

# Patient Centredness, Values, Equity and Sustainability: Professional, Organizational and Institutional Implications

Mara Gorli \* and Serena Barelo

Department of Psychology, Università Cattolica del Sacro Cuore di Milano, 1, 20123 Milano, MI, Italy; serena.barelo@unicatt.it

\* Correspondence: mara.gorli@unicatt.it; Tel.: +39-02-7234-3975

**Abstract:** The concept of “patient centredness”, or “patient-centred care”, has been studied so far in a variety of declinations, perspectives, and practices. This paper suggests conceiving it as a *collective achievement* that is negotiated between multiple actors of a system, and that includes social practices and relationships that are woven together through the material and immaterial resources available in organizational settings and contexts. By focusing on the three core dimensions that compose the value of patient centredness, which are the attention to the individual, to the relational and to the organizational dimension, the paper invites to consider new and critical perspectives for research and intervention on such essential topic. Three directions are indicated for future studies: (1) Reconciling evidence-based medicine and patient-centred care through mixed-method sensitivity to healthcare research; (2) Revisiting the traditional assumptions on validity and impact, investing on new ways for assessing, measuring, and monitoring patient-centred care; (3) Investing in participative, practice-based and situated processes for guaranteeing the possibility to get close to the complexity of processes and to work on personal, professional, and organizational developments. The invitation is to consider these pathways to connect patient-centred care with new meanings of value, sustainability, and ethics in healthcare.

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## 1. Introduction

The concept of “patient centredness”, or “patient-centred care”, has been studied so far as an umbrella term including a variety of declinations, perspectives, and concrete care practices.

Patient centredness is an approach to medical practice which emphasizes the narrowness of adopting a mere disease centred approach and calls for an added exploration of patients’ desires, preferences, values and concerns with the aim to increase patients’ involvement in the management of their care plan [1,2]. It has served as an argument to support or criticize the actions (or lack of actions) of healthcare professionals, organizations and systems directed to the patient—conceived as a person, citizen and consumer around whose priorities and expectations the care system should be organized [3].

Patient centredness can be conceived as a *collective achievement* that is negotiated between patients and multiple health providers, including social practices and relationships that are woven together through the material and immaterial resources available in organizational and relational settings and contexts [4,5]. Linked to the possibility of such collective achievement, many efforts, actors and elements might intervene. Putting the patient *at the centre* does not mean that something other goes to the periphery, rather that

many components get a specific encircling position thus to create an interconnected service. Such service is made of “acts of care”, communication aspects, values, ethical concerns, equity of treatments, moral decisions, responsibilities and implications that all together create the place for accomplishing healthcare sustainably.

According to the scientific debate, we consider three core pinnacles that compose the value of patient centredness:

- i. the attention to the individual level (i.e., what is “valuable” in the perspective of the person, being the single and unique patient, caregiver or the single practitioner operating in the healthcare sector);
- ii. the attention to the relational level (i.e., what is “valuable” within the therapeutic relation and between the actors in the process of care);
- iii. the attention to the organizational level (i.e., what is “valuable” from an organizational point of view, which is constituted by the interconnected aspects of processes, relations, practices and spaces through which care is conceived, elaborated, enacted, experienced and assessed along every moment of the care path).

Throughout these core elements, patient centredness assumes a very complex framework, within which both a bright side and a dark side of the patient-centred discourse are made visible.

## 2. The Bright Side of Patient Centredness: The Values and Value Implied

The prodromes of patient-centred care are deeply rooted in the ethical implications of the healthcare profession, which has always been based on deep respect for patients as unique subjects, and the obligation to care for them on their terms. Thus, according to this perspective, patients are conceived as persons “in context” of their own social settings, listened to, informed, respected, and engaged in their care—and their care expectations are carefully considered in the decision-making process (but not mindlessly enacted) during their health care journey. The literature debate on the values behind patient-centred care is wide, but we can summarize the main dimensions of this paradigm as follows:

1. The ‘patient-as-person’, that means understanding the unique subjective meanings attached to the illness for each individual patient. Within this dimension operates also a biopsychosocial perspective, that means the consideration of social and psychological (as well as biomedical) factors involved in the illness experience [6].

2. The ‘health professional-as-person’, that means full awareness of the influence of the subjectivity of the healthcare professional on the care practice [7]. This dimension touches also the well-developed debate around evidence-based and “art and craft” medicine [8].

3. The therapeutic alliance, that means developing shared therapeutic goals and enhancing the communication and the relationship between health professional and patient. Connected to this, is the approach that focuses on shared power and responsibility, i.e., considering the sensitivity to patients’ preferences for information and shared decision-making, and the appropriate responses to these. In this light, the patient is seen as an active player in his/her own care journey, which means fostering engagement in health and disease management [9].

Therapeutic alliance means also investing in inter- and intra-professional relationships, directed to the advancement of knowledge and collaboration under the key-purpose of cure and care [2].

