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Call for multidisciplinary papers on:

“**The relevance of care**”

For the July–September 2019 issue

The dossier will be coordinated by Laure Com-Ruelle (IRDES, France)

and Katia Julienne (HAS, France).

This call for papers is addressed to researchers in health, philosophy, political science, law, economics, and sociology as well as to actors in the health and medico-social field.

Articles are expected **before 11 March 2019**

Against the backdrop of health scandals related to drugs or other health products and in a context of medical desertification, the media, politicians, and citizens have been taking up the issues and debates concerning the relevance of care, defined as appropriate care at the right time for the right person. This has been the case, for example, with the critics of Pink October, an awareness campaign on early detection of breast cancer generalized to all women. The opposing arguments balance the risks and traumas of the practice with the expected benefits and outcomes, thus referring directly to the question of the relevance of care.

These questions are reinforced by the regular publication of reports illustrating national[1] and international variations in care practices. In particular, the publication of the report “Geographic Variations in Health Care: What Do We Know and What Can Be Done to Improve Health Care

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[1] In France, this phenomenon is regularly the subject of “Atlas” by IRDES. Documents available online: http://www.irdes.fr/recherche/ouvrages.html.

Performance?" by the Organisation for Economic Co-operation and Development (OECD) in 2014 increased awareness that regional variations in medical practices, whether in prevention, diagnosis or treatment, is a global phenomenon. The report demonstrated that these variations are not only explained in terms of the health status of the population, nor in terms of patient or professional preferences. It also demonstrated the limitations in the share of national responsibility in structuring the health system. In addition, recent OECD work has highlighted the strengthening of the role of quality in health system regulation and efforts to strengthen the relevance of care ("Caring for quality in Health: Lessons Learnt from 15 Reviews of Health Care Quality", OECD, 2017).

Thus, the utilisation use of relevance of care in regulating patient care has now appeared in its own right as a strategic subject for the quality of care and a major challenge for patient safety and the organisation of the healthcare system. In initiating the analysis on what relevant care is and including it in a global analysis, the American doctor Vikas Saini[2] proposes integrating the economic dimension into the very definition of the concept. Good care would therefore be *care that optimizes health and well-being by delivering what is necessary, requested by the patient, clinically effective, socially equitable, and responsible in relation to the limited resources of our planet.* The "value" of a treatment would thus be assessed using a ratio/balance that takes all these aspects into account.

The question of taking into account the economic aspect also refers to the broader question of social inequalities. Research in France suggests that, social inequalities generate differences in treatment. For example, the use of knee replacement surgery or hysterectomy may be linked to education level, socio-economic background, and residential area (OECD 2014). The few studies available do not allow us to draw conclusions as to the reasons for these differences. However, hypotheses have been put forward that refer to the social representations that professionals have of their patients, and in particular with regard to their ability to understand, implement, and respect prescriptions, rather than to a belated recourse to medical treatment (Baudelot et al. 2016).

Should this economic question therefore be included in the definition of "good care"? What happens to the initial definition of relevant care when the practitioner confronts economic and social realities? The answer to this question is not closed and is the subject of a substantive debate.

Socio-economic conditions, as well as the question of financing the health care system, could be examined as determinants of this relevance or as variables impacting relevance. In the context of this call for contributions, each contributor will thus be free to propose his or her own definition of the relevance of care and to extend the reflection initiated here, while not however being limited by it. Indeed, this call for contributions opens the question of the relevance of care at the crossroads of ethical, political, and professional logics, as well as in the health and medico-social fields.

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[2] Speech at the conference *La Pertinence des soins : tous concernés* [The relevance of care: everyone is concerned], organised by the Haute Autorité de Santé (HAS), on 14 November 2017.

The analysis of the issues raised by the various actors makes it possible to understand local, national, and even international realities, as well as the questions specific to the context in which care is provided: care at home, in the office, hospitalisation in an institution or at home, outpatient care, or care in a psychiatric hospital. Each context may lead professionals to redefine their practice and rethink their relationship with their patients. What is an informed choice? How can a low level of education or cognitive or psychological limitations be taken into account? Who should accompany the patient in the expression of his request and how should this be done? The patient-physician relationship has historically been built on a paternalistic model, in which the doctor, belonging to the elite, *knows* and the patient *executes* (Pierron 2007). The erudition of doctors, the length of their studies and the difficulty of accessing them are still today a valuable social marker, especially among the working classes or among the low-skilled. This gap in social positions continues to influence the patient's relationship with professionals, and sometimes generates unequal treatment (Leclerc, Kaminski, and Lang 2008) that is detrimental to the transmission of the information necessary to ensure the relevance of care. So how can we remove the hierarchical relationships induced by old social habits, by the gap in education levels, or in social positions?

