

Editorial

# Beyond Empowerment in Rheumatology Care

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In this issue of *The Journal of Rheumatology*, Carluzzo et al<sup>1</sup> explored different factors that contribute to the empowerment of individuals with arthritis. The study used data obtained from 12,560 US participants in the Live Yes! INSIGHTS program, based on socio-demographic information and patient-reported outcome measures (PROMs) about physical and mental health, emotional support, and empowerment. The instruments used in the study included the Patient Reported Outcomes Measurement Information System (PROMIS)-29 Profile v2.1, the PROMIS Emotional Support Short Form v2.0, and the Healthcare Empowerment Questionnaire (HCEQ) to measure empowerment.

The main questions were these: “(1) What is the relationship between key study variables (sociodemographics, arthritis type, physical and mental health, and emotional support) and patient empowerment; and (2) Which characteristics contribute most to explaining differences in patient empowerment outcomes?”<sup>1</sup> Emotional support, physical health, gender, arthritis type, and education were the most relevant factors associated with empowerment. Further, the authors highlight the importance of emotional support to positively affect the experience of empowerment and, thus, care and outcomes.

The authors refer to 2 measures of empowerment: Patient Information Seeking (patients’ ability to ask questions and get explanations and advice) and Healthcare Interaction Results (patients’ experiences with talking to providers, obtaining answers, having their choices respected, and getting help and information). A third measure, Degree of Control, was excluded during the validation of the HCEQ due to patient feedback and to account for contextual factors in the US health insurance system.<sup>2</sup>

All 3 of these measures reflect an approach to empowerment as a construct that exists at an individual level for the patient and

within specific patient–provider interactions. While addressing empowerment at this level is necessary to optimize direct care for individuals with arthritis—and rheumatic patients in general—it does not account for the full picture of what empowerment should mean in health care. Further, Carluzzo et al<sup>1</sup> found no strong relationship between patient empowerment and socio-economic or other demographic variables such as race/ethnicity. However, the cultural dimensions of empowerment should still be part of any definition of this concept we uphold in rheumatology, considering the sociodemographic characteristics of patients, as mentioned by the authors in the study limitations<sup>1</sup>. Thus, it is important that we take a deeper dive into the concept of empowerment in rheumatology care, its limitations, and what we can do to achieve improved patient outcomes.

The concept of empowerment has been described from various disciplinary lenses, including education, social psychology, critical theory, gender studies, rural development, and health. Numerous definitions and approaches have been identified throughout health literature, framing empowerment as a tool for health education and promotion, as well as health self-management in the context of chronic illness.<sup>3,4,5,6,7,8</sup> It is considered fundamental to improve outcomes and communication between patients and providers, increase satisfaction and therapeutic adherence, and optimize healthcare resources.<sup>9</sup> Empowerment can be viewed as either a process or as an outcome in itself.<sup>5,6</sup>

The World Health Organization describes empowerment as “a process through which people gain greater control over decisions and actions affecting their health. To achieve this, individuals and communities need to develop skills, have access to information and resources, and have opportunities to have a voice and influence the factors affecting their health and well-being.”<sup>9</sup> Though focused solely on the process, this definition reflects a broader conceptual framework for empowerment, grounded in individual and community dimensions. However, it is rarely operationalized; instead, existing instruments such as the HCEQ measures are predominantly based on the social-psychological conceptualization of empowerment.<sup>4,6</sup> This common approach to empowerment centers on attributes like control, self-efficacy, self-care, coping strategies, and health

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literacy from an individual perspective.<sup>4,6,10</sup> Further, rheumatology treatment models that aim to incorporate empowerment using this approach limit patient-led approaches to mostly self-management after remission has been achieved, instead of throughout the whole process.<sup>8</sup>

Participatory healthcare is meant to allow patients to take more active roles in making decisions about their health and increase their autonomy.<sup>5</sup> However, the social-psychological definitions of empowerment as they are commonly used suggest that the patient lacks control and power unless given or encouraged by providers and the social environment. Empowerment is indeed a process of bringing power, as the word suggests, but who brings power to whom and under which assumptions matters. Perhaps, in our attempts to uplift patients, we reinforce the idea that they are helpless unless they are helped, and that the provider is the dominant force who graciously shares some of their power. This ignores the simple fact that patients already have control and power over their lives and health.

Instead of thinking that it is the provider's role to bring power and information to patients unilaterally and vertically, we consider that rheumatology care evaluations, interventions, and outcomes should be thought of as a pedagogical process. Tracing back to the development of the concept of empowerment, we highlight the work of Paulo Freire.<sup>11</sup> Though he never explicitly mentioned empowerment, his ideas of emancipatory education have been a helpful foundation for conceptualizing this process

even in health.<sup>4,12</sup> A more comprehensive framework of empowerment in this sense would take form as a continuous process of recognition, reflection, dialogue, co-construction, and community. Thus, we propose the ReDCo framework (Figure 1):

