



Original Article

Personalised medicine: The cognitive side of patients

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ABSTRACT

Background: Although the fashion for the “personalised” or “stratified” approach to medicine is valuable in exploiting the omic signatures of the individual patient, too little attention has been paid to the influence of psychological and cognitive factors in the care process. The aim of this paper is to highlight the importance of those individual psycho-cognitive components in affecting how people act to prevent, cope and react to illness, decide about different therapeutic options, interact with health care providers, and adhere to treatment.

Methods: We reviewed the medical and psychological literature about the effect of cognitive and psychological dimensions on treatment efficacy, on patients' global satisfaction, and on treatment compliance.

Results: Psychological dimensions have been proved to impact on treatment efficacy, on patients' global satisfaction, and on compliance to treatment. However, there are substantial individual differences among patients; therefore, it is important that physicians recognise how to apply these general recommendations to each individual patient, alongside the omic information emerging from the molecular diagnostic laboratory.

Conclusion: The exam of the current literature allows one to derive several strategies which can help health professionals to improve the patients' understanding of their disease and involvement in the whole care process.

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1. Introduction

Patients are typically seen as passive recipients of care. They have trust in their doctors, comply with treatment decisions and don't ask questions. An important ideal emerging from the development of personalised medicine is to enable patients to be participants and guides in their own health care. Involving patients in treatment related decision-making is in line with the increasingly acknowledged patients' right to autonomy and self-determination. Several studies have assessed patients' wishes within a personalised medicine framework: the possibility to have adequate information and permission to participate in decisions which affect them; the possibility that clinical staff might accord such information with empathy, dignity, and respect; the possibility to be told about the options for treating or managing their condition; and the possibility that their preferences might be taken into account [1,2]. These attributes are important, not only just because people prefer to be treated by clinicians who are good listeners and good at informing, advising, and educating them, but also this type of care may contribute to better health outcomes [3], to a higher adherence to treatment recommendations [4], and to increased trust in health professionals [5].

In order to customise patient care, personalised medicine has already led to several changes in the treatment setting, where the efforts by academia and industry have been channelled to both improve diagnostics and prognosis of diseases, and, through the development of biomarkers of drug response and adverse effects, improve the safety and efficacy of those drugs. However, besides the detailed description of both the biological makeup of the individual and the molecular characteristics of the disease, other elements have a relevant role in the process of care, namely patients' cognitive and psychological characteristics. Indeed, the way in which each patient reacts to his/her illness, understands his/her clinical condition, forms an opinion about possible treatments, adheres to treatments, copes with treatment side effects, and interacts with the whole health care process adds new dimensions to human uniqueness in the same way that genetic information does. Patients' psycho-cognitive aspects also need to be factored into the picture by defining a personal profile of how the patient recognises his/her specific needs and values, habits and behaviours, hopes and fears, beliefs and cognitive dispositions [6]. Psychological dimensions impact on treatment efficacy: the process of integration of patients' goals, preferences and concerns with medical evidence and provider experience leads to high-quality medical decisions. A systematic review of 86 clinical trials [7] found that providing patients with clearly presented evidence led to: 1) improved understanding of treatment options and screening recommendations; 2) more accurate expectations of possible benefits and risks; 3) choices more consistent with informed values; and 4) higher patient satisfaction. Patients who are able to seek knowledge, those

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who understand what is being communicated, those who can judge what is appropriate to their own situation and able to apply treatments are more likely to have better health outcomes in general. Given these results, to be fully effective personalised medicine needs engaged and informed patients who are encouraged to discuss various treatment options, the possible consequences of those options, and then to arrive at an informed decision about the best action to take. This engagement ensures that patients remain involved in following the various stages of treatment evolution. As a consequence, patients have an increased responsibility to control their own health care; this includes the ability to understand and act on health information (health literacy), and the ability to work together with clinicians to select appropriate treatments or management options (shared decision making).

2. The informed patient: health literacy and understanding information

Health literacy entails people's knowledge, motivation and competence to access, understand, appraise and apply health information needed to make judgements and to take decisions concerning healthcare, disease prevention and health promotion [8,9]. It is known that patients with low health literacy tend to have poorer health status, tend to be less likely to adhere to prescribed treatments, to comply with self-care plans, and to experience more drug and treatment errors [10]. A recent review by Berkman and colleagues [11] revealed that low health literacy correlates with a differential use of certain health care services, a decreased participation to screening and influenza immunizations, a poorer ability to correctly take medication, to understand medication labels and health messages and, among elderly persons, higher mortality. However, limited health literacy is not only an issue for vulnerable groups such as the elderly or people with a low level of education. Around 40 to 60% of medical information provided by health practitioners is forgotten within a few minutes, and these percentages increase in old age; furthermore, not all of the information "remembered" is correctly recalled [12]. A recent study revealed that 47% of the general population faced difficulties in understanding, judging and applying information to make decisions regarding their health [13].

