation for the large number of publications on this issue, but the great availability of government open.data on the topic has certainly counted. Governments around the world have made data publicly available on COVID-19 tests, case numbers, hospitalisations and deaths, and a wide range of researchers, media sources and data scientists have curated and used this data to inform the public about the state of the coronavirus pandemic (2) and to accelerate the investigation and control of these infections

(3,4). The World Health Organization has defined the pandemic as an infodemic due to the overflow of data on Covid-19, on the social factors involved in the spread of the virus and also for the impact of fake news (5). At the beginning of the pandemic in Italy, the government provided data on Covid-19 statistics for each city, province and region online. Such data was accessible to anyone as data tables included in long comprehensive reports published online as pdf files. However, they were not in a machine-readable format, such as .xls or .csv. A researcher from Palermo, Andrea Borruso, president of the Ondata association, transformed these data into a useful format and republished them in his personal archive. After less than a day, the government joined github.com and created a user and some repositories for the daily publication of open data on covid-19 in Italy (<http://blog.ondata.it/ondata-sul-coronavirus-and-success-really/>). Science and experts have worked together thanks to the Internet to find solutions and create infrastructures; for example, the Italian Institute of Physics itself is providing data on surveillance on Covid-19 (<https://github.com/InPhyT/COVID19-Italy-Integrated-Surveillance-Data>).

The availability of open data on Covid-19 and their use allow some considerations to be made. The impact of many open government data on the scientific world has been very positive. The scientific response observed during the epidemic is a demonstration of the capabilities of modern science to react rapidly to emerging threats to global health by providing and discussing the essential information to understand the etiological factor, its spread, preventive measures and mitigation strategies (6). In this regard, it seems appropriate to highlight the role that higher education, also based on the skills gained from scientific debate, must have in favouring emergency management. By definition, emergencies are different from routine and the skills that professionals, and in particular health professionals, have at their disposal to carry out their work correctly in routine conditions are not sufficient in emergency conditions. The results of the research must provide them, but also learning by doing, possibly in simulation, the sharing of experiences with professionals from other sectors of knowledge.

In this regard, we like to describe the experience

of a group of students of a high-level training course on infectious risk organised by the Department of Medicine and Surgery of the University of Parma in developing a website that elaborates open data on healthcare-related infections provided by Clinics and Territory Hospitals and is designing a 3D map of three regions in order to animate it with icons and real-time information on infections. The project is called RISVO and is available online for all (<https://risvo.github.io/>) professionals, patients, citizens to understand and contribute to the development of a new way of practicing experimental research on the territories, higher education but also university and social mission. On these pages we report the results of some scientific evaluations on the usefulness of adequate training practices: the review by Strini V et al. highlights how in the management of the insulin pump in addition to adequate training with respect to direct patient care, training is also required for nursing staff in emotional support. Rubbi I et al. highlights how training through simulation played a key role in improving the skill of ECG evaluation among students.

Longo D et al conclude that the Student-Evidence Based Practice Questionnaire in the Italian version has proven to be a valid tool for assessing students' approach to Evidence-Based Practice. Dall'aglio R et al. highlight the usefulness of clinical experience in the training of psychiatric rehabilitation technicians.

Contrary to what happened in the scientific world, the impact on public opinion of the avalanche of open data on Covid-19 has been controversial. If on the one hand the massive entry of the health system into the homes of users with data and advice, as never before, has positively influenced the behaviour of the majority of the population, it is evident that the unguided interpretation of such a large mass of data has also generated resistance and misunderstandings. Perhaps, differences in citizens' adherence to infection prevention and treatment measures are influenced by their perceptions of government policy and the willingness to collect unchecked information on how to address their behaviour in the digital age and realm of mass influence of social media on citizens (7). Communication defects were evidenced, the need for politicians and public health agencies to identify targeted policies for disseminating information for the public

made up of people with different needs was highlighted (8). It is conceivable that the emergency of doing has taken over and communication has not been adequately managed to make “entering the house” feel not as an occupation but as an institutional presence of care and assistance. The pandemic has made it possible to share the fall of disciplinary boundaries between operators, but not to enrich the contact with the user. The fall of disciplinary boundaries is certainly a positive aspect and Sena B. and De Luca E. highlight in these pages how limited interprofessional collaboration could constitute signs of mono-professional Brest Unit management and potential devaluation of the role of oncology specialist nurses in managing patient care. Carbone R et al. Inter-professional collaboration, specialist skills and specific training are a key element of the ICU teamwork.