- Recognition – To exercise their agency in the context of disease, patients must first be able to acknowledge their condition to themselves and others. This involves recognizing their experience as valid and valuable, and being able to share it on their terms in addition to the biomedical terms preferred by providers. Significantly, patients with rheumatic diseases often experience a sense of invisibility and invalidation due to the characteristics of their conditions, contributing to stigma and isolation.<sup>13,14,15,16</sup> Therefore, recognition and acknowledgment must also come from the patient's family and care network. In addition, providers should make an effort to validate the experience of disease on the patient's terms throughout its course. This recognition stage is fundamental for the emotional support highlighted by Carluzzo et al<sup>1</sup> to exist.
- Reflection – Once a health condition is recognized in the specific form it takes at a given time, the healthcare triad—formed by the patient, patient's family and care network, and provider—should engage in a shared reflection about its implications and possible courses of action. This reflection should consider contextual factors at an individual level and at a healthcare system level, both of which affect the degree to which a patient can exercise power. Any course of action should consider

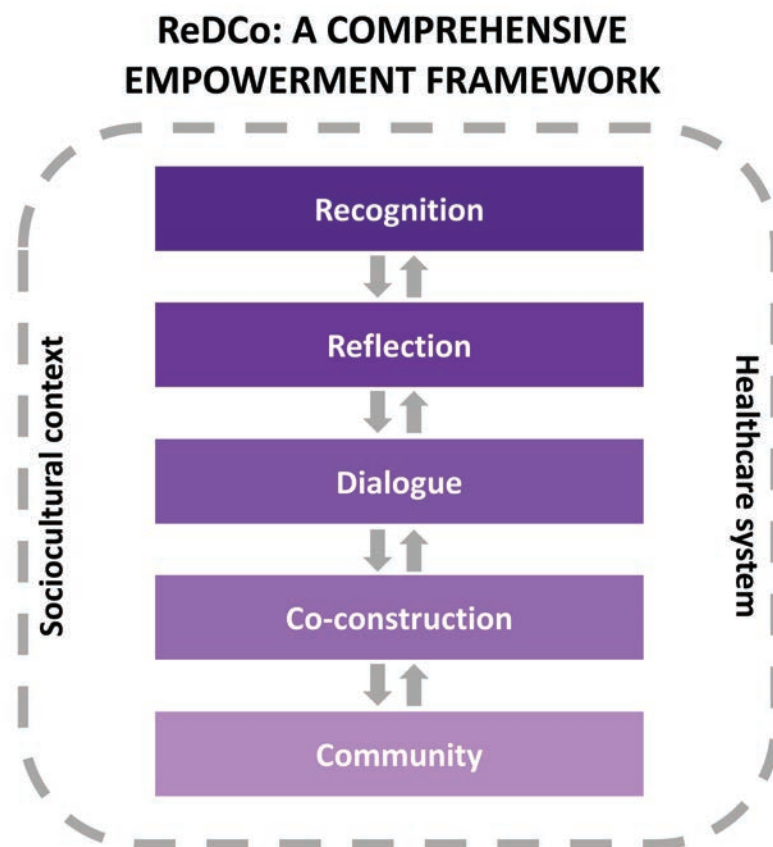


Figure 1. A comprehensive empowerment framework: recognition, reflection, dialogue, co-construction, community (ReDCo).

the patient's capabilities and needs, and how prepared the health-care system is to cater to those needs. This contextual reflection is shown, for example, during the prior validation of the HCEQ, where the authors identified the idea of "control" as limited and misleading in a healthcare system such as that of the US, where insurance places restrictions on choice.<sup>2</sup>

- Dialogue – Patients already have power and control to different degrees, regardless of whether their environment gives it, let alone their providers. This power should be recognized as valuable in a clinical relationship based on negotiation and dialogue, especially for people with rheumatic diseases who incorporate their conditions into everyday choices and evolving life plans beyond what providers can control. In this sense, a praxis of empowerment is generated through critical and continuous dialogue among the healthcare triad, where all actors are seen as equal contributors in a horizontal exchange and where all actors bring power to the clinical setting to make shared care choices.

- Co-construction – Positive outcomes, and how they should be measured and reported, are defined and agreed upon by the actors given their values, goals, and contexts.<sup>17</sup> This is a process of co-construction of care in the vein of patient involvement in research partnerships. Indeed, previous studies have identified patient participation as an integral part of developing and validating PROMs,<sup>18,19</sup> and this should be replicated in individual patient–provider interactions.

- Community – Patients are able to bring power to each other in a way that providers cannot, due to shared experiences and understanding. This mutual understanding contributes to the recognition aspect of the empowerment process and creates a community of patients who can get organized to more easily gain influence and control over factors that determine their well-being in their environments. Notably, true empowerment cannot focus on the individual level without also incorporating a macro view at healthcare systems and policies. Stressing process and psychological aspects at the expense of political outcomes (ie, the redistribution of social and material goods) is not an acceptable model of empowerment aiming to reduce health inequities.<sup>20</sup>

Empowerment in rheumatology care has fallen into conceptual and methodological misunderstanding, where only the psychological processes have been highlighted and measured. While these frameworks are helpful, they are insufficient, especially when considering rheumatology care globally. We face different patient preferences at individual and cultural levels, and considerable variability in healthcare systems and care networks.<sup>10</sup> Therefore, we need to reframe empowerment in more comprehensive terms to generate a praxis of empowered care. We also need to develop instruments that help measure empowerment and positive outcomes for patients in different contexts, in a more collective way. Moreover, we need to reach more complex solutions that do address the problem as a whole—as an issue of both patient–provider interactions and of health equity in a broader sense.

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