

## **EDITORIAL INTRODUCTION**

### **ICPCM EDUCATIONAL PROGRAM ON PERSON-CENTERED CARE: CARE PLANNING, SHARED DECISION MAKING, AND INTERPROFESSIONAL COLLABORATION**

*James Appleyard, MA, MD, FRCP<sup>a</sup> and Juan E. Mezzich, MD, MA, MSc, PhD<sup>b</sup>*

**Keywords:** person-centered medicine, educational program, person-centered care, International College of Person Centered Medicine, listening, narrative, communication, common ground, comorbidity, palliative care, interprofessional collaboration

**Correspondence Address:** Prof. James Appleyard, Thimble Hall Blean Common, Kent CT2 9JJ, United Kingdom

E-mail: jimappleyard2510@aol.com

## **INTRODUCTION**

This journal issue includes the third part of the Educational Program on Person-Centered Care of the International College of Person Centered Medicine (ICPCM) that in its initial version was presented at the 6th International Congress of Person Centered Medicine in New Delhi in November 2018. The overall themes of the four papers [1–4] are the planning of care, shared decision making, and interprofessional collaboration. In addition, there is the Lima Declaration 2018 entitled “Towards a Latin American Construction of Persons-Centered Integral Health Care,” which recognizes how important these concepts are to the

---

<sup>a</sup> *Board Advisor and Former President, International College of Person Centered Medicine; Former President, World Medical Association; President, International Association of Medical Colleges*

<sup>b</sup> *Professor of Psychiatry, Icahn School of Medicine at Mount Sinai, New York; Hipólito Unanue Chair of Person-Centered Medicine, San Marcos National University, Lima; Former President, World Psychiatric Association; Secretary General and Former President, International College of Person Centered Medicine*

development of general strategies for integrated health care with persons placed at the center of and as the goal of health actions. Reports from the Symposium on Person-Centered Medicine held during the 2018 World Medical Association's Conference in Reykjavik and the First Peruvian Conference on Person-Centered Medicine add further evidence of the importance of these perspectives.

Shared decision making has been shown to improve patients' knowledge and ability to participate in decisions about their care and improve the quality of clinical decision making. Clinicians and patients (often with family participation) decide together based on clinical evidence and the patient's informed preferences about any appropriate investigations, treatments, management, or support packages. It involves exploring relevant evidence-based information about options, outcomes, and uncertainties, together with decision support counseling and a systematic approach to recording and implementing patient's preferences [5, 6]. Though also leading to improvements in health outcomes for people with long-term health problems [7], it is only slowly filtering into mainstream clinical practice [8].

## **THE CLINICAL CONSULTATION**

Shared decision making starts with a person's story, which should be allowed to be recounted as a complicated narrative of health and illness told in words, silences, gestures, physical observations, overlain not only by objective findings but also with associated implications, fears, and hopes. The narration is a therapeutic central act because to find the words to contain the disorder and its attendant worries gives shape to and control over the uncertainties of the illness. As the physician listens to the patient, he or she follows the narrative thread of the story in all its existential cultural, familial, biological, social, psychological, and spiritual dimensions.

This encompasses an awareness of health and disease from which the meaning and purpose in both an illness and the experience of recovery emerge. Disorder "labels" become secondary to the life of the person.

## **LISTENING**

The act of listening, so essential to the process, enlists the physician's interior resources – memories, association curiosities, creativity, interpretive powers, and allusions to other stories by the person and others to identify meaning. Only then can the physician hear and confront the person's narrative questions "what is wrong with me?" Why is this happening to me? And what will be the result [9]?

Listening to stories of illness and recognizing that there are often no clear answers to patients' narrative questions demand the courage and generosity to

tolerate and to bear witness to unfair losses and random tragedies [10]. Accomplishing such acts of witnessing allows the physician to proceed to his or her more recognizably clinical narrative tasks: to establish a therapeutic alliance, to generate and proceed through a differential diagnosis, to interpret physical findings and laboratory reports correctly, to experience and convey empathy for the patient's experience [11], and, as a result of all these, to engage the patient for effective care.

