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Más allá del pensamiento abismal, hacia las teorías generales de la salud: Aprendizajes del COVID-19

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## Dedications

I dedicate this work to all the healthcare professionals from all the various systems of health that are engaged in bridging improved health services and seeking how to best serve those most in need and vulnerable.

## **Conflicts of interest**

No conflicts of interest to disclose.

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Quito, marzo de 2023

Deleh

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#### Abstract

My growing restlessness as a biomedical doctor drew me to anthropology, and to the study of labels in the COVID-19 pandemic health spectrum, so I may start understanding the complexity of health care beyond my clinical work. In this study I conduct field work at 4 distinct sites, with the methods of interviewing, focus groups and participant observation. The physical sites included Pano, a Kichwa town in the Ecuadorian Amazonia, at AMUPAKIN a Kichwa midwife-led health center near Pano in the Amazonia, and in Santa Rosa, a village in the coastal province of Santa Elena in Ecuador. The fourth site was my online and in-person exchange with biomedical doctors as part of my volunteer work during the pandemic. I use the key theoretical frameworks of Naomar de Almeida Filho and Boaventura de Sousa Santos, and Eduardo Kohn on the unified theory of health, invisible realities in knowledge and the form of being respectively. The result is multiple tables summarizing the prominent themes from the COVID-19 experience narrative of the general public in Pano and Santa Rosa, the midwives at AMUPAKIN and the biomedical doctors I encountered along my journey. Also, a summary list of labels weaved across the theory of health of Filho are uncovered, showing multiple examples of invisible realities, and highlighting the severe shortcomings of biomedicine in the rural areas of Pano and Santa Rosa, and the successful health response encountered in the Amazonia region in Pano and with the midwives.

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#### Introduction

Two strikingly different experiences in the Ecuadorian coast village of Santa Rosa, and the Amazonia town of Pano, highlighted how an invisible reality of community response in COVID-19 can be successful, when equipped with its own resources and a medical system that can replace a failed biomedical one in crisis. People in Pano of the Kichwa tradition had their plants and their network of health mobilized and served all those that became ill, similar to the experience of the midwives nearby to Pano in AMUPAKIN. Meanwhile, biomedical doctors also made significant advancements and exercised creativity in helping the patients they got in the clinics and hospitals, despite the lack of clarity and guidance that was offered to them. These were the key findings that the study set forth on labels in COVID-19 health conditions emphasized.

This thesis study I embarked on was a result of multiple interests, personal journeys, professional preferences, intriguing books and a series of encounters that led me to accept my chosen theme. I did not intend on studying labels, I had not even seen any medical research on the theme before joining anthropology, but it made the most sense after I witnessed the diverse signs and symbols including language, that people used to refer to things and events.

In Chapter 1 I laid out how I initially started wanting to conquer challenges that several generations of medical social scientists have been faced with in addressing the inefficiencies of the dominant biomedical health care model in making people healthier and happier—an interest that sprouted during my early years in medicine. This conquest soon enough seemed too large, and I realized after several courses of anthropology, that my contribution to the field needs to be precise and well situated. At the same time, I was noticing several trends in how people were referring to COVID-19 (the pandemic, the virus, the covid...) as the pandemic hit, and was encountering studies that showed the impact of the name of the disease or health condition on the outcome of the patient's health. Meanwhile, theories of health, and writings on cognitive injustices and the invisible forms of knowledge were my growing focus in my electives of anthropology. These all combined to create my questions for the study: what are the labels of health conditions relative to SARS-CoV-2 and across the various levels of healthcare? Where are they found? Who are they made by? All these questions were of course using a lens that defied generic definitions of health and knowledge.

Chapter 2 is where I achieved two tasks combining a description of methods and additional theory. The first task was the description of where my study happened and with what methods particularly. My study was done across two provinces in Ecuador, one is the coastal Santa Elena, and the other is the Amazonia Napo. In both these provinces I studied specific patient and community illness experiences in Santa Rosa and Pano. In Archidona, Napo I studied the work of traditional Kichwa midwives. This allowed for a contrast of two very different populations, a Mestizo and an indigenous group, each with their own qualities. My study also had a virtual component. I integrated my everyday experience in medicine as a physician virtually working with a non-profit organization during the time of my thesis and conducted online literature reviews surrounding COVID-19. My methods included of course ethnography, participant observation, focus group discussions and semi-structured interviews.

The second task was more complex and sought to further refine the framework within which I would collect and analyze my fieldwork. In this second task I introduced another set of concepts, mainly the fields of semiosis and form as presented by Eduardo Kohn. I chose to keep these concepts or theories for the second chapter, with the methods, because semiosis and form appealed to me as tools with which I connected the fieldwork to the grandeur theories on abyssal thinking, and health definitions in COVID-19, ultimately finding the invisible. Form and semiosis helped me make sense of the vast information I received during my fieldwork, and their inclusion was a turning point in my thesis work. It was through these tools that I was able to understand how I could study labels outside of the hegemonic biomedical system and begin to trace the invisible realm I became so intrigued by.

In Chapter 3 I presented a comparative summary and analysis of the field work done amongst the Santa Rosa and Pano communities. The multiple excerpts from patient interviews, and daily encounters, along with the descriptions of the communities' reality during the pandemic, were used to create a summary of the key prominent themes during my fieldwork in COVID-19 health conditions in each of these 2 sites. As I looked into these themes in closer detail and applied the tools of semiosis and form, asking myself what it was that these patients and communities were trying to know or knew about the pandemic health conditions, I arrived at a set of unofficial labels. These labels were ultimately the recurrent references I observed in both or one of the communities. These labels allowed me to compare and contrast what people in Santa Rosa and Pano went through early in the pandemic. Indeed, both communities did not use conventional terms, like COVID-19 infection, in any of their narratives or daily life. Rather, they both had adapted labels that were familiar to them in suffering of the body to reference how COVID-19 impacted or changed their health. People used descriptive labels that could make sense of their past and their present and forecast their future. No new biomedical labels—in labs or medicines reference—were being used and the label hospital became a heavily negative symbol in both communities, reflecting the scarcity in biomedical resources available to them and the poor reliance on biomedicine for help in the pandemic.

Meanwhile, the main differences in labels that were found included: in Pano, a Kichwa rich community, people had labels for plants and pandemics in both the Kichwa and Spanish language, and those labels carried a very positive notion of strength and resilience. They provided a vocabulary of hope to the people in Pano, and reflected a reality connected to previous pandemics survived by their Kichwa ancestors, which defied the prominent narrative in Ecuador at that time (May 2020) of death and weakness. Also, people in Pano still had a semi-operational public clinic and health care providers available, more so than in Santa Rosa and that contributed as well to the more positive experience in Pano.

These key differences and similarities between Pano and Santa Rosa offers a great connection to the next chapter 4, that provides the comparison and contrast between the Kichwa midwife healer experience and the professional doctor experience and the labels that arose there.

Chapter 4 is divided into two parts. Part A addresses the Kichwa midwives' process of confronting the pandemic highlighting introspective methods (as individuals and a group) to understand the new reality, the recollection of knowledge transmitted from their ancestors on infectious diseases that spread rapidly, and their own individual expertise acquired through their years studying select plants. Even though labels defining the SARS-CoV-2 health conditions were not prominent in their narratives, there was a rare term in Kichwa that came to surface during the pandemic, *Eikulumarzo*. The most prominent labels in the midwives' work during the pandemic were those that defined the types of medicinal treatments offered to those trying to prevent or treat the virus.

Part B of Chapter 4, offers the biomedical doctors' narrative knitted from experiences with doctors from various countries and backgrounds of practice (private and public system). Their narrative was one very familiar to me given my background, and described how commonly

used conventional (ICD) labels that classified COVID-19 were made, and what additional labels were being drawn up by the doctors. The narrative also highlighted the challenges of practicing the right and up-to-date biomedicine amidst a novel pandemic. The biomedical logic did not allow for quick and extrapolated (based on other pandemics) conclusions on how to manage the COVID-19, and hence, many experimentations were ongoing, both officially (as research) and unofficially (individual doctors testing their theories on patients).

With these 4 unique COVID-19 experiences—the Pano public, the Santa Rosa public, the Kichwa midwives and the biomedical doctors—the final chapter 5 is a conclusion. Labels, I asserted, are modes of classifications for shared experiences and important signs that carry value of specific ideas and concepts. The way of making and the content of labels were essential to examine since they revealed the disconnection in modern medicine, where misunderstandings and infodemic prevail and biomedical terms inappropriately dominate.

Based on the narratives of chapters 3 and 4 I then extracted the key labels and weaved them together within the unified theory of health by Filho, with its various circles in disease-illness-sickness and normal, private and social health. Through this exercise I concluded that official disease labels relating to the SARS-CoV-2 were dominated by the biomedical model investigating the virus in labs and fell short in supporting healthy communication across the biomedical health care professionals and between the doctors and their patients. Moreover, COVID-19 became a feared term (for stigma or self-concern purposes) and was avoided in patients' recollection of their illness.

A diverse number of labels describing illness and sickness existed in the patients' and families' narratives but none of those were utilized by public health or biomedical professionals to facilitate understanding of the pandemic to the communities; a sort of invisible reality lies here. Also, plants and caregiving were an important source of labels in Pano and with the midwives, and these resulted in an overall positive and resilient outlook in the narratives offered by the individuals; another glimpse of invisible realities in health is offered here.

A final note on the forms in which Kichwa midwives and biomedical doctors process knowledge and multiplicity is presented. I was unable to identify many labels for how Kichwa midwives go about their diagnosis and management of patients with COVID-19—other than the term *Eikulumarzo* which was inherited from their ancestors that experienced similar pandemics. I came to learn it has to do with their different form of doing medicine, and from my unrealistic expectation that I could find a dictionary of terms that defines the work the traditional midwives do.

We, the biomedical and medical anthropology communities, have much to learn of the invisible realities shaping medicine and health, whether in resilient or isolated communities or advanced traditional medical practices.

#### 1. Chapter 1. An Anthropology in Health

In this first chapter, I guide the reader through an appreciation of why and how I have selected the study of labels in health conditions using the SARS-CoV-2 experience as my lens to explore widely diverse debates in modern medicine. Modern medicine is a knitted assembly of epistemologically distinct modes of practice in health care. The lens of SARS-CoV-2 labeling allows me to highlight select distinctions, while relating them to a medical humanities reality and study. Labeling health conditions is an increasingly examined field. Thus far, investigators have mainly focused on uncovering what kind of impact a label can have on a patient condition and their health outcomes. Labeling in health conditions is not only about the label of the disease itself. Labels in health can be studied more amply when we adopt ampler theories or understandings of health, like that presented by Naomar de Almeida Filho, and which can then be related to the conceptual framework of Boaventura de Sousa Santos on Abyssal Thinking modes.

#### 1.1. Anthropology as Medicine for my Medical Practice

Let me begin through offering a short self-critique on my personal journey in medicine and anthropology. This critique is meant to provide the context to the questions of the thesis and to demonstrate the internal and practical struggle that many modern physicians are going through.

Soon after working as a full-time physician, I felt a growing restlessness within. Perhaps it was more of an uneasiness. My journey in biomedicine so far included 6 years of an accelerated medical school, 1 year of personal investigation through travel and righteous volunteerism, 4 years of specialized training and 2 years of working in the academic and NGO world. I was certain anthropology would help me find my medicine for this new restless uneasiness I was experiencing.

The practice of Western biomedicine taught by books and in lecture halls seemed incomplete or insufficient for the care I was looking to provide my patients with. Of course, I encountered numerous straightforward clinical problems that biomedical education had prepared me well to handle. These straightforward problems were ones with well-defined acute symptoms and signs and effective curative treatments for them. Examples are: certain rashes, infections (skin, respiratory, gastrointestinal, urinary, sexually transmitted...), certain bumps or growths on the skin, bone fractures, inflamed tendons and many other acute conditions.

