

EDITORIAL INTRODUCTION

The Role of Culture and Experience in Person Centered Medicine

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Introduction

Culture and experience appear clearly within the core conceptualization of Person Centered Medicine. This is so since the early roots of this perspective in ancient Asian civilizations [1] and the Hellenic ones, cradle of Western civilizations [2]. This is also the case in the millenarian cultures of the Americas [3] and of Africa (e.g., the *Ubuntu* [4]). In broad terms, all of them articulate a comprehensive and harmonious framework of health and life and promote a highly personalized approach for the treatment of specific diseases and the enhancement of quality of life. These early roots represent much more than museum pieces, as most of them continue *mutatis mutandis* to inform life in today's world, particularly in traditional societies [5] but also to significant extent in industrialized ones.

The core concept of Person Centered Medicine involves placing as the goal and center of health and health care the whole person in context [6]. The importance of context in this regard is epitomized by the views of the Spanish philosopher Jose Ortega y Gasset, who said *Yo soy yo y mi circunstancia, y si no la salvo a ella no me salvo yo* (I am I and my circumstance, and if I do not save it, I do not save myself)[7].

The centrality of culture in Person Centered Medicine has been pointedly documented through a study conducted by the International College of Person-centered Medicine (ICPCM) with support from the World Health Organization towards the systematic conceptualization and delineation of person- and people –centered medicine and health care and the development of procedures to measure progress in these directions. Through a review of the literature and consultations with international panels, the following eight broad categories indicative of person centered health care were identified: 1.Ethical

Commitment, 2.Cultural Sensitivity, 3.Holistic Approach, 4. Relational Focus, 5.Individualized Care, 6. Common Ground for Participative Diagnosis and Care, 7. People-centered Systems of Care, and 8. Person-centered Education and Research [8].

This paper will review in some detail cultural sensitivity in terms of *cultural awareness and responsiveness* as a key concept underlying person centered medicine. It will then examine experience and the engagement of subjectivity in clinical care, and the place of experience, values, and culture in the person-centered diagnosis model developed under the auspices of the International College of Person Centered Medicine. Finally, a set of papers, many related to culture and experience, published in the present issue of the *International Journal of Person Centered Medicine*, will be introduced.

Cultural Awareness and Responsiveness in Person Centered Medicine

As revealed by the literature review and consultation study previously mentioned [8], one of the eight key conceptual categories underlying Person Centered Medicine is cultural sensitivity, more fully expressed as cultural awareness and responsiveness. Unfolding further this concept, it has been posited by Mezzich and Perales concerning person centered clinical care [9], that cultural awareness and responsiveness may involve as strategic clinical activities the following:

a) Awareness of the cultural diversity (ancestral and presently contextual) with which the patient identifies himself/herself.

- b) Awareness of and respect for the patient's cultural explanations about his/her health and illness.
- c) Awareness by the clinicians involved of their own cultural identity.
- d) Integrative response to the patient's and clinicians' cultural identities in the diagnostic and therapeutic processes.

At the same time, it should be noted that several of the other key conceptual categories of Person Centered Medicine also have cultural, experiential and contextual connotations. This is certainly the case concerning Category 1, Ethical Commitment, as respect for the patient's cultural identity seems consubstantial with respect for the person's dignity. Category 3, Holistic Approach, also would require the consideration of culture in the conformation of a complete theoretical framework of illness and health. Category 4, Relational Focus, is largely experiential, and therefore culturally-informed. Category 6, Common Ground for Participative Diagnosis and Care, is also, as the preceding one, largely experiential. Furthermore, Category 7, People-centered Systems of Care, involves awareness of the community's views on health and required services and their engagement for the design, implementation, monitoring and evaluations of health policies and services.

