

Data, theories and metaphors: primary healthcare research through art, relationships and science

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Introduction

Thank you for the great privilege to address today the community of researchers and partners from the Centre for Primary Health Care and Equity during this Annual Forum. As a medical doctor specialised in Preventive Medicine and Public Health, it is a real honour for me to give the 2019 Ian Webster “Health for All” oration.

Before I go any further, I would like to show my respect and acknowledge the Bedegal people who are the Traditional Custodians of the Land, of Elders past and present on which this meeting takes place. I would also like to acknowledge the contribution that indigenous populations make to modern societies in three countries that have shaped my life: Australia, where I now live with my family; India, where I experienced some of the most defining moments of my life; and, of course, Canada, where I was born in a remote northern community.

When Mark Harris asked if I would accept to give this oration, I felt humbled. I accepted but did not expect how hard it would be to prepare for this. After a few days of excitement, I started to realise I had no clue what to say. Of course, I had lots of scientific material but, really, what was it that I wanted to communicate? Doubt and a certain amount of fear go through your mind as you prepare for something like this. For weeks I have now asked myself why? Why did they ask me? Why did I say yes?

Talking to Mark about it a bit later helped me find a thread. Maybe I could talk about the conceptual models and frameworks that seem to emerge along my path, as I conduct studies on primary care and healthcare systems? This comforted me as I have always been fascinated by theories, concepts and definitions. And Mark knows how obsessed with words I am. This must be a topic that would interest anyone, right?

For once, I could have an audience other than my family, friends and colleagues, who are tired of hearing me explore the intricacies of defining words, such as access and accessibility, performance or even data and metadata, but also going on about scientifically measuring the attributes of crème brulee and the real

meaning of the words fruit and vegetable. Don't ask me about this last one, it is a very long story. Little did I know, however, how much I would learn researching for this talk. Mark, you have contributed to my obsession with meaning in a way you cannot imagine.

I have always wondered why I got so interested in concepts and theories. And I truly cannot really remember when.

I have had the blessing of being the last kid of a family of four, a lot younger than my siblings, born in a remote community on the north eastern shores of the Gulf of St-Lawrence on the Atlantic Ocean. This is the kind of upbringing that gives you a lot of time to read and the harshness of the weather creates an isolation quite conducive to introspection. Is this where I got the passion for access to healthcare?

My brother, many years older than me, studied philosophy and anthropology, and the books that I found in his big trunk included many of the literature greats that have influenced me. As you can imagine, I was odd at school in my choices of books and topics for essays, especially in the social context of a mining and fishing village in the north eastern part of Quebec, south of Labrador. Early on, I wanted to work in Africa.

Did playing ice hockey from the very young age of four made me interested in understanding teamwork and how teams achieve higher levels of functioning? Could skiing the backcountry hills of the North influence me to want to consider context into my future studies?

Did my classical guitar training shape any of my papers on primary care reform?

Or was it David Bowie's conceptualisation of his own persona that drove me towards theories and concepts?

I wondered if me ending up travelling to India instead of Africa during my medical studies brought a sort of mystical dimension to my career. Could my focus on equity be coming out of these days providing clinical care to tribal settlements in mobile clinics in south India?

How did I end up many years later being asked to talk about the concept of intersectionality at an international conference whilst I did not even know the term? Only to realise whilst reading about the concept that my interest in inequity in access for vulnerable people and the cumulative disadvantage they experience was already intersectoral in nature.

Many questions, many many questions...

These musings somehow got to some answers. And some of these answers will serve as the basis for my talk today. I want to take this opportunity to discuss the interplay of data, theories and relationships and how concepts and theories contribute to science. Using examples coming out of my work in primary care, I will advocate for an increased use of theories to guide empirical studies and empirical foundation for the construction of theories in primary care. I will argue that some metaphors can guide our use of concepts to avoid some pitfalls in the creation and dissemination of knowledge in primary care and, as I will argue, there is a bit of art in all this as well.

Before I continue, let me quote Richard Wagamese, an Obijwa author from my country of birth.

“Knowledge is not wisdom. But wisdom is knowledge in action. I command a lot of facts. I comprehend a lot of concepts. That does not make me wise or even intelligent. It just indicates what I have memorized. But when I activate those facts and concepts to find the greatest, grandest version of myself, and then use them to work toward that vision, I begin the process of wisdom.”

