

# Using Human Factors Approach to Evaluate Patient-Centered Cancer Care

Safa Elkefi<sup>1</sup>, Onur Asan<sup>1</sup>, and Tina W. F. Yen<sup>2</sup>

<sup>1</sup>School of Systems and Enterprises, Stevens Institute of Technology, Hoboken, USA

<sup>2</sup>Medical College of Wisconsin, Division of Surgical Oncology, Milwaukee, Wisconsin, USA

## ABSTRACT

Patient centered care has the potential to provide true value to the patients, so it got a lot of attention and became the goal of care for health care systems. In this paper, we explore the evolution of patients' position in healthcare and focus on conceptualizing a new adequate socio-technical framework that can serve for the evaluation of the effectiveness of PCC approaches in cancer care settings.

**Keywords:** Human factors, Systems engineering, Patient-centered care, Cancer care, Health Management

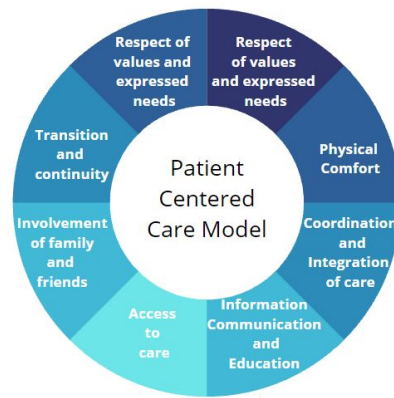
## INTRODUCTION

Patient-centered care (PCC) approaches are considered crucial for the delivery of high-quality care to patients. However, there is a considerable ambiguity concerning the exact meaning of the term and the optimal method for measuring the process and outcomes of PCC (Mead and Bower, 2000). PCC is of critical importance in the context of cancer care where the therapeutic alliance between patients and their clinicians is frequent in time over extended periods of time. Confusion about how to apply good patient-centered care practices, however, sanctions the efforts made to adopt it. In the name of patient-centeredness, hospitals have been adopting models used by boutique hotels (Fred, 2016). Although such amenities might enhance the patient's experience, they do not necessarily achieve the goals of patient-centered care. The concept of patient-centered care has received increased attention since the publication of the 2001 Institute of Medicine (IOM) report *Crossing the Quality Chasm* (Institute Of Medicine, 2001). This study explored a framework for defining health care quality and improving systems of care summarizing delivery of health care in six core values: safe, effective, efficient, patient-centered, timely and equitable. Since then, myriad clinical, policy, and research initiatives have been launched to promote the study, advancement, and implementation of patient-centered care. Many initiatives focused on developing technologies that help fostering PCC by increasing patients' access to information and facilitating self-monitoring and patient convenience (ElKefi and Asan, 2021). Research has described technology

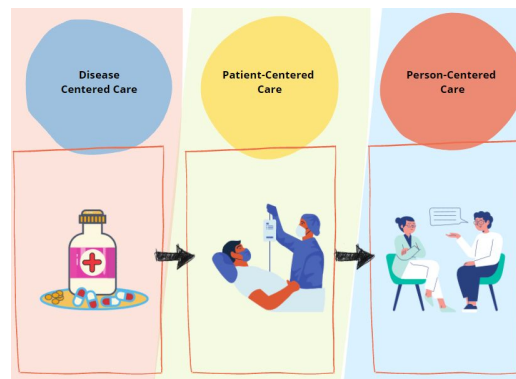
use in medical encounters that are based on a PCC approach, but much remains to be done to provide meaningful, conceptually grounded measurement of PCC and to develop tools that can describe it, measure it, and evaluate its effectiveness. Not having a universal PCC definition has hampered conceptual and empirical development efforts (Mead and Bower, 2000). This paper makes an important contribution to the literature by historically examining the evolution of the definitions of patient-centered care, summarizing the existing measures adopted to measure its components. It also suggests a socio-technical framework to evaluate the effectiveness of patient-centeredness. The framework considers the cancer patient as a center of a set of processes from a systems perspective.

