

The Dark Side of Health Care Coproduction

Health literacy as a requisite for the co-production of care

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Abstract—“Patient involvement” and “patient engagement” are two buzzwords in the field of health care provision, whose statement is recurring in most of the current international health care reforms. Both of them suggest a reconceptualization of health care: from a provider-led service, it turns to be a co-produced service. Consistently, the patient is understood as the subject rather than the object of care, being engaged in any phase of the provision. Nevertheless, most of the patients are not able or they are unwilling to be involved in the provision of care. Information asymmetry, psychological weaknesses, and poor health literacy hinder the activation of the patient. Lacking a process of patient enablement, co-production of care is doomed at remaining beautiful words. This article depicts the results of a descriptive literature review aimed at discussing the relation between health literacy and patient involvement. Although health literacy is widely understood as a key determinant of patient activation, it is infrequently addressed within the initiatives proposed at the empowerment of the patients.

Keywords — Co-production, health care, health literacy, patient involvement, patient engagement

I. Introduction

The “bio-medical” model of care is still prevailing among health care professionals [1]. In general terms, it lies on three basic assumptions. First of all, the bio-medical philosophy maintains that “health” should be conceived as the total absence of disease. Secondly, the best way to cure the disease is assumed to be the reduction of the patient’s body to its small constituent parts, in order to separately treat and heal them. Last but not the least, medicine is understood as a form of engineering, which has the purpose of curing the ill-status through a purely scientific method [2]. In a sum, the bio-medical approach to care focuses on the illness and neglects the subjectivity of the patient: health care provision is aimed at fixing the cellular abnormalities which produce the fall of the health status, regardless of the patient’s identity [3].

In the last decades the pre-eminence of the bio-medical model has been challenged by alternative philosophies, that conceptualize the provision of health care as a mainly relational issue. Among the others, the “bio-psycho-social” model of care recognizes the complexity and the interdependence of the determinants of well-being, assuming that the decline of the health status could be produced by biological factors, as well as by social, environmental, and behavioural ones [4]. From this standpoint, the provision of care should not be perceived as a singular episode, during which a clinical treatment is provided. Quite the opposite, it is

meant as a human encounter, during which two agents share mutual information and define a joint strategy to deal with the illness [5]. It follows an integrated approach to understanding the disease, that recognizes the point of view of both the providers and the patients [6]. Eventually, the latter are engaged in the provision of care, acting as co-producers rather than as objectified bodies undergoing a clinical treatment. According to this perspective, the encounter between the health care professional and the patient is revisited in the light of the idea of co-production: such a reconceptualization is aimed at enhancing the appropriateness and the quality of care by virtue of the activation of the patients’ sleeping resources.

II. The idea of co-production in health care

Adhering to the traditional bio-medical philosophy, the patient is understood as a mere consumer of care. He/she is situated at the end point of the process of health care provision, unable – and in most of the cases unwilling – to participate in it. According to this bounded perspective, the patient has been assumed to be the object rather than the subject of care. He/she has been perceived as an impersonal body needing a clinical treatment, which has the purpose of fixing the ill-status. As a consequence, the patient has been prevented to take an active part in the provision of care, that solely relied on the professional autonomy of the provider.

Such an approach is currently opposed by the latest reforms aimed at reshaping the management of public services in a perspective of engagement of the users [7]. Indeed, as argued by Bovaird, co-production is recognized as inherent in the provision of public services, due to the long-term relationship that usually connect providers and users and the role played by the latter to complement the value creation [8, p. 847]. With specific regard to the provision of health and social care – as pointed out by Marks and Lawson [9, pp. 209 and followings] – co-production generates several valuable outcomes. Firstly, the involvement of the patient in the provision of care is an asset-building process: it enhances the ability of both the parties to arrange appropriate solutions through a collaborative approach. Secondly, co-production generates a more balanced distribution of the tasks among the patients and the health care professionals, engaging the former to back up the activities of the latter. Lastly, co-production of care boosts the reciprocity between the users and the providers, inciting the commitment of both of them in the delivery of care as partners rather than as principals and agents.