However, many (if not most) patient problems carried a more profound complexity, even when the presenting symptoms fully resolved. A complexity that could be due to various reasons: long-standing disease with multi-organ pathology, or poorly defined and understood disease (from a biomedical perspective), or a lack of curative treatments. Examples of these are diabetes, high blood pressure, chronic back or knee pain, fibromyalgia (a condition of diffuse body pains), and irritable bowel syndrome (a condition of chronic abdominal intermittent pains and irregular bowel habits).

These more complex, common health conditions require models of care that are flexible, patient-centered and holistic. Their pathophysiology theory and reality are also continuously being re-examined to better understand and describe them and their treatments. Their management also often requires a knowledge on nutrition, psychology and an acknowledgement of a patient's cultural, social and spiritual context. Biomedicine falls short here. Physicians are not equipped with sufficient skills beyond understanding the pathophysiology and medicinal treatments. Several of my mentors during my early years of study were cognizant and vocal about biomedicine, and steered me towards exploring other system practices of medicines as summarized next. This search into other systems may have instigated some of the restlessness I described above, since it allowed me to entertain the possibility that other ways of doing medicine are possible.

First with regards to biomedicine, several classifications exist for differentiating between the various modern medicine modes. Biomedicine refers to the medicine that is based on biology and physiology frameworks. The Western conventional biomedical mode is not truly the only biomedicine practice in modern day, since several other branches have arisen, such as functional and anthroposophic medicine, which also base their methods on biology and physiology theory. However, for the ease of reference I use biomedicine to refer to the Western conventional biomedicine. It is noteworthy to mention here that this type of biomedicine is often referred to as the scientific evidence-based mode since it requires that all the methods involved in it are proven by rigorous gold standard research, where all the conditions are controlled, except for the intervention under study.

Second, non-biomedicine systems are ones that apply various frameworks, including metaphysical theories in health, and at times even biological and physiological. Non-

biomedicine is a slight misnomer, when we consider that biology and physiology are not limited to the science of the dominating academic institutions, but can also include those studied in ancient systems—however, this is another debate. The non-biomedical modes are quite variable and dissimilar, and are classified in multiple ways. The WHO (2018) typically refers to this category as the traditional and complementary medicine (TCM). They recognize that there are traditional ways of practicing medicine upheld by local healers and in less common instances traditional institutions (like with Ayurveda, Unani and Traditional Chinese medicine). They also recognize that there are increasing complementary approaches to biomedicine. For example, sound or music therapy despite not being explained physiologically, they are accepted as valid modes of complementary treatment that can be added on to the set biomedical treatment, since they have demonstrated effectiveness in studies. Yoga, acupressure, myofascial release techniques are additional examples.

Meanwhile, the classification or label of alternative medicine is at times apparent in academic western literature to denote the non-biomedicine treatment chosen to replace the biomedical option (be it sound, music, oil, herbs or other). For ease of reference, I refer to traditional, complementary and alternative medicine, as simply, the alternative medicine.

Third, and a relatively new system is the integrative system. With the growth of the nonbiomedical repertoire of techniques and methods, the biomedical institutions are already adapting to this reality. There is growing interest in integrative medicine, which is considered a blend of biomedicine and non-biomedicine that has been tested to some extent using the biomedical research techniques, even if occasionally not fitting the biology and physiology epistemology theories of biomedicine. The leading institute in North America on integrative medicine has been the Weill Center in Arizona, which has developed curricula for biomedical healthcare professionals, so that they may integrate their knowledge with popular complementary techniques. The questions remain, is this truly integration? Or is it epistemological and cognitive domination? Can different modes of medicine be merged?

Since I started exploring the above systems, I have incorporated into my biomedical practice select and compatible non-biomedical techniques. I received training in cognitive behavioral therapy and motivational interviewing, and turned to fields like mindfulness meditation, pranic healing, and Ayurveda (a form of medicine originating from the ancient Vedic sciences of present-day India). These changes I made to my clinical practice were meant to better connect me to the individual patient. As I made these changes and pursued these alternative paths, I became overwhelmed by the growing scientific literature in this field, and the quantity

of data to study. There seemed to be hundreds of ways to heal and accompany people in their journeys to health.

I began to increasingly see my role as a healer doctor; one that can listen and activate a sort of symbolic response in the patient. We, in biomedicine, often speak about how to better engage patients with their medical treatment. However, we are far from understanding the spectrum of this science of engagement (beyond motivational interviewing) and how it may impact patient health outcomes. From one perspective, the engagement of patients with their treatment (be it a pill or an exercise) has been studied as a placebo effect at times. I was amazed one day when I read an article from 1985, "The Doctor as a Placebo", which considered the doctor as a drug and studied how different doctors had varying effects in their patients when they prescribed the same medication! (Clyne 1985) More recently, the placebo effect has been more accurately and precisely considered as a "meaning response" that is activated in patients (Moerman 2022).

The range and vastness of medicine, especially in the understudied or less known themes of it, such as the placebo and meaning response, inspired me. I decided to keep engaging with alternative medical systems and my own foundation in biomedicine in search of—some sort of—bridge (at the level of the patient or provider). A bridge between the growing forms of medicine of the 21<sup>st</sup> century. This bridge would facilitate useful exchanges for advancing in medicine without prejudice to the dominating epistemology.

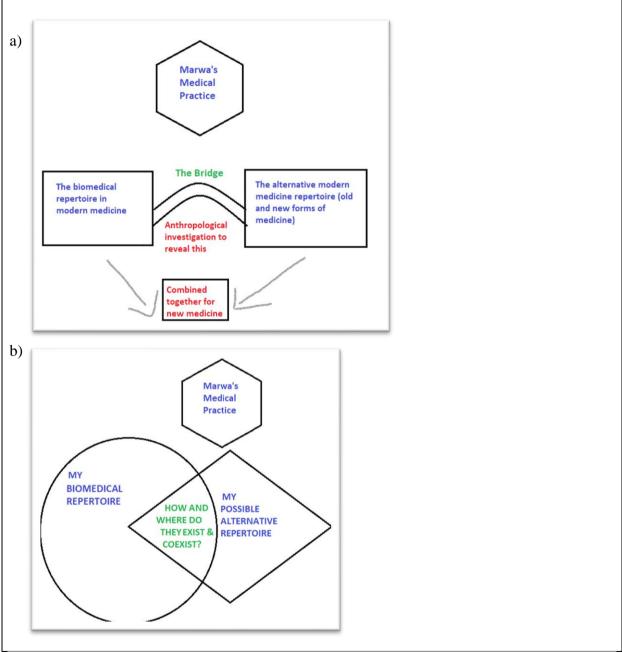
This is how and when I came to anthropology. Initially, I looked to medical anthropology to find that bridge between the diverse practices I engage with.<sup>1</sup> In the figure below I illustrate what I was seeking in anthropology as a novice student. The figure shows boxed types of medicine that were accessible to my clinical practice, with a traced bridge between them (Figure 1.1.a.).

After a few months studying anthropology, it became apparent to me that this theoretically constructed bridge was an illusion, an imagined utopia for medicine. A bridge would mean the roads of each medical system would have to meet somewhere, and in most cases the

<sup>&</sup>lt;sup>1</sup> Medical anthropology is a subfield particularly interested and involved in the debate over modern medicine, not only epistemologically, and ontologically, but also in the day-to-day practice. In the early days of medical anthropology, there was a focus on the traditional, often native and indigenous, exotic modalities of medicine, and certainly, the field has undergone similar waves as has the mainstream anthropology department. They have similarly flown through frameworks of evolutionism, relativism, functionalism, structuralism, perspectivism and post-waves of all these (Sobo 2004). So, what initially started as a subfield dedicated to the study and dissemination of native medical systems marginalized by national conventional systems, has become a more critically oriented field, along with medical sociology certainly, that criticizes hegemonic processes of research, education and practice innate to the biomedical system.

systems I was interested in had very different epistemologies, making a bridge irrelevant. I also realized that I must first learn to ask the questions that open up to the complexity, rather than simplify and standardize the practice of modern medicine (as I was trying to do by learning additional alternative practices). This realization led to a state of mind or framework in my investigation depicted (Figure 1.1.b.).

### Figure 1.1.a My medical practice framework and pursuit of anthropology preanthropology and 1.1.b. My medical practice framework intra-anthropology



Source: The Author

The boxed, rigid and memorized repertoire, opened up to different shapes, and somewhere in their irregular shape they met in Figure 1.1.b. They—the biomedical and alternative—could

never fully coexist in my own medical practice, since their form was not compatible, however, they certainly could converse and exchange and perhaps even coexist or flow differently in the lives of patients I intersect with. This is the mentality with which I entered my fieldwork investigating themes in medical anthropology, which I describe next.

#### 1.2. Labels in health conditions of SARS-CoV-2

When the SARS-CoV-2 commenced in December 2019 globally, and locally in Ecuador in February 2020, my focus of study became clear. I knew that I wanted to study intersections in diverse health care structures throughout the pandemic, stemming from my own base of biomedicine, so that I may address more grandeur debates in healthcare reform beyond the biomedical model. Here, by health structures, I am referring to the healthcare levels that Arthur Kleinman categorized as a useful approach to serve inter-modern medicine study (Kleinman 1986).

He identifies three levels or parts where healthcare is constituted: professional, folk and popular. The professional is the formal sector of healthcare delivery, and typically is equal to the conventional Western biomedicine. In certain countries the strong traditional systems if formalized into national health plans can also be considered professional, like Traditional Chinese medicine in China and Ayurveda and Unani in India. In most countries however, when these latter non-western biomedical practices are present, they are grouped into folk healthcare, along with other traditional or alternative medical practices. The popular level is the healthcare practiced inside homes and orchestrated by the lay family members and neighbors or friends.

I knew that I would study the pandemic across healthcare structures, but I still needed a specific theme to focus that study. A theme that was already being investigated across the healthcare structures pre-pandemic, and the pandemic may provide new insights or perspectives on it. So, I decided to study: the global labels of health conditions involving the SARS-CoV-2 at the various healthcare levels, the underlying processes involved in generating these labels, and the potential impacts of the virus labels on people's lives. This is to say, I will be using the case of health labels, official and unofficial, through the pandemic experience to highlight essential lessons and findings that may contribute to the active debate on how the distinct medical systems of the world are fitting together or perhaps, not fitting within the global health system.

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#### 1.3. What are Labels in Health Conditions?

Labels are codes, names, phrases and, or descriptions, which we use to classify experiences in order to facilitate communication, understanding and exchange. Labels in health conditions are consequently references to the normal and abnormal states in human health. They are multi-purpose, and are generated to define or describe experiences in health. In most instances, labels in health conditions are generally understood as diagnoses, which are terms that are meant to specify the illness, disease or sickness in a patient.

These diagnostic labels are prominent in the health reality given their multiple uses. First, they are used internationally by health institutes and other biopharmaceutical groups that aim to study diseases and their pharmaceutical treatments. They also provide frameworks for healthcare professionals (doctors, nurses, lab technicians, etc.) to study, learn and communicate patient conditions, which makes them able to provide appropriate treatment and contribute to organized research in biomedicine. Meanwhile, patients depend on labels to form their own frameworks in health, understand their condition implications, search for treatments across the health care levels, and seek support from fellow patients with similar diagnosis. Communication between patients and healthcare professionals is also facilitated by sharing an understanding of common labels in naming illness, disease or sickness (Sims et. al 2020).

