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LETTER TO THE EDITOR

Shared decision-making in mental health care: have we overlooked the collective level?

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In contemporary health care systems, patients are envisioned to acquire a more active role, as compared to the past, a revolutionary paradigm shift known as "patient-centered" care [1]. The concept describes a fruitful collaboration among physicians and patients to secure that treatment decisions are consonant with patients' preferences and needs, while patients are given the information and support they need so as to actively participate in their own care [2]. Therefore, patient participation and patient empowerment constitute the pillars of patient-centered care.

Patient participation may occur at the individual as well as at the collective level. At the heart of patient participation on the individual level is the shared decision model. Shared decision-making (SDM) has been defined as "a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences" [3]. Thus, SDM encompasses the delivery of evidence-based information about options, outcomes and uncertainties alongside decision support counseling and a system for implementing patients' informed choices. In spite of its strong clinical and ethical justification, there is a low uptake of shared decision-making models in routine clinical practice. Recently, Slade draws upon successful examples of social marketing and the hospitality industry to suggest ways of circumventing the cultural barriers that hinder transitioning of mental health systems towards community-based services [4]. As a complementary to this discussion and as a vehicle for eliciting transformation in the mental health systems, we would like to stress that patients may also be involved in health decision-making on local, organizational, national and international levels [5]. In this reasoning, patient associations may participate in various realms of decision-making, such as guideline development, government policy, in hospital boards and others. This taps shared decision-making at the collective level. In spite of the widespread acknowledgment that patients' collective action may be conducive to shaping health policy and service provision, research on the topic is still in its infancy.

The most well-known mixed methods investigation has been the De Montfort study in the UK, which explored a cross-section of health consumer groups, their interrelations and their impact on health policy at a national level. The study addressed five disease groups, including mental health. Findings indicated that patients, users and carers have valuable perspectives and that policymakers are keen on taking them into account. As a corollary of this, health consumer groups are increasingly involved in the policy process, fostering thus a more inclusive and effective model of governance in health care [6]. Concerning an indirect comparison between mental health and physical health groups, the former were found to prioritize influencing policy, while among their successes was considered the replacement of the term "mentally ill people" by "people living with a mental illness" or "people with mental health problems" in the psychiatric jargon. Nonetheless, firm conclusions could not have been drawn and researchers called for the development of research and other methodologies that would facilitate extrapolation of this experiential knowledge in ways that would dispute clinical knowledge.

In a similar vein, from the realm of research on health policy, Souliotis et al. developed and validated an instrument, the Health Democracy Index, for measuring patient association participation in health policy decision-making [7]. Their instrument was adapted to a pan-European context and was utilized to gauge the degree and impact

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of cancer patient association participation in health policy decision-making in EU-28 [8]. Their research revealed that a high degree of participation is not necessarily translated into impactful participation and that the establishment of a health-care law based on patient rights, as well as to the formation of coalitions among patient organizations and the provision of training to its members is a way forward for fostering a democratic environment in health [9]. Nonetheless, their research was based on oncology patients, and therefore, it remains to be seen if their findings are replicable on mental health groups in EU-28, especially in light of the structural discrimination surrounding mental health [10].

Preliminary findings from utilizing the HDI on mental health groups in Greece indicate negligible degree and impact of participation on health policy, probably ascribed to the preponderance of the biomedical paradigm, the weakness of the patient movement and the omnipresence of stigmatizing attitudes. Family associations appear stronger than patient associations; however, they lack the necessary resources and training to exert some influence.

Therefore, a way forward to transforming the mental health system to render it more patient-centric should also address patient participation at the collective level. Changes in the macro-level may be facilitated by undertaking measures at the macro-level as well, such as establishing laws and regulations that would be inclusive of patients or by implementing initiatives that would encourage patient advocacy. As a corollary of this, cultural change may be induced which in turn may exert an influence on the patient–physician relationship. Therefore, research on patient association participation on health policy decision-making and identification of its correlates, as in the case of oncology, will shed light on ways of enhancing the role of patients in shaping health policy. In this reasoning, and in a top-down fashion, shared decision-making at the clinical level will also be fostered.

Compliance with ethical standards

Conflict of interest On behalf of all authors, the corresponding author states that there is no conflict of interest nor was there any financial support given. The manuscript does not contain clinical studies or patient data.

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