In substance, co-production of care assumes that the health treatment should not be delivered by the provider according to a one-way transfer approach. Rather, the patient is understood as an active part of the process, playing a relevant role in planning, implementing, and assessing it. More into details, the patient supplies several inputs that are essential to enhance the appropriateness of health care provision, such as reliable information about the health status as well as solid facts about the root causes that produced the illness. In addition, the user participates in the process that leads to the transformation of the inputs in outputs: on the one hand, he/she is called to comply with the instruction of the providers and, on the other hand, he/she collaborates in the delivery of the treatment through self-care. Last but not the least, the patient is the part of the medical encounter who is better able to assess the translation of health care outputs in health outcomes, thus providing significant feedbacks about the effectiveness and the appropriateness of the treatment received [10].

From this standpoint, it could be argued that freedom of choice alone does not suffice to realize a concrete model of health care co-production. Actually, the engagement of the patient implies a process of activation – generally defined “patient empowerment” [11] – according to which the user is enabled to take part in the provision of care. Letting the patient to participate in the diagnosis of the ill-status and in the arrangement of the medical treatment, it is possible to appreciate the multiple dimensions and determinants that affect the individual well-being [12]. Besides, engaging the patient, it is possible to improve the results achievable due to the value added produced by the co-production of care [13].

Several studies have examined the relations between patient empowerment, provider-patient communication, and health outcomes, outlining a positive linkage between these three dimensions [see, among the others, 14 and 15]. Consistently, many scholars claim for the importance of both patient activation and co-production of care in order to achieve outstanding health outcomes dealing with – as illustrative examples – mental health illnesses [16], diabetes [17], and chronic diseases [18]. On the other hand, despite the research in the field of health care co-production is currently blooming, the determinants of patient empowerment and involvement in the provision of care are thus far poorly discussed. The activation of the patient is often assumed to be a panacea to the ills of health care provision; at the same time, a comprehensive framework aimed at addressing the factors that affect the engagement of the patient is still lacking.

Scholars who are interested in the co-production of care usually neglects the “dark side” of patient involvement. Actually most of the patients are unwilling to take part in planning and delivery of care, first of all due to the information asymmetry and the vulnerability that detach them from the health care professionals [19]. Such a disengagement is further exacerbated because of the psychological weakness perceived by the patient, that is caused by the perception of the illness and the consequent fall of the health status [20]. In fact, the emergence of the disease provokes a condition of dependency of the patient toward the provider, who is conceived as a healer, or the sole agent who is able to fix the ill-status handling a scientific approach.

Inadequate health literacy is one of the key motivation of patients’ unwillingness to participate in the provision of care as well as of their perceived dependence toward health care providers. In fact, poor health literate patients are not able to appropriately navigate the health system; rather they rely either on the advice of informal caregivers or on the guidelines of health care professionals. However, up to the present scant attention has been paid to the relationship between health literacy and patient engagement in the provision of care.

III. Health literacy: a determinant of patient involvement

Health literacy generally indicates the ability to handle the data concerning the protection of the individual health status, such as the instructions contained in prescription bottles or medical recipes [21]. Indeed, “literacy” – or the ability to comprehend written and oral health information – and “numeracy” – or the expertise to process the numerical data included in health information materials – are the basic skills that describe health literacy. Joining these two competencies, the literature has conceived the concept of “functional health literacy”, that expresses the patients’ readiness to perform the every-day tasks related to the management of the individual health status [22].

Some scholars have expanded this definition, arguing that health literate patients disclose interactive and critical competencies, too [23, 24]. Indeed, health literate patients are able to manage their own well-being by comprehending the health information, as well as by establishing appropriate relationship with the actors that operate within the health system and discriminating the different options available to protect and promote their health status. Summarizing these points, health literacy could be described as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”, as reported by Baker [25, p. 878]. Consistently, Heinrich defines health literacy as the sixth vital sign, claiming that it could “decrease health disparities and improve overall health outcomes” [26, p. 219].

Scholars maintain that poor health literate patients are unwilling to be involved in the decisions that affect their health status. Rather, they prefer to delegate the choices that concern the treatment of their ill status to informal caregivers and to health care professionals [27, 28]. In fact, inappropriate health literacy interferes with the ability to observe clinical prescription: it produces inappropriateness in the access of care, poor service quality, and growing costs [29, 30]. As well, low health literate patients are not aware about the determinants of well-being and about the resources or the services that could be exploited to protect and promote the health status [31]. As a consequence, they are not able to appropriately navigate the health system and are more likely to exhibit risky behaviours [32]. From this standpoint, the achievement of an adequate health literacy should be promoted as an approach of “universal precaution” [33, p. 22], activating and empowering patients to be engaged in the provision of care.