Part 1 - concepts and theories to guide empirical research

The most obvious relationship between theories and data lie in the structure that concepts and theories can give to the analytic process. Theories enable better measurement and study of complex realities. This is important for various reasons.

First, we tend not to be able to measure everything, and we do not know what the impact of unmeasured factors on analytic results is. Second, whilst empirical analyses demonstrate in a rigorous way the association between different variables, these associations can only be interpreted within the context of previous empirical findings and through the recourse to frameworks to assess their internal validity. Third, whilst many studies have rigorous qualitative or quantitative analytical processes, the fact that they are only a partial view of the universe of potential results greatly limits their external validity without the capacity to assess limitations and impacts of context on the findings.

Early in my career, following a first small scale descriptive study of anaemia and Tuberculosis amongst Tribal populations I conducted during one of my clinical rotation in South India (Africa had to wait), In my first

formal study, whilst working as a clinician at the refugee clinic in Montreal, we looked at the factors associated with the acceptance by refugees of the Tuberculin skin test and their subsequent acceptance of treatment for latent tuberculosis infection using the Health Belief Model, published by Rosenstock and colleagues in 1950. We tried to explain why we had difficulties in bringing asylum seekers to our screening program.

However, the studies that most significantly influenced my use of concepts and theories to guide empirical assessments of primary care reform were those conducted under the mentorship of my dear colleague Raynald Pineault. Under his guidance, I learned to use Donabedian, Barbara Starfield and Donna Safran's conceptualisations to understand utilisation and experiences of care, functionalist theory to look at organisational models and configurations, and institutionalisation theory to assess system transformation as demonstrated in this study protocol framework we published in 2010.

This happened in a series of population-based and cohort studies between 2003 and 2012. The "accessibility and continuity" study, the "evolution" study and the "MaChro-1" study were highly empirical

studies where statistical analyses were subjected to conceptual scrutiny.

Using a conceptualisation of primary care organisations as a foundation, looking at the vision, resources, structures and practices elements, we developed measurement tools to assess the experience of care, organisational attributes and contextual factors that would influence primary care reform in Quebec province.

Through a series of complex configurational analyses, ascending hierarchical classification and multilevel regression models, the studies we conducted over the span of ten years demonstrated the various impacts of primary care reform.

Developing a taxonomy of models enabled us to assess the level of conformity of new models of care with best-practice attributes of primary care and the collaboration and integration of care at the regional level. It also enabled us to discuss how the new models of care were in fact all the same or if there was heterogeneity in how they had implemented the reform. In reverse, we demonstrated that some organisations not part of the new models of services delivery were in fact already working like the best performing models.

We also demonstrated improved accessibility and continuity of care, increased capacity of primary care providers to manage complex patients without involvement from specialists, and, as illustrated in these two graphs, better management of chronic illness, with group practices and specialist clinics demonstrating lower chronic care management scores compared to Family medicine groups and the taxonomic models describing the new models of care.

These studies also demonstrated a limited impact on utilisation of care, emergency department presentation and hospitalisation and, unfortunately, negative impacts on equity, with the very poor seeing a deterioration in their level of affiliation with primary care, even in new models of primary care delivery.

The complexity of analysing an entire reform of primary care, with the changes in the overall configuration of care affecting the local dynamic of provision of care, population coverage and equity, required a strong conceptualisation to guide the multiplicity of associations between variables in order to find policy insights.

Even the most complex multilevel configurational analyses needed to be tested against not only the previous empirical findings on the topic, but also the

foundational theories coming from other fields of inquiries.

This also enabled us to lead cross-provincial syntheses of reforms and provide a qualitative and deliberative synthesis using the same conceptual frameworks and aligning the findings of disparate studies in a unifying analytical frame.

Part 2- developing and assessing theories with empirical data

In addition to needing concepts and theories as the foundation of our thinking and measurement, we also need empirical findings to inform, test and refine existing theories and, at times, to develop new concepts and theoretical foundations based on the observation of real phenomena through scientific methods.