Therefore, the route to involving patients in the care process requires that patients are provided with transparent and credible information about their diagnosis, the chance of benefit and the risk of harm from various therapeutic interventions in a more effective manner. Knowledge also confers confidence: patients are more likely to trust their capacity to make decisions when efficiently informed [14]. A recent study showed that 80% of patients want the clinician to tell the truth about their diagnosis, and more than 70% wanted to know the risks associated with each therapeutic option; furthermore, 67% wanted the provider to explain how the options might impact on their quality of life [15]. In addition, patients want information about medicines, firstly to help decision-making, and then to assist ongoing decision-making about the management of those medicines [16]. But the information needs to be given in a language which takes into account the particular aspects which make up the cognitive state of each individual patient.

3. The engaged patient: from good information exchange to engagement

The process of involving patients in their care decisions does not only require health literate patients, but also require a "health literate friendly system" which decreases the information and power asymmetry between doctors and patients (i.e. the doctor knows everything, the patient nothing). This means improving patients' grasp of information through a language that is matched to their educational level, and allowing patients to effectively state their own preferences and concerns.

In other words, the information exchange needs to be two-way: the health professional provides information to help explain the clinical situation and subsequent decisions, and the patient provides information

on his/her values, preferences, lifestyle, beliefs and previous knowledge about the illness and its treatment [17]. The first type of information flow ensures that all the relevant treatment options are on the table; the second ensures that these could be evaluated by both the healthcare professional and the patient within the context of the patient's specific needs. When this happens, the health professional can create the shared knowledge necessary to consolidate the patient's engagement and to successfully execute the shared decision process. However, it seems that this does not happen as frequently as patients would like. A recent study found that there is a gap between what patients want and what they get with respect to engagement in health care [15]: over 80% of patients strongly want their health care provider to listen to them, but just over half say it actually happens; also, 70% wants their provider to explain the risks of the therapeutic option(s), but this also happens only in half of cases.

There is some evidence moreover, that good information exchange within a good healthcare professional–patient relationship could be considered as a therapeutic intervention [18] because it helps in preserving or improving the patient's ability to deal with his/her illness, and even in maintaining a good quality of life. This is particularly relevant in the chronic phase of any disease, as it helps to increase the patient's vitality and social functioning, and to reduce the incidence of depression and anxiety. Further, the possibility of being involved in treatment decision making is of major importance in life-threatening diseases, whose treatment course passes through key decision points, and for those illnesses whose treatment options do not lead to clear-cut differences in survival outcome, but which may vary in their impact on the patient's physical and psychological wellbeing [19]. All such considerations apply a fortiori in the case of elderly patients, who often suffer from multiple diseases, comorbidity, frailty, and social isolation [20]; a recent review by Nobili and colleagues [21] illustrates the need for an integrated and comprehensive approach to the care of elderly people, especially among internists. Indeed, it is particularly important that internists take into account the complexity and the overlapping health and social problems of elderly patients, paying attention to genetic and biological factors as well as lifestyle, psychological, cognitive and social characteristics, and to the way these elements interact to determine multimorbidity, or interfere with medication compliance or with the adherence to healthy lifestyle recommendations.

To take into account the patients' cognitive and psychological determinants, and to involve patients in the care process, however, does not imply forcing every patient to assume power and responsibility; some patients do not want to share the decision making process with health professionals. In such cases, however, patient engagement is still important in that it encourages patients to provide information about their health and wellbeing values, their information and practical needs, the treatment side effects, and so on. The more engaged the patient, the more abundant and precise will be the information flow from patient to professionals.

4. Health professionals' role in informing and engaging patients

On one hand, recent advances in diagnostics facilitate the process of obtaining a precise diagnosis at molecular level, leading to planning the most effective therapeutic strategy, and predicting the most probable prognosis. On the other hand, greater scientific and clinical clarity has prompted growing patients' requests for help in fully understanding the science behind their medical condition, and to be subsequently supported in participating in the care process. A good example is in the unravelling of familial conditions. Despite the increased use of informal sources of information external to the healthcare setting such as the Internet, the patient–health professional interaction still represents a critical juncture for the exchange of health information [22]. What can health professionals do to improve their patients' health literacy and their understanding of their personal disease? Doctors faced with making time to explain diagnostics and pre-treatment tests, and the

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