EDITORIAL INTRODUCTION

Engagement and Empowerment in Person Centered Medicine

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Introduction

Engagement and empowerment are important concepts in Person Centered Medicine (PCM). Engagement refers to the act or state of personal interaction that is often crucial as part of thinking and implementing a medicine and health that are person-centered. Empowerment refers to the enablement of a person to fulfill his or her rights and responsibilities. These concepts are usually inter-related as empowerment tends to be carried out as part of an engagement process. While both concepts are relevant to human activities and human relations in general, they certainly have a major significance in the health field.

Their place in PCM is related to both its principles and strategies. As such they have often being part of the institutional journey of PCM [1], now ten years old. Their conceptual place and implications in PCM are reviewed briefly next.

Engagement and Empowerment and the Principles of Person Centered Medicine

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 [2].

Conceptualization in terms of fundamental activities, has widely 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) [3, 4]. The last feature, *medicine with the person*, directly involves engagement and empowerment.

The ascertainment of a comprehensive set of key indicators of PCM has been a substantial concern for programmatic development. A research landmark, with support from the World Health Organization, has encompassed the systematic conceptualization of person centered medicine and the development and validation of a prototype Person-centered Care Index [5]. This work has involved critical reviews of the literature as well as focused international consultations. It elucidated eight key concepts underlying person centered medicine, as follows: 1) Ethical commitment, 2) Holistic framework, 3) Cultural awareness and responsiveness, 4) Relational and communicational focus (for which the establishment of empathy is crucial), 5) Individualized care, 6) Common ground among clinicians, patient and family for joint diagnostic understanding and shared decision making, 7) people-centered and integrated health systems, and 8) Person-centered education and health research.

One can argue that several of these key principles of PCM are connected to engagement and empowerment. This includes, as first principle, ethical commitment, which encompasses respect for the person's autonomy and promotion of the person's life project [6], both of which are bases for empowerment. The third principle, cultural awareness and responsiveness, also relates to empowerment in terms of self-identity and cultural engagement and support [7]. The fourth principle, relational and communicational focus [8], is directly connected to engagement and then to empowerment. Finally, the sixth principle, establishing common ground among clinicians, patient and family for joint diagnostic

understanding and shared decision making [9], involves empowering the person to participate actively and prominently in the caring for his or her own health.

Engagement and Empowerment and Person Centered Medicine Strategies

As pointed out by Groves [10], on the basis of her experience with the International Alliance of Patients' Organizations (IAPO) and the International College of Person Centered Medicine, healthcare policy decisions, at whatever level they are made, will ultimately affect patients' lives. There is, therefore, a moral imperative that they play a meaningful role in developing healthcare policies and, if done well, it helps to ensure that policies reflect patient and caregiver needs, preferences and capabilities.

Empowerment is not possible without having necessary information and opportunities for involvement but it is not merely that but the ability and confidence to take action based on the knowledge people have [10]. The European Network for Patient Empowerment (ENOPE) [11] says that an empowered activated patient is one which: understands their health condition and how to manage their lifestyle and condition; feels able to participate in decision-making and make informed choices about treatment and feels confident to challenge and ask questions of health professionals or where to find, evaluate and use the information they need. With the increased use of terminology regarding empowerment and person-centered care, it is important to ensure that this is not just rhetoric with the actual practice not changing in line with the language.

The All Party Parliamentary Group on Global Health in the UK [12] collected over 100 overseas examples of patient empowerment such as those relating to self-care, patients as experts, shared decisions and choice. They concluded that by giving patients the opportunity to expand their role and equipping them to do so new models of care are possible.

Schmolke, Amering and Svettini [13] have posited that empowerment has become an essential role for professionals in the psychosocial field focusing on self-help forces, self-realizing power and resources of persons as counter-forces against challenges in critical life situations – in contrast to demoralization and resignation. Empowerment as an attitudinal concept is an effective tool for professionals to reinforce often forgotten strengths and capabilities of their clients in order to regain autonomy in their life and active participation in the community [14].

Laugharne and Priebe [15] suggested that empowerment seems to have impacted more at an organizational level than on individual care and suggest that this might reflect the fact that the power differential between service users and providers is an extremely stubborn phenomenon, with a tendency to persist even in "person centered" and consumer-led services. They warn that the ethical and the economic arguments for patient choice should not be confused, the latter possibly granting a person choice among different institutions offering the same paternalistic approach to treatment decision-making.

Also illustrating PCM strategies involving engagement and empowerment, is the challenge of addressing the global epidemic of chronic disease [16], for which the United Nations and the World Health Organization [17] have called all components of society to action. Addressing chronic disease is particularly compelling for our International College of Person Centered Medicine given that effective care for such conditions requires indispensably the engagement of persons and their sense of responsibility to undertake actively and creatively the adjustments in life style that we all must make to maintain and improve our health.