Most of the research on diagnostic labels—summarized in a recent study protocol led by Rebecca Sims (2020)—asks questions on how labels are used and understood in biomedicine, and the implications of that. The main conclusion that can be drawn from such studies is that there is no conclusive answer on whether diagnostic labels are mostly beneficial or harmful; it always seems to depend on the context and diagnosis. Diagnostic labels can be ambiguous and confuse the patient, when the medicalized term is applied but no accompanying descriptive explanation is provided. Diagnostic labels can also lead to stigma and discrimination against patients, especially with mental health, infectious and pain conditions, and can affect how patients sees themselves. In this sense, labels can cause bad health outcomes when patients' health complaints are dismissed due to the connotations of a certain label (for example, a patient with chronic back pain, having a potentially threatening and new complaint of pain dismissed by their healthcare team). Meanwhile, labels can help validate a patient's experience or reality, and be a way of organizing solidarity in health suffering. Diagnostic labels, the predominant form of labels in biomedicine, have a recent history in global health. Nosology, the branch of biomedicine specifically dedicated to classifying disease, creates diagnostic labels for old and newly discovered health conditions. A joint task force at the WHO leads the most prominent global effort to standardize nosology, through its model of classification, the International Classification of Diseases, ICD. This task force—formed of experts from countries of the Global North mainly—reviews the pertinent scientific advancements, publications and reports (by conventional medical institutions) and generates their recommendations for new labels or revised old labels.

The idea for an international classification system originated in the 18<sup>th</sup> century through the work of various scientists, mainly statisticians, that wanted to standardize causes of death, so that they could track trends in mortality and assess impact of interventions. By the 19<sup>th</sup> century the classification had grown to capture a large proportion of diseases beyond causes of death. The international institute of statistics consisting of representatives from North America and Europe led the process and content of the classifications. By the time the WHO took over the responsibility of classifying diseases, most of the foundation and structure of the ICD was done. So, the ICD system was clearly driven by a western biomedical model of care.

The WHO in its 11th version of the ICD in 2019 included, for the first time, nosology based on traditional medicine from Chinese, Japanese and Korean medical systems (WHO 2021). This certainly goes along with the WHO attempt to recognize the diversity in modern medicine and include other non-biomedical systems. However, this step remains far from sufficient in empowering a plural-health system.

Furthermore, the ICD is criticized for being too pathologically driven, too medicalized in its terms, thereby not reflecting the reality that healthcare professionals face in their work. When patients complain of signs and symptoms, which do not fall into a clear pathological diagnosis, the professional struggles with classifying the disease for themselves and the patient (Jutel 2010). Hence, the ICD system despite being useful for epidemiologic purposes, remains inefficient or inappropriate in the practical sense of labeling in medicine.

Alternatively, there are other initiatives to label health conditions by pharmaceutical industries, such as the MedDRA, Medical Dictionary of Regulatory Activities, which aims to create coding systems in medicine to facilitate research and reporting globally. These labels here can be even more technical than ICD and less pertinent in the clinical setting, creating a further dichotomy between the theory and practice of biomedicine.

#### 1.4. What are Labels in Health Conditions Beyond Regulatory Classifications

Labels, I resolve, are classifications of health-related states. The entities generating regulatory diagnostic classifications have very specific priorities—epidemiologic and public health mainly—and address a limited reality of the health experience. Other priorities arise when the state of health is considered from the patient, community and healthcare team level. What needs to be or is classified can go beyond the ICD-like systems.

Physicians' priorities for generating labels include: guidance for the medical practice and, or research, facilitation of communication with colleagues, and providing patients with adequate explanations on their conditions. The medicalized (made medical or very technical) terminology in ICD-like systems, serve the first two priorities of physicians. However, the latter priority is not served by ICD-like systems alone. Physicians resort to a sort of practical lingo for addressing the spectrum of the human health experience, beyond a dichotomy of normal and abnormal states. In this practical lingo ICD terms can be used outside their standard context to serve a cultural purpose of understanding illness; like telling a patient they have arthritis while the ICD official diagnosis should be chronic knee pain based on diagnostic criteria. Or non-ICD terms can be used as diagnostic labels, like labeling the illness as, too much sun exposure, rather than heatstroke.

Meanwhile, the global general public constituting the patients, do not have an ICD-like system or medical classification repository that captures labels in health. The closest attempt in creating such a repository can be found in medical humanities, in the theories and models in patient health experiences: "the Health Locus of Control theory, the Explanatory Model, and the Self-Regulation Model" (Haller et. al 2008). In these we find a review and analysis of the descriptions, symbols, signs and terms made and used by patients in representing their health condition. These include personal, cultural, societal and biomedical components, and at times align with the structures of healthcare described—the folk, popular and professional.

For example, in the explanatory model, the semantic network map is used to compare patient health experiences and generate models for specific ICD disease patterns like depression or diabetes. However, the main criticism with explanatory models is that they are primarily centered on an acceptance of ICD systems in labels as the only valid ways to describe health. This allowed reductionist health explanations to prevail, even from the patient perspective. Explanatory model exercises can limit how patients can define or label and consequently see their health. Post-structuralist and post(post)-modernist movements in social sciences commonly make such criticisms, and advocate for individual patient health narratives that respect and recognize individual complexities avoiding disease-specific modelling.

From a non-biomedical perspective and in the region of Latin America, the social sciences (medical anthropology most prominently) have contributed to the popularization of controversial labels, promoted as folk illnesses (such as *susto* and *nervios*). These folk illness labels have even made it to recent editions of the WHO ICD document, where they are classified within the non-biological non-physiological labels, indicating diagnoses that need to be managed psychologically or with culturally competent approaches. Such handling of folk illness labels as diagnostic labels is potentially dangerous, since it undermines the patient experience and the health systems of select populations with their respective epistemology and nosology process. Such labeling also assumes that the biomedical center has understood the entirety of folk illness theory and reality, which is very far from the truth. Folk illness reality remains a mystery to biomedicine.

So, there are two types (at least) of labels in health: One is a standard, official, professional, and scientific-proclaimed side that is primarily led by a biomedical-oriented system using mainly medicalized, diagnoses with codes to serve an industrial, epidemiologic purpose. The other type(s) is less concrete and investigated; it is dispersed and blurry, though we know it exists since we have seen its traces in the standard labels, and in the social science investigations into theories of health.

Hence, an investigation into labels of health conditions must be mindful of both these known and less-known types of reality in labels.

#### 1.5. Where does this leave my original proposal to study labels in health conditions

With the data presented so far on labels, I could focus on the obvious, which is assessing the role of SARS-CoV-2 and COVID-19, diagnostic labels, in the health beliefs and outcomes of people. However, such a study would employ too much reductionism in labels and implies acceptance of the dominant ICD system as sufficient labels. It also would go against my original proposal to study the intersections of biomedicine and non-biomedicine practices and engage more inclusive perspectives in health.

So, I will opt for a study on all labels, which is likely to be: incomplete at best, chaotic and unintelligible at worst. This study searches for more precise references to health relating to the SARS-CoV-2 pandemic. Though my search will not be restricted to biomedical

institutions, it will still be limited by my humble abilities as a biomedical physician and student anthropologist to imagine where labels or references in health during COVID-19 times can be found. Also, though I seek primarily pandemic-specific data and references, but I will not ignore the history and context which accompanies the relevant pre-pandemic time and may come up during my study.

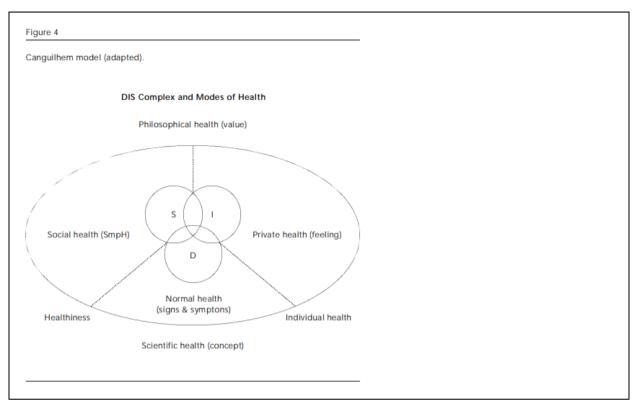
In brief, this study focuses on the following questions: How and with what do we label good health, and bad health, illnesses, diseases, and sicknesses potentially relating to SARS-CoV-2? Are there unlabeled processes or officially unknown labels in SARS-CoV-2 related healthcare that biomedicine should consider labeling? Is labeling always relevant or pertinent in classifying or knowing health during COVID-19 pandemic times?

First, what is health? Better said, within which context does my handling of the term health so far fall into?

#### 1.6. Semantics of Health

The WHO defines health in its constitution as the "state of complete physical, social and mental wellbeing, and not merely the absence of disease" (WHO 2021). The three states of physical, social and mental do not exist in parallel or independently but are rather intertwined. The translation of the WHO definition into a wholesome and practical application for the individual and collective human experience is challenging, both in health and social sciences. Several attempts have been made at piecing individual components of the health definition in practical terms. Very few works have attempted to address the whole definition. The work of a pioneer epidemiologist and public health scientist and physician, Naomar de Almeida Filho, is one example of this.

Filho (2013) in his work "Towards a Unified Theory of Health-Disease" brings together medical science, social science and philosophy in proposing a complex application of a definition of health. He argues that health is a compilation of several components that have been mistakenly assumed to individually represent the whole of it. This misrepresentation often promotes biomedical hegemony epistemologically and ontologically, and a review of a more wholesome theory of health that is non-ontological and multiple is possible. In Figure 1.2., I reproduce the representation of this wholesome health complex from the original text of Filho.

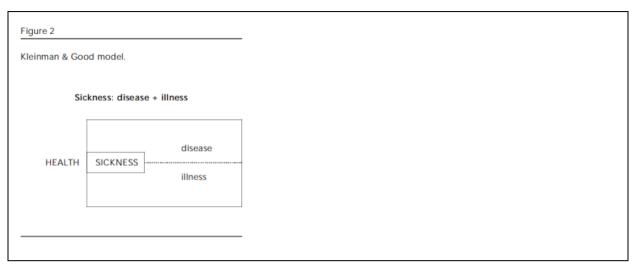


## Figure 1.2. Filho's adapted health model from Canguilhem, encompassing components previously unmentioned (Filho 2013)

Source: Filho (2013)

First, Filho demonstrates how the disease-illness-sickness (DIS) complex is placed at the core of an understanding of health but is certainly not all of it. The original proposal of the DIS complex came by Good and Kleinman (Figure 1.3.)—who developed it with an intention to show health beyond just diseases and consider the other spectrums of suffering in health that patient experiences across cultures demonstrate. Their depiction of the complex in Figure 1.3., highlights disease as the biomedical diagnosable state opposite to normal health, illness as the detectable state lacking health per individual measure, and sickness as the socialized personal suffering and experience in each of the illness and disease processes.

# Figure 1.3. The health models of Kleinman and Good depicting health vs. disease, illness and sickness (Filho 2001)



Source: Filho (2001)

Previously, the DIS complex was considered to be sufficiently encompassing a theory of health. It was enough to contemplate DIS to understand health, since it considered the individual, the scientific and the social aspects to health. However, with the mapping offered by Filho, the complements of the DIS are made apparent. Consequently, illness is to private health, what disease is to normal health and sickness is to social health.

Considering the DIS and their complements at play allows for a more complex epidemiologic model in health. This model is further refined when the philosophical, scientific, individual and public modes of health are considered. The philosophical mode of health is the fluctuating value placed and given to it, and which overlaps with the social and private dimensions. The private, is how individual experiences along with normal states of health create within us an interior notion of being healthy. The scientific mode is what academics and scientists (of biomedicine predominantly) tell us about health, and that is received by the various sources of journals and social media, and ultimately approved by the disease diagnosing doctor. The public health or healthiness is the mode denoting social health and intersections with normal health that happens on a national scale typically and is delivered.