However, it is not only communication defects that have generated resistance and misunderstandings. Much attention is now being placed by the mass media on those who reject the vaccine, the so-called no vaxes and on those who reject the controls that some governments adopt to contain the spread of the pandemic, for example the so-called no-green passes. Vaccine scepticism has existed since the advent of technology itself. However, the mass spread of social media and open data through them is considered by many to be the main cause of the significant expansion recently acquired by the “anti-vax” movement (9). In reality, the literature tells us that the causes of the phenomenon are various (10). An article by Israeli authors (11), for example, highlights how health personnel and citizens who have taken care of people affected by COVID 19 accept the vaccination campaign much more easily than health personnel and ordinary citizens who have not had to take care of patients suffering from COVID-19. Political reasons are called into question, but we believe that the reactions that have thus manifested themselves in recent months are also the result of how the “sick” and the “illness” have been represented as numbers, as epidemiological data de-humanizing the different situations. A person affected by Covid-19 is considered dangerous, guilty of the transmission of the virus. This is a recurring phenomenon not only today. Even Alessandro Manzoni described how the sick person was transformed into an “infecter”.

The sick must be isolated and purified, they must undergo medical supervision together with their “close” contacts; in care environments, the path referring to covid-positive patients is defined as a “dirty” path. The situation is often compared to a war episode and the terminology commonly used recalls the language of war: in vaccination centres we speak of “recruitment”, health personnel are “on the front line” and doctors and nurses have been considered heroes”. Every day, we are presented with the “bulletin” of the dead. Ultimately, the fight against the virus is an “epochal battle”, the pandemic is being fought and it is no wonder that in this climate those who do not think like the majority are seen as “the enemy” and “the enemy” organises himself or herself, contests, and makes his/her voice heard in every way.

It is not up to us, as researchers, to judge who among the contenders is right or wrong. The only opinion that we are allowed to express publicly is the rejection of violence.

The task of science is to study the phenomenon and, if anything, to analyse how the data collected and communicated are used. Even no-vaxes use open data, even some abstruse fac-news use them, even among scientists the interpretation of open data sometimes gives rise to different and conflicting opinions. Science cannot and must not take into consideration also the opinions that are dissonant with respect to those provided by the majority of studies. The doubt, in fact, has always been at the origin of scientific research and has sometimes managed to unhinge entire paradigms based on dogmas that are considered irrefutable. It is worth mentioning as example the debate between Galileo and Bellarmine about the theory of heliocentricity, or Harvey and Hobbes about the function of the heart.

The task of science is also to analyse the phenomenon to understand what its causes are. And to find out, it must intercept conflicting opinions, doubts, even using the methodologies of social science. And this is true in all areas of knowledge, including health. The scholar must explain to the doctor why the patient does not take the drug prescribed, why alternative treatments are successful, why a health system considered to be among the best performing in the world is seen by users as medical malpractice. Only in this way

will science be able to provide operators with the skills necessary to face and solve this age-old problem.

Cristine L Borgman, communication scholar argues that four rationales for sharing data from the sciences, social sciences, and humanities are: 1) to reproduce or to verify research 2) to make results of publicly funded research available to the public 3) to enable others to ask new questions of extant data, and 4) to advance the state of research and innovation (12).

But scientific data need also to be contextualised and situated in communities, being parts of so called Epistemic cultures (13), as sets of arrangements and mechanisms associated with the processes of constructing knowledge, and include individuals, groups, artefacts, and technologies (14). Data sharing about Covid-19 is also the way we can understand how social practices are informed by 'imaginaries of data use' (15) as the possible ways in which the data are imagined and projected into the future in age best described by dystopic narratives. Such imaginaries play out within public discourse, policy evaluations, as well as research practices in data science and social sciences like the Science, Technology & Society frame can play its part in understanding and researching how data impact on society and science and rework the idea we have of the world we live in (16). Nobody can deny how much the technologies we use to understand the world are intimately connected to the ways we choose to live in it (17), and how much data inform the way we make daily and global choices about our future.

