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Volume 5

Information Practices and Knowledge in Health

Edited by
Céline Paganelli
Viviane Clavier

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Introduction

This collective work, the fifth in the series *Health Information*, brings together eight contributions. It deals with health information and communication and highlights strong trends or "movements" in the field of health, which consist of many dimensions to be articulated in order to approach knowledge and information practices.

A first movement involves the growing visibility of health issues in the public space, an observation that dates back more than 20 years, as shown by issue 95 of the French journal *Réseaux* published in 1999 on "Science, the sick and the public space". This issue focused on patients and patient organizations that had acquired legitimacy in the public arena, thus contributing "to a new way of thinking about the relationship between science and the general public". This relationship, according to the authors [CAR 99, p. 10] "[was] less of an asymmetrical relationship of expertise and pedagogy, but rather [allowed for] the expression of scientific uncertainties, the sensitive involvement of caregivers or the claims of patients" [*ibid.*]. The media appear to be the key players in this publicizing of health issues. As early as the 1980s, television relayed appeals for donations or compassion for the Telethon [WAL 98]; the "media coverage" of AIDS or the story of contaminated blood provided the opportunity for "tests of strength" between the political, medical and judicial arenas, as well as for the internal tests of strength in the journalistic field on the "legitimate definition of information" [CHA 94]. Beyond the media space, society as a whole is, according to the health sociologist Pierre Aïach [AÏA 98] and the anthropologist, sociologist and doctor Didier Fassin [FAS 98], going through a process of

Introduction written by Viviane CLAVIER and Céline PAGANELLI.

medicalization that they consider to be a cultural transformation. Protecting ourselves and fighting against illness, detecting and preventing risks, staying healthy, etc. have become a constant preoccupation, elevated to the rank of a movement: healthism [CRA 82]. This "concept", which emerged during the 1970s and 1980s, refers in particular to the Foucauldian thesis according to which individuals come to adhere to social norms of their own free will, even though they are not forced to do so. According to Hélène Pouliquin, healthism is recognized as "an elevation of health to the rank of virtues and morality, accompanied by an individual duty to maintain health by making individuals responsible, even if at the same time the state disengages from acting on the social, political and economic determinants of health" [POU 15, p. 26]. Promotional discourse and consumer practices are part of this trend, as Benoit Lafon shows with another neologism he calls "sanitarization" to indicate, once again, a double movement perceptible in the "consumer press" [LAF 20]: on the one hand, the consideration of public health issues in entire sectors of the economy, which, beyond agriculture, concern various industrial activities such as agri-food, chemistry or electronics. On the other hand, the increasing consumerization of healthcare is manifested in the growth of medical devices, "reimbursed" by complementary health insurance organizations in competition with each other (glasses, hearing aids, etc.), or by the ever-expanding dynamics of the drug industry towards other areas to be medicalized (well-being, smoking, etc.). This same tendency can be found in food, as attested by a third neologism coined in 2009 by the food sociologist Jean-Pierre Poulain [POU 09]. Thus, the "nutritionalization" of food refers to the management of food in the context of a specific pathology by a health professional specialized in nutrition. It also refers to the massive diffusion of nutritional knowledge in health education, prevention campaigns and the media.

A second movement is linked to the reconfiguration of public service in hospitals and health institutions, and to the evolution of forms of management that aim to reconcile a number of "complex and manifold challenges" [GRE 19]. The context is marked by cost reduction, rationalization of professional activities, inequalities in social and territorial access to healthcare, the aging of the population and the increase in chronic diseases. Nevertheless, the healthcare on offer must always be improved in order to ensure patient satisfaction. Thus, the development and modernization of information systems for public and private institutions is part of a policy to improve administrative, logistical and care processes [VIG 18]. Among these systems, the Electronic Patient Record (EPR),

although not recently introduced, is emblematic of the evolution of hospital practice and is the result of both the need for traceability of actions and decisions associated with patient care and the need for coordination between specialists in charge of patients [MOR 18]. The deployment of EPRs in healthcare institutions has made it possible, thanks to surveys of health professionals, to specify expectations in terms of information (relevance, availability, reliability, security, real-time updating, etc.); integration of heterogeneous data or definition of knowledge meta-models to promote semantic interoperability between terminologies [CAB 17]. Thus, the organization of knowledge and the information practices of professionals are at the heart of reflections on the design or uses of these health information systems.