The multiplicity of actors and logics thus leads us to question the relevance of care at the three levels of analysis of the action.

At the micro level, questions can be posed concerning the role of health professionals, the transformation of the patient's role (from patient to patient-actor/expert), patient-physician interactions, the making of care decisions...

At the intermediate level, the relevance of care leads us to question the role of local and regional authorities, and the spatial challenges they face, but also the professional dynamics in a social space where tensions between the different professions are omnipresent (Peneff 1992; Arborio 2001; Robelet, Serré, and Bourgueil 2005).

Finally, at the macro level, the question of the governance of public health policies leads to questioning the economic, social, and ecological challenges that feed political and ethical debates on the definition of good care and the evaluation of the relevance of care.

These three levels of analysis may be implemented separately or collectively in order to allow a global understanding of the relevance of care through three themes:

- The challenge of organising the health system

- The role and place of the patient

- Encourage, support, and evaluate

1. The challenge of organising the health system

A first subject would be to focus on the organisation of the health system, whether through its funding methods, the ethical issues that affect it, or the socio-economic upheavals it faces.

Demographic changes, the increase in knowledge, and solutions available to doctors, as well as the contribution of new technology (robotic assistance, administrative digitisation, diagnostic software, etc.) are disrupting the health and medico-social landscape and raising questions about the need to reform the current health system.

Organisation, financing, and relevance of care

To what extent does fee-for-service funding influence the choice of professionals in favour of certain better paid care ? Or even generate a certain amount of supplementary demand or redundant actions? Do financial incentives at the collective (institutional) and individual level (payment for public health objectives, ROSP) influence practices? How? What role do they play?

In the context of therapeutic strategy, how do the actors exchange their knowledge and take into account each other's' opinions and needs? For example, what importance and recognition should be accorded to the work and cost of coordination of home hospitalisation? How is the management of resources organised, especially in cases of scarcity due to unequal spatial distribution? Can the development of e-health become a major response in improving the relevance of care in areas poor in health professionals? And are home hospitalization and outpatient surgery relevant responses to the structural lack of available places and services in some regions?

In the face of global environmental issues, a final sub-theme refers to questions related in particular to the overuse and misuse of resources. To what extent should these issues exist in the question of the relevance of care? Are these environmental issues taken into account in the choice of institutions and professionals in proposing a care orientation?

The organisation of the health system and digital tools

The possibilities offered by computer tools and information technologies suggest the potential for multiple improvements. With the possibility of sharing experience-acquired knowledge through a data base, it is possible to foresee better care coordination. The digitisation of files and the creation of dynamic databases containing data on millions of cases will make it possible, for example, to assess the efficiency of possible treatments for a given patient.

Consequently, the massive arrival of computerized medical data, such as medical practice dossiers or the digitization of medical archives, addresses the totality of ethical issues surrounding the management and use of Big Data.

Can existing means be used to take advantage of this data to improve diagnosis? Are current structures able to ensure the administration and security of this data while making it available to professionals? How can the application of patients' rights be ensured, and in particular the right of access and deletion of data concerning them? Is it desirable to maintain this right with regard to medical data? Should the scientific knowledge provided by these databases be made available to patients and their representatives (patient associations, user representatives, etc.) in order to improve their understanding of the pathologies and the various possible responses? How can this transmission to the layman be carried out?

The question of the system structure refers not only to the question of prescriptions at a given time (for diagnostic, therapeutic and preventive procedures, health products, hospitalization, etc.), but also, from a dynamic or longitudinal point of view, to the path itinerary around a therapeutic strategy.

2. The role and place of the patient

A second theme questions the patient's role in the definition of the best care. In recent years, the patient-professional relationship has become part of a new paradigm, that of the expert actor, which, by affirming the experiential knowledge of the patient, challenges the dominant relationship that previously prevailed. The doctor is no longer the only knowledgeable person. The patient now has access to abundant information, both institutional and secular, organised and transient. The professional/patient relationship is increasingly seen as a partnership relationship, with the possibility open for the co-construction of a therapeutic itinerary (Pierron 2007; Karazivan et al. 2015). What assessment can be made of user participation in administrative and evaluation bodies sixteen years after the adoption of the 2002-2 law renovating social and medico-social action?