## **PATIENT-CENTERED HISTORY**

Despite the popularity of the concept in the past 30 years, there has been a little argument of perspective, in literature, about the definition of patient-centered care (Mead and Bower, 2000). It has been an evolving concept, originally depicted by Edith Balint, 1969 who described patient-centered medicine as understanding the patient as a unique human being (Balint, 1969) while for McWhinnie, 1986 it is an approach where the “physician enters the patient’s world to see the illness through his eyes (Levenstein et al., 1986). In 1998, Delbanco and colleagues developed a self-described utopian vision for a patient-centered health care system called PeoplePower (Delbanco et al., 2001) where the relationship is supported by “computer-based guidance and communication systems”. Don Berwick, former administrator for the Center for Medicare and Medicaid Services, has popularized the slogan adopted by Delbanco and his group, “Nothing about me without me” acknowledging that patient-centered care is not always evidence-based. In his 2009 Health Affairs article, he argues that nonevidence-based care should occasionally trump evidence-based care, if this is what the patient wants. He emphasizes that patient-centered care is related to one’s set of decisions and choices of circumstances and relationships in healthcare. Some researchers doubt the correlation of this definition with human patient centeredness. Some other researchers have linked the definition of patient-centered care to the services provided that respect or respond to the individual’s perspectives: including preferences, needs, feelings, ideas, expectations, concerns, and values eliciting by that the patient’s perspective on his health situation, understanding his psychological context and reaching a shared-value-based middle-ground. Researchers from Harvard Medical School, on behalf of Picker Institute and the Commonwealth Fund, defined 8 primary dimensions of patient-centered care model identified in (Figure 1), using a wide range of focus groups, recently discharged patients, family members, physicians and non-physician hospital staff combined with a review of pertinent literature (Constand et al., 2014). An extensive body of the literature has emerged over the years suggesting that patient-centered care should include fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making joint decisions, and enabling patient self-management. In 2015, the World Health Organization released their framework on “people-centered



**Figure 1:** Patient-centered care model.



**Figure 2:** Evolution of patients' position in care models over time.

health services,” (World Health Organization, 2015) emphasizing a focus on a system that adopts individuals’, careers’, families’, and communities’ perspectives into a trusted health care system. This article and others aspire to person-centered care rather than patient-centered care, especially for chronic illnesses.

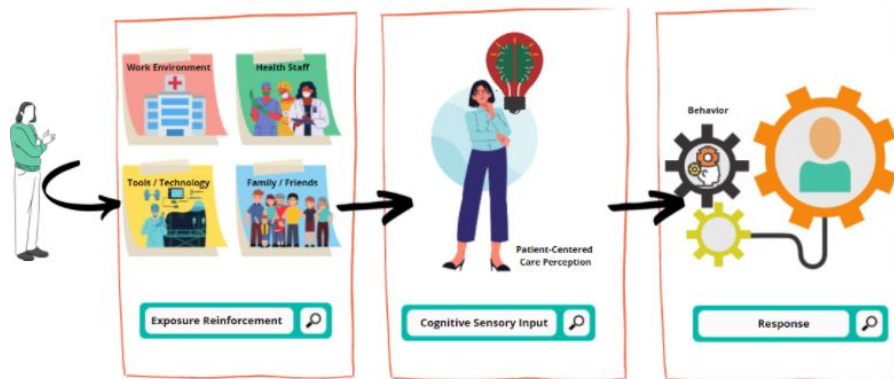
This approach consists of treating patients as individuals and as equal partners in the business of healing making care personalized, coordinated, and enabling (The Health Foundation, 2016). Instead of treating people like victims of diseases, this model recognizes their need for more than one professional to support them emphasizing their capabilities and potential to improve their own health by themselves. It also provides a different and complementary way to the visit-oriented approach furnishing a more accessible and continuous care over time. Figure 2 represents the evolution of patients’ position in healthcare services from a disease-centered care to a patient-centered care to finally a person-centered one.

Patient-centered care remains, then, a complex phenomenon with several definitions, but a consistent theme among them is the quality of interactions between patients and clinicians. Clearly these definitions themselves leave ample room for interpretation. It is noteworthy that patient-centered

care depends also on the environment as it may differ among settings. This implies the importance of examining co-creation of care. Co-creation consists of establishing productive interactions between patients and healthcare professionals to improve outcomes especially in situations of complex tasks, uncertainty, and time constraints (Kuipers et al., 2019). Improving care coordination requires a deeper understanding of the processes involved in delivering personalized care, including the various members of the distributed care team with their interdependent activities over time and the work system itself with the tools and resources allocated (Carayon et al., 2020). This is in line with the renewed focus of Human Factors and Ergonomics on systems approaches.