Focusing attention on the central construct of culture, one may recognize that it refers to the systems of knowledge, values, institutions, feelings, experiences, and practices that constitute social systems, including families, communities and societies. As proposed by Choudhry and Kirmayer [10], person-centered care involves a reorientation of clinical practice around understanding and engagement with the patient as a person. A crucial aspect of this reorientation is systematic attention to the social world in which the person lives, both in terms of individuals' developmental history and biography and their current life circumstances. Human beings are social and cultural beings. We are born unable to fend for ourselves and spend the first decades of life acquiring language and learning to navigate cultural constructed social worlds. Cooperative social activity is essential for human adaptation and flourishing. For millennia our environments of adaptation have been primarily humanly constructed and our biology and ways of life have undergone co-evolution. Hence, medicine and psychiatry must take culture and social context into account in understanding and responding to illness and promoting health and well-being. However, as our social worlds have changed with new technologies, forms of community, and global networks, so too has the nature of culture. Thus, one must consider the shifting meanings of culture in relation to new configurations of the social world.

Furthermore, Kirmayer, Bennegadi and Kastrup [11] argue that systematic attention to culture, guided by relevant conceptual frameworks is essential to obtain a comprehensive picture of patients' lifeworlds and respond appropriately to their health problems and concerns. Crucial to this approach is the recognition that culture is

not simply a matter of discrete social factors, values or beliefs, but constitutes the matrix of meaning, discourse and practice through which structures of power, inequality and social position are constructed, legitimated and maintained [12]. As such, understanding the ways in which cultural identities are played out in a given society, community or clinical setting must be central to any vision of a person-centered medicine that aims to provide equitable and effective care. Moreover, given that culture provides the language and the settings which people use to negotiate shared values and perspectives, attention to culture is an important bridge between person- and people-centered medicine. This aims to acknowledge the social determinants of health and address the political issues raised by inequalities at local, national, transnational and global levels, as proposed by the *2014 Geneva Declaration on Person- and People-centered Integrated Health Care for All* [13] and its accompanying academic paper [14].

Experience, Empathy, and the Engagement of Subjectivity in Clinical Practice

Person centered care should not therefore be reduced to the individualization of care or the respect for patients' rights, as it aspires to something more: the recognition of the individual subjectivity of the whole person of the patient beyond what characterizes his or her illness or his status as patient [15]. What is of interest here is dealing with the inner world of a patient in his particular situation of suffering and dependence caused by illness, like in Aristotle's *Nicomachean Ethics*: "Cure of a unique person and not a generalized nosological case, in a specific situation, within a specific, unrepeatable period of one's life" [16].

As pointed out by Botbol [17] crucial psychological dimensions for clinical practice are not only subjective but also holistic. The recognition and assessment of these dimensions requires improvements in the parameters and guidelines for the appraisal of evidence, beyond the rigidity and narrow scope of what is usually termed evidence based medicine (EBM), because their holistic perspective implies constant interactions between ill and positive health aspects of the patient's health status. This is so also because their subjective components apply not only to the views of the patient and related family but also to those of health professionals.

In addition to the attention paid to the medico-biological aspects of the person's health status, a person centered assessment needs then to give adequate consideration to the patient's subjective feelings [17]. In a variety of clinical situations, with a range of causalities, it is essential to keep in perspective the factors involved in the patient's health situation. Beyond reasserting this principle, we need to make explicit the methodology for accessing these subjective dimensions among different partners involved in the diagnostic process and the therapeutic relationship. For health professionals, the only

way to access these dimensions is often what the patient and carers say in words or show through their behaviors, as long as these words or acts can trigger in the clinicians enough empathy to approach the patient's subjective feelings to which these expressions are related.

At first considered as the professional's ability to listen sympathetically to the comments of the patient and to integrate his wishes and needs, the notion of empathy has gradually widened to include representations that the physician (or other health professional) make of the clinical situation in which the person in need of care is involved. In short, these are representations that the professional makes of the health situation of the person suffering through his/her (the professional) own empathy, triggered by the words and the acts of the patients and of their carers. This mechanism is well described by the concept of "metaphorizing-empathy" proposed by Lebovici [18] from his work with babies and their mothers. It is also close to the notion of "narrative empathy" proposed by Hochmann [19] based on his work with autistic children and on the philosophical ideas brought up by the noted French phenomenologist Paul Ricoeur in his book "Time and Narrative" [20]. It is also consistent with Kleinman's assumptions [21] on illness narratives. This important development in PCM marked the full recognition of the role of the physician's subjectivity as a diagnostic and treatment tool in the physician-patient relationship.

