

A Reconceptualization of the Negative Self-Stereotyping of the Patient-Partner to the Introduction of the Patient Perspective Consultant

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ABSTRACT

The label of “patient-partner” is widely used when referring to a person living with a specific health condition that participates in research teams or consults on clinical practice guidelines. However, being a patient-partner says nothing about one’s potential role outside a biomedical context. Labeling a person as such can be detrimental to their perception of themselves. The intention of this paper is to provide a philosophical conceptual framework to understand the complexities and consequences of labeling people as patients outside of direct healthcare. A philosophical hermeneutic approach was used to explore how labeling and self-stereotyping can affect the patient-partner, leading to the possible erosion of their personhood. The authors suggest that research teams instead employ the more accurate and dignified term, “patient perspective consultant.” Accurate titles allow team members to relate to each other, leaving room for everyone to contribute meaningfully. The shift from patient-partner to patient perspective consultant does not change the nature of the role. It clarifies the context through increased accuracy, and adds dignity and purpose.

INTRODUCTION

Integrated within a graduate course on the philosophy of health for Master’s and PhD students, we explore a variety of related topics through our own experiences, interpretations and perspectives. Among course activities of learning how to interview, process data, and interpret and analyze data, we write a paper of common interest. This educational experience provides students with opportunities to explore their own and other people’s health situations using personal experiences, conversations, and transformative learning approaches.

The purpose of writing this manuscript is to provide a philosophical conceptual framework for a topic of common interest and perspectives reflective of current research topics: the meaning of being a patient outside of healthcare¹. Currently, the title “patient-partner” is widely used when referring to a person living with a specific health condition, such as chronic pain, who participates in research or consults on clinical practice guidelines and practices. Rarely do researchers and clinicians read outside of their discipline despite a growing amount of qualitative patient perspective

research, which would allow them to learn from the other such as the patient-partner. Consequently, taking up a topic about the possible negative effects of the self-stereotyping patient-partner with the potential for the erosion of personhood requires input from disciplines other than medicine, such as philosophy, psychology, disability studies and education.

BACKGROUND

We as human beings are always observing, reflecting and interpreting the world around us and always from the perspective of our unique ever-evolving experiences that form our lifeworld. As a person who is living with chronic low back pain from bicycling accident, a recent diagnosis of psoriatic arthritis, and even more recent diagnosis of advanced metastatic prostate cancer, I am frequently a patient. As the teacher of this course, my medical conditions are revealed openly for discussion that include both as an academic researcher as well as from a patient perspective. Through these diverse experiences and evolving perspective, my medical conditions provide a unique viewpoint that can be of value to researchers and clinicians. One viewpoint is to realize that being a patient-partner says nothing about my potential role in this non-medical context. It is limiting in so much as it leaves everyone at a loss of how to interact with each other. Researchers and clinicians have a much better sense of how to work together because of their related backgrounds, language, and understandings of the topic of interest. How do we even begin to describe the participation of the patient-partner other than knowing from their label that they are patients (that, outside of direct healthcare, they are not), and they are partners? This ambiguity may promote further negative self-stereotyping for the patient-partner as the divide between “them and us” remains perpetuated.¹

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The Role of the Consultant

If we think about the role of the patient-partner and the potential they can bring to research, we discover that their experiences, reflections, and perspectives can make valuable contributions to research and clinical practice because of the conditions in which they are continuing to learning to live with adversity and ambiguity. Over time, people living with chronic health conditions accumulate knowledge, experience, and skills to self-manage their specific condition, hence, they have accumulated a knowledge base to an extent even more than a medical student can be taught didactically or perhaps even imagined. This is the work of qualitative research: to provide insight into human conditions not yet experienced by others.

These appear as real-life examples or cases to learn from people who have first-hand experiences. There is certainly a positive trend to increase involvement of people with chronic health conditions in the health education sector as stated by the following: “The active involvement of patients in health professional education is increasing partly due to the recognition that patients have unique expertise derived from their experience of illness, disability or the effects of the social determinants of health.”² The word “consultant” seems a better fit as it describes in general terms how they can meaningfully participate with others. As a “patient perspective consultant,” the person living with their health condition, the researchers and the clinicians now have a common ground of understanding to how to work together. In this light, the word “patient” now has context as it refers to a perspective based on their experiences while in healthcare and explains that their role in this context is that of a consultant.³ This makes way for the development of positive self-stereotyping, because being a consultant is positive and can be supported by others on the research team. When we adopt the label of patient-partner into our sense of self, we may be negatively influencing the totality of our personhood.