Conflict of interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article

References

1. Raynaud M, Goutaudier V, Louis K, et al. Impact of the COVID-19 pandemic on publication dynamics and non-COVID-19 research production *BMC Med Res Methodol*. 2021 Nov 22;21(1):255. doi: 10.118
2. Yiannakoulis N, Tooby R, Sturrock SL. Open government data, uncertainty and coronavirus: An infodemiological case study. *Soc Sci Med* 2020 Nov; 265:113549. doi: 10.1016/j.socscimed.2020.113549/s12874-021-01404-9),
3. Lucas-Dominguez R, Alonso-Arroyo A, Vidal-Infer A, Aleixandre-Benavent R. The sharing of research data facing the COVID-19 pandemic *Scientometrics* 2021 Apr 26;1-16.)
4. Zeng X, Song X, Ma T, Pan X, et al. Purpose Open Data to Discover Therapeutics for COVID-19 Using Deep Learning. *J Proteome Res* 2020 Nov 6;19(11):4624-4636. doi: 10.1021/acs.jproteome.0c00316.)
5. Abrams, E. M., Szefer, S. J. (2020). COVID-19 and the impact of social determinants of health. *The Lancet Respiratory Medicine* 8(7): p.659-661. [https://doi.org/10.1016/S2213-2600\(20\)30234-4](https://doi.org/10.1016/S2213-2600(20)30234-4)
6. Moro M, Yildirim M, Jach Ł, Nowakowska J, Atlas K. When science goes viral: The research response during three months of the COVID-19 outbreak *Biomed Pharmacother*. 2020 Sep;129:110451. doi: 10.1016/j.biopha.2020.110451. Epub 2020 Jun 23. 9
7. Al-Hasan A, Yim D, Khuntia J. Adherence to COVID-19 Mitigation Recommendations by the Government: A 3-Country Comparative Evaluation Using Web-Based Cross-Sectional Survey Data. *J Med Internet Res*. 2020 Aug 11;22(8):e20634. doi: 10.2196/20634.
8. Ashraf Ahmed, Arif Mohaimin Sadri, M Hadi Amini. Data-driven inferences of agency-level risk and response communication on COVID-19 through social media-based interactions. *J Emerg Manag*. 2021 Special Issue on COVID-19;19(7):59-82. doi: 10.5055/jem.0589
9. Armitage R. Online 'anti-vax' campaigns and COVID-19: censorship is not the solution. *Public Health*. 2021 Jan;190:e29-e30. doi: 10.1016/j.puhe.2020.12.005. Epub 2020 Dec 16.
10. Lang R, Atabati O, Oxoby RJ, Mourali M, et al. Characterization of non-adopters of COVID-19 non-pharmaceutical interventions through a national cross-sectional survey to assess attitudes and behaviours. *Sci Rep*. 2021 Nov 5;11(1):21751. doi: 10.1038/s41598-021-01279-2.)
11. Dror AA, Eisenbach N, Taiber S. et al. Vaccine hesitancy: the next challenge in the fight against COVID-19. *Eur J Epidemiol*. 2020 Aug;35(8):775-779. doi: 10.1007/s10654-020-00671-y.)
12. Borgman C. The conundrum of sharing research data. *J Am SVoc Sci Technol* 2012. 63: 1059-78.
13. Knorr-Cetina, K. *Epistemic cultures: How the sciences make knowledge*. Cambridge, 1999 MA: Harvard University Press.
14. Van House, N.A. Science and technology studies and information studies. In B. Cronin (Ed.). *Annual Review of Information Science and Technology*. Medford, NJ, Information Today 2014 ; 38 : 3– 86.
15. Leonelli, S. *Data Science in Times of Pan(dem)ic*. Harvard Data Science Review 2021 : 3.1 DOI10.1162/99608f92.fbb1bdd6 <https://doi.org/10.1162/99608f92.fbb1bdd6>
16. Valladares, L. Post-Truth and Education - STS Vaccines to Re-establish Science in the Public Sphere. *Sci & Educ* (2021). <https://doi.org/10.1007/s11191-021-00293-0>
17. Jasanoff, S. (Ed.). *States of knowledge: the co-production of science and social order*. 2010, London: Routledge.