Experience, Values, and Culture in Person-centered Diagnosis

In order to address concisely but orderly the presence of experience, values and culture in person-centered diagnosis, this section outlines first general diagnostic methodological considerations, the place of a cultural formulation, and philosophical work on values as developmental precedents. It then briefly describes the place of experience, values and culture in innovative person-centered diagnostic models.

General Diagnostic Methodological Considerations

In contrast to disease-centered diagnostic systems such as the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth Edition (DSM-5)[22] and the World Health Organization's International Classification of Diseases, Tenth Revision (ICD-10) [23], Person-centered Integrative Diagnosis (PID) [24], developed under the auspices of the International College of Person Centered Medicine, represents a model for the diagnosis of health (both illness and positive health) aimed at not just identifying diseases present but also at establishing a thorough informational base for optimal clinical care. This shifts the concept of diagnostic validity from etiopathogenic nosology (faithfulness in identifying diseases) to clinical validity (usefulness for planning and

conducting care), as articulated by Schaffner [25] in philosophy of science terms.

In relation to the design of new person-centered diagnostic models, Salloum and Mezzich [26] organized a number of focus and discussion groups with a variety of health stakeholders (health professionals, patients, family members, and advocates) at international events in Athens (Greece), Uppsala (Sweden), and Timisoara (Romania). In an overwhelming manner, the participants in these three settings affirmed that diagnosis should go beyond disease. Participants unanimously responded that diagnosis should also cover dysfunctions and a great majority of them affirmed it is very important to include positive aspects of health. Of note, over 83% of the participants endorsed the inclusion of experience of health as part of diagnosis. Furthermore, there was unanimous agreement on incorporating contributing factors (including risk and protective factors), and on the use of dimensions and narratives in addition to conventional categories as descriptive methods. Participants also emphasized that diagnosis is a process and not only a formulation and highlighted the partnership between caregivers and service users as fundamental.

Along these lines, the PID represents an ethical commitment in terms of concern for the person's dignity, complexity, uniqueness and autonomy. This is expressed by the thrust of person-centered medicine and its diagnostic model to address and assess all what is relevant for clinical care, including health status (from illness to disabilities to positive health), contributing factors (risk and protective factors) and health experience and values. And to carry this endeavor with the purpose of ameliorating illness and promoting health and in a manner that is collaborative, empowering and respectful with the presenting patient and family [24].

The Cultural Formulation as Starting Point

As noted above, one of the three key domain levels of Person-centered Integrative Diagnosis calls for an evaluation of the *Experience of Health*. A major aspect of such domain level involves a broad concept of culture with an emphasis on its experiential base. In line with this, a suitable operational precedent was the Cultural Formulation [27, 28] proposed for and then included in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [29, 30]. This Formulation was considered one of the few significant innovations in DSM-IV, but was published there in a minimal fashion. A sketch of this approach and tool follows.

The Cultural Formulation is a procedure aimed at preparing a short ethnographic evaluation of a person presenting for assessment and care. The task may be seen as one of translation between two languages or frames of reference. The "internal" framework includes the patient's current perspective on his or her condition and situation as well as more general concepts of identity, health and illness as presented verbally in words, phrases, and associated modes of reasoning and displayed in illness behavior. The other framework corresponds to the clinician

seeking to map what he or she has learned about the patient's illness onto the conceptual framework of clinical psychiatry. The information that the clinician needs to carry out this interpretive task, may go beyond what the patient has spontaneously volunteered and may require asking direct questions but framing them in terms of the patient's own vocabulary of metaphors, models and concepts.

The cogency of proposing the Cultural Formulation as starting point for the developmental task at hand is supported by the wide international experience being accumulated with this instrument in various countries, such as Canada [31], Indonesia [32], the Netherlands [33, 34], Sweden [35], Switzerland [36], and the United States [37-39]. The data-based research and conceptual analyses listed above covers work with local populations as well as, in some cases, with recent immigrants, which extends their international interest.