Social health is a crucial aspect to highlight for the purpose of the proposed study. Its definition was mainly advanced by Bibeau and Corbin into the "system of signs, meanings and practices of health" (SmpH), which considers health beyond the "curative practices". This system aims to understand the communities' sphere of "symbolic production, corporal, linguistic and behavioral signs [which] are transformed into symptoms of a given illness,

acquiring specific causal meanings and generating social reactions" (Filho 2013, 9). Social health recognizes notions of health that are beyond the pathological, biological and physiological. It also potentially serves to identify labels in health conditions from specific populations' perspective, beyond the biomedical model as I established above.

The point of my summary here on Filho's theory of health is to overcome my simplistic use of the term, health, and to stimulate an appreciation in the reader for what the term represents. Filho, as an epidemiologist inspired by the call to cognitive justice, is keen to develop a complex computational model that can be fed diverse inputs to produce clear health outputs (Filho 2013) (Santos 2007). His work is an interdisciplinary project in health modelling, capable of synthesizing up-to-date conclusions in multiple fields within a single map given the full health definition it pursues, beyond the mere absence of disease.

Also, with such a renewed and ample theory, my original question on the pursuit of labels in health conditions is resituated within a web of concepts and multi-dimensions whose sum defines health.

So, are labels witnessed across this web definition of health? How does this web contribute to my proposed study of the SARS-CoV-2 labeling processes? Are labels synonymous with anything Filho and the cited social scientists in his work describe?

Yes, this enlightened frame is still consistent with my initial questioning of: how and what do we label in good health, and bad health, specifically illnesses, diseases, and sicknesses potentially relating to SARS-CoV-2? Are there unlabeled processes or professionally unknown labels in SARS-CoV-2 related health care that biomedicine should consider labeling? Is labeling always relevant or pertinent in classifying or knowing health during COVID-19?

I have already presented labels as known standard regulatory classifications, and unknown yet possible forms in classifying health. The revised health definition by Filho now demands that I approach fieldwork mindful of all that the term represents. It demands that I avoid reductionist conclusions solving health problems, especially since I am not approaching a single, defined dimension or aspect, but rather brushing across the various interfaces in health. The known popular labels (ICD primarily) fall in the disease and corresponding normal health dimension that is more easily discerned. Meanwhile, the possible labels fall within the social and private dimensions of health, and their complements of illness and sickness.

Additionally, despite that these labels do not overtly show up, identified as such, in the analysis by Filho, however, his scheme of depicting health is all contingent on classifications;

recognizing the social, the public, the individual, the normal, the scientific, etc. He has, in simpler terms, labeled the various dimensions within which health is done. He has also agreed with a classification of the DIS complex, and consequently labeled its complements into social, normal and private health. With this overarching classification model of health, my investigation into labels within the SARS-CoV-2 is best situated.

Now that I have outlined the field of health and labels making it more familiar, a question persists on how an unknown label can be made known. How can health professionals and healers pursue the study of unknown labels, since I have highlighted it as possible? To understand this, I refer to the inspiring discourse that introduced me to approaching unknowns in medicine, such as labels, and which Filho in his cognitive justice pursuit also draws on in his work; the field of abyssal thinking by Boaventura de Sousa Santos.

#### 1.7. Abyssal Thinking

Santos (2007), a leading sociologist, from Portugal, with most of his work based in and learnt from the Global South, has rewritten theoretical models in epistemology for 21<sup>st</sup> century social science. These models are set in ecologies of knowledge, specifically epistemologies of the South, and explore cognitive injustices as a way towards social emancipation. Health and social science discourses benefitted from drawing on his non-traditional analysis and language, which allowed the inclusion of the non-conventional, non-Western perspective (Noronha, Meneses and Nunes 2019).

The main paradigm I draw upon from Santos' work for confronting the unknown labels is his modern abyssal thinking concept.<sup>2</sup> With this, Santos models the empirical foundation of Western thought. He uncovers the cognitive injustices that absentmindedly reoccur and allow the control of knowledge processes in academicians and scientists of the Western system.

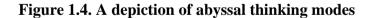
What is abyssal thinking? Abyssal thinking is the resulting dominant mode of thought, based on hegemonic Western (global North) cognitive practices, and the consequent cognitive injustices towards global (South) systems of knowledge. In it, information received—on law and science—is interiorized and digested in a way that does not allow the imagination of

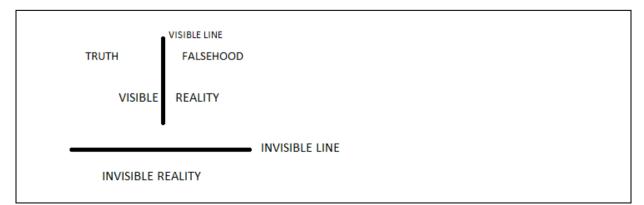
<sup>&</sup>lt;sup>2</sup> Certainly, Santos is not the only social scientist that has approached the topic of modern ways of knowledge and highlighted their deficiencies and shortcomings in acknowledging and incorporating other ways of knowing. Similar concepts to abyssal thinking exist from scientists like Bruno Latour and other post-modern enthusiasts. However, I choose to work with Santos' method of presenting this modern thinking since it complements the theory of health framework, I have taken by Filho as the next chapters will show.

anything beyond what is already known and accepted by the Western method of knowing. Abyssal thinking consequently becomes essential for the maintenance of the mainstream Western epistemology and ontology. We—as Western trained scientists and physicians almost intuitively find ourselves in abyssal thinking modes given the way knowledge is taught to and produced by us (Santos 2007).

How does abyssal thinking work? Abyssal thinking functions along a set of designated—by the modern person, scientist or other—lines, which can be visible and invisible. These lines have come to exist through two mechanisms. One, through the operation of current popular knowledge paradigms, we see the clear visible line arise between truth and falsehood. Two, through an intentional neglect of other possible paradigms through history and modern day, an invisible line arises that separates the permitted visible reality from the veiled, invisible, yet possible reality. The invisible line is difficult to comprehend since it is asking us to submit to an unknown, "non-existent" set of possible realities that do not align with Cartesian modes of visible line thinking we have grown familiar and accustomed to, and which epistemologies of the South movements try to go beyond.

Figure 1.4 is an illustration inspired by Santos' description of abyssal thinking. In the figure I attempt to demonstrate how the lines and realities, truth, and falsehood, and known visible and unknown invisible are entwined. With this depiction an understanding of an unknown is made tangible. The subtle existence and function of the unknown as a base for creating the platform of the known is made clear. The ability to easily differentiate true and false forms in knowing science is a result of a visible line that is held up or maintained by the neglected (possible) multiplicity in knowing beyond the definite truths and falsehoods existing in the unknown forms.





Source: The Author

Summarizing the prominent way of knowing in science offers the foundation with which we may approach necessary revolutionary changes in our thinking processes. In the medical sciences we can appreciate this in that conventional Western medicine revolves on an abyssal thinking mode that is ready to be revised. What is and is not good medicine functions along a visible line whose method is the laboratory biomedical and clinical research.

This research constructs a visible reality where we can clearly say what is true and false, with nothing in between—even though the truth and the visible line constantly change in medicine depending on the more recent research. The invisible realm in medicine is increasingly pursued by social and medical scientists trying to expand our ways of knowing of health. It, the invisible medicine, is also potentially accessible through the non-biomedical systems that I have presented earlier. Specifically, the way of knowing in alternative medicine can enlighten processes of knowledge that the mainstream global medical science production group is leading—with the university and pharmaceutical groups.

Invisible medicine is also the topic, or the pursuit made by multiple authors inspired by Santos and include the work of Filho presented earlier, and Susana de Noronha. Noronha presents through her own artistic monographs an exploration on knowing the health of patients by patients, a typically less recognized form of knowledge or knowing. Noronha's work presents an example from the growing movement searching for missing descriptions in health and its medicine (Noronha 2019).

Furthermore, the resurgence of ancestral and older medical systems evident through national policies and select academic investigations, particularly into herbal medicine, is evidence of the possible invisible realities that are waiting to be adequately acknowledged in the visible realm. Interestingly, their invisibleness is a product of the same systems that are now promoting their research and resurgence.<sup>3</sup>

To attend to such invisible realities in health and its medicine, it is crucial to continue accumulating and highlighting examples of invisible cases. The idea behind exploring the invisible reality of medicine here, is not to invalidate or disprove the current visible practice in the field, but rather, to explore the possibility of other knowledge that may improve the current design of global health systems. Let me outline an example of invisible labels that emphasize the relevance of undertaking a study of (specifically) labels in SARS-CoV-2. This

<sup>&</sup>lt;sup>3</sup> This is in reference to large academic centers in biomedicine that are now searching for herbal cures to designate as new biomedical treatments, through the study of several departments, such as ethnobotany and phytochemistry.

example will highlight how even in the labeling of conditions there is a hegemony and opportunity for identifying abyssal thinking modes.

The example involves the case of folk syndromes, such as the commonly debated *susto*, *nervios* y *mal de ojo*. The recognition of these illnesses or disorders were neglected by leading authorities in global health for years. They were dismissed as some psychological cultural dysfunction (Nogueira, Mari and Razzouk 2015). Through the works of anthropologists that looked into the experiences and realities of these health conditions, the existence of the suffering or sickness of patients was validated. This led to an official global health label in the ICD realm—with titles such as Problems associated with cultural factor—that accounted for the symptoms patients with folk syndromes experienced (ICD 2020). This is certainly not enough for recognizing a once invisible reality, but it is an eye-opening experience into the transition of knowledge across the set lines Santos describes.

This highlights the point in how Western biomedicine can miss, overlook or even be dismissive of non-conventional medical realities. There is an impatience with the methods of knowledge in the unknown realities to biomedicine. This impatience in understanding or appreciating the non-conventional, alternative led to it receiving a label of cultural, which undermined the methods of knowing, the ontology and epistemology of the respective folk system.

In my specific case study, I am evaluating the invisible knowledge involved in labeling health conditions, beyond an ICD dominant classification, and aligned with an interdisciplinary health definition. This health definition is founded on an exploration of realities beyond the normalized set abyssal lines.

I study the SARS-CoV-2 related experiences while focusing on the special theme of labeling processes and their results. This is meant to allow me to transcend the biomedical and nonbiomedical dichotomies. Thereby, delving into a deep appreciation of the health complex, to then arrive to an unknown invisible reality, perhaps, that which may contribute to the understanding of epistemologies of the South. This whole study may also, perhaps, undo some of my own abyssal thinking that my own journey has led me to.

#### **Chapter 2. Building my Anthropology Approach**

It galls us that Western researchers and intellectual can assume to know all that it is possible to know of us, on the basis of their brief encounters with some of us. It appalls us that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce, and then simultaneously reject the people who created and developed those ideas and seek to deny them further opportunities to be creators of their own culture and own nations.

-Linda Tuhiwai Smith

In this chapter I lay out my methodology in the field and the analysis. I include contextual data on my fieldwork sites. I also introduce the concepts of semiosis and form which will be used in the analytical framework in chapter 5 to synthesize the narratives and experiences from the results of chapters 3 and 4.

#### 2.1. The Theory for a Multi-Sited Approach

Coming from a medical sciences background, I have struggled with piecing together a methodology that is valid and solid enough, while not reproducing hegemonic systems of knowing I have already claimed to sail away from. Planning and accepting my methodology were a journey in itself. Thinking of where and how I will study my question became an obsession. I struggled to find a reasonable method since I was rethinking my own reason. I also wanted to allow the fieldwork to point me to my question, as it rightly should.