In spite of these arguments, health literacy is infrequently addressed within the initiatives aimed at the involvement of the patient. Hence, this paper shows a descriptive literature review of the scientific papers dealing with the engagement of the patients in the provision of care, with the purpose of providing a tentative answer to the following questions of the research: is health literacy taken into account devising interventions directed at the activation of the patient? Is health literacy recognized as a determinant of patient engagement or rather as an outcome of the patient involvement in the provision of care? The following section describes some methodological notes. Then, the findings of the research are discussed, drawing from them several concluding remarks.

IV. Methodology

In order to collect the articles that informed the literature review, the Author consulted the database “Scopus Elsevier”, the largest abstract and citation database of peer-reviewed literature in the fields of science, technology, medicine, social sciences, and arts and humanities. The following criteria of research were included in the field “article title, abstract and keywords”: “‘health literacy’ AND ‘patient engagement’”, “‘health literacy’ AND ‘patient involvement’”, “‘health literacy’ AND ‘patient activation’”, and “‘Health literacy’ AND ‘patient empowerment’”. Neither temporal restrictions nor limitations based on the article type were introduced. On the whole, 99 items were retrieved, mainly consisting of articles published in peer reviewed journals and editorials. The collected contributions were arranged in an electronic worksheet, in order to remove duplication. As a result, 16 redundant articles were removed.

The remaining 83 items underwent an in-depth analysis of their abstract with the aim of selecting the relevant article for the literature review. For this purpose, several exclusion criteria were adopted. More into details, the articles that did not discuss the relation between health literacy and patient activation were excluded; as well, conceptual paper were not included in the research, in order to avoid a theoretical bias dealing with the importance of health literacy to enhance patient involvement in the provision of care. Last but not the least, the contributions that dealt with patient engagement in purely descriptive terms were removed. In the end, 16 items were included in the literature review; all of them consisted of papers published in peer reviewed journals.

V. Discussion of the findings

Patient involvement and shared decision making represent two ethical imperatives for health care professionals, as well as two important priorities on the policy agenda in most of the Western countries. However, the engagement of the patient requires high levels of health literacy and a significant self-efficacy perception [34, 35]. It follows a concern that the initiatives aimed at inciting patient activation could deepen health inequalities, marginalizing disadvantaged and poor health literate patients. Nonetheless, Durand and co-authors have argued that low literate patients could especially benefit from initiatives aimed at enhancing their participation in the

health care provision [35]. Indeed, co-production of care generates positive outcomes that affect: their participation in shared decision making, their commitment to self-care, and the levels of patient safety. Couto and Comer have expanded this point, describing patient engagement as a catalyst for the process of change of health care systems. It enhances users’ expertise, thus favouring healthy behaviours and encouraging a more appropriate use of health care services [36].

In a recent literature review, McCaffery and colleagues have discussed the effectiveness of a specific tools aimed at enhancing the involvement of patients in shared decision making, that is to say the Patient Decision Aids (PtDAs) [37]. The Authors claim that the ability to effectively use a PtDA does not rely solely on the quality of the tool, but also on the patients’ levels of health literacy, to be conceived in terms of functional, critical, and interactive skills. Actually, patients with inadequate health literacy express lower preferences for involvement, exhibit frequent lack of understanding, develop low mutuality and reciprocity with providers, and do not motivate health care professionals to adopt patient-centered approach to care. Besides, McCaffery and co-authors maintain that existing PtDAs do not address the needs of poor health literate patients, being tailored to expert users. From this standpoint, shared decision making represent a “challenge” for patients with low health literacy, who are usually not able to deal with them. Hence, both scholars and practitioners are called to acknowledge the needs of inadequate health literate patients, devising appropriate strategies and tools to encourage their participation in the provision of care [38].