Personhood in Context

Our personhood represents who we have come to believe we are based on all of our experiences, relationships and projections past and future. Personhood is understood to mean the totality of how someone perceives themselves, through their lived experiences and within the lifeworld they have created throughout their lives. Metaphorically, we can see this as the interweaving of fabrics of our lives based on experiences, family, culture, society, education, health as a multi-dimensional influencer, as well as the numinous relational encounters we have with other people within a diversity of life contexts. Our identity is, therefore, not a singular aspect representing self but a complex one that ebbs and flows as we find our place in the world. We can be a

mother, a father, a sister or brother, a student, a teacher, a doctor, and a researcher as well a multitude of other combinations. Who are we, one could ask; our answer is complex because it is contextual? At times, we are students, professors, researchers, athletes, educators, or artists, but most of all caring, empathetic and compassionate human beings, however, unfinished works in progress. As explored by White⁴: “In existential thought, characteristics of human personhood are innate and are to be discovered” (p. 83).

Exploring one’s personhood means to look inward into one’s self, reflectively and interpretatively. Students explore their sense of personhood at first by situating themselves in many different ways. Marie (a MSc. student) writes of her exploration into this activity. “The contextual nature of our identity means that seemingly contradictory aspects shine through in different situations. I might feel old in a room filled with undergraduates, but quite young at a retirement information meeting. I might feel very French in a room filled with Québécois, and very Québécoise in a room filled with French nationals. Yet, this does not make me partially French and partially Québécoise; my whole being is both French and Québécoise. This modularity, where bits and pieces are added and removed depending on our environment is a testament to the complexity of human identity. This may at first seem to be unrelated to our topic at hand, however, this is necessary to help ground oneself within their own life context, their personhood.”

Kristina (a MSc. Student) responds with a reflection provoked by a paper she read. “We are all people figuring out the meaning of our own personhood through experiences, self-discovery, and self-reflection. We have the right to define our own personhood thus mislabeling one’s personhood is simply unacceptable. Is the concept of personhood even articulated in the healthcare system? An article by Speraw,⁵ entitled “Talk to Me—I’m Human”: The Story of a Girl, Her Personhood, and the Failures of Health Care,” points out the moral failure occurring from health providers that focus solely on one’s disease rather than one’s personhood.”

Veeresh’s (a PhD student) reflections of being a patient are profoundly relevant, because he has lived his whole life requiring scheduled monthly visits for blood transfusions in healthcare. “Ever since the earliest years, I have grown up as “patient.” In India, I got diagnosed at the age of 6 months old with a genetic blood disorder known as “beta thalassemia major.” This condition requires regular blood transfusions to survive as well as it entails a poor prognosis. My parents were bluntly told that I would not survive beyond my first birthday. After visiting an expert hematologist in the city of Bombay, I became a baby trapped in

the healthcare system; I received a better prognosis of living to 7–8 years of age. Fortunately, today in the high-income countries, the lifespan is nearly “normal.” On this ongoing journey of parents’ concerns, doctor visits, and treatment centers, one’s personhood goes out the window, and labels such as “sick baby,” “sick child,” and “patient” begin to creep in. Hence, the “gnawing” at the personhood gets a head start from early childhood. Persons with genetic health conditions start seeing themselves and believing that he/she is a patient first and a person second. My question to all is, “Who is responsible for this?” Seeing one’s self as a person and making people see you as a person has tremendous positive impact on ones’ personality to achieve and realize dreams like anybody else in society. For that to happen is a process. If I need to respond to the question about how I took control of my personhood, I would say moving to Canada from India was the best thing for me, because first, the management of my treatment was regularized and that gave me hope to pursue my dreams of attaining a good education by attending college and university. After completion of my undergraduate degree, I was thrilled to work full-time for nearly 15 years, after which, I decided to return to school for my graduate degree and continued to pursue my PhD at McGill. These accomplishments give a person who faces health challenges a degree of normalcy with respect to the contribution one makes to the society, which in turn gives confidence and sense of purpose to life. Thus, helping to gain ones’ personhood defines us as well as completes us to face the world head-on.”