4. The patient-centred organizational model, which represents the redesign and the reshaping of hospitals with the aim of moving from functional towards process-oriented organizational forms, focusing on the process of care instead of on divisional, self-referential departments forcing patient transfers within the hospital [10], ([11], pp. 152–170), [12–14]. The patient-centred organizational way means also putting at the center the network and knots that co-operate in considering the cure and care needs: patient/caregivers associations and patient advocacy, inter-agencies and inter-institutional collaborations

that may be directed to common goals and a complementary use of resources and competences.

Implementation of patient-centred care and patient engagement in routine practices is expected to improve patient outcomes by increasing self-management ability [15], treatment adherence [16], preventive behaviours [17,18], participation in shared decision making [19], satisfaction with care [20], and improving overall quality of life [21,22]. Moreover, many studies reported notable effects of a patient-centred approach to care on improvement in various patient-level outcomes such as distress, functioning, physiologic measures (e.g., blood pressure) and health service utilisation [23,24].

At the level of the organizational context, patient-centred care is acknowledged to result in more effectiveness and efficiency for a better allocation of available resources in accordance with the patients' needs and care expectations [10,25], and in a more positive working environment for staff. Research indicates that burnout is highly associated with long-term workload and stress of conscience. Patient-centred care seems to relieve staff's stress of conscience, as healthcare practitioners are enabled to provide appropriate care [22].

### **3. The Dark Side of Patient Centredness: The Risks Implied and the Co-Destruction of Value**

Who can be against patient-centred care? Presumably, there are not many who subscribe to such a position. Indeed, it would seem difficult to come up with a valid reason for why patients should not be at the centre of their care journey.

A patient-centred approach to care holds promise for improving health equity by better engaging patients in their health care. On the other side, however, some scholars are raising concerns about possible "dark sides" of greater patient centredness risks engaging more those sections of the population who already benefit from better health or care access associated with social status and opportunity, serving to increase inequalities by further marginalizing those already suffering from relative exclusion. There is no consensus regarding which groups of patients patient-centred care is best suited for. There is, however, a risk that it might be "too beneficial" for some but not for others. If one of the ideas is to involve those who can make informed decisions and actively participate in their care, there is a risk that some persons will take advantage of the situation, using their strong voice while others with weaker voices might be disadvantaged.

There are also persons who do not wish to be involved in their care, regardless of the reason. It might be difficult to operationalize and provide patient-centred care appropriately. For instance, this approach might be unsuitable for those older persons with a limited capacity to make informed decisions. Many older persons become dependent on others due to age-related illnesses and/or impaired cognitive functions; this way of conceptualizing patient centredness does not account for the complexities involved in decision-making for such older persons.

As already mentioned, it is an essential dimension of patient centred care that the available resources should be allocated in accordance with the patients' needs and expectations. A system of shared decision-making can be expected to provide resourceful patients with more opportunities (not only at the economic level, but also more health literate) to increase their share of healthcare resources. Since these resources are finite, their gains would come at the expense of other—probably more vulnerable—patients. The losers will likely be found among those who are already worst off in other respects, for instance among those with less than perfect mastery of the language in which the shared decision-making takes place, and other groups subject to structural discrimination. We therefore have reasons to be on our guard against a potential ethical conflict between shared decision-making and a non-discriminatory healthcare.

Moreover, there is a significant risk that the engagement of patients in the design and delivery of care may turn into value co-destruction [26] that may occur when the many healthcare actors (the patients, the healthcare professionals, the hospital managers, etc)

participate in co-creating health services by bringing contrasting expectations, conflicting inputs, and diverging ends. These issues should be detected and handled to realize the full potential of patient-centred initiatives.

Moreover, as well as the focus of patient-centred care is on the patients and their rights, staff and their personhood risks being often neglected. This might diminish the value of the staff as autonomous persons, which in turn might result in poor working conditions, demotivation, and high turnover rates. There might hence be a risk that only patients/clients are considered persons, while staff are not. There is a constant risk of healthcare staff being overloaded by duties and engagement in their patients. This increases the risk for compassion fatigue, characterized by a gradual lessening of compassion and exhaustion. Compassion fatigue includes feelings of hopelessness, constant stress and anxiety and sleeplessness or nightmares. Compassionate care is included in the patient-centred approach, however, meaning a bond between the healthcare provider and the ill person [27]. On the one hand, compassionate care is positive, but on the other hand there is a risk. Although compassion is at the heart of all care, it is even more crucial in patient-centred care. Therefore, the risk of compassion fatigue in patient-centred care needs consideration as a further possible dark side of this approach.

#### 4. The Opportunities of Patient Centredness: Walking Future Directions

Given the above solicited argumentations on values and risks of a wide and complex paradigm, as engaged academic researchers we take position in direction of a broad and critical discussion around the goals, means, and methods of patient centredness, inviting to reflexively question taken for granted specifications and conceptions of patient-centred care.

