

**Mezzich JE, Kirisci L, Salloum IM, Trivedi JK, Kar SK, Adams N, and Wallcraft J (2016):
Systematic Conceptualization of Person Centered Medicine and Development and
Validation of a Person-Centered Care Index
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SUPPORT DOCUMENT

Introduction

The study on the systematic conceptualization of person centered medicine and the development and validation of a Person-centered Care Index presented as candidate for the Expanded Reason Awards was conducted by a research team under the auspices of the International College of Person Centered Medicine and with support from the World Health Organization, and published in 2016 by the peer-reviewed *International Journal of Person Centered Medicine*.

A brief statement follows on the background and relevance of research on conceptualization and metrics in Person Centered Medicine. Then, the value and implications of the study presented as candidate for the Expanded Reason Research Awards are addressed.

Relevance of Research on Conceptualization and Metrics of Person Centered Medicine

Since the inception of Person Centered Medicine (PCM) as a programmatic movement, one could find the articulation of science and humanism as a core concept [1, 2]. This revealed a prominent concern for conceptual clarity, illustratively to formulate humanism as the essence of medicine as well as to engage the scientific method as an essential tool [3].

An ongoing scientific effort in PCM involves systematic conceptualization [4]. Another one, reflecting concern for precision in description and prediction, looks at metrics and measurement in its various forms and levels [5, 6]. These two lines of work are outlined below.

Conceptualization

Almost from the beginning of its institutional journey, PCM has been defined as an approach that places the person in context (not organs or disease) at the center and as the goal of medicine and health care [7].

Conceptualization in terms of fundamental activities, has included a formulation of PCM as a medicine *of the person* (of the totality of the person's health, including its ill and positive aspects), *for the person* (promoting the fulfillment of the person's life project), *by the person* (with clinicians extending themselves as full human beings with high ethical aspirations) and *with the person* (working respectfully, in collaboration and in an empowering manner with persons presenting for care) [8, 9].

Another fundamental activity with definitional implications has involved communication and relationships. This is an area of enormous value in PCM research, education and clinical practice [10, 11]. In relation to this, PCM is sometimes referred to as relationship medicine [12], where engagement of the subjective and promotion of empathy are considered crucial [13].

Attempts at understanding have also looked at the dynamics of PCM. It has been posited, for example, that PCM is dedicated to the promotion of health as a state of physical, mental, socio-cultural and spiritual wellbeing as well as to the reduction of disease, and founded on mutual respect for the dignity and responsibility of each individual person [14]. The exploration of such dynamics in social processes and systems has been cogently presented as well [15].

A fundamental activity in PCM emerging largely from interactions with the World Health Organization, has been the articulation of person-centered clinical medicine and people-centered public health. These two concerns are now often considered as two sides of the same medal [16, 17].

Along similar lines, significant value for the conceptual delineation of PCM has been derived from the unfolding of longitudinal development processes. This has been denoted by growing inter-institutional collaboration through a world-wide journey [18, 19], including significant continental and regional developments [3].

Interdisciplinary work and perspectives centered around the whole person have been also valuable contributors to PCM conceptual maturation [20]. Relevant here are inter-disciplinary collaboration [21, 22] as well as broader and global inter-professional considerations [23, 24].

The identification of key concepts underlying PCM, has prominently emphasized its ethical base. This indicating that ethics is fundamental for all medical activities, including clinical care, education and research [25-27]. It has also been argued by two recent presidents of the World Medical Association that PCM represents an ethical imperative for the medical profession [28].

The ascertainment of a comprehensive set of key indicators has been a substantial ongoing concern of PCM [29]. Systematic work in this direction has involved critical reviews of the literature as well as focused international consultations.

Metrics

Aristotle, the philosopher *par excellence*, was also a naturalist and often engaged medicine's models and activities as framework for his theories [30]. His concern and recommendations for precision in measurement and prediction were informed and shaped by the above mentioned broader perspectives and disposition [31].

The development of measurement theories and models have been stimulated by precision concerns, and often have proceeded through systematic comparisons. Such comparisons have led from nominal, to ordinal and then to ratio measurement models, moving in the direction of increasing precision power and at the same time decreasing applicability in real fields. Illustratively, Botbol has argued cogently for selecting research models suitable for the features of a particular area of psychological research [32].