If the physician cannot perform these narrative tasks, the patient might not tell the whole story, might not ask the most frightening questions, and might not feel heard [12]. The resultant diagnostic workup might be unfocused and therefore more expensive than need be, the correct ailment might be missed, the clinical care might be marked by noncompliance and the search for another opinion, and the therapeutic relationship might be shallow and ineffective. The narrative is absorbing. It engages the listening physician and invites an interpretation. It gives him or her the experience of "living through," not simply "knowledge about" the characters and events in the story.

## EFFECTIVE PRACTICE

The effective practice of medicine therefore requires narrative competence, that is, the ability to listen, acknowledge, absorb, interpret, and act on the stories and plights of other people [13]. The narrative also provides information that does not pertain simply or directly to the unfolding events. The same sequence of events told by another person to another audience might be presented differently without being any less "true." This is an important point. In contrast with a list of measurements or a description of the outcome of an experiment, there is no self-evident definition of what is relevant or what is irrelevant in a particular narrative. The choice of what to tell and what to omit lies entirely with the narrator and can be modified, at his or her discretion, by the questions of the listener.

This approach gives the physician insight into medicine's four dimensions – physician and patient, physician and self, physician and colleagues, and physicians and society [14]. With narrative competence, physicians can reach and join their patients in illness, recognize their own personal journeys through medicine, acknowledge kinship with and duties toward other health care professionals, and inaugurate consequential discourse with the public about health care. By this approach physicians can integrate their patients as persons with themselves, their colleagues and people in the wider communities and nations to provide renewed opportunities for respectful, empathic, effective, and nourishing medical care.

## CONTRASTING MODELS OF MEDICAL CARE

Engels' biopsychosocial model of medicine and the person-centered movement in medicine look broadly at the patient as a person and his or her illness [15]. Narrative provides the means to understand the personal connections between the patient and the physician, the meaning of medical practice for the individual physician, physicians' collective profession of their ideals, and medicine's relationship with the society it serves.

Narrative is concerned with experiences rather than with propositions. Unlike its complement, logic/scientific knowledge, epitomized in evidence-based medicine through which a detached and replaceable observer generates or comprehends replicable and generalizable notices, narrative knowledge of the person leads to local and particular understandings about one situation by one participant or observer. Logic/scientific knowledge attempts to illuminate the universally true by transcending the particular; narrative knowledge attempts to illuminate the universally true by revealing the particular.

The growing narrative sophistication has provided medicine with new and useful ways in which to consider patient–physician relationships, diagnostic reasoning, medical ethics, and professional training. Medicine can, as a result, better understand the experiences of sick people, the journeys of individual physicians, and the duties incurred by physicians toward individual patients and by the profession of medicine toward its wider culture.

## INTEGRATING KNOWLEDGE INTO CLINICAL PRACTICE

Sacket and his colleagues found that those who have studied the phenomenon of clinical disagreement, as well as those of us who practice medicine in a clinical setting, know all too well that clinical judgments are usually a far cry from the objective analysis of a set of eminently measurable “facts” [16].

In the language of empiricism such an observation could be interpreted as ascertainment bias [17]. Evidence supports the claim that doctors do not simply assess symptoms and physical signs objectively: they interpret them by integrating the formal diagnostic criteria of the suspected disease (that is, what those diseases are supposed to do in “typical” patients as described in standard textbooks) with the case-specific features of the patient’s individual story and their own accumulated professional case expertise. Narrative therefore provides meaning, context, and perspective for a person’s predicament. It defines how, why, and in what way he or she is ill [18].

The study of narrative offers a possibility of developing an understanding that cannot be arrived at by any other means. It provides a framework for

approaching a person's problems holistically, as well as revealing diagnostic and therapeutic options. Furthermore, narratives of illness provide a medium for the education of both patients and health professionals and may also expand and enrich the research agenda. Indeed, it is thought that anecdotes, or "illness scripts," may be the underlying form in which we accumulate our medical knowledge. Medical students rely on anecdotes of extreme and atypical cases to develop the essential ability to question expectations, interrupt stereotyped thought patterns, and adjust to new developments as a clinical story unfolds [19].

Evidence-based medicine lacks a way of measuring existential qualities such as the inner hurt, despair, hope, grief, and moral pain that frequently accompany, and often indeed constitute, the illnesses from which people suffer. The increasing pursuit during the course of medical training of skills deemed "scientific" and practical, which are readily measurable but inevitably reductionist at the expense of those that are fundamentally linguistic, empathic, and interpretive distorts the clinical method.