A third movement concerns patients taking responsibility for their own health. The notion of "health democracy", which appeared in the political field and was used for the first time by the public authorities in the early 2000s, covers citizen participation in health policies [ARV 16] and was officially included in the functioning of the French healthcare system by the law of March 4, 2002, relating to the rights of patients and the quality of the healthcare system [LET 09]. The role of users, sick or healthy, of their relatives or of patients' associations is thus recognized when it comes to health issues [LEF 18]. Combined with the development of liberal economic policies in the health sector, "health democracy" seems to have led to an increase in control regulations [DEM 14], the emergence of the patient-client, thus promoting a consumerist approach to health [BAT 08], or even the instrumentation of users, as denounced by certain associations [LEF 18]. Nevertheless, this evolution has been accompanied by the development of systems for accessing health information, allowing patients to consult information or share their experiences; associations to publish documentation on the Internet or to structure communities for exchange and sharing. Thus, the user takes control of health issues by discussing the issues with medical professionals, supporting a loved one, or dealing with a diagnosis or the evolution of an illness, in order to find practical information or verify scientific data. According to a 2016 IPSOS survey, more than 68% of French people have already consulted the Internet to find medical information, whether it be via collaborative sites, general sites dedicated to health or institutional sites [CAS 16]. The medical profession, friends and family, and the media are also sources of information that are sought after. A real knowledge base is then developed, "lay expertise" that emerges among patients. This expertise is based on lived experience and considers

that people, through their personal experience of an illness, acquire specific knowledge on the issue. It is recognized by users of discussion forums or social health networks, who consult these systems to solicit testimonies from patients or former patients [PAG 11]. It also consists of real medical and scientific expertise. Indeed, patients, often through associations that bring them together, invest in the scientific field, appropriating specialized knowledge in order to make their voices heard and participate in the governance of the healthcare system [AKR 12]. The development of this form of expertise is facilitated by access to specialized information resources via the Internet. Although the notion of the expert patient is now well established, it in fact conceals a very contrasting reality. First, because it reduces the patient's identity to their illness [GRI 20], and second because it does not take the diversity of situations into account. The availability of information resources and easy access to digital devices do not guarantee the appropriation of knowledge. Studies on health literacy, which the WHO defines as "the personal characteristics and social resources needed by individuals and communities to access, understand, evaluate and use information and services to make health decisions"[1], show the diversity of the necessary skills (informational, media-related, medical, etc.) and the constant need to update these skills [MAR 17]. The implementation of mediation actions or systems, relying in particular on documentary mediators [TET 20], therefore appears essential. Finally, using therapeutic education to improve health literacy would contribute to supporting patients in the appropriation of knowledge related to disease and, more generally, to reducing inequalities in access to care [MAR 17].

A fourth movement concerns the development of digital devices in the service of health, a sector that is experiencing various kinds of initiatives and constant growth. Estimated at 2.7 billion euros in 2014, the e-health market is dominated by innovative start-ups specializing in telemedicine[2]. These include technologies that enhance health knowledge[3], such as those that take

1 See: https://www.who.int/healthpromotion/conferences/9gchp/health-literacy/en/.

2 Pôle interministériel de prospective et d'anticipation des mutations économiques, Prospective. E-santé : faire émerger l'offre française en répondant aux besoins présents et futurs des acteurs de santé, Synthesis, Edition Marine Automne, Nicole Merle-Lamoot, 2016. Available at: https://www.entreprises.gouv.fr/files/files/directions_services/etudes-et-statistiques/prospective/Numerique/2016-02-Pipame-e-sante-synthese.pdf.

3 Picard R., Serveille H., Vial A., Technologies et connaissances en santé, Public report, December 2013. Available at: https://www.vie-publique.fr/sites/default/files/rapport/pdf/273726.pdf.

medical investigation further or reduce surgical risks, and that are used to rationalize and control the production of care. We should also mention other applications, such as medical imaging, training devices (for surgical procedures, for example) for learning, individual training and simulation, or even connected objects, which are "composed of sensors designed to transmit information via a mobile application or a web service" [BEY 17]. More focused on data than on knowledge, applications intended for self-quantification aim to collect, measure and compare various variables in order to improve well-being, and maintain or improve health status [CAM 16]. The incursion of new players in this very lucrative market – only 32% are from health sectors such as medical industries, insurance, hospitals and physicians according to [STA 18] – reveals different concerns and interests. Adrian Staii identifies the economic models that regulate this market, as well as the actors who continue to invest [STA 18, pp. 217–218]: 28% are pure players who develop activities in the field of mobile health; 23% are actors outside the health sector (IT and digital industries) and 11% are non-market organizations (associations, NGOs, etc.). Thus, connected health may prove to be one of the most blatant indicators of the loss of autonomy of traditional health players in a market now dominated by digital players, who are legitimate in prescribing standards in the well-being market [*ibid*, p. 220].

The book is organized in eight chapters. The first two chapters focus on the field of health information and its evolution in the context of Open Access, and aim to characterize health information from the point of view of its uses and associated practices.

