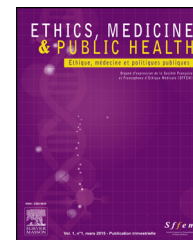




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PRACTICES AND CONCEPTS

Personalised medicine. Bringing narrative tools to Carpem



Médecine personnalisée – apporter des outils narratifs au Carpem

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Summary How can a cutting-edge research programme with its concomitant experimental and therapeutical applications such as CANcer Research and PErsonalised Medicine (Carpem), with a strong rationalistic component and deeply focused on the disease, correspond to the ethical dimension of medicine process involving the patient as a collaborative member? The first part of this article describes the challenges and the present state of the Carpem programme, its multi-system model and the differential value of the interpersonal, relational and communicative abilities involved, emphasizing the need for the human and social sciences. In line with the multidisciplinary cross-work developed between the authors, the second part interrogates the concept of "personalised medicine" in the light of the "Narrative turn" of narrative-based medicine (NBM) and proposes a framework derived from literary studies resorting to concepts and tools such as dialogism, (close) listening, and body/language reciprocity to promote interaction, interpretation and care, towards a Patient-centred precision medicine.

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MOTS CLÉS

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Résumé Comment un programme de recherche et d'applications expérimentales et thérapeutiques de pointe tel que *cancer research and personalised medicine* (Carpem), de forte conception rationaliste et largement axé sur la maladie, peut-il répondre au dessein d'une médecine de vision éthique et impliquant le patient en tant que sujet dans tout le processus ? La première partie de cet article décrit les enjeux et l'état actuel du programme Carpem, ses interrogations sur les limites d'un modèle multi-systématique en ce qui se rapporte aux dimensions relationnelles, interpersonnelles et communicatives, dont on reconnaît l'efficacité en termes thérapeutiques. Inscrite au cœur de la notion même de « personnaliser », cette problématique peut s'enrichir des acquis de la *narrative-based medicine* (NBM), comme le développe la seconde partie de l'article. Dans la lignée du travail de collaboration multidisciplinaire des auteurs, il s'agira d'envisager l'apport de certains concepts des études littéraires – dont le dialogisme, l'écoute, et la réciprocité corps/langage – au développement d'une médecine de précision centrée sur le patient.

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Introduction

Cancer Research and PErsonalised Medicine (Carpem) is a cross-disciplinary program, created in 2012 in straight collaboration between Paris/Descartes University and two Paris-Parisian hospitals, HEGP and Cochin/Hôtel-Dieu. It develops research and experimental therapeutics in the field of personalized medicine (also called precision medicine) leading to a better understand the mechanisms of carcinogenesis and the relationship between tumour and host microenvironment, to an improved cancer patient management. The ethic dimension and an integrative approach combining technical and communicative skills still a major challenge to improve the quality of medical intervention. Furthermore, the use of tools issued from literary criticism can provide a framework for better interaction, interpretation and care. This paper emerged from an engaged and collaborative dialogue across disciplines, between clinical scholars in oncology and narrative medicine, two fields that share a concern for the human.

Personalised medicine

Personalised medicine has been defined by the American director of the Council for Science and Technology as “the adaptation of medical treatment to the individual characteristics of each patient, with the goal to classify individuals into sub-populations according to their susceptibility to disease or response to certain treatments. Recent and rapid advances in genomics and molecular biology are revealing a growing number of new genome-related molecular markers for the presence of the disease, susceptibility to disease or differential response to treatment. It is now possible to use such markers as the basis of new genomics-based diagnostic tests for identifying or confirming disease, assessing an individual's risk of disease, identifying patients who will benefit from particular interventions or tailoring dosing regimens to individual variations in metabolic response. This approach is also a promising way for development of new therapeutics specifically targeted at the physiological consequences of the genetic defect(s) associated with a patient's disease. Preventive or therapeutic intervention

will be offered to those who will benefit sparing expense and side effect for those who will not” [1]. Its development in oncology requires a better understanding of mechanisms of carcinogenesis, identification of prognostic biomarkers and targeted therapies to assess the management of patients with a greater accuracy by using targeted and scientifically proven treatments. The traditional one-size-fits-all paradigm is going to be replaced by one that focuses on individualized patient care using specific genetic profiles and medical histories. In this context, eight sites have been approved in France to become a so-called “SIRIC” (cancer integrated research sites) under the second French cancer plan. Their aim is to strengthen the capacity of multidisciplinary research in a competitive way, each site organising and managing interdisciplinary programs of cognitive research and organising the dissemination of knowledge and practices. Personalised medicine is nowadays rather called “precision medicine”, which does not imply the needs of everyone. However, it appears as a new and promising tool to combine with patients' preferences to reach a new paradigm of “patient-centred personalised” describe what was happening yet in a model of personalised medicine. The second one was to understand the feelings of all participants (what they were thinking and feeling about the impact of this new model). The third one combined evaluation and analysis to propose an action plan dedicated to build new practices that would be a better answer to both practitioners and patients' expectations.

Challenges and limits

The main objective was to improve the patients understanding of the goals and limit of the so-called “precise medicine” and include them in the construction process of a centred and personalised medicine. We created two distinct and multidisciplinary committees (a joint committee and a patient committee) to both know the action (the status of the information sharing) and to reflect on the action.

The Joint committee (JC) gathered some searchers of the Medical Ethics and Forensic Medicine Laboratory of the University Paris Descartes with practitioners and searchers participating in medical and scientific aspects of the Carpem

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