We believe that patient centredness needs new openings and critical perspectives for allowing a sensitive management of future needs [28–30]. New complexities are surfacing and require complex responses. It is crucial to understand what research paths may serve, what facilitation of processes and organizational interventions can concur to make patient centredness sustainable and rich of new values for walking necessary and innovative directions.

##### *4.1. New Directions for Research: Reconciling Evidence-Based Medicine and Patient-Centred Care through Mixed-Method Sensitivity to Healthcare Research*

So far, there have been concerns that patient-centred care, with its focus on individual needs, might be at odds with an evidence-based approach, which tends to focus on populations. Fortunately, that debate has been laid to rest; proponents of evidence-based medicine now accept that a good outcome must be defined in terms of what is meaningful and valuable to the individual [31]. Patient-centred care, as does evidence-based medicine, considers both the art of generalizations and the science of particulars [32].

In terms of research methodology, we therefore claim the importance of mixed-methods (i.e., qualitative and quantitative approaches to data collection) to grasp the different qualities of the issues at stake. Sometimes quantitative insights in terms of self-reported or bio-physiological data are necessary to demonstrate the impact of interventions oriented to promote patient-centred care according to the logic of evidence-based medicine. Qualitative phenomenological methods, on the other sides, can give insights about the inner meanings that subjects attributed to the care experience. Narrative methods and narrative-based medicine may produce the crucial understanding of the different perspectives “at the centre” of the care process [33–36]; ethnographic approaches may delve into cultural features, and participative/reflexive methodologies may uncover silent voices that need to be heard. Patients and practitioners may be co-researchers of their own healthcare contexts, thus involving the changing of the traditional position of academic scholars with a supposed neutrality in the research process.

#### *4.2. New Directions for Validity and Impact: Revisiting Assessment, Measurement, and Monitoring*

To approach sensitively the contexts, single patients and practitioners should be monitored in the differences they bring, in terms of perspectives, representations, values [37,38]. Inclusion of different angles, perspective, and voices is the premises for a proper positioning of the core activities at the centre of the care process. Scales, but also interpretive analysis of the hidden values undergoing healthcare processes, are to be constructed to support new knowledge and fertile argumentations that take the different perspectives into account. Monitoring, assessing the impact (at the clinical, psychological and also economic levels) and proving the validity of patient-centred approaches means also accompanying differences in their own expression and identifications. Subjectivity is key to understand the healthcare interpretation in context and history.

#### *4.3. New Directions for System Interventions, Training Projects, and Organizational Developments: Investing in Participative, Practice-Based and Situated Processes*

“How to” accompany and how to support a sustainable development of the patient-system, the practitioners-system and the organizational-system is a key issue. Internal models, internalized cultures, educational perspectives, and organizational model which are explicitly intended to support patient-centred care should be explored at all levels to understand the intricacies and the potentialities of the healthcare sustainability and of its system of values. Collaborative research and co-production of care, involving participatively researchers, patients, practitioners, and the management levels of healthcare organizations, is crucial for getting close to the current and actual issues at stake in nowadays global scenarios.

### **5. Concluding and Launching the Issue**

This Special Issue aims to explore and discuss the concept of sustainability in healthcare under these premises.

Sustainability is here intended as strongly linked to the values that are put in place throughout the process of “putting the patient at the centre”. Such values are constituted by a combination of many levels and facets. In literature, levels have often been treated in a cleaved way: the value for patients [9,39,40], the economic value [41], the organizational value [42–46], the values for professionals [2,47,48]. Diverse facets make the picture even more complex: values can be moral values, can be ethical, can be economic and financial, can be deontological or social.

We envisage this Special Issue becoming a cornerstone of the scientific literature, which illustrates the potential of patient-centred practices and its related values to make healthcare sustainable through the promotion of a more equitable and ethical care provision. We are interested in opening up a collection of papers that dig into this field, and illustrate the many possibilities, interpretations and questions connected to the challenges of pursuing a sustainable care, under the orientation of patient centredness and an aware positioning and debate around values in play. The invitation is open to an interdisciplinary debate, welcoming studies that are grounded on the different social sciences applied to healthcare: psychological, sociological, organizational and management studies, as well as economics, philosophical and anthropological views all are able to enrich such field, and to propose new attention to navigate this intricate debate and future possibilities for healthcare, with a specific look to the professional, organizational, inter-relational and institutional implications.

The Guest Editors would like to invite original research (both quantitative and qualitative), reviews, theoretical frameworks, methodological reflections, case studies, and protocols from all disciplines which illustrate via case studies and existing projects how patient centeredness contributes to achieving healthcare sustainability at local, regional, and national and international level. We also welcome contributions which outline the

benefits of patient centredness in relation to patients and health care organisations, and the future potential of patient centeredness and the role it can play in reaching healthcare sustainability.

The settings and situations can be diverse, for example chronic care management, mental health, medical education, organizational interventions, patient and consumer health education, digital health, participatory research.

Submitted manuscripts should not have been published previously, nor be under consideration for publication elsewhere (except conference proceedings papers). All manuscripts are thoroughly refereed through a single-blind peer-review process.

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