The field created my study. In my initial fieldwork, I was not certain what it was I was looking for. I simply looked to gather stories of COVID-19 survivors and sufferers. It was only when I sat down to read what my initial data had to say, and reflected on field notes, that the idea of searching for labels in health conditions arose. The next portion of fieldwork allowed me to polish the idea, and my search strategy.

Finding the topic of my study was one grand challenge in this research. Identifying my strategy and methods was another. Similarly, to how the fieldwork generated my final topic, the fieldwork also pushed me to the methodology it necessitated. Initially, I contemplated creating a quantitative approach aiming to collect surveys from patients, health care professionals, survivors of COVID-19 and others. That data from surveys would be coupled with focus group discussions that evaluated important themes, to draw out conclusions on what labels people used in referencing COVID-19 and what impact they (the labels) may have

had in peoples' lives. However, as I got involved with communities suffering high rates of SARS-CoV-2 infections, I appreciated the diverse methods anthropology called me to explore. The work by Tim Ingold (2017), which describes the 21<sup>st</sup> century practice of anthropology resonated deeply: "Anthropology, I maintain, is a generous, open-ended, comparative, and yet critical inquiry into the conditions and possibilities of human life in the one world we all inhabit" (Ingold 22). Anthropology is one of the few surviving sciences that allows researchers to think outside a closed box that modernity and we have imposed. The field is meant to be the lifeline to imagination in science, within logical reasonable sense. However, this logic and reason is founded on an appreciation of the diverse ways of doing knowledge, that social scientists like Santos remind us of.

In another book exploring methods in anthropology, Ingold speaks about how this open-ended inquiry is to be done. "In anthropology, then, we go to study *with* people. And we hope to learn *from* them. What we might call 'research' or even 'fieldwork' is in truth a protracted masterclass in which the novice gradually learns to see things, and to hear and feel them too, in the ways his or her mentors do" (Ingold, 2013, 2). The emphasis on the prepositions *with* and *from* are transformative, since they invite us to be human, and to remain students of our research participants. Hence, how can a methodology be drawn before the field is entered, and before the members of the study are met.

So, I entered the field looking for teachers. I was keen to figure out what it is that the field wanted me to see, to hear, to know, to learn and then write. My entrance to the field happened through somewhat of a coincidence, or necessity.

In the month of April 2020, following the increased media coverage of the unfolding crisis, due to the SARs-CoV-2 virus infections, in the city of Guayaquil, in the Guayas province, I travelled to the province—from my home in Quito at the time—to voluntarily conduct an assessment of the situation for an international NGO (which I will reference as MG). MG was interested in supporting the local response. My role would involve visiting local hospitals and health centers and writing a report that would clarify potential areas for funding for them.

During my time in Guayaquil, by the second week to be precise, I noticed that there was a significant amount of financial and material support pouring into the city, as my interlocutors were informing me, and as I was witnessing in field visits. The hospitals I was visiting had stocks of equipment, including medications and protective materials pouring in. Consequently, I began to enquire about the needs of neighboring sites to Guayaquil, and so I learned of the

neighboring province of Santa Elena, where the suffering was similar to Guayas, however, they had less support given their lack of political affiliations and industrialization. Hence, I refocused my assessment to Santa Elena, for the time spanning May through July 2020. It is in this province that I decided to conduct my anthropological investigation into labels during the pandemic. I was taken by the striking stories, and the ongoing suffering and limited access to services in the communities I encountered, specifically in Santa Rosa.

The idea of searching for labels was born during my time in Santa Rosa meeting with survivors of COVID-19 and designing a health program that could support the local response. The ideas on how to study or construct my report on my study of labels came when I did my second part of the study in the Amazonia of Ecuador, which was also inspired by coincidence. After I returned to Quito for a break from the fieldwork in Santa Rosa in June 2020, I was invited to visit an Amazonian locality, Pano, and specifically the village of Sapo Rumi located in it. The invite was by my professor, Dr Michael Uzendoski, who was alerted to increasing numbers of infections there—himself being a member of that community. This visit turned into fieldwork, which blossomed into two parts, a study within a community in Pano and another in a midwife center in Archidona, both of the Napo province.

My decision to include multiple sites in my final writing stemmed from an appreciation of what sincere anthropology, authentic to my own process of learning and study, can contribute to my original objective to transcend biomedical dichotomies in my own background and reach a more humane and effective practice in medicine as a doctor.

In the time between going from Santa Rosa to the Amazonia, it quickly became clear to me that there was a distinction between ethnography and other anthropological tools. Again, Ingold's words resonated: "Anthropology is studying with and learning from; it is carried forward in a process of life, and effects transformations within that process. Ethnography is a study of and learning about, its enduring products are recollective accounts which serve a documentary purpose" (Ingold, 2017, 3). Though ethnography was all I knew of anthropology before entering my coursework, the many anthropologists I was exposed to over the past 2 years, made it clear that what I was doing was a "living ethnography" as Juileta Quirós (2018) refers to it, a sort of anthropology from within, that was in a constant wave of production and reproduction of itself.

In this kind of anthropology, spontaneity and openness are key features. The techniques are centered around participant observation, including active listening and dialoging. In Santa

Elena, I engage with the people in the Santa Rosa town and health actors of the province as a health volunteer and researcher, rallying information for possible financial aid for the town. In Napo, I engage with the people of Pano in July 2020, and the people and midwives of Archidona in March 2021, as a visiting volunteer, doctor and investigator; all roles which I interchangeably enter. In Archidona specifically, my role felt like I was beyond a participant observant. I became a member of the local projects, the local processes of going about the day, and this will become apparent in chapter 4.

In addition to participant observation, I conducted semi-structured and focus group interviews with survivors of COVID-19 and family members of people who did not survive. This generated material that I could transcribe, code, analyze and gave my study a comforting sense of systematic approach that I needed to reassure myself of the scientific nature involved with such an increasingly spontaneous study.

Despite having chosen my fields for study quite incidentally, they did turn out to be very fitting and appropriate for contrasting SARS-CoV-2 pandemic experiences. Their contrast provided a solid foundation to ask questions into the nature of labels and their processes, while avoiding the universalization of or romanticizing context specific findings. The coastal area of Santa Elena was mostly inhabited by Mestizos and the Amazonia areas of Napo were mostly inhabited by Kichwa people.

To make the contrast more apparent, I will highlight the facts and features of each of my study sites (Figure 2.1.). I will also outline the specific methodologies applied throughout my time. Following that, I will summarize the virtual methods used throughout my time in both provinces, and after.



#### Figure 0.1. A map of Ecuador with Napo and Santa Elena provinces circled

*Source:* Map of Ecuador, map.commersis.com *Note:* Part of the map was edited by the Author.

#### 2.2. The Santa Elena Province

Santa Elena is the youngest province in Ecuador, lying on the coast of the country bordering the Pacific Ocean with a population of 308,693 per the 2010 national census. The province gained its independent status from the neighboring Guayas province in 2007, following protests and a history of resistance—of the select present day Santa Elena territories—to exclusion from political representation in congress by the Social Christian Party that dominates in Guayas. The province is divided into 3 cantons, including Santa Elena, Salinas and Libertad, and their economic subsistence depends on tourism, fishing and a petroleum refinery. The majority of the population—over 79%—identifies as mestizo, and lives in rural settlements (Gobierno Autónomo Descentralizado Provincial de Santa Elena 2009).

Santa Rosa is one of the six parishes or *parroquias* in the canton of Salinas, which has a total population of 68,675 individuals. The average age of the population in Salinas is 26 years, which is consistent with the overall province census data that shows a predominantly young population, and an illiteracy rate of 4.5%. Santa Rosa is considered an urban parish, and one of the three main fishermen hubs in the province (INEC 2010). Prior to the pandemic this parish was well connected with neighboring parishes and provinces outside Santa Elena, with the fish and tourism it allured locals and internationals alike.

In addition to its connections with other local sites, Santa Rosa is known to attract the attention of drug dealers knows as *narcotraficantes*, that seek, and even capture, fishermen in order to transport drugs to the United States of America (USA) via the ocean route. Over 80 local fishermen have consequently been captured and put in prison in the USA with drug trafficking charges. This phenomenon with drugs, also results in a notable amount of drug abuse within the parish of Santa Rosa, as narcotics are easily accessible and promoted (El Comercio 2020).

My methods in the province of Santa Elena included:

1- Participant observation with provincial and governmental health officials and physicians, and locally active civil society groups. As an active observant in the midst of the crisis, and its organized (at times unorganized) health response, I experienced the needs assessments and planning processes for health interventions by local health figures. I visited intensive care units and observed the treatment of patients infected with the virus. I also conducted multiple unstructured interviews initially, and semi-structured interviews eventually in the capacity of designated contact point for the international NGO, which yielded valuable input from my investigation perspective as well.

2- Semi-structured interviews with select informants, including individuals and families in the town of Santa Rosa of the province of Santa Elena, that have suffered with health conditions during the SARS-CoV-2 pandemic, and whose condition was most likely attributed to the virus (given the limited access to testing). These were done in the capacity of an independent student researcher, and I was introduced as such. The informants were identified through a civil society group I was participating with as part of my MG NGO work.

#### 2.3. The Napo Province

The Napo province is situated in the Northern part of Ecuador and is one of the Amazonian provinces, with an autonomous decentralized form of governance. The province consists of 5 cantons, Tena, Archidona, Quijos, Carlos Julio Arosemena, y El Chaco. Most of the population—over 56%—identify as indigenous, with the Kichwa ethnicity being the most majority. The subsistence depends on tourism, and agriculture. The canton of Archidona has a population of 24, 969 individuals, with an average of 24 years, and an illiteracy rate of 9.9%. Meanwhile, the canton Tena has a population of 60,880 an average age of 24 years and an illiteracy rate of 4.8% (INEC 2010).

Pano is a parish in the Tena canton. The main source of economy is the local agriculture, and many inhabitants have businesses or work in neighboring larger towns.

My acceptance of the invitation to Pano was motivated by the humanitarian and academic field reports surrounding the escalating infections in indigenous communities and the fears of the already weak healthcare systems of the indigenous communities of South America (MSF 2020, United Nations 2020, CONFENIAE 2020). The national reports in Ecuador showed that the Amazonian provinces, with a primarily indigenous population, had lower incidence and mortality rates from the SARS-CoV-2 virus compared to the rest of the country (MSP 2020, Sirén 2020). This could be attributed to multiple reasons, including the availability of resources for testing and diagnosis, and reporting systems in these provinces.

Furthermore, Napo was an ideal province to incorporate into my search for labels, since the community had a prominent indigenous health system that allowed me to explore the pandemic experience intersections between biomedicine and non-biomedicine practices. Pano certainly offered input into how people with persisting ancestral traditions organized their health. In this community I capture the patient and family experiences with illness during the pandemic, and spend several days speaking to community members.

Meanwhile, my fieldwork in Archidona, almost a year later, exposed me to a professional element in the non-biomedical system, which I felt I lacked at the time. Having reviewed the data collected between Pano and Santa Rosa, I found myself in need of a perspective that challenged the biomedical doctor perspective I myself was immersed in for researching and writing. My professor, who was my original contact for Pano, suggested the association of Kichwa women midwives of upper Napo, Asociación de Mujeres Parteras Kichwas de Alto Napo (AMUPAKIN) a Kichwa-midwife led center in the province. My study at AMUPAKIN captured the professional healer perspective in the pandemic. Here I stayed with older women who had been practicing medicine throughout their lives and were now incorporating COVID-19 treatments. Their medicine could be considered part of the traditional, alternative, ancestral, non-biomedical health system.