It is the core clinical skills of listening, questioning, delineating, organizing explaining, interpreting, and discerning meaning that provide a way of integrating the very different worlds of patients and health professionals. Whether these skills are performed well or badly are likely to have as much influence on the outcome of the illness from the patient's point of view as the more scientific and technical aspects of diagnosis or treatment.

Anecdotal clinical experience may be unrepresentative of the average patient and thus a potentially biased influence on clinical decision making. Evidence-based clinical decision making involves the assessment of the current clinical problem in the light of evidence from the aggregated results of hundreds or thousands of comparable cases in a defined population sample, expressed in the language of probability and risk.

The "truths" established by the empirical observation of populations in randomized trials and cohort studies cannot be mechanistically applied to individuals or episodes of illness where the symptoms and behaviour need to be seen in context.

The generalizable truths gleaned from clinical research trials relate to the samples and, thereby, the study population's story, not the stories of the individual participants. There is a serious danger of erroneously viewing summary statistics as hard realities. Reification is what has been termed "misplaced concreteness." The dissonance we experience when trying to apply research findings to the clinical encounter often occurs when we abandon the narrative-interpretive paradigm and try to get by on "evidence" alone [20].

## MENTAL AND COMORBID CONDITIONS

In the first article of this journal issue, Helen Millar [1] illustrates these points in her discussion on person-centered care planning and shared decision making for mental and comorbid conditions with the aim of addressing mental health issues to achieve better compliance with treatment, health and social outcomes and improved quality of life for those living with chronic physical conditions. It is important to recognize the advocacy in the slogan “No health without mental health” [21]. She highlights the developments in the evolving model of person-centered coordinated care in the light of the challenges of the growing epidemic of physical comorbidity in the mentally ill.

She reviews with the key developments supporting proactive and preventative strategies and interventions to tackle comorbidity in this population. Excessive deaths due to comorbidities especially cardiovascular disease continue to contribute to the significant reduction in life expectancy in people with mental health problems. Coordinated collaborative systemwide strategies encompassing shared decision making in prevention and early intervention including lifestyle and pharmacological management are crucial to improve quality of life and life expectancy [22].

We need to help create the conditions for person-centered coordinated care by involving commissioning bodies, patient groups, and practitioners along with community providers. Contemporary models of care for comorbidity emphasize the importance of coordination in the management of physical well-being from the onset of treatment of people with mental health problems in order to ensure better outcomes, improved overall well-being and a longer life expectancy.

## ONCOLOGY AND PALLIATIVE CARE

Paul Glare [2] illustrates the importance of shared decision making in oncology and palliative care emphasizing the centrality of the person and the need to understand the risk and benefit in the context of oncological and end-of-life care decisions for each individual [23]. Rapid advances in cancer research, the development of new and more sophisticated approaches to diagnostic testing, and the growth in targeted cancer therapies are transforming the landscape of cancer diagnosis and care. These innovations have contributed to improved outcomes for patients with cancer, but they have also increased the complexity involved in diagnosis and subsequent care decisions. Added to this complexity, focusing on state-of-the-science biomedical treatment may lead to ignoring the psychological and social (psychosocial) problems associated with the illness [24]. Ignoring these issues can compromise the effectiveness of health care and thereby adversely affect the health of cancer patients. Psychological and social problems created or

exacerbated by cancer – including depression and other emotional problems – lack of information or skills needed to manage the illness; lack of transportation or other resources; and disruptions in work, school, and family life – cause additional suffering, weaken adherence to prescribed treatments, and threaten patients’ return to health [2]. Glare discusses some of the new strategies, which engage appropriate expertise and technologies for treating the disease while ensuring a person-centered approach to caring for cancer patients and their families [25].