Focusing on scientific information, Chérifa Boukacem-Zeghmouri and Hans Dillaerts report on the regulations induced by Open Access, which has developed significantly in recent years in all scientific fields. However, its adhesion and legitimization are particularly significant in the health field. Plan S, which encourages the publication of research results from public grants in journals or platforms that respect the founding principles of open science, has strongly changed the model of scientific communication in the health field, since scientific research in this field is essentially based on calls for proposals. Moreover, the introduction of new publication models and new actors (Gold publishers, megajournal publishers, preprint servers or predatory publishers), the positioning of historical actors who produce medical information within STM publishing, new practices in terms of publication, dissemination strategies, valorization and mediatization of

knowledge all take new criteria into account, such as the general public or reputation on social networks. The researchers situate their reflections in the current context (2020–2021), that of the Covid-19 pandemic, and show that the health crisis highlights the importance and complexity of the issues of publication and dissemination of validated scientific information. Finally, they raise the question of the future of scientific journals, which are not equipped and organized to disseminate research results in real time, to the benefit of preprint platforms, which receive researchers' publications as they progress.

Between opportunities and risks, this first chapter provides elements for understanding the changes underway for all of the actors in scientific and technical information (STI) within the health field.

Chapter 2, written by Céline Paganelli and Viviane Clavier, offers a methodological contribution aimed at characterizing health information by studying the information practices of health professionals and the organization of knowledge. Thus, returning to the documentary perspective, which approaches treatments according to their uses, health information is presented as strongly linked to contexts of use and practices. Based on the results of field studies and corpus analyses conducted in the field of health for more than 10 years, the researchers propose to rediscuss the contours of health information and put forward elements that allow it to be characterized.

The following chapters aim to understand how actors, whether professionals or citizens, inform themselves, how questions of evaluation of the information collected arise in a sector where the reliability of information is crucial and how health literacy can be considered in digital environments or in relation to specific populations.

In Chapter 3, Eloria Vigouroux-Zugasti, Olivier Le Deuff and Amar Lakel propose a reflection on health literacy in digital information environments. A concept that appeared in the early 1970s, in parallel with that of information literacy, health literacy goes far beyond the framework of informational or media skills and is becoming, particularly with the evolution of health information provision, a public health issue and challenge. In this chapter, the authors question digital health literacy based on the results of field studies: an automatic analysis of web corpora containing health information, as well as a longitudinal qualitative survey on

online health practices among a retired population, using digital technologies. The results highlight several trends: the dominant place of the press and health professionals in the health information available on the Internet and the very minor voice of patients. They also show the need for users to develop skills that will enable them to be more comfortable when searching for health-related information.

Digital health literacy covers a variety of skills (informational, digital, media-related, health-related, etc.) that are difficult to evaluate because they require regular updating. The acquisition of these skills is a matter of training, as well as of mediation mechanisms, the reinforcement of which, by relying on health professionals and mediation actors, seems to be a necessity. However, beyond the aspects relating to training and mediation, the chapter clearly shows that public health policies must take up the issue of digital health literacy insofar as it constitutes a major challenge for therapeutic education.

Chapter 4 is written by two Finnish researchers from the discipline of Library and Information Science: Kristina Eriksson-Backa and Stefan Ek. These researchers are interested in the health information behavior of older people – their interests, the sources they use, the reliability criteria given to information sources, etc. – and propose methods to assess their level of health information literacy and medical knowledge. The notion of information behavior is borrowed from Tom Wilson[4] and the empirical results were obtained through a survey sent by mail to 1,000 Finns aged 65–79 years. A total of 281 responses were completed and returned by a majority of women (57%), almost half of whom were aged 65–69 years and had an intermediate level of education (44%).

Health information literacy refers to skills related to information literacy, the ability to recognize a need for health information, evaluate and use this information in daily life to make good health decisions, use information ethically and legally and so on. Most studies relate literacy levels to the age of individuals and their ability to read and understand health-related materials. There are many questionnaires designed to measure health literacy. Recent studies have shown an association between low health

4 "The totality of human behavior in relation to sources and channels of information, including both active and passive information seeking, and information use (Wilson 2000, p. 49)".

literacy, poorer health status and increased use of hospital care. Conversely, better health literacy could be an important factor in the adherence to prescribed treatments. One of the contributions of the authors' research is to highlight a link between the mastery of health information and the perception of patients when communicating with health professionals.

The next two chapters address issues of prevention in health information and communication.