AMUPAKIN was founded in 1998 by Maria Antonia Catalina Shigunago, and its current president is her daughter and midwife Ofelia Salazar. The midwife members at the time of my stay there were 9 and came from multiple communities in Archidona including: Awayaku, Rukullacta, Rumipamba, Papanku, Rumipamba, Salazar Aitaca, Ayapata, Chaupishungu, and Lushian. AMUPAKIN is supported by the Federation of Indigenous Organizations (FOIN), which forms part of the Confederation of Indigenous Nationalities of the Ecuadorian Amazonia (COFENAIE), which itself welcomes all the indigenous community representations of the Ecuadorian amazon region.

Below I will present a brief background into the essential medical reality themes of the AMUPAKIN midwives. The following is what I had learned before my visit to AMUPAKIN about Kichwa medicine and the theoretical framework in which their work resides. I use it to better familiarize the reader with the work of the midwives that forms a large part of the ethnography later.

It is crucial to have a clear handling of traditional medicine and indigenous populations as I begin to explore their work. Indigenous is a word that is used to refer to original inhabitants of

a territory. Indigenous people are often defined or distinguished—for lack of a better word from each other by their language, rituals, cosmovision, social relations and daily practices, including economic subsistence methods. In Ecuador, there are 13 indigenous communities, 8 of which are mainly in Amazonian regions, 4 in the coast, and 1 in the highlands (INEC 2006). The Kichwa constitute over 49% of the indigenous population, however, this community is non-homogenous in their daily life practices, beliefs and knowledge. This indigenous group is spread across the country, from the amazon to the coast. Hence, saying indigenous medicine is a loose, non-specific term applied to all the diverse systems of folk medicine in indigenous groups (per the healthcare structures of Kleinman defined in Chapter 1).

Traditional medicine can be said to be equally non-specific. Eduardo Menéndez, an anthropologist investigating epistemologies of traditional medicine questions the popular use of the term. In his work, he concludes that traditional medicine is mistakenly thought to exist in isolation from present day realities and considered to contain static theories and beliefs of the past only. The relations to and influences by the dominant Western medical system on the constantly changing traditional medicine reality is consequently missed by calling it traditional (Menéndez 1994).

Meanwhile, the WHO (2021) defines traditional medicine as: "the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness". The definition is ample and is intended to generate a single label for a largely unconnected network of medical systems, since in the eyes of the global health biomedical institution they are undifferentiated.

In the case of AMUPAKIN, additional terms that have been used to refer to the work the midwives do include ancestral medicine, plant medicine, shamanism, and midwifery. These terms still fall short however, in describing the medical work done and promoted by the midwives. For the sake of easy referencing, I refer to their medicine as ancestral, since it was the term, most used by them to refer to their medical reality.

With this short diversion into the world of indigenous and traditional medicine, I present the methods used in the Napo province.

In Pano the methods included:

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1- Semi-structured interviews with individuals and families that have suffered with health conditions during the SARS-CoV-2 pandemic, and whose condition was most likely attributed to the virus (given the limited access to testing). My key contact in identifying the informants was Dr Michael Uzendoski, inhabitant of Sapo Rumi and FLACSO professor.

Meanwhile in Archidona they included:

- 2- Participant observation in the center of AMUPAKIN.
- 3- Unstructured, and semi-structured interviews with select midwives and doctors at the local health center.
- 4- Focus group interviews with the midwives.
- 5- Semi-structured interviews with local pharmacy personnel, government health center personnel and general public on their experiences during the pandemic from the onset in March 2020, and up to March 2021. For these interviews I selected my own informants by visiting the respective sites of interest.

#### 2.4. The Virtual Methods

Beyond these methods in the physical spaces of Santa Rosa, Pano, and Archidona, I used several methods to generate an ethnography of the biomedical experience. This I did by collecting essential data from the growing virtual space that consisted of search engines and journals, and meeting platforms for health professionals. The following summarizes these methods:

- 1- Review of national and local reports on COVID-19 pandemic situation issued by governmental health authorities in Ecuador.
- 2- Review of global health guidelines on clinical care of patients with COVID-19 issued by the WHO and select academic universities based on an online review.
- Participation in global health conferences organized by universities and WHO on topics relating to SARS-CoV-2.
- 4- Virtual meetings with MG NGO healthcare staff regarding the COVID-19 pandemic situation in Ecuador and globally.

#### 2.5. Data Analysis: The Tools for the Results

With this summary of methodology describing the spaces and techniques I use in data collection, I still had to consider how I would find the unknown or invisible that Santos had motivated me to search for. I needed a method for analyzing what I was hearing, seeing, doing and speaking myself. The questions that came to me were: how was I to go about synthesizing and understanding my data, including my field notes, interviews and publications? What mental framework am I setting out with as I review the accumulated data?

As I thought through the connection between the invisible, knowing the unknown, and transcending lines that regulate our thinking processes, the work of Eduardo Kohn (2013) in "How Forests Think", came to mind. In the chapter, "Forms Effortless Efficacy", form is implied as a sort of invisible silhouette that all living things can be observed to have and produce, either within and, or outside them. Kohn highlights how the immaterial, at times unseen, features shaping non-human life can help us find and voice the expression of our own unseen form, understand its logics and properties, and thereby gain an appreciation of "what it means to think" (Kohn, 2013,160). He also makes the reader understand how the form of being is constituted by the "constraints on possibility [that] emerge with our distinctively human ways of thinking" and the general patterns produced by these constraints (Kohn, 2013, 158).

Kohn builds up this description of form by referring to the anthropology beyond the human he conducted in the Ecuadorian amazon in the Napo province. We see how the form of rubber trees noted in their arrangement around water, follows a possibility-constrained way aligning with the unidirectional water flow. The water moves in its specific form, dictating much of the inter-being forms of life around it. Understanding the form of water can shed light into the form that other beings take up as a result of this interdependence. Similar to how we see form or general patterns in this non-human constrained way of being, we can look within the human realm for constraints generating such general patterns.

The thinking in and of form is a difficult yet essential exercise. If I can trust that my thinking process has a particular form resulting from constraints that have polished its shape, then, I can take that as a starting point. Perhaps the lines that regulate the visible and invisible realities in modern knowledge constitute these constraints, or form. Perhaps the work of Santos and Kohn overlap in that one is speaking of form and the other is depicting form in knowledge and thought process. In that sense, it is essential to recognize that the invisible and

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visible realities Santos highlights, in the case of medical knowledge and in the mind of the modern researcher or physician in my case, are based on a biomedical center as its reference.

The question then arises, what are the tangible and imaginable methods in arriving to form and, or the realities of dominant medical knowledge? Kohn also offers direction here; he presents the methods by which form can be made more practical, more real: semiosis. It is the process of manufacturing, signaling and interpreting signs that are symbols, icons and indices, and can be found in the visual, verbal, and sensory experience (Barbieri 2008, Kohn 2013). Semiosis offers techniques that urge us to reconsider our limited attention to the ways of communication and interpretation across human and non-human life, labels included!

This field has classically been attributed to Charles Sanders Peirce, a philosopher and mathematician. Peirce promoted the understanding of semiosis as involving the triad with the sign, the object and the interpretant, and the three types of signs: symbolic, iconic and indexical (Barbieri 2008) (Figure 2.2.a. and 2.2.b.). The triad is intended to show the 3 components that go into making a sign process. The object or the referent (as some semiosis texts refer to it) is what the sign or signifier is aiming to refer to by its representation, and the interpretant or signified is the concept intended to be shared. So, the word symbol 'hospital' is trying to refer to that specific building and the interpretant or signified is the place where medical staff works, or healthcare is performed. This aspect of the interpretant is most versatile, since the concept that is relayed is dependent on what the individual using the word is trying to say about it or make of it (a hospital as a place where doctors work versus a hospital as a place where people die of disease). In simpler terms, the interpretant of a sign and object may be quite distinct from person to person and context to context.

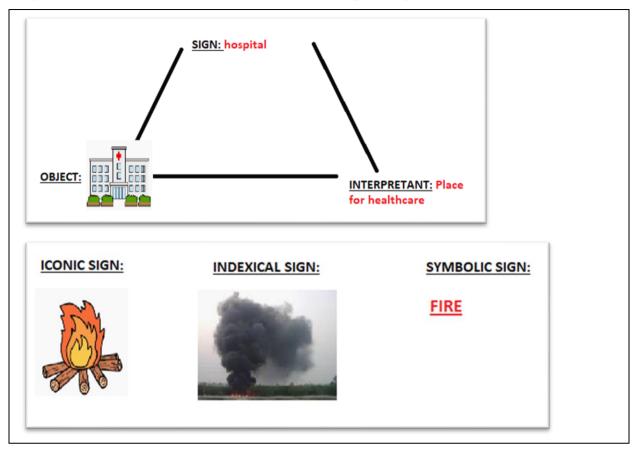


Figure 0.2.a. Semiosis analysis triad and 2.2.b. Type of signs

Source: The Author

Meanwhile, the types of signs can be explained as the following: symbolic signs, involving words for example, are conventionally assigned by the representation (and its code-maker or designer) and hold no similarity to that signified. While iconic signs, images for instance, resemble what is being signified. The indexical signs, like the smoke of a fire, are caused by that which is being signified, the object (University of Vermont 2020). It is these components that are often emphasized when semiosis is summoned to discussions that search for and uncover meanings in our daily life communications beyond the symbolic language.

Peirce in his presentation of semiosis presents it as an interpretive process primarily. However, semiosis can also exist more amply, as a process that aims to manufacture and signal signs. Also, signs often belong to more than one category, they are not just symbolic or just indexical. Typically, they are symbolic and iconic or symbolic and indexical.

So, semiosis is a sign process that considers how living and non-living beings come together to generate and receive meaning, and it can be used to outline thinking and acting forms in living beings. By studying what symbolic, iconic and indexical sign processes prevail in a specific reality, I can imagine the silhouette that the thought of that reality is assuming, since the process highlights how signs are being made sense of. Let me consider what that means in my world of medicine.

Considering semiotic principles truly opens up many avenues to discuss styles of theorymaking, and knowledge realities. It gives us an awareness of where and how a field is situating its collective mind, its knowledge process. My main claim here, which perhaps I have overstressed already, is that semiosis is truly relevant to outlining how we think health works, specifically how the systems addressing health think. How are people, scientists, and physicians communicating growing pools of information in biomedical health theory, and what are they relying on to communicate? What does this say about our form? (Does it even matter—a question that has been on my mind since I started this mental exercise in form and semiotics?)

This brings me back to labels in health conditions. Labels can be considered semiotic references or signs. When labels are used in health conditions, whether for diagnosis making, or classifying medications or identifying relations between health and disease agents. Considering labels in a semiotic framework to assess their type, understand the underlying concepts for them and comment on their role, will speak to the code-makers' reality. So, if I return to the concepts, I explore in chapter I on the official and unofficial labels, I can now, with the addition of a semiotic frame delve deeper into their analysis and their reflection of their code-makers' form.

This is consequently what I do in analyzing the data collected.

I look at labels as semiotic references and identify them in the various types of data I have, in order to arrive at understanding the form of thought processes of distinct groups I encounter. This will lead me to the insights into what labels during the pandemic taught us, and what next.

Let me present examples of what considering labels through semiotic frameworks is. For that I will return to the chapter one discussion on official and unofficial labels.

The official labels are primarily symbolic signs, with occasional iconic components (for example, sudden infant death syndrome, signifies the image that the symbol incurs, the name is quite descriptive to the condition). Labels in ICD use medicalized symbolic terms that bear no resemblance or relation to a patient or physician. The terms are normalized as referencing signs for diverse human conditions. The result of such simplified basic terms to reference disease is that you end up either with or without the condition, there is no middle ground; it is

either true or false. Dichotomies abound in biomedical labels. These very dichotomous descriptions of biomedical health end up being the prime material used to communicate across biomedical professionals, between patients and physicians, and between healthcare professionals and institutions. Insurance companies reimburse based on these labels, pharmaceuticals research based on these labels, and so on. Biomedical health is too reliant on these symbolic labels for functioning its systems.