Peer-assistance

Psychiatric units have been developing peer-assistance programs as part of their therapeutic itinerary since the late 1980s in the United States and more recently in France. The principle of these programs is to encourage patients at the end of their care itinerary to share their experiences and to support patients at the beginning or during their treatment. The impact of "peer-support workers" (United States), "peer-helpers" (Canada) and "peer health mediators" in France seems positive both for the patients with whom they work and also for themselves (Le Cardinal et al. 2013). Can the development of *peer-assistance programs* facilitate the involvement of patients in their therapeutic itinerary, beyond the experiments conducted in psychiatric units? The development of these programmes has raised many questions such as the legal status of this activity. Should "peer health mediators", as they are known in France, carry out this activity on a voluntary basis or, on the contrary, should we consider remuneration? Does this activity constitute employment like for disabled workers in ESAT or is it a therapeutic activity? Should we consider recognizing the professional skills used, requiring training, qualification, or certification?

The patient-professional relationship

Patients are expected to give their consentment to care, to be able to make informed choices since the adoption in France of the Public Health Act in August 2004 (Bergeron and Nathanson 2014). However, not all patients are socially and academically equal, so how can informed consent be ensured? What about the patient's freedom of choice? How can we analyse and implement therapeutic education? Are targeted communication campaigns effective for all audiences? Are they not likely, in the context of prevention communication, to generate a form of habituation that renders poor service to the initial objective, such as campaigns against HIV and the worrying decline in condom use among young people?[3]

In the patient-professional relationship, if the patient is to take an expert and knowledgeable place, professionals must agree to break with habits and traditions (Pomey et al. 2015). How can relational practices of professionals be transformed? How have health and medico-social facilities evolved to take into account this paradigm shift? How can this relationship with the patient be taught and learned? How far does the responsibility of professionals go in supporting the patient's decision? Social stratification results in unequal positioning of patients as partners of professionals. What are the levers available to these professionals in getting the patient to accept this position and make an unguided decision? Finally, is it desirable to wait for everyone's informed choice? Is this not an illusion?

3/ Support, encourage, evaluate

A final theme questions the teaching and implementation of the relevance of care in professional practice. Indeed, the development of this notion generates not only a change in the patient-professional relationship as mentioned in theme 2, but also a change in the processes of the elaboration of a medical response.

Training and support in the relevance of care

Introducing the notion of the relevance of care into the professional's analysis of the health of his patient could lead to a different diagnostic approach. In some professional training courses, teachers rely on the testimony and intervention of patients. Is this an effective lever in aiding future professionals to consider the relevance of care? What concrete changes does the introduction of this concept into daily practice mean for us? How do professionals adopt the recommendations for good practice? What are the resources available to public actors and professionals in implementing this change in practice and in assisting their patient? What do the clinical case analysis meetings tell us about the dissemination, assistance, and collective definition of the relevance of care? What are the tools for improving the relevance of care? How can useful tools for professional decision-making and prescription software be assembled?

Evaluation of existing mechanisms

As with any systemic change, evaluation is essential, both in improving existing mechanisms and in improving understanding of the real changes brought about by the crucial nature of this research. What data should be exploited from this perspective? How can we ensure the ethical use of this data and its security, particularly when making dossiers available to professionals? What autonomy should be granted to evaluation bodies? Should the use of this data for evaluative or improvement purposes be entrusted to private organisations? The question of evaluating the care offered to a patient refers, as has been mentioned, to the relationship that the professional

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[3] Despite nearly 20 years of targeted communication, an Ifop-Bilendi survey published in the spring of 2018 showed that 26% of French people aged 15 to 24 wrongly believe that there are drugs to cure AIDS (13% more than in 2009). They believe that a vaccine can prevent the transmission of the virus and 32% believe that they are less likely than others to be infected.

has with his patient. So how can the professional’s practices be evaluated? How is a relational dynamic assessed in the context of care?

Some precisions

Contributions from foreign experiences will be particularly welcome. Moreover, while three themes have been identified to highlight the diversity of the issues, the contributions may of course combine them to highlight their interactions. Finally, it should be recalled that this call for contributions is multidisciplinary and is addressed both to researchers and to actors in the field of social protection. Multiple viewpoints and even controversies between disciplines would be quite appropriate in this issue.

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