## **SHARED DECISION MAKING FOR OTHER GENERAL CONDITIONS**

Appleyard and Snaedal [3] explore the concept of shared decision making in a range of different chronic conditions included within a Cochrane review. The complexities of the decision-making process and the confounding variables create difficulties in obtaining and measuring reproducible outcomes. The beneficial effects of shared decision making including indicators of physical and psychological health status, and people’s capability to self-manage their condition when compared to usual care, are greatest when there is more frequent follow-up and continuity of care with the person’s personal clinician. “Common ground” is achieved through empathic communication skills with the provision of evidence-based information about options, outcomes, and uncertainties, together with decision support counseling and a systematic approach to recording and implementing patient’s preferences.

## **INTERPROFESSIONAL COLLABORATION**

The biomedical, social, psychological mental spiritual needs of a person can only be fulfilled within a team. In the final article of this journal issue, Tesfamicael Ghebrehewet [4] delineates the key elements that facilitate interprofessional collaboration and identifies the main benefits of and barriers to its development. Interprofessional collaboration in health care occurs when multiple health workers with different professional backgrounds provide person-centered care by working with patients and their families across different settings [26]. It is well accepted that, within each profession, there are varying levels of competence and it is impossible for a single health professional group to provide a continuum of person-centered and cost-effective care [27]. However, the different health professionals can pool their knowledge and expertise to provide person-centered care by working in collaborative practice. For effective collaboration, key barriers must be addressed by the different health professionals. Interprofessional collaboration and communication are largely achieved through interprofessional education

during certain periods of their training. Key benefits of interprofessional collaboration and teamwork include fewer medical errors, improved patient outcomes, and better patient safety [28].

## **THE REYKJAVIK SYMPOSIUM ON PERSON-CENTERED MEDICINE**

A Symposium on Person-Centered Medicine was held during from the World Medical Association Ethics Conference in Reykjavik 2018 [29]. With medical care being increasingly driven by management systems founded on cost containment, cost efficiency, and cost efficacy, doctors are becoming burnt out especially in the United States within the complexities of an insurance-based system and in the United Kingdom by narrowly based directed government policies. Doctors are increasingly unable to fulfill their ethical obligations to their patients and are becoming “disconnected” from their work environment.

Through trusted and healing relationships developed within a professional “space,” a person-centered approach with people over time can achieve the required integration and coordination of care that leads to better health, effective health care, and lower cost. Systems of care need to be built around primary care as the core foundational element to ensure that all people are seen and helped for the right reasons, at the right time, by the right professionals, and in the right place. By integrating primary, secondary, tertiary, preventive, and end-of-life care, it was affirmed that such systems will collectively produce healthier persons, healthier people, and healthier nations.

## **FIRST PERUVIAN CONFERENCE ON PERSON-CENTERED MEDICINE**

At the conference the personalized integral clinical approach was affirmed to be indispensable in the practice of PCM; this implies recognizing the causality, the clinical demarcation, the diagnosis, and the integral treatment, assessing the circumstances of the situation in which each person is treated [30]. The strategic organizational design for person-centered integral health care reaffirms that formation of comprehensive networks of health services must include multidisciplinary and multifunctional teams and intersectoral work accompanied by strong social participation. There is therefore a greater responsibility in health systems for all health care professionals and indeed the community at large to believe in and be committed to these fundamental principles revolving around the centrality of the person, the genuine concept of medicine as the art as well as the science of caring for the life, the integrity, and the well-being of all.