Thus, Chapter 5, written by Cécile Loriato, proposes to study information on HIV/AIDS prevention from the perspective of the categorization of audiences and the hierarchization of actors in the journalistic narrative. Since the end of the 2000s, new biomedical prevention tools have been proposed, including Pre-Exposure Prophylaxis (PrEP), which is used for HIV prevention by HIV-negative people and is mainly recommended for men who have sex with men (MSM). The publicization of PrEP has sparked controversy around homosexuality, HIV and risk because it calls into question years of prevention based on condom use as the only known and effective tool. In this context, the researcher studies the construction of the journalistic narrative on biomedical prevention. She examines, on the one hand, the use of epidemiological categories to designate people at risk and, on the other hand, the hierarchical structure of the journalists' account of prevention, in order to understand how this contributes to the total or partial exclusion of certain actors, actions, events or problems. The results show that information on biomedical HIV/AIDS prevention is constructed mainly from the point of view of scientific experts and mobilizes mostly stigmatizing epidemiological categories.

Through this analysis, the researcher contributes to the characterization of media information on prevention. Journalistic discourse on prevention gives a predominant place to scientific expertise. Indeed, the views on the biomedical prevention strategies of doctors and researchers specializing in HIV/AIDS are predominant, while the views of associations and users of these means of prevention are hardly heard. This reliance on experts can be explained in part by the fact that some journalists are not very close to the field of HIV/AIDS, which leads them to give preference to information from the communication services of medical or health institutions which have institutional legitimacy.

Chapter 6, written by Aude Chauviat, also addresses prevention information, as disseminated in prevention campaigns. She situates her argument in a particular historical context, that of the National Prohibition campaign in the United States (1919–1933). Based on content analysis of a corpus of more than 200 pamphlets published by the Anti-Saloon League, as well as a sub-corpus of 82 pamphlets mobilizing health information and created for the most part by the Scientific Federation for Temperance, she shows how health information was mobilized in the prevention campaign against alcohol to the detriment of a moralistic approach to the issue. She postulates that this shift to a preventive discourse based on health information is similar to a form of medicalization of alcohol-related problems and marks an evolution towards a *medical* approach to health, made possible by the acquisition of legitimacy of scientific discourse among the general public.

This contribution proposes a contextualized approach to health information. While anti-alcohol prevention campaigns rely more on specialized information, it is because for one, the discipline and international scientific community specializing in the question of alcohol is becoming institutionalized and more structured, and in parallel, popularized scientific discourses aimed at the American population are emerging.

Finally, the last two chapters address health information from the perspective of knowledge organization and representation.

Chapter 7 presents the testimony of Dr. Four, a private practitioner specializing in ophthalmology, on the role played by professional journals in updating medical knowledge for the practice of his profession. This testimony is very instructive for research on the information practices of health professionals and on the organization of knowledge. Indeed, Dr. Four has been regularly monitoring professional journals for many years (24 years). This activity is integrated in his weekly schedule, since he devotes 15 hours of his time to reading journal articles and processing the bibliography. To practice general ophthalmology, it appears that updating knowledge is essential in many areas of ophthalmology, some of which evolve more rapidly than others. This interview is an opportunity to indicate the fields in which information is more scarce or, on the contrary, those in which it is abundant but, paradoxically, little summarized. These different cases require greater efforts in terms of information research, whether to find rare sources, summarize numerous publications or validate sources. Thus,

information practices are fully integrated into medical practice and the information obtained constitutes a strong point in support of the diagnosis, assessment, treatment protocol, referral of patients to other specialists or justification of therapeutic decisions from a medical–legal point of view. This knowledge, built up and developed over time, is recorded in a document base, the organization and structuring of which are designed *by* and *for* Dr. Four's medical practice, and is presented in detail in the chapter.

Chapter 8 by Marcin Trzmielewski and Claudio Gnoli is a joint contribution on the evolution of medical knowledge organization systems (MKOS) from the 1960s to 2019. These researchers are both specialists in knowledge organization, a field of activity and research that focuses on the design, study and critique of methods for organizing and representing knowledge, most often implemented in libraries and documentation centers. Based on a review of 71 articles published in information and documentation sciences, this chapter describes the main families of MKOSs, the most represented being ontologies, thesauri and classifications. The increase in the number of publications on this subject since 1960 reflects both the vitality of the field of knowledge organization, particularly in the United States and Canada, and the strong dynamics of scientific production in medicine, and the generalization of health information on the medical Internet. Beyond the study of the structuring of concepts, the relationships between concepts, and the evolution of the various fields of medicine, this chapter presents a complete analysis of the "general public" or specialized users of MKOS. The study also focuses on the document processing process and questions the testing of specialized classifications organized by discipline in the face of interdisciplinarity. It appears that this field is still dominated by concerns related to the representation of knowledge, for which classifications also raise socio-cultural or political questions.

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