Contributory Philosophical Work on Values and Needs

Attention to such values and needs is crucial to medicine's ethics commitment and the importance of individualization of care. In pointed reference to these aspirations, values-based medicine has been promoted both scholarly and as a component of United Kingdom Health Department policies [40] and has been found conceptually consistent with person-centered care [41, 42]. This perspective is acquiring wide international resonance, even among the proponents of evidence-based medicine. Sacket et al [43] have agreed that patient values must be integrated into clinical decisions if these are to serve the patient.

The Place of Culture and Values in Person-centered Diagnosis and the Latin American Guide

The plan for developing a diagnostic informational level on Health Experience and Values [44] as part of the Person-centered Integrative Diagnosis (PID) model based on the Cultural Formulation and pertinent philosophical work on values included the following tasks:

1. Refinement of the coverage of the cultural framework of ill health, to consider suffering (which is included in the Cultural Formulation in terms of disease categories and idioms of distress, but not as a broad and fundamental health concern)
2. Coverage of the experience of positive health, including wellbeing (not pointedly covered by the nosologically oriented Cultural Formulation). It was considered desirable that this coverage go beyond the documentation of standardized health status (the first informational level of the PID).
3. Coverage of the person's values, needs, wishes, concerns, and expectations as promoted by values-

informed practice with growing international resonance, and not pointedly covered in the Cultural Formulation.

Later on, the PID model informed the development of a practical diagnostic guide, the Latin American Guide for Psychiatric Diagnosis, Revised Version (GLADP-VR), published by the Latin American Psychiatric Association (APAL) in 2012 [45, 46] for the use of psychiatrists and other health professionals in the region.

One can identify various points in the person-centered diagnostic formulation of the GLADP-VR [47] that ensure that a number of elements relevant to the whole person's health culture and values are organized as integral parts of the diagnostic process and not only as accessory or optional considerations as it usually happens in conventional diagnostic systems. The following are some of these specific points:

- Under Health Status, functioning and positive health are pointedly considered. Quality of life is primarily assessed through the patient's self-perception, cultural interpretation and rating.
- Under Health Contributors, both risk and protective factors (internal and external, biological, psychological and socio-cultural) are considered.
- Under Health Experience and Values, narrative summaries on personal and cultural identity, suffering (its recognition, idioms of distress, illness beliefs), and experiences and expectations on health care are included.

Furthermore, the procedure for engaging clinicians, patient and family in the diagnostic process serves to establish a common ground for joint diagnostic understanding and shared decision-making [48, 49].

A survey of Latin American psychiatrists comparing perceptions on the GLADP-VR with those on the ICD-10 and the DSM-IV, revealed that the GLADP-VR was found advantageous because of its cultural responsiveness and being integrative and person-centered [50]. This illustrates the usefulness of person-centered diagnosis in articulating culture-informed science and humanism for optimizing clinical care.

Introducing the Papers in this Issue of the Journal

The role of culture and experience in person centered medicine is illustrated by several articles in the present issue of the *Journal*. All the papers published are briefly introduced below.

The first paper, by Roger Ruiz-Moral from Francisco de Vitoria University, Madrid, on an existential outline of person centered medicine, examines the idea that "medical problems" are always "problems of living" that reflect the

existence of a “vital dimension” that is different from the biological, psychological and socio-cultural dimensions. He argues that “the subjective truth” implicit in the “vital dimension” can only be approached through reflection and interpretation in the context of a *dialogue* between the professional and the patient/family with the objective of deciding on the action(s) that can better lead to reaching some concrete wishes or desires (values), that in turn require the participants to take on obligations and responsibilities. This relational perspective defines the “person centered” clinical approach as a practice based on *dialogue*, importantly involving *deliberation* and *collaboration*.