Ongoing Personhood

In life, we experience many encounters; some events are mundane while others can be extraordinary. We then reflect and interpret on how our lived experiences (sometimes with help) become interwoven into the fabric of our life and how they fit, or not, in our historical effective consciousness.⁶ This process of experience and reflection adds to our unique perspective on our life and identity. As such, we are the product of all our collective experiences, from childhood through to adolescence, to young adulthood, in middle age and older age. All these interactions within our life-worlds constitute our historical effective consciousness.⁶ These are the foundations of our personal narratives and stories, uniquely different than others but always adding to the greater narratives shared by many. Hence, the purpose of qualitative research is to offer insight into experiences that others may have not yet personally or professionally encountered. This hermeneutic approach to research and education offers the opportunity to explore meaning and context through conversation with metaphors as a useful way to make sense of complex ideas.⁷

“To be historically means that knowledge of oneself can never be complete. All self-knowledge arises from what is historically pregiven, our personal substance, because it underlies all subjective intentions and actions, and hence both subscribes and limits every possibility for understanding any tradition whatsoever in historical alterity” (p. 302).⁶

Understanding with the Use of Metaphors

The following from Marie demonstrated how she interpretively used a familiar metaphor to help explore new lived experiences. In this context, the metaphor of fabric and weaving is incredibly accurate for her understanding. Marie writes, “Natural fibers come from an animal, be it a sheep, alpaca or silkworm and have different properties depending on the breed, nutrition and environment of the animal. This fiber is entirely unique and cannot be exactly replicated. The fiber is then carded and spun into yarn and woven into fabric. The fabric that comes from that fiber is therefore also unique not only due to the fibers used, but the person doing the weaving.” Our experiences and identities are just as unique as hand-woven fabric from natural fiber. By ascribing generic traits to ourselves, we move away from our unique identity and toward self-stereotyping.

Historical Effective Consciousness

Every experience we have then becomes woven into our historical effective consciousness,⁶ meaning that our identities are vulnerable to the influence of others who may even unknowingly be eroding our personhood. For example, to diminish a person’s historical effective consciousness with being the label of patient-partner although they are members of a research team, along with academic researchers and clinicians may erode their personal attributes and accomplishments. Being an academic or clinical researcher or healthcare provider carries substantially more status than being a patient, partner, or otherwise. To be a patient-partner while in healthcare makes sense when a person with a health condition in direct contact with healthcare seeks to work closely with a healthcare provider. However, extending the label of “patient” beyond direct healthcare applications for a person who frequently must access healthcare, when participating on research teams or as a consultant for clinical practice, for example, is inaccurate.

Another way to understand the uniqueness of personhood is to view it as a horizon of understanding, expanding with each new experience. Our personal horizon refers to the depth and breadth of understanding we accumulate over a lifetime. For example, a young person begins life with a limited horizon of self and world but with time, events, reflection, experience and perspective, evolves an historical effective consciousness over time, wisdom of sorts.

This horizon is a metaphor for the range of vision that includes everything that can be seen from a particular vantage point.

A person without a personal horizon of understanding is unable to see far enough from what is close at hand and consequently over values that which is nearest to her. On the other hand, “to have a horizon” (p.302)⁶ means not being limited to what is only perceived as immediate but being able to see beyond it. This is a case of challenging the label of patient-partner. At first glance, we may not see a problem with this label because it is catchy and informs others that a different kind of partner is present. However, looking beyond this horizon (our discipline-specific horizon) of understanding, we learn that such labeling can be detrimental to how the patient-partner understands their own historical effective consciousness as experienced through their ever-evolving horizon.

Labels Matter

Being labeled a patient outside the context of healthcare is simply inaccurate. While sitting in on a research meeting, I am a patient perspective consultant, but not a patient. Given the importance of context in defining human identity as discussed above, ignoring context with the use of the “patient” label lacks the sensitivity, respect, and title-accuracy that should be afforded to any member of a research team. On the other hand, the word “consultant” comes from Latin *consultare*, which means “to take the advice of/to deliberate.” Essentially, people living with a condition are providing their advice and their own personal definition of that condition to the “experts” that add value that no quantitative scale can ever measure. This perspective will help the research team and its individual members broaden their horizons of understanding of the condition and thus come up with better rounded solutions to the issues at hand. The term patient perspective consultant leads to questions. Questions are a result of interest and curiosity.

We have learned from other disciplines such as community rehabilitation and disability studies a label is akin to stereotyping as it dissolves personhood to accommodate who? Patients are patients, not of their own volition, but due to external circumstances. Patient-partners, on the other hand, although they are part of the research project voluntarily, did not choose to become patients and certainly did not decide to make a career out of “patient-hood.” To them, the research group is not solely about a research project, but about a condition that they know intimately and that affects every aspect of their lives. To label patient-partners as such is to strip them of their life’s identity, complexity, and accomplishments and to only retain a single fact: that they are a patient. As Hovey et al.⁶ explains, “These narratives

add meaning to the person as a stay against only having a clinical-pathological understanding of what is happening to our body and as a person.” (p. 95).