As biomedical doctors most of our meetings, clinical consultations with patients, studying and teaching revolves around the symbolic signs, language specifically, referring to concrete microscopic or macroscopic knowledge made by biomedical labs or clinical trials. In interviewing patients to diagnose their problem, I mainly ask questions like: when did the symptom start, where is it, what makes it worse, what makes it better, what have you tried for it, has it happened before, etc. I demand answers that are concise, simple, symbolically coded for my mind to then process algorithms on likely diagnosis and potential treatment.

More and more, the role of the physical exam which is meant to pick up on indexical signs (resulting abnormalities in or emissions of the human body, that clue me to the object of the problem the patient has) is diminishing, and any physician can attest to that. More and more, the biomedical practice relies on a limited history taking from the patient, basic to no-physical exam, laboratory tests, and radiology generated images of the body, to generate rigid, medicalized labels that determine treatment recommendations. This is quite beneficial in a way, since it ensures an element of quality and transparency in healthcare. However, it also leads to the same rigidity that Santos outlines as abyssal thinking. With biomedical knowledge processes, I cannot accept another medical epistemology beyond my own, because it is mentally impossible given that I operate in this plane of truth and false.

Meanwhile, the unofficial labels that are not so apparent to me, a biomedical physician, are a sort of mystery. I am not sure that there is consistency or consensus over what they constitute or where they are.

I know that in my own clinic, labels appear in several ways. In patients that have no clear diagnosis with the ICD criteria biomedical institutions give me, I end up relying on a descriptive label to explain the back pain or the knee pain or the emotional states they feel. These descriptive labels I sometimes draw out, so that a patient can understand the object (their ill condition) through the image (resembling the imbalance I presume is happening), so that the concept is more likely to be understood as I am approaching it. At times, I use an ICD

label that is prompted by a clinical setting, meanwhile, its use can signify a different object to a colleague. To me, cholecystitis (a gallbladder infection) signifies the need to manage the patient in a hospital with an interdisciplinary team, to the radiologist it means a certain brightness in a particular pattern on an ultrasound and to the surgeon it signifies emergency surgery. This "multiplicity" in biomedical ICD labels adds another dimension to the study of official labels, and has been studied by Annemarie Mol (2002), a medical anthropologist in Holland, who focuses on the anthropology of the body.

She has increasingly questioned assumptions about how the body is handled in biomedicine. Her book, "The Body Multiple", is centered around the enactment and doing of diseases, through her ethnography engaging with multiple actors at a hospital in Holland. She shows how a single disease entity, like atherosclerosis, can hold a multiplicity in its significance, and is consequently enacted differently within the biomedical profession.

There are pathophysiological, clinical and statistical types of atherosclerosis, resulting from a web of human and non-human actors. Mol's semiotic analysis of the events happening at the hospital, makes these enactments of the body multiple in atherosclerosis clear and appreciated. This multiplicity allows a novel appreciation of how biomedicine ontology is diversely produced and understood amongst its practitioners and users, and consequently eliminates the imagined uniformity in labels surrounding biomedical nosology and productions of disease. Such an appreciation of multiplicity allows us then, as medical professionals, the humbleness to question the rigid line between truth and false made by the biomedical model in health and disease, since it is obvious that even with a specific label, the enactment is multiple, not restricted to a single truth in that disease.

Furthermore, the enactment of atherosclerosis is a sign process itself. Atherosclerosis is the symbolic sign, the respective representations vary between the radiologist who points to atherosclerosis by a specific image or the pathologist who uses a dead specimen, and the interpretant is even more diversified since the radiologists' concept of atherosclerosis is a very physical and concrete finding in the arteries, while an internist's concept interpretant is a wider-spectrum physical and non-physical condition that needs medications and possibly surgery.

Other discrete or unofficial labels I have experienced in clinic, include: a patient's response with a particular facial or body movement to a question or touch, and its signifying of underlying possibilities of disease. Here the patient has become the code maker and I am interpreting the physical indexical signs generated stemming from their ailment. These signs are prominent and many in the physical exam of patients. My favorite is the Dix-Hallpike test, a bedside exam where I rotate a patient's head in a particular way to see if a certain sign is generated with their eyes, that cues me to the presence of a specific condition causing their dizziness symptom.

Beyond my own clinical work, I am mindful of the mystery that folk illnesses pose in biomedicine and have had personal experience with these conditions. Community healers in villages I have visited as a biomedical doctor do not label patient health conditions with word symbol labels when treating them. These healers communicate their process of diagnosis by rituals, descriptive labels that rely on imagery (a type of iconic and symbolic sign), or induce certain indexical signs in the patient or healing object (a patient reacting in a certain way to the movements of a healer or an object), or very rarely refer to biomedical ICD labels (like anemia, diabetes, hyperthyroidism) to explain the treatment they offer the patient. A diagnosis never seemed relevant or necessary by the healer.

I am also mindful of the labels generated by more globally organized health systems like Ayurveda and traditional Chinese medicine. These systems use symbolic-iconic descriptive signs for health conditions. (I use the term descriptive to suggest that words used in a particular way that describes more than names directly, create a vivid image symbol of the interpretant concept). In their evaluation of the patient, they provide a conclusion that describes what element they may be lacking in their physical and non-physical system. So, the very dosha or organ or channel (there are specific terms used by these systems that refer to non-physical health processes that happen within the human being) name is used to indicate the location or nature of the problem. Though this can arguably also be considered solely symbolic, however, there is an element of imagery that is consistently displayed by the descriptive naming of health conditions.

For example, an Ayurveda recommendation can consist of something like: the fire component is in excess in the gallbladder causing it to get inflamed, more air behaviors, postures or foods are necessary to fix this. There is some looseness, or variability in how health conditions are referenced. Indexical signs in these systems also show-up often. The reading of the facial features, the tongue, the pulse are common ways to find indexical signs that point to imbalances in certain parts of the body, and upon which health recommendations are made. Also, there is labeling in the conditions of health. The type of body or individual constitution is a common process in these health systems. In Ayurveda, a consultation with an expert practitioner of that system can tell you where and how you can find balance for your health state. Even if one is free of disease, health recommendations are still available and plenty. The hard lines separating diseased and healthy states are not as significant in these systems, since health consists of a wide spectrum that can be pursued independently from disease. Labels need not be one-word symbols but can be fluid descriptions.

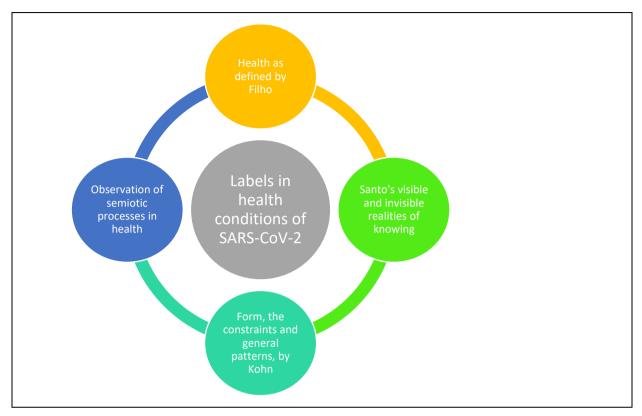
The more I think about form and semiosis starting with labels as a way to understand knowledge, the more I see that the notion of visible and invisible realities is made, in my case, with biomedicine as the visible center. This is to say, that perhaps a discussion of visible and invisible realities of knowing is invalid when considered from another school of epistemology, since their lines drawing the form of their knowledge are not based on discrediting other realities, nor are they based on a hardline between truth and falsehood. This is again where the role of the interpretant, or "the third half" is understood.

In an article titled "Truth Disputes in Ayurveda", the malleability of truth in health conditions discussion in Ayurvedic platforms is made apparent. Truth is not some fixed point to be marked, but rather it is a range to be debated based on old and new evidence, and it not only involves theories of knowledge, but also the wisdom of experts and novices to Ayurveda (Wolfgram 2010).<sup>4</sup>

The possibility that visible and invisible realities of knowing may be of relevance only to the biomedical practice, draws the (dreadful) question: are labels also just relevant to biomedicine? And are my attempts to search for labels in health conditions, beyond the biomedical model, too ethnocentric? The fieldwork I present will ultimately provide the answers, since I delve into the COVID-19 pandemic experiences with a diverse group of individuals.

<sup>&</sup>lt;sup>4</sup> This was quite a delightful read, since it simplified in my mind the form of Ayurveda that I was starting to appreciate as I read texts about the field that were already pointing me to that direction.

# 2.6. Connecting it All



# Figure 0.3. Tying Together the First 2 Chapters in Theory and Methods

Source: The Author

As I approach my fieldwork results in the next chapters, I have set the figure above as the framework for data review and analysis (Figure 2.3.). Labels in health conditions of the pandemic are ultimately what I am seeking. This theme is interrelated to diverse debates in current medical anthropology and health science research and can provide insight into various ways of doing health beyond the dominant biomedical model.

Health, I resolved, is not merely the absence of disease. A discussion of health must consider the multi-dimensional parts to it. This health definition allows me to consider the spectrum of knowledge in health. The form of the biomedical modern knowledge is dichotomous, rigid, constrained by lines defining truth and falsehood, and ignorant of other lines that may intersect with its own and even sustain it. Semiosis is grounding most of this theory; it is capable of taking the abstract notion of form, into a concrete and practical thing, into a lined silhouette.

In the last section on how I conduct data analysis, I explained how semiosis and form frameworks will ultimately guide the structure of my findings in the search for labels. This ultimately aims to open up the biomedical perspective to other ways of knowing. The aim is not to convert me into a non-biomedical physician, or to attack the biomedical way of knowing. The aim is to build humility and understanding in a hegemonic system gone unchecked, and explore the possibilities lying within the intentionally obscured and invisible knowledge. Through this exercise, I can learn my limits, and weigh in on the journey to cognitive justice in a globalized world.

# **Chapter 3. Into the Public Patient Reality**

### 3.1. Organizing the Results by Group Narratives

The task is grand. I am piecing together pandemic stories across provincial borders in Ecuador and at times international borders. I do not aim to derive universal conclusions based on this approach, but rather open up to a complexity that defines how people have experienced and reacted pragmatically to the pandemic. In the next two chapters I will present the results of the defined methods from the second chapter using the tools of semiosis and form.

Through the multi-sited approach conducted, three main groups of actors in my fieldwork during the pandemic became apparent. These groups are consistent with Kleinman's classification of structures in healthcare: the folk, the popular and the professional.

- The popular healthcare group: The people infected (or likely infected) with SARS-CoV-2 and their families: this included the people of Pano and the people of Santa Rosa. I summarize a narrative of their experience in this chapter, highlighting important themes.
- The folk group: as I explained in chapter 1, folk includes the local alternative, nonspecialized and typically labelled unprofessional (by a national health system standard) healthcare providers: the Kichwa midwife group are considered in this group. I present a review of their work pre and during the pandemic in their respective communities and health center.
- The professional group: this includes the biomedical doctors working in the community clinics and hospitals. In my study this included the specific professionals in Ecuador, and in the NGO, I was with at the time of the fieldwork. I knit their (and my) experience into a short ethnography, also in chapter 4.

These groups are certainly not the only ones present in the narratives; however, they are the ones I have chosen to highlight. Other players that are considered and important to trace include: the scientific institutions and pharmaceuticals, the regional and national governments, the non-governmental organizations (NGOs), the hospital administration, and of course the SARS-CoV-2 itself.