Adopting this standpoint, van der Weijden and colleagues carried out a qualitative key-informant study involving 75 experts in guideline development and shared decision making, with the purpose of exploring how clinical practice guidelines could be revisited in order to facilitate shared decision making [39]. The findings of this study suggest that the strategies to improve patients-providers communication should include a strong reference to the health skills of the users. Hence, the communication between the patient and the provider should be tailored on the characteristics of the former, here included the individual levels of health literacy. Developing this point, Weymann, Härter, and Dirmaier have proposed two study protocols dealing with diabetes and chronic low back pain. In the light of the findings of their study, they claim that the tools employed in patient-provider communication should be tailored to relevant characteristics of the former, among which health literacy. In fact, by virtue of the personalization of these tools, it is possible to boost the patients’ expertise in regards with health issues, improving both adherence to medical prescriptions and self-management of care [40, 41].

Drawing from the assumption that inadequate health literacy is generally associated with poor management of long-term health conditions, Edwards and colleagues have developed a model that conceives health literacy as a multidimensional construct, which evolves over time through social interactions. Hence, consistently with the findings of a longitudinal qualitative study based on serial interviews, they suggest that health literacy is the result of an accumulation process, which gradually brings to shared decision making and self-care [42]. Adhering to this point of view, Arar and co-

authors identify the involvement of the patient as one of the main vectors that lead to the enhancement of health care provision and, consequently, to higher health outcomes [43]. In these terms, health education should be conceived as a key requisite to realize a full-fledged involvement of the patient in the provision of care. Thence, addressing poor health literacy is a first concern of health care professionals to improve the effectiveness of their practices.

Wondering about what works in patient engagement, Coulter maintains that the education of the patients about health issues is essential to enhance their involvement in the management of care. Indeed, to incite the activation of the patient, providers should primarily enhance the individual health skills and knowledge [44]. However, traditional styles of patient-provider communication do not adequately address the transfer of health competencies and skills. More engaging relational methods – such as motivational interviewing and personalized patient information materials – are beneficial for this purpose, since they incite the engagement of the users.

Hamrosi, Raynor, and Aslani maintain that the provision of written medicine information serves as an effective information sharing tool, fostering patients health literacy and enhancing their willingness to be involved in health care [45]. On the other hand, most of health care professionals tend to neglect the value of information sharing, due to problems such as: lack of time, worry of creating anxiety in the patient, and perceived complexity of the message. As a consequence, providers usually underestimate their role in encouraging patients engagement in shared decision making. In addition, the Authors argue that while the lack of access to the internet is no more a huge barrier to retrieve health information, the ability to use and process the latter is still limited, preventing the activation of patients in shared decision making [46]. Therefore, the reliability of the data retrieved from the sources of health information, here included the World Wide Web, should be enhanced, supporting patients in handling them.

In the end, filling the information asymmetry that divide patients from providers is essential to empower the former. A fair relationship between patients and health care professionals is essential for this purpose. In fact, it improves the reliability of the communication and reduces risks of misunderstandings [47]. From this perspective, although stressing the importance of separating health literacy and patient empowerment as conjoined twins, Schulz and Nakamoto conclude that they generate intertwined outcomes. Indeed, health literacy without patient empowerment creates dependence of the patients on providers, while patient empowerment without health literacy produces high risks of inappropriateness [48].

vi. Conclusions

Even though several Authors support that the most common measures of health literacy and patient activation are weakly correlated with each other, suggesting that health literacy is a mere skill-based construct [48, 49], the impacts of poor health literacy on patient engagement is a widely neglected issue. The findings of this study show that co-production of care – usually dealt with in terms of user

empowerment, involvement, and/or engagement – could not be fully realized lacking a process of patient enablement. The ability of the latter to navigate the health system as well as to collect, select, process, and understand health information is a prerequisite of his/her involvement in the provision of care. In fact, the empowerment of poor health literate patients produces significant risks of inappropriateness, undermining the long-term sustainability of the health care system. The findings of this study suggest that a closer collaboration between patients and health care professionals is essential to enhance the willingness and the capability of the former to participate in the provision of care. Besides, improving the reliability of the sources of health information should be assumed as both a policy priority at the macro-level and as an imperative strategy at the meso and micro levels.

In spite of its limitations, that mainly originate from the focus on the database “Scopus-Elsevier” to collect the articles included in the review and from the subjectivity of the criteria used to select the relevant papers, this study paves the way to further developments. It emphasizes the “dark side” of health care co-production, calling for an in-depth analysis of the relation between health literacy and patient involvement in the provision of care. In addition, the findings of the study suggests that an health literacy concern should be included in the initiatives aimed at the activation of the patients, with the purpose of enabling the latter to co-produce health care.

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