Occasionally a Patient: Always a Person
Richard Bruce Hovey, BEd, MA, PhD

Introduction
Currently within the Canadian research landscape, patients as partners or ambassadors have become part of the fabric for research funding; “nothing about me without me” (1). My recent personal experiences at pain conferences and research team meetings as a patient partner, who is also an academic researcher, suggest we need to evolve a philosophy of engagement that serves both the patient and the researchers and/or clinicians. This Perspectives' contribution is intended to open up possible conversations about the role of patient experience and the interconnections needed to build strong research communities, through a consideration of a person-centered relational model (2). To help locate and describe the role of the patient within the structure of a scientific research community I turn to the work of Merleau-Ponty: 

The world and man [human-beings] are accessible through two kinds of investigations, in the first case explanatory [scientific] and in the second case reflective [philosophical]” (3) (p. 497)

Whereas, researchers and clinicians engage the theory of pain to understand how it manifests and how to treat it (the scientific); the person living with chronic pain does so as a lived experience which is reflective (the philosophical). For the later, this highlights we are always a person. We are persons who happen to also be living with chronic pain. We are only occasionally a patient when directly engaged within the health-care system. Perhaps, this is where collectively we begin to directly address this divide among us. Although together we share a vested interest in pain; we experience, understand, and express it quite differently. This further suggests that working together in a meaningful way means finding a shared understanding (epistemology) and language of how we experience and communicate pain, learning to learn from each other (ontology), and building relationships that are meaningful, functional, and successful for everyone.

Meaningful Partnerships
The quote from Merleau-Ponty succinctly describes the position, understanding, and context of the researcher and/or clinician seeking to explain pain through a theoretical, objective, positivistic analysis of pain and its treatments. On the other side, the patient or person living with pain enters into this new world of living with pain as an unwilling and unsuspecting sufferer. The world of the person living with chronic pain is primarily qualitative, philosophical, and reflective. Our pain is understood and spoken through our narratives, not numeric scales. Although these two perspectives are focused on the same topic, pain, they are approached, understood, and experienced profoundly different.

Co-creating a shared space and language necessitates that not only do persons living with chronic pain need to learn the scientific/clinical language of pain to help to learn to live with it but that also researchers and clinicians need to learn how to listen to persons living with pain. We need to bring together the quantitative and the qualitative aspects of the pain experience. In other words, we need to meaningfully reunite the scientific and philosophical aspects of understanding pain in its complexity as “data.” Only then will we have utility through research, clinical practice, and pain self-management to enhance the experiences of everyone involved.

The Question Is: How Do We Do This?
I believe we need to consider moving away from the title of Patient Partners. It is too generic and somewhat dismissive. Within the hierarchical health-care system, the patient is the one who too often is silently patient. There needs to be a transformation away from the label patient into one based within a person-centered relational model. This is where persons living with pain can become known for what we can bring to the discussion as allied health researchers and/or clinicians seeking to explain pain through a theoretical, objective, positivistic analysis of pain and its treatments. On the other side, the patient or person living with pain enters into this new world of living with pain as an unwilling and unsuspecting sufferer. The world of the person living with chronic pain is primarily qualitative, philosophical, and reflective. Our pain is understood and spoken through our narratives, not numeric scales. Although these two perspectives are focused on the same topic, pain, they are approached, understood, and experienced profoundly different.

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1 Division of Oral Health and Society, Faculty of Dentistry, McGill University, Montreal, Quebec, Canada

Corresponding Author:
Richard Bruce Hovey, Division of Oral Health and Society, Faculty of Dentistry, McGill University, 2001 McGill College, Suite 537, Montreal, Quebec, Canada H3A 1G1.
Email: richard.hovey@mcgill.ca

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consultants, advisors, educators, advocates, or patient perspective partners. Our purpose and role are made explicit and so too are our contributions. Labeling persons on the other hand can be problematic; they narrowly define or run the risk of stereotyping a person, group, or communities. The label patient partner narrowly forgets that when outside of health care we are not patients at all; we are people who can make powerful, unique, and valuable contributions. Then, we can begin to co-create a well-defined sense of purpose and context as to why we are partners that all researchers and clinicians can understand and respect. Over time, with the right conversations and relationships, we will be able to engage better with our clinical and research partners not merely as patients but as people working synergistically together within a community of health care. This is a foundation of a strong research team in which we all belong and make valued and meaningful contributions.

**From Patient to Person-Centered Researcher**

The World Health Organization (WHO), at its 2009 World Health Assembly, declared for the first time person-centered care as a pivotal health-care strategy. This remains a central strategic principle, along with integrative and universally accessible care, in the WHO’s 2014-2019 Work Program. People-centered care is concerned and philosophically oriented toward people and their health experience, perspectives, culture, circumstances, and values rather than their diagnosis. This predicates a shift from labeling a patient as “fibromyalgic,” for example, to a person who lives with fibromyalgia (4). Fundamental to the philosophy of person-centered research is the careful development and active endorsement of productive relationships. It places an interest on the importance of relationships in bringing people from diverse backgrounds together to rethink and reorganize research teams by focusing on philosophies and practices of synergistic and relational research (4-6). This concept of person-centered research challenges our thinking to go beyond interprofessional and interdisciplinary research team models; as being a patient is neither a discipline nor a profession. An adoption of this person-centered approach finds a community of researchers, who as persons, all make unique contributions. With this shift, the possibility of mere inclusion (mandated) can move toward creating a sense of belonging that humanizes and supports all members as people. A fundamental concern for the development of person-centeredness integrated into research teams is awareness of and appreciation for the important elements found in the relational aspects of working together. These aspects include all relationships. This includes the relationship among the researchers themselves who may have different understanding about each other’s research methodologies (eg, quantitative versus qualitative paradigms) or are from different disciplines or specialty areas that approach research differently. These conversations, with persons living with chronic pain or other health conditions, in which we are invited to participate in research are fundamental to this person-centered relational process (2,9). The foundational and philosophical underpinnings found in this description of person-centered care can be modified and transferred to the development of person-centered research communities where everyone has a role, purpose, and are enabled to make valued contributions (7-9).

**References**

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**Author Biography**

Richard Bruce Hovey, BEd, MA, PhD, is an associate professor with the Division of Oral Health and Society, Faculty of Dentistry, McGill University. Dr. Hovey’s research utilizes philosophical hermeneutics and phenomenology to concentrate on bridging gaps among theories, philosophies and practices in healthcare, communities and individuals.