## EDITORIAL INTRODUCTION

# **Conceptualization and Metrics in Person Centered Medicine**

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#### Introduction

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 validational 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. Among other metrics areas of relevance to person centered medicine are those involving item response theory, as discussed by Embretson & Reise [46] and Kirisci et al [47]. Another metrics area of considerable relevance to person centered medicine refers to Bayesian statistical modeling [48].

# Introducing the Papers in this Issue of the Journal

The first five articles of the Journal's present issue correspond fully to conceptualization and metrics of PCM. All the seven papers published in this issue are briefly introduced below.

The first article on Systematic Conceptualization of Person Centered Medicine and Development and Validation of a Person-centered Care Index by Mezzich et al [49] 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. 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) Peoplecentered 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.

The following four articles correspond to a Special Section on Metrics in Person Centered Medicine Research, which was guest edited by Professor Levent Kirisci, the Journal's Statistical Editor.

The first article in this Section by Kirisci et al [50] reviews the purpose of metrics in PCM research and

addresses prominent aspects of modern quantitative methodology, focusing on liability to substance use disorder (SUD) addiction as an example. Liability to SUD is defined as the resultant of all factors influencing the probability of SUD development, a latent complex trait characterized by multifactorial inheritance, manifesting in variation in the risk for and severity of SUD. Approaches that would allow integrating observable phenotypic information are needed to estimate individual liability to addiction. One such approach is based on item response theory (IRT) and comprises three articles that cover important measurement issues in statistical modeling.

The second article in the Metrics Section was authored by Vanyukov et al [51] and discusses dimensional approaches to the measurement of liability to addiction. They noted that biomedical research applied to complex disorders has historically been guided by a group-defined disease orientation rather than a person-centered healthoriented approach, which has represented an obstacle to the development of prevention and treatment methods. Thus, there is a need to redirect studies to augment diagnostic systems with individualized phenotypic measurement. Consequently, the goal of the paper was to develop a pragmatic dimensional perspective on the complex traits underlying probabilities of disorder development. To this effect, they conducted selective literature reviews of the foundation and methods for measuring liabilities to complex disorders and consultations on practical approaches. The paper presents novel applications of person-centered principles in psychiatric research, focused on the quantitative measurement of the individual phenotype along the full scale of the latent trait of liability and its understudied aspect, resistance to the disorder.

Kirisci et al [52] wrote the third article in the Metrics Section, which addressed Item Response Theory (IRT) to assess dimensionality of substance use disorder (SUD) abuse and dependence symptoms. They posited that IRT provides an opportunity, within a person-centered framework, to accurately gauge each person's severity of disorder that, in turn, may inform intensiveness of treatment. The aim of this study was to determine whether the SUD symptoms indicate a unidimensional trait or instead need to be conceptualized and quantified as a multidimensional scale. Their sample was composed of families of men and women who qualified for a DSM-III-R diagnosis of substance use disorder (abuse or dependence) and families of adult men and women who did not qualify for such SUD diagnosis. IRT methodology was used to assess the dimensionality of DSM-III-R SUD abuse and dependence symptoms. A bi-factor model provided the optimal representation of the factor structure of SUD symptoms in men and women, yielding a single common factor, corresponding to general liability to addiction, combined with second-order factors corresponding to drug-specific liabilities. They suggested the approach may be helpful for addressing intensity of treatment in a personcentered manner.

Stone & Leventhal [53] authored the fourth article in the Metrics Section, aimed at accounting for multidimensionality in item responses in patient-centered and patient-reported outcomes measurement as well as at using Bayesian methods of relevance to person-centered medicine. They employed platforms for implementing Bayesian analyses to estimate and analyze IRT applications to health-related assessments. The platforms appeared to involve straightforward translations of the response probability model along with specifications of the model parameters and prior distributions for the model parameters. Bayesian analysis of multidimensional IRT models may be helpful to researchers and scale developers in measuring health sciences outcomes in person-centered medicine research.

The next regular article in this Journal's issue was written by Phillips et al [54] concerning adolescent resilience assessment in person-centered medical care in Canada. They noted that acquiring resilience and psychological strength is central to adolescents' development. The study's objectives were to assess resilience in youth in a person-centered manner of merit to participants themselves, as well as to identify characteristics of resilience such as self-control and optimism. Their sample was composed of 59 adolescents from three sites: a small Canadian city, a remote town and one northern Ontario First Nations Reserve. They found resilience scores to be statistically valid and comparable across gender, but lower among reserve indigenous youth. The main value of the resilience scale was as a dooropener to deeper, person-centered discussions. Only via interviews the researchers learned that youth had often adapted positively to the adversities identified in standard social/medical histories and named these as sources of strength and resilience rather than stress.

The last regular article was authored by Kar and Singh [55] from Lucknow, India in reference to person centered care for the Dhat Syndrome, a culture-bound condition or idiom of distress prevalent in South East Asia and often manifested as anergia, depressed mood, anhedonia and decline in sexual ability as perceived sequel of semen loss. The authors conducted a literature review to elucidate different management strategies for the Dhat syndrome and to explore the relevance and feasibility of a person centered approach. Out of 65 articles found, 17 were selected for analysis. Most studies advocated the role of anti-anxiety and antidepressant medication. Several also emphasized the role of sex education, relaxation exercises, supportive psychotherapy as well as cognitive behavior and insight oriented psychotherapies. Some studies focused on issues relevant to person centered care, including empathetic listening, non-confrontational attitudes, individualized care, and collaborative approaches. They concluded that reflecting the recommendations from the literature review, a person centered approach may be an effective, feasible and acceptable model of care for persons presenting the Dhat syndrome.

This Journal's issue ends with announcements for the 10th Geneva Conference on Person Centered Medicine and the Fifth International Congress of Person Centered Medicine in Zagreb, Croatia.

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