When I started my PhD, during my fourth year of medical residency, I wanted to build on my first experiences in research. Still wanting to go to Africa, I ended up taking up an amazing project to study equity in access to health care in urban areas, based in the state of Kerala, in South India.

Through these studies and the guidance of Louise Potvin, Andre-Pierre Contandriopoulos, Pierre Fournier and Slim Haddad, I got seriously interested into the seminal theoretical work in sociology, economics and organisational theory. Reading Rawls and Amartya Sen introduced me to the concepts of capabilities and equity in opportunities.

One of the works I got interested in was actually a novel, Zen and the art of motorcycle maintenance. In that book, the protagonist struggles to define quality. In reality, quality is a neutral word that simply means the attribute of something. But it is a complex word because people have given it a meaning that emphasizes only the good side of it. When we use quality as a word we use it to mean good quality, not bad quality. Like the hero of this novel, who was obsessed in defining quality with motorbikes engines and was constantly dismantling and reassembling engines to improve quality, it is difficult for us to define quality, but we all know when we see it.

I took on such a challenge with access to health care. A construct that is understood by everyone but a challenge to define. I, in fact, started to measure access before I really had thought about what it was.

Trying to get out of quantitative data the complexities of equity in access to healthcare in urban slums and more formal settlements of South India proved to be a challenge, and full of limitations. Even though we found that physical access to care was already limited for the very poor, the very sick, and those living in towns with limited public availability, one of the realisations was that we were not capturing the true reality I was observing.

This framework was published in 2013, around 10 years after embarking on a PhD course and five years after having defended the thesis. It came out of the triangulation of data, literature reviews, synthesis of theoretical frameworks and, indeed, many discussions and debates with colleagues, especially with Mark Harris and Grant Russell, co-author of this work, and Slim Haddad and Jeannie Haggerty.

Paradoxically, the framework emerged from an empirical thesis, demonstrating all the limitations of the published work. But it also emerged from these limitations.

After finishing a PhD, you often need some rest, if not literally, at least from your thesis work, literary. It took me a long time to get back to the work and complete the framework, its justification and developing the

narrative that, I think, as made it a successful framework. Its contribution is really to have combined the healthcare seeking process, at the centre, with the reflexive relationships of services attributes at the top and people's abilities at the bottom, and demonstrating key factors enabling or limiting access at each steps of the journey. One of its limitations, its simplicity and linearity compared to the real complexity and recursivity of access to care, also helped to make it useable.

Part 3- conceptualising research process and relationships

I have presented in the previous two parts the direct relationship between conceptualisations and theory and empirical data. These are obviously the most obvious relationships in the triad that I have elected to talk to you about today. But interestingly, there is increasing evidence and expressed needs to also look at theoretical contribution to the actual process of creating research and in influencing relationships and behaviours in healthcare systems. There are, for example, increasing calls for calls for theory-based clinical assessment, innovation and improvement.

I would like to look first at a recent research process that I had the chance of being part of, called the Sorento group. This project aimed at reanalysing and synthesizing the results coming out of 10 Primary Care Reform Projects Conducted in Australia, Canada and the United States. The projects were diverse, had various objectives, no common measurement framework and combined both quantitative and qualitative perspectives. The objective was not just to synthesize the findings from these studies, published in the literature, but to reanalyse the data with a new common objective. Small task across such a diversity of projects across three countries.

Following a series of preparatory meetings, the team of experienced research went on to design a process to achieve what we felt was a unique form of mixed method reanalysis of data. Building on existing synthesis, action research and deliberative frameworks, we basically designed the collaborative reflexive-deliberative synthesis approach. This approach includes a series of look backs at the published studies, refining, organizing, interpreting and integrating the findings in iterative steps. The notion of blending the experiential knowledge of researchers, whom often have accumulated knowledge that go

beyond the studies included in the synthesis, was core to this approach.

This approach enabled us to look specifically at Teamwork across 10 studies that did not purposefully intend to look at teamwork but somehow accumulated significant material that was relevant to this topic. The collaborative reflexive-deliberative approach to generate new knowledge that would reveal various commonalities and differences with regards to reforms of primary care in various countries. Somehow, this approach really shaped our relationships and created a very strong international primary care team that evolve into the IMPACT team looking at Innovative Models Promoting Access to Care Team.