Self-Stereotyping Personal Reflections

Veeresh offers his experience of being labeled a patient throughout his life. “Being born directly into the healthcare world, I am constantly referred to as a “patient” everywhere I go—hospital, school, work even in the comfort of my own home surrounded by my family and friends—I have this label woven into me. This leaves an imprint, a stamp on one’s mind. Am I this “sickly” person? Can I dream to have a life like others? The narrative needs to change and become context specific from a “patient” to a “person” to help diminish the possibility of a negative self-stereotyping.”

Marie adds her reflections on the effects of labeling on her experiences with PTSD. “I live with post-traumatic stress disorder. I have for over 13 years now, and it went undiagnosed for 12 years specifically because physicians I had seen didn’t want to label me as a “psych patient.” Two separate physicians diagnosed me with “highly situational depressive mood and anxiety” during those 12 years, both giving me a different version of “you know, so you don’t get labeled.” Both these physicians at least unconsciously understood the potential harm in labeling and self-stereotyping and tried to avoid it happening to me.”

Historically, self-stereotyping has been important in social psychology because prominent theorists thought that it was an unavoidable consequence of group membership. Conceptualizing self-stereotyping more broadly than is done today, they argued that being viewed a certain way because of one’s group membership undoubtedly should affect how individual group members see themselves. The modern importance of self-stereotyping stems from the functions it is thought to serve. Some researchers argue that self-stereotyping can translate into beliefs and behaviors that help support existing inequalities between groups in society. Other researchers argue that self-stereotyping fulfills the need to feel close to other group members. From this perspective, self-stereotyping is beneficial in that it creates a sense of group unity and solidarity. Research documenting other functions of self-stereotyping needs to be done.^{13,14,15}

Belonging versus Fitting In

Self-stereotyping occurs when someone’s belief about their own characteristics correspond to common beliefs of a group they belong to. One belongs to a group by identifying themselves with people with similar interests or similar characteristics. One can belong to many groups.^{13,14,15} However, labeling and placing people into groups leads to self-stereotyping. Self-stereotyping can influence how we

think about other people and how we think about ourselves. Self-stereotyping may lead to judgement and misguidedness. In the healthcare domain, people living with a condition are placed into categories and are often referred to as “patients.” What connotation do you get from “patient”? What synonym can you derive from “patient”? Is it healthy for one to believe that they are a “patient”? Is someone a “patient” because they had an experience with the healthcare domain?¹ Do I become a “patient” because I need stitches from cutting my finger by accident when making a salad?

Self-stereotyping in its most positive sense tends toward creating a sense of belonging, or as Gadamer would say “feeling at home.”⁶ This is shown in studies looking at self-stereotyping for sororities and fraternities.⁸ This perspective, although truthful and valid, is not accurate in the case of patient-partners, because association with such groups is voluntary, unlike living with a chronic condition. A sports team fan or a fraternity member associates with a sports team or fraternity by choice and can shed the emblems (clothes, jerseys, hats, etc.) associating them with those groups should they wish to disassociate from them. A chronically ill person cannot shed their chronic condition.

A recent personal observation from Richard (teacher) explores positive/negative self-stereotyping while attending one of his recent frequent visits to a hospital observed positive reinforced self-stereotyping with a group of surgeons. “During a medical appointment [Pre-COVID19], I was waiting in the hospital’s cafeteria. I watched as a group of three people arrived for lunch wearing scrubs, surgical hats, with face masks dangling below their chins. Over the next 15 minutes, several others appeared, all wearing more or less the same uniform. Not one person in this group took off their hat or masks (these were turned to one side) while they ate their lunch. This was a positive display of a group identity, an example of positive self-stereotyping, because being a surgeon is a socially constructed positive stereotype with status and prestige.”

Another observation on the same day was from a (my personal) patient’s perspective. In this case, I was a patient because I was there for medical examinations and/or treatments. In a waiting room, where men and women sit patiently in their underwear covered by a robe that never seems to fit properly, risking the exposure of some random body part, we endure. I realize it is a necessary indignation to facilitate the medical examinations that follow. The self-stereotypical patient accepts this temporary ignominy for a greater cause, their health. However, once I leave the hospital, I am no longer a patient. This does not mean that I forget about my experience because it adds to my sense of personhood, however, it should never replace it.