Introducing the Papers in this Issue of the Journal

Engagement and empowerment are present in various forms and extents in the papers published in the present issue of the *Journal*. They are briefly introduced below.

The first regular article was authored by Emmanuel Kumah from Pisa, Italy concerning a study on "Tracking Trends in Patients' Hospital Experiences" [18]. The purpose of this paper was to determine whether an upward trend in patients' reported positive experiences could be established in organizations that have a long history of surveying their patients, including hospitals at Oxford University, University College London, and Central Manchester University. Their observations indicated that healthcare organizations may not be fully using patient experience data to inform quality improvement. More policy-level actions and effective organizational leadership seems to be required for the goal of promoting person-centered care through care experiences.

The second article comes from Samantha Hack et al reporting on "Provider and Consumer Behaviors and their Interaction for Measuring Person-Centered Care" from Baltimore, USA [19]. As they noted that higher rates of person-centered care (PCC) are associated with greater treatment adherence and positive treatment outcomes, a study was undertaken to assess how a consumer information subscale and a consumer decision making subscale are not correlated with provider subscales and that consumer perceptions of person-centeredness and of consumer involvement in care are significant independent explanatory variables concerning therapeutic alliance, treatment adherence, and mental health care system mistrust. Cross-sectional survey data was collected from 82 mental health care consumers receiving services at two Veterans Health Administration (VHA) facilities in the USA. Significant correlation between consumer participation and PCC subscales was mixed. When conducting PCC research, investigators should consider how the outcomes they are examining inform the method through which they measure patient-centeredness.

The third article by Yaara Zisman-Ilani from Dartmouth College in New Hampshire, USA and colleagues in New York and Baltimore [20] presented a study on "Comparing Digital vs Paper Decision Aids about the Use of Antipsychotic Medication: Client, Clinician, Caregiver and Administrator Perspectives". They evaluated attitudes and readiness for digital DAs among four stakeholder groups: people with psychosis, clinicians, caregivers, and administrators. Semi-structured interviews were conducted on 19 respondents who were presented with a paper version of the Decision Aid (DA) and were asked about their readiness to use a digital DA. Results suggested that the introduction of digital DAs into psychiatric medication consultations requires further research to understand what type of digital DAs can offer an optimal combination of accessibility and ease of use.

Belinda Dewar and colleagues in the United Kingdom presented in the fourth article a study on "The Caring Conversation Framework to Promote Person Centered Care: Synthesizing Qualitative Findings from a Multi-Phase Research Program" [21]. Secondary analyses were conducted on the qualitative findings in the final reports of five studies involved in the implementation of the CCF. The analyses showed consistent positive outcomes for staff in their interactions with patients, families and others. This included greater self-awareness during interactions, development of stronger relationships, and more open dialogue that supports relational practice. The secondary analyses confirmed the applicability of the framework across a number of different settings, strengthened confidence in its value, generated fresh insights to inform further research, and developed a deeper insight into the attributes of the framework and its application.

The fifth article by Nelson Raúl Morales-Soto from Lima, Peru, reported on a study of "Latin American Experience and Responses in Disasters: Person-centered Perspectives" [22]. A review of the literature on disasters in Latin America was conducted. Indicators of person centered medicine appeared to be present in much of the reviewed Latin American disasters literature. The Latin American region is beginning to express high interest on PCM and on its implementation, in relation to renewed concern for ethics and human values. The promising value of person-centered educational exercises to enhance disaster preparedness was illustrated. Disasters and their impact tend to correlate with social disorganization and deficient status of prevailing health policies. Social resilience and preparedness are key to maintain development and prevent impoverishment. The health sector is remarkably vulnerable to disasters and requires the adoption of holistic and integrated approaches to be prepared for and manage disasters effectively for the benefit of persons and communities.

The last regular article was authored by Chandramani Thuraisingham and colleagues from Malaysia and dealt with "The Chaperone in a Medical Examination and Therapeutic Relationship: A Literature Review and Critical Discussion" [23]. The purpose of this study was to explore the issues involved in the engagement of chaperones in medical examinations in various countries and their implications concerning ethics and appropriate therapeutic relationships. A review of the medical literature in English between 1990 and 2016 was conducted. Common themes and five main questions were elicited. The findings obtained were complemented with a critical discussion on ethics and therapeutic implications. Having clear guidelines for intimate medical examinations provides the physician sound defense concerning allegations of misconduct and lends security and transparency to patients. Medicolegal recommendations and standards of practice should be aligned with patient values and societal expectations. Good role modelling and teaching of professionalism in medical education years are important towards the ethical practice of medicine.

This Journal's issue ends with information on important PCM events. These include the program of the Second Latin American Conference of Person Centered Medicine in Lima, Peru; the announcement and program for the 10th Geneva Conference on Person Centered Medicine; and the announcement and program outline of the Fifth International Congress of Person Centered Medicine in Zagreb, Croatia.

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