The second example relating to research methods and how theories, or meta-theories, could contribute to relationships relates to some recent work I have had the opportunity to conduct with my colleague Kim Sutherland. Through two recent publications, one on lever of change in health care and one on unwarranted clinical variation, we have used a rigorous synthesis approach to develop meta-theories that build on a series of previous conceptualisations. These meta-models aim to put together the right model, the right

theory, for the right problem, based on existing theories or empirical findings.

In the unwarranted clinical variation example, we used a systematic review process, followed by a deliberative classification and coding system to gradually classify studies and distil the common threads and diverging aspects that they were providing on the underlying concept we were after.

The result was a simple framework, with strong internal consistency that emerged from previous models. It outlined both unwarranted and warranted clinical variation, based on the actual relation of the care provided with needs of patients, preferences of professionals, elements of context or even changes in the evidence-base in the field. This was our way to evolve a specific conceptualisation, and the associated at times simplistic measurement approaches.

We do hope that we built on the shoulders of giants. This work, we argue, is strong from a conceptual perspective but simple in representation so that it can influence change at the clinical level by supporting a process of assessment of clinical practice.

Discussion - empirical theories and metaphors

In this presentation, I have tried so far to illustrate various utilisation of theories and concepts in interactions with empirical data, highlighting how theories should be the foundation of good analyses and how insights from real world analyses should in return support the refinement of theories and concepts. This even in a field like primary care, which has not traditionally seen a lot of conceptual work compared to other fields of science. Or is it health services research in general which suffers from a relative lack of theoretical work and has a few static theories not regularly challenged by empirical analyses, syntheses and meta-analyses?

I have also tried to illustrate how conceptual work can actually also provide some foundation for how we act in research and in trying to influence behaviours in healthcare systems. These two other perspectives are important because of the increasing realisation that there is massive waste in healthcare and in healthcare research.

Many interventions aiming at improving primary care practice, I would argue, are poorly conceptualised, often adopting study design that try to eliminate the potential impact of context and human behaviours

whilst the reality is the context and the fit of the intervention with or its impact on human behaviour is actually what will create the effectiveness of the intervention. In healthcare research the question is not so much “does it work” but instead “where and for whom does it work”. Not too dissimilar to the way Indigenous cultures conceptualise meaning and being.

The waste in research also, I would argue, require recourse to conceptualisations and theories to support the appropriate syntheses of existing knowledge and a way to fill the void left by the lack of measurement of context and organisational factors that may be important but undocumented. I have argued that some methods, such as the reflexive deliberative synthesis approach, can enable to generate the meta knowledge in primary care that we need to guide the reform process.

Being both a decision-maker, through my work at the Agency for Clinical Innovation, and a researcher in primary care and more broadly healthcare systems, I have witnessed also the power that a good conceptualisation can do for the translation of research into practice, both policy and clinical practice. And it’s really about translation, if not through co-creation but, let’s face it, clinicians and decision makers need to

learn from many more studies than they can participate in, so translation is needed from researchers from many more studies that they have been able to lead or be part of as well.

Having a strong framework to discuss about research with clinicians and policymakers is key for good knowledge brokering. Without a strong understanding of theory, all these facts, statistical associations and findings are just chaos, randomly or even inappropriately put together to assemble a narrative which lacks wisdom. This is especially true because we don't measure all aspect of life in limited research studies.

This has also come clear to me through witnessing how the access framework I had developed through my PhD studies in India became used. I am very proud that the paper has now been cited in more than 600 academic work and has been used in hundreds of real improvement projects, especially in primary care and for vulnerable populations. I have not found yet a study that has demonstrated the relevance of all dimensions of the framework and people still contact me to give them the measurement tool which would capture all dimensions of the framework (I can tell you this does not exist).

However, when I recently looked at the coverage of the conceptual framework through their combined contributions, these studies are increasingly validating the dimensions and components of the theoretical underpinnings. Furthermore, they illustrate how certain component have not been represented correctly has part of the visual representation of the framework. If it is true that an image is worth a thousand words, I will argue that sometimes you also need a thousand images to convey the complexity of a single word. How can access to healthcare be represented by a single figure? Let's not confound the visual representation of a theory for the actual theory.