In the second article, on Emergence of Coproduction and Participatory Care in European Clinical Practice, Dawid Sześciło from the Faculty of Law and Administration of the University of Warsaw in Poland, reviews if coproduction practices in European health care systems have already gained a status of significant trend and what are the outcomes of their implementation. This is approached through a literature review of coproduction practices such as self-management, expert patient initiatives, peer support networks, and shared decision making. He concludes that co-production participatory care strategies, such as shared decision making, empowerment and peer support, are significantly emerging in European health care systems, but their widespread development and implementation are still incipient.

Third is a paper on Patient-Centered Care and People-Centered Health Systems in Sub-Saharan Africa authored by Jeroen De Man and colleagues from the Institute of Tropical Medicine of Antwerp, Belgium, Makerere University in Kampala, Uganda and the World Health Organization. The article explores the indicated topic and potential barriers to implementation, with a focus on public first line health services. For this purpose, they developed an analytical framework based on expert knowledge, field experience, and a conceptual literature review. Factors contributing to limitations in the implementation of patient-centered care are structured in three distinct but interacting layers. They conclude by arguing the need for further fine-tuning of the framework outlined in this paper, investing in the contextual validation of measurement tools for patient-centered care, and testing solutions in a participatory action research approach.

Ulrich Hegerl and colleagues from the Department of Psychiatry and Psychotherapy of Leipzig University in Germany authored the fourth article, presenting a person centered care approach for depression and prevention of suicidal behavior based on the European Alliance against Depression. It involved a comprehensive and person-centered community-based four-level-intervention concept aimed at improving the care of patients with depression and preventing suicidal behavior. The included levels were training and support of primary care providers, a professional public awareness campaign, training of community facilitators, and support for self-help of persons suffering from depression and their relatives. Their research showed a significant reduction in suicidal behavior and various changes in intermediate outcomes,

including those concerning attitude and knowledge in different populations.

The fifth article by Janet Perkins and colleagues from Enfants du Monde, Geneva, Switzerland, examined the role of men in improving maternal and newborn health (MNH) in Burkina Faso. It involved working with men to help them become active participants in maternal and newborn health. Interventions aimed at influencing the role of men included a strategy designed by health workers and community members through which men who were exhibiting positive behaviors in supporting women were selected by local leaders and trained to educate other men in the community on care for women and newborns. Preliminary results suggest that in particular due to the “model husbands” strategy, men are participating more actively in MNH. Notably, men are starting to accompany women to health facilities for antenatal care regularly and they are more aware of care practices for women during and after pregnancy and for newborns, which has led to increased utilization of MNH services.

Ann Karin Helgesen and colleagues from the Faculty of Health and Social Studies, Østfold University College, Halden, Norway, authored the sixth article involving a grounded theory study on changing men’s everyday lives in nursing homes. They found change in the men’s everyday lives after the special activity program for men only was offered. Their own influence on the content of the conversations and on the activity itself was described as limited. This appeared to be not important for them, as the most essential issues were ‘being together’ and ‘getting away’. Conditions relating to the men themselves, the place where the activities were held and the nursing personnel all had an impact on how important the activity program was for the men. They concluded that a more person-centered approach in future activity programs is likely to enhance the residents’ integrity and well-being, and allow them a degree of self-determination even while residents in a nursing home.

The seventh article was authored by Charlotte Veenvliet and colleagues from Utrecht and Nijmegen in the Netherlands and from Drammen, Norway. It was aimed at enhancing emotional interactions with older persons through nursing interventions in home health care. Ten nurses/nurse assistants participated in this exploratory pre-post test study. They were asked to audiotape visits with older persons (65+) before and after an audio-feedback intervention. Older clients’ implicit and explicit expressions of emotional concerns as well as nurses’ responses to these expressions were rated. The nurses were given feedback based on the audio-recordings and the observations and were asked to reflect on the audio-feedback intervention. Receiving feedback was taken in very well by the nurses working in home health care and the feedback intervention seemed to enhance emotional interactions in home health care with older persons.

This Journal issue ends with announcements and program outlines from upcoming person centered medicine events in Madrid, Lima and Geneva.

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