The importance and scope of measurement have been highlighted by Economics Nobel laureate Joseph Stiglitz. He stated that “What you measure affects what you do. If you don’t measure the right thing, you don’t do the right thing” [33]. Furthermore, concerning his field of economics, he pointed out that assessment tools should incorporate a broader concern for human welfare, not just economic growth. Along these lines, one could argue in the health field that evaluation should not be restricted to diseases and their management but also cover positive health and well-being, as person-centered integrative diagnosis has implemented in theory [34] and practice [35].

Diagnostic models and practical guides, at the outset, may be unilevel or multilevel [36]. The second one is responsive to the prevalent complexity of health data [37] relevant to substantiate effective health actions in a world that often includes multi-morbidity [38] as well consideration of disabilities [39] and positive health [40, 41].

Within a given diagnostic level, variables may be organized as categories (as traditionally occurring in medical classification systems) [42], dimensions (as increasingly considered to augment precision power), or nominal or narratives [to delve into the intricacy of the unique, such as a contextualized experience) [43].

A major metrics concern in health systems involves the validation of diagnostic systems. This includes the consideration of validation criteria, among which feasibility or acceptability, reliability and validity are prominent. Feasibility or acceptability is usually measured in terms of basic descriptive statistics, such as frequencies. Reliability or replicability is usually approached in terms of inter-rater agreement and test-retest replicability. Adequate statistics for agreement on categorical diagnostic variables includes the kappa coefficient [44] and on dimensional variables involves intra-class correlation coefficients [45]. All the above considerations are of general health systems significance and also of particular interest for person centered medicine.

Study on Conceptualization and Metrics of Person Centered Medicine Presented for the Research Awards

The study on Systematic Conceptualization of Person Centered Medicine and Development and Validation of a Person-centered Care Index by Mezzich et al [46] presented as candidate for the Expanded Reason Research Awards, in response to the strong conceptual and research needs identified above, was aimed at elucidating the core concepts of person centered medicine and healthcare, the design of a prototype measuring instrument, and the study of its metric structure, acceptability, reliability and validity.

It utilized a systematic review of the literature, consultation exercises with broad international panels composed of health professionals and representatives of patient and family organizations, and quantitative and qualitative data analyses as methodological procedures for addressing the study questions.

The following key concepts underlying person centered medicine were elucidated: 1) Ethical Commitment, 2) Cultural Sensitivity, 3) Holistic scope, 4) Relational Focus, 5) Individualized Care, 6) Common Ground for Collaborative Diagnosis and Care, 7) People-centered Systems of Care, and 8) Person-centered Education and Research. On this basis, a Person-centered Care Index (PCI) was developed composed of 8 broad items and 33 sub-items, each measured on a 4-point scale. The study of the PCI suggested it had strong internal consistency, unidimensionality, and quite substantial acceptability, inter-rater reliability and content validity.

Study Features Related to the Expanded Reason Awards

- Quality, topicality and rigor: The research questions were of high importance for the progress of the new perspective on Person Centered Medicine, as shown by the relevance statement presented first. The research questions on conceptualization and measurement are at the core of any scientific development. They were addressed with a multiprong approach involving a critical review of the literature, broad international consultations with a range of health professionals and patient and family representatives, and completed with creative group reflexions for the design of a suitable instrument, which was then validated concerning applicability, reliability and validity.
- Transdisciplinary and unifying vision: Person Centered Medicine in terms of its underlying theoretical concepts and practical implications clearly involve an integration of science and humanism, from biology to spirituality in order to promote the health, well-being and fulfillment of whole persons.
- Soundness of the anthropological, epistemological, ethical and meaning foundations: The proposed approach is eminently anthropological as it is centered on the whole person. Its epistemological foundations involve the articulation of science as essential instrument and humanism as the essence of medicine. Ethics was found to be at the core of the conceptualization of Person Centered Medicine, and this has unfolded in the range of programmatic activities being conducted by the International College of Person Centered Medicine. Concern for meaning is denoted by efforts towards the fulfillment of the life project, including spiritual dimensions, of all persons involved.
- Breadth of the bibliography: The scope of the international literature consulted is indicated by the 115 bibliographical references listed in the presented study.

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