### **Scales Between Measuring and Evaluating**

Concerns about variation in standards of medical care, coupled with increasing digitalization strategies throughout the health care sector have served to encourage quantification of all aspects of care varying from timely access to care, availability and accessibility, quality of care and its efficiency (Mead and Bower, 2000). The existing definitions and measurement approaches often fail to address the complexities involved in understanding quality of care. It is perception of quality, rather than clinical indicators of quality, that drive service utilization and are essential to increasing demand (Mead and Bower, 2000). However, gaps can occur between the concepts theorized and the empirical value of the measures especially for variables like patient-centeredness where the development of reliable measures depends on the clarity of theoretical relationships and processes' modeling (ElKefi and Asan, 2021). Several measurement scales exist to measure patient centeredness from patients' perspective. Paul A. Heidenreich, 2013, associates the patient-centered care evaluation to the measure of patients' satisfaction with the care, the cost of delivering it and the impact on health outcomes (Heidenreich, 2013). Some others associate it to patient involvement as a dimension in several studies (Ree et al., 2019). Nevertheless, measuring patient-centeredness is difficult, evidenced by the sheer volume of measurement tools developed and evaluated in different contexts. In cancer care, assessing the provision of patient-centered care, comprehensive and psychometrically robust patient-reported measures are needed (Tremolada et al., 2015). Several measures were implemented, like the Quality of Patient-Centered Cancer Care (QCCC) which measures the quality of patient-centeredness by covering the six Institute Of Medicine's endorsed patient-centeredness dimensions (Tzelepis et al., 2018). Among the measures characterizing patient-centeredness, there is currently no systematic approach in place to measure the quality of the provision of PCC and evaluate the effectiveness of its practices. Furthermore, patient-centered quality indicators should be developed to measure the patient-centered care in practice relating it to its components and especially to the care settings it is evaluated in (cancer care, primary care, etc.), together with the context of the frameworks, (educational program, patients' engagement, etc.). Because only the patient can determine whether care aligns with his expectations and values, and because each patient has unique needs and



**Figure 3:** Proposed framework to evaluate PCC effectiveness.

values, patient-centered measures need to be inspired from the care settings they are evaluating. It is also noteworthy that the newly diagnosed cancer patients require more support than other patients, considering the emotional distress and mental pressure they are undertaking that is related to the cancer diagnosis, the treatments' paths followed and the physically demanding care processes (Institute of Medicine (US) Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, 2008). Also, care is provided by a multidisciplinary team of clinicians and providers, which further complicates measuring the effectiveness of the patient-centeredness in technology design and communication processes.

### **Patient-Centered Effectiveness Socio-Technical Framework**

Our approach to measuring PCC is grounded to the conceptual framework we are suggesting that evaluates the effectiveness of patient-centered care based on a sociotechnical perspective. We link the cognitive perception of patients towards PCC (*Cognitive Sensory Input*) to their exposure to external factors (*Exposure*) that may affect their (*Cognition*) behavior as explained in the (Figure 3).

The patient-centeredness perception (*Cognitive Sensory Input*) impacts patients' behavior. Placing the subject on the agenda of a consultation, followed by a discussion of management options with associated benefits and risks that is adjusted to the patients' context can help doctors personalize their recommendations and will improve health outcomes as patients can feel they are part of the care they are being given. Information building on patients' existing knowledge is more effective than communicating standard information in general.

### **Cancer is More Than a Suffix in the Framework Name**

Patient-centered care in oncology settings has proved to change the behavior of cancer patients as it successfully engages the patient by incorporating his bio-psychosocial support system into care delivery and to ensure sustainable development (Miller, 2016). Involving cancer patients meaningfully in the

processes and responding to their emotions as part of PCC adoption, have been linked with better health outcomes, more trust and better engagement of patient in their care (Tevaarwerk *et al.*, 2018). Thus, to evaluate the effectiveness of PCC initiatives, the cognitive perception of cancer patients needs to be studied in relation with their behavior within the care settings (Trust, Satisfaction, Anxiety, Engagement, etc.). From another side, achieving high-quality care is a complex pursuit in any settings especially for cancer care and improving the patient journey requires an integrated system of care and productive interactions among many system levels (National Academies of Sciences *et al.*, 2018). By understanding the work system components, the design and integration of tasks, technology, and clinical processes can be reviewed to better support the respective needs of individuals while optimizing system performance. A supportive work environment and a highly engaged workforce are highly correlated with improved quality of patient-centered care and hospital performance (Balbale *et al.*, 2015). At the population level, case managers, navigators, quality officers, and administrators may track outcomes across patients. A study conducted in 2017 on post diagnosis treatment communication with cancer patients highlighted the importance of coordination between specialists, primary care, and other people involved in the care processes with patients to deliver necessary care (Klabunde *et al.*, 2017) as problems in coordination can lead to fragmentations in the health outcomes and processes (Rowland *et al.*, 2006). However existing initiatives and care planning processes are facing system barriers to adoption and implementation. To sum up, tools and initiatives designed to improve health delivery through PCC need to be inspired from systems engineering principles as recommended by the IOM and the National Academy of Engineering in order to identify, develop, and sustain best practices informed by the needs of survivors, caregivers, clinicians, organizations, and communities (Tevaarwerk *et al.*, 2018).

## CONCLUSION

Delivering good quality care can be measured with the effectiveness of its patient centeredness. A holistic approach recognizing health care as a dynamic socio-technical system in which sub-elements interact with each other remains necessary to better understand the system and its constraints.

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