## REFERENCES

1. Millar H. This issue. Person-Centered Care Planning and Shared Decision-Making for Mental and Comorbid Conditions. International Journal of Person Centered Medicine 8(4): 17–30.
2. Glare P. This issue. Shared Decision Making for Oncological, Chronic Pain and Palliative Care. International Journal of Person Centered Medicine 8(4): 31–40.
3. Appleyard J, Snaedal J. This issue. Shared Decision Making for Other General Conditions. International Journal of Person Centered Medicine 8(4): 41–46.
4. Ghebrehiwet T. This issue. Inter-professional Collaboration for Person-Centered Care. International Journal of Person Centered Medicine 8(4): 47–53.
5. Salzburg Global Seminar. 2011. Salzburg Statement on Shared Decision Making. British Medical Journal 342: d1745.
6. Stacey D, Legare F, Col NF, Bennett CL, Barry MJ, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R, Trevena L, Wu JHC. 2014. Decision Aids for People Facing Health Treatment or Screening Decisions. Cochrane Database of Systematic Reviews 1: CD001431.
7. Coulter A, Entwistle VA, Eccles A, Ryan S, Shepperd S, Perera R. 2015. Personalised Care Planning for Adults with Chronic or Long-Term Health Conditions. Cochrane Database of Systematic Reviews 1: CD010523.
8. Coulter A, Collins A. 2011. Making Shared Decision-Making a Reality, King's Fund, London.
9. Greenhalgh T, Hurwitz B. 1999. Narrative Based Medicine: Why Study Narrative? British Medical Journal 318: 48–50.
10. DeSalvo L. 1999. Writing as a Way of Healing: How Telling Our Stories Transforms Our Lives, Harper, San Francisco, CA.
11. Fox R, Lief H. 1963. Training for “Detached Concern.” In: H Lief (Ed). The Psychological Basis of Medical Practice, Harper & Row, New York, pp. 12–35.
12. Jones AH. 1997. Literature and Medicine: Narrative Ethics. Lancet 349: 1243–1246.
13. Engel GL. 1977. The Need for a New Medical Model: A Challenge for Biomedicine. Science 196: 129–136.
14. Sackett DL, Rosenberg WMC, Gray JAM, Haynes RB, Richardson WS. 1996. Evidence Based Medicine: What It Is and What It Isn't. British Medical Journal 312: 71.
15. Charon R. 1993. Medical Interpretation Implications of Literary Theory of Narrative for Clinical Work. Journal of Narrative & Life History 3: 79–97.
16. Greenhalgh T, Hurwitz B. 1998. Narrative Based Medicine: Dialogue and Discourse in Clinical Practice, BMJ Books, London.

19. Hurwitz B. 2000. Narrative and the Practice of Medicine. *Lancet* 356: 2086–2089.
20. Cassell E. 1982. The Nature of Suffering and the Goals of Medicine. *New England Journal of Medicine* 306: 639–645.
21. Millar H, Abou-Saleh MT. 2011. The World Federation for Mental Health (WFMH) – International Network for Person-Centered Medicine (INPCM) Project: *International Journal of Person Centered Medicine* 1 (1): 92–97.
22. Adams N. 2012. Finding Common Ground: The Role of Integrative Diagnosis and Treatment Planning as a Pathway to Person-Centered Care. *International Journal of Person Centered Medicine* 2 (2): 173–178.
23. Weiner JS, Roth J. 2006. Avoiding Iatrogenic Harm to Patient and Family while Discussing Goals of Care Near the End of Life. *Journal of Palliative Medicine* 9: 451–463.
24. Schnipper LE, Davidson NE, Wollins DS. 2015. A Conceptual Framework to Assess the Value of Cancer Treatment Options. *Clinical Oncology* 33: 2563–2577.
25. Hoerger M, Epstein RM, Winters PC, Fiscella K, Duberstein PR, Gramling R, Butow PN, Mohile SG, Kaesberg PR, Tang W, Plumb S, Walczak A, Back AL, Tancredi D, Venuti A, Cipri C, Escalera G, Ferro C, Gaudion D, Hoh B, Leatherwood B, Lewis L, Robinson M, Sullivan P, Kravitz RL. 2013. Values and Options in Cancer Care (VOICE): Study Design and Rationale for a Patient-Centered Communication and Decision-Making Intervention for Physicians. *BMC Cancer* 13: 188.
26. World Health Organization. 2010. Framework for Action on Interprofessional Education & Collaborative Practice. [http://www.who.int/hrh/resources/framework\\_action/en/](http://www.who.int/hrh/resources/framework_action/en/)
27. Ghebrehewet T. 2015. Inter-Professional Education for Collaborative Practice in Health Care. *International Journal of Person Centered Medicine* 5: 74–77.
28. Leonard M, Graham S, Bonacum D. 2004. The Human Factor: The Critical Importance of Effective Teamwork and Communication in Providing Safe Care. *Quality & Safety in Health Care* 13: i85–i90.
29. Summary Report of the Symposium on Person Centered Medicine at the World Medical Association Ethics Conference in Reykjavik 2018. This issue. *International Journal of Person Centered Medicine* 8(4): 57–58.
30. Report from the First Peruvian Conference on Person-Centered Medicine 2018. This issue. *International Journal of Person Centered Medicine* 8(4): 59–63.