Whilst you can see that I advocate for the increasing use of theories and concepts in both research and practice, I will end this talk with some advice and words of caution. My interest for theories has also drawn me to analyse and question the actual use of theories, not just the lack of recourse to theories to support critical thinking and action. That is where art comes in!

To provide this advice, I will use a few metaphors, using a simple theory combing colours, size and position.

The first metaphor I will use is the ghost. A ghost is defined as an apparition that is not real. In a similar fashion, conceptual or theoretical ghosts are often appearing. You think you see something but it's not there.

This is what happens if we cite a theory but do not really use it to guide our studies. The study is theory-based in name only and its true essence is not what its representing to be.

The second one is the monster, or in this instance, the Frankenmodel. This is what happens when people are trying to combine in a single model, elements that come from various models or theories but mixing them in a non-coherent way.

The model ends up being made of disparate body parts that do not really fit together. When conceptual foundations are concerned, picking and choosing what fits with our goals amongst different theories and ignoring other components of these theories that do not quite fit with our aims may end up creating confusion.

The third metaphor is the Zombie, or in this case Zombie ideas, defined as ideas that have proven wrong but refusing to die.

In my experience, theories are there to guide us especially when their precepts are contradicting what we're trying to demonstrate. Using a theory by name only is cold comfort and, ultimately misleading, since people will attribute to the study a much stronger rigour and validity than what was claimed by naming theories as part of it.

In a similar fashion, Frankenmodels often emerge from the fact that certain theoretical aspects end up being poorly measurable in reality and therefore we end up picking from various conceptualisations the easily measured elements, even though they all provide a partial view and combine them. Zombies are often ideas that serve a purpose but should not be confused with theoretical frameworks.

When theories are proven to be wrong, we should be able to put them to rest. But often, they survive because it is unimaginable to challenge them.

To finish on a more positive note, I would like to use the metaphor of sustainability and the cycle of use of products to emphasize some of my rules in terms of conceptual foundations. I'll talk here about the 3Rs: reduce, reuse, recycle.

We need to reduce since, sometimes, we do not need a new model, and resisting fads with new names

should guide us. I still use some theories from the 1950s that are still very valid. Indeed, some of my work on equity was based on readings from the Greek antiquity.

We need therefore to reuse and ensure that as a collective we learn to use these conceptual underpinnings to our studies. We need to go back to the classics, old and new, and at times repair the antiques to be able to use them. Sometimes they just use words that have somehow gone out of fashion but are still perfectly good to convey the meaning intended.

At times however, we need to recycle and build on existing models to create a new use for their fundamental principles. To a great extent, I feel that this is what I did with the access model where I systematically scoped the literature to understand what access was, compared it to empirical findings, and tried to reshape existing models with the influx from theories from other fields of study. So, whilst I built mostly on the work of Penchanski and Thomas and Frenk with regards to access, the framework was also a redefinition of their coherent framework with the perspective of Sen and Giddens.

To come back to Objjwa wisdom, I encourage you to use concepts and theories, knowledge, for the purpose of action, in research, in practice. Primary care practice and primary care research are complex fields. We're not talking about studying inanimate matter here, were talking about human interactions, complex systems with autonomous actors and moving parts. Adopting some common frameworks is key to make sense of all this, despite the invisible parts we can never fully measure.

In terms of research, we need to make it multidisciplinary, inter-disciplinary and transdisciplinary because of that complexity.

Building these transdisciplinary relationships also requires you to understand the language that academic general practitioners, sociologist, anthropologists, economists, will speak, and the assumptions that guide their methods and interpretations.

The fact that I travelled so much somehow may explain why I pay so much attention to language, to meaning, to culture. Translating this attention to details and applying the rigour of concepts into day to day practice or research is not easy.

I know that I have not picked an easy topic for my talk today, but I thought I had to stay true to the passion

that Mark insightfully identified could be my topic. Please forgive me for raising these challenges and opportunities to make theories work with data and people.

We often use words without truly paying attention to the fact that they may not be interpreted the same way by people hearing them. Understanding the meaning of words and rigorous use of concepts to support communication and real use of knowledge remains a challenge part of human interactions. It may require courage and the task at hand is almost heroic.

But, even in research, we can be heroes, if only just for one study, for one day.

Thank you.