The experiences described above touch on a phenomenon described by Latrofa et al.⁹: when individuals belong to an

ingroup that is stigmatized or threatened within a larger group, they are more likely not only to identify with the characteristics of this ingroup, but also act in ways that showcase these characteristics. For patient-partners within research teams, to be labeled as patients is likely to both have them describe themselves as patients outside of healthcare more often and adopt stereotypical behaviors and characteristics of patients, even outside of direct healthcare.

Usually, where a large group of similarities are involved, stereotyping is an easy way to label the group (e.g., in a hospital setting). When persons with a certain condition, such as “thalassemia,” get labeled as a “thal patient” instead of “persons with thalassemia,” we begin to see ourselves first as a patient than a person. This negative self-stereotyping happens in a sub-conscious way, and we start seeing ourselves first as a “sick person” than just as a “person.”

Erosion of Personhood

The patient-partner title remains obscure, inaccurate, and potentially harmful to the people who have been given this label.¹⁰ “The loss of personhood happens within medical sciences when the individual patient is objectified in terms of a mere multiplicity of data. In a clinical investigation all the information about a person is treated as if it could be adequately collated on a card index. If this is done correctly, then the relevant data will all uniquely apply to the person involved. But the question is whether the unique value of the individual is properly recognized in the process. In other words, are we treating the patient partner as a member of the research team with insights just as valuable as the researchers, or as a subject to be studied to generate data?” (p. 81).

Gadamer¹⁰ speaks to the incongruity of referring to individuals as “patients” outside of the healthcare context. He speaks to the push and pull of, on the one hand, wanting to fit in and in doing so, flattening our individual identity, and on the other hand, knowing and affirming who we are and our unicity as individuals to identify what we need to feel at home. He explains that to “sustain our internal balance” (p.81) between fitting in and feeling at home, we must find our place and purpose in the world and our community. In other words, patient-partners may accept this label as an attempt to fit into the research team, but in doing so, shrink their identity to fit into what is expected of them and forgo any hope of feeling at home and purposeful within this very team. Without a clear definition of one’s role in unfamiliar situations, one might feel unsure of expectations of themselves and others, creating a kind of participation paralysis.

In the context of health research in which recruitment of patient-partners is deemed necessary for a specific project, the label patient-partner becomes affixed to the person

holding that title. To be given access to the research group, the patient-partner must accept the label and integrate it into their own identity. In this context, they are no longer a person offering insight into a patient perspective (a consultant); they are a patient, even outside of healthcare. They are altering their personal identity to fit the requirement of patient-partner and thus, according to Gadamer, moving away from “feeling at home” and closer to “fitting in.”¹² Without a title that names their role, like researcher or healthcare provider as clinicians, the patient-partner title remains vague, not only to the patient-partner, but to all the other team members.

CONCLUSION

We took up the challenge of confronting the label of “patient-partner” outside the context of healthcare to prevent negative stereotyping and the erosion of personhood through offering a straightforward suggestion of a title change to “patient perspective consultant” within research teams. We believe it is important for researchers, clinicians, and everyone else to widen their horizon of understanding by being aware of the work done in other disciplines regarding the harmfulness of labels. This work is the result of decades of research and serves as a building block for allowing people to belong:

“Research has shown that when people become engulfed in the client or patient role, it is difficult for them to see their own capacities and strengths. People are robbed of their power and trapped in their passive roles. The focus on needs within a deficit framework is one of the ways our society constructs vulnerability.”¹¹

Consciousness of being affected by history is primarily consciousness of a hermeneutical “situation.” To acquire an awareness of a situation is, however, always a task of particular difficulty. The very idea of a situation means we are not standing outside it and hence are unable to have objective knowledge of it. We always find ourselves within a situation and throwing light on it is a task that is never entirely finished.

The shift from patient-partner to patient perspective consultant does not change the nature of the role, it clarifies the context through increased accuracy. It also affords patient perspective consultants the respect and dignity that is afforded to the other members of the research team. The steps involved in materializing this change will

help foster awareness and thoughtfulness of working with people from outside our discipline. ❖

Authors' Contributions

Richard B. Hovey, BEd, MA, PhD, conceptualized the content of the manuscript, provided original content writing, drafting, editing and participated in the critical review, and submission of the final manuscript. Veeresh Pavate MEd, Kristina Amja BSc and Marie Vigouroux BA participated in the development of this manuscript by providing original content writing contributions, researching and reviewing relevant literature, actively edited and drafted the final form of the manuscript for submission. All authors have given final approval to the manuscript. No funding was provided for this study. All authors declare that they had no competing interests.

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