In this chapter, I draw upon the experience of two different communities (in culture and resources) in Santa Rosa and Pano and engage with my initial questions on where labels can

exist in a COVID-19 health reality. I show in this chapter that indeed a study of the patient and community experience in health engaging tools of semiosis and form, to look for patterns in labels, yields important signs and symbols that have been overlooked. These signs and symbols tell us what is important to the patient and community experiencing the pandemic. Furthermore, crucial differences across communities in their labels can cue us to explanations on why pandemic experiences can be exceptionally different. I show that in Pano many labels for plants exist in contrast to Santa Rosa, along with labels connecting historical pandemics of Kichwa ancestors. The preparedness of Pano with local plants and ancestral knowledge of pandemics and visible through their select labels, I hypothesize, was potentially contributing to the low mortality and community resilience in Pano, in contrast to Santa Rosa.

My data reflects an effort to search for patterns in an increasingly complex and messy science. A science that had to endure a grueling pandemic crisis since the onset of 2020. In these next two chapters I delve into the past, present and future, engaging with various sectors and actors that have suffered through the pandemic.

#### 3.2. A General Patient Narrative from Ecuador

No two patients are alike: this is an important lesson I recall drilled into me as a medical student. However, despite the uniqueness of patients, thankfully there are patterns or collective processes of experiences that we can appreciate in the sickness and health of the human being (as social science, alternative and biomedical models highlighted). In investigating the experience of the local people in Santa Rosa and Pano, I contrast stories from very distinct settings.

Santa Rosa, as I have mentioned, had suffered unfathomable loss and death in the early days of the pandemic. On my first visit to Santa Rosa in April 2020 the town was still recovering from a dreadful first wave of SARS-CoV-2 infections. Many people I met had stories of family members that recently passed away or suffered with the virus. The town was still locked down, and the patrolling military did not allow any fishermen to go to the sea, and so families lost their only access to food there. The government and municipal health clinics were closed in the peak of the pandemic because of infected staff, and that limited people's access to public doctors. There was a notable heaviness in the town, a solemn feeling spread across. People did not talk much, and words that were spoken always carried sadness or pain in them.

On my second visit in June 2020, I felt the town was more vibrant with a sense of renewed liveliness. The sounds of children playing on the streets was soothing the heaviness and sadness. The fishermen had started going out to sea again, and there seemed to be hope. The health clinics were still closed but planning to open soon. During this visit I spoke at length to over 10 families of deceased patients and surviving individuals that were infected with the SARS-CoV-2 virus.

Meanwhile, Pano, despite reporting large numbers of infections with COVID-19, had no excessive loss or death and consequently, no grief evident in their experience during my visits (Sirén et. al 2020). People still had access to a public health clinic during the peak of the pandemic and at the time of my visit. This clinic provided free consultations by a biomedical doctor and dispensed the usual paracetamol for fever and pains.

I visited the town in July 2020 after returning from Santa Rosa on an impromptu visit that turned into a fieldwork opportunity. At that time, the wave of infections across the households of Pano had recently subsided, as reported by the community. I conducted 10 semi-structured interviews with various individuals over 3 days. These interviews included the same questions I had posed in the Santa Rosa setting too.

It was fascinating to see how the interviews I conducted with individuals and families unfolded into a patient narrative. Upon reviewing and coding the interviews of families from both towns, I encountered several themes, some were specific to one town and others showed up in both. A summary of these themes is presented in Table 3.1., followed by a general contrasting narrative from each community, that includes examples of data that led to the Table 3.1. content. An analysis of labels concerning SARS-CoV-2 is introduced throughout this chapter and is concluded at the end.

In table 3.1., the 5 themes that are filled in green are the ones that appeared similarly in both towns. The themes in blue are specific to Pano, and the themes in orange are specific to Santa Rosa. Though some aspect of these latter themes may overlap, fundamental differences exist in how people of each town addressed them, and so the choice to highlight them as different.

#### Table 0.1. The themes from interviews in the towns of Pano and Santa Rosa

Pano	Santa Rosa			
Prevention of illness highlighting: masks, taking care of oneself and limiting physical contact				
A chronology of inciting event and symptom onset				

Animated descriptions of symptoms and naming with symbolic, iconic, and indexical signs

Revelations, physical and metaphysical, during the personal and familial illness

The caregivers throughout the illness period (children, parents, grandparents, neighbors)

Pursuit of multiple healthcare options by caregiver or patient as symptoms evolved

# Scarce availability of laboratory testing for COVID-19

The access to safe biomedical health centers and/or doctors, and their specified diagnosis and medicines	The limited access to biomedical doctors, and medicines
The treatments taken: biomedical prescriptions from doctors (pills, injections, vitamins and serums) and non-biomedical (home remedies, gifted traditional plants, vaporizations) from family, neighbors and healers	The treatments taken: biomedical prescriptions from doctors (pills and serums) and non- biomedical (home remedies and market- purchased eucalyptus) from family
The network of information sharing during the pandemic: neighbors, elders, healers, shamans, and younger individuals specifically for social media dissemination	The network of information sharing during the pandemic: social media messaging, and limited communication with neighbors and family

#### Reluctance and fear of hospitals

Hope and optimism for life after COVID-19 infections	Grief and fear over COVID-19 related loss
Knowledge on local plants for combatting new infections	Living post-illness and accepting a different functional status

Most interviewees elaborated on how prevention of illness during the pandemic consisted of using masks, cleaning appropriately, limiting contact with others and taking care of oneself. With regards to limiting contact, the people of Pano mentioned this at times, but the reality implied by the stories signaled that was not happening. Neighbors often visited, drinking parties still happened in the neighboring town that people frequented, and often when people were ill, they went outdoors and even visited neighbors. In Santa Rosa the contact limiting, and quarantine was different. There were no stories about neighbors or friends' meeting, there were no parties. The military circulated regularly, and fishermen that were desperate for food or income braved the ocean at night to fish. People were limited on food and medicines and encountered the virus usually on market or work visits. The infections spread fast, despite that people reported mask use. One reason could be the wrong application of the mask, which comes up in several interviews, where the inciting event is said to have been due to someone who wore the mask below their mouth.

With regards to taking care of oneself this phrase was interestingly recurrent in almost all interviews of both towns. However, the intended meaning of it varied; I began to recognize this phrase as a symbol for different concepts in each town. In Pano (similar to what I saw with the Kichwa midwives in Archidona) taking care implied that you paid attention to your daily activities and food, balanced rest and work, avoided risky places and maintained faith in the power to be healthy. In Santa Rosa, taking care meant using the preventive measures, of using a mask and limiting contact, cleaning, and eating and exercising right.

The onset of the illness thought to be COVID-19 was in most cases accompanied by a reasoning of how and when it happened. People in both towns had a clear sense of where and/or who had been the culprit for their illness. In Pano, people more often cited some shortcoming from their end—not taking care—that made them more exposed to illness.

Revelations, personal and familial, were experienced by people recovering from strong infections, and at times they were associated with mystical experiences, which I will share in the excerpts of this chapter. People felt transformed by their illness experience. Several had specific moments where they felt saved or like they had returned from death.

Caregiver networks were also clearly present in most excerpts I presented from both towns, and they seemed very pertinent and central to the recovery of the patient. The caregivers in Santa Rosa were primarily the children that lived with or nearby the older members. Meanwhile, in Pano the caregivers were children, parents, grandparents, neighbors, shamans and other local healers that sent recommended treatments for COVID-19.

The fear of the biomedical hospital, and the reference to it as a symbol for eminent death were prominent in both towns. This is especially peculiar because interviewees (from both places) were still able to distinguish between the biomedical doctor that is good, attentive and necessary in the home or health center, and the dangerous untrusted hospital were the authorities try to kill patients.

Most of the individuals interviewed—not surprisingly—did not have laboratory testing to confirm their SARS-CoV-2 infection. However, they were all certain that their disease or health condition, during the pandemic, was related to SARS-CoV-2 (or covid as they mostly refer to the virus). This certainty was due to the specific symptoms of loss of smell, loss of taste, an unprecedented fever and/or shortness of breath, which became indexical signs representing COVID-19.

Not all the themes were so consistent between the towns, after all, Santa Rosa had witnessed a huge trauma with "dead bodies on the street" becoming a popular reference to the suffering the town endured in April 2020. My key informant in Santa Rosa, WF, provided a concise and informative summary of this distinct reality in the town:

No one knew here who was sick and who died. Amongst friends, people talked, saying drink this water (aguita) or prepare this or that. The hospital was one's own home, each one prepares the water and drinks it. But here, no one knew who got sick. And who died. And if they died, they threw them out of the house and took them directly [to the cemetery]. In the hospitals they did not accept patients, only one hospital accepted, and no one wanted to go there, because it was contaminated. People made hospitals of their own homes...The disease never announces itself; it comes in suddenly... Here in Santa Rosa, since the 19th of March [2020] in April and May, 137 friends and neighbors died, many others improved, and stayed *flacitos* [thin], it was a miracle of God. (WF, Santa Rosa, June 2020)

Perhaps the difference in mortality rates in the towns I visited played a role in how people told their stories and some differing themes I picked up on. And maybe the different mortality rate can be explained (partly at least) by what the people report in their stories: like absence of health centers, lack of local resources like plants, lack of community organization and networking and a general sense of defeat.

For starters, one of the distinct themes was in how story-telling of the pandemic was done. The description of symptoms in Pano, often came off as a performance in most interviews. The people used animated tones, reenacted certain symptoms with body expressive movements, prompting iconic representations or vivid images of the suffering their bodies and minds had passed. This will be obvious in the excerpts too; I point out how people describe rather than just list their symptoms. In Santa Rosa symptoms were typically listed, there was not an engagement in the recall of how the physical body felt or was in most instances. The words used were plain and symbolic: diarrhea, cough, fever for example.

The people of Pano when referring to non-biomedical remedies often named multiple local plants provided or gifted by family elders, neighbors or healers. *Guayusa, animi, matiku, chuchuwasu* were commonly cited names. In Santa Rosa home remedies were prominent, but limited to common fruits (orange, lemon, pineapple), spices (cinnamon) or market-dependent plants (eucalyptus), prepared based on social media posts seen or personal experience with them before the pandemic. There was no practice of caring between neighbors or healers evident from the interviews in Santa Rosa.

The access to biomedical services, specifically doctors, was something that was given importance by all interviewees; it was vital that a doctor assessed the patient, be at home or in a clinic. In Pano, a public free clinic was still functioning and dispensing medicines. In Santa Rosa, it was not the case as I highlighted earlier, no clinic was open, and doctors were scarce within the town; most had to seek doctors by phone, go to another town to find them, or wait for ambulances that never arrived. When patients in Santa Rosa did find a doctor, the biomedical pharmaceuticals prescribed were often too costly for them to buy, they had to pick one treatment over another or suffer financially to buy medicines and stay without food.

A community driven network for sharing treatment options (specifically plant recommendations), and narratives about how to take care of oneself was evident in Pano, and went beyond just the family circle. This network also cautioned people in town about who was infected. The local healers and shamans, and the elders played a role in providing the knowledge and advice to guide this community network. In Santa Rosa, there was no apparent communication web amidst the chaos of the pandemic specific to the community. People were receiving reports from WhatsApp over what the pandemic is and receiving advice from the ministry of health to go to the hospitals and clinics, but that was not even available or relevant to them.

Life after surviving an infection with COVID-19 was also distinct in these towns. Though there were people in both towns that still felt they were recovering after weeks of infection (a phenomenon that biomedicine has highlighted and labeled as Long COVID-19), most of the interviews in Pano were hopeful and optimistic about their lives at the time. People in Santa Rosa were still in grief, especially the ones who had suffered with the death of a close relative or friend. The people who still had physical complaints (usually sensation of weakness), expressed a negative outlook on life after COVID-19, and were resigned to the new functional status the virus had bestowed on them.

#### 3.3. Select Excerpts from Santa Rosa

In these excerpts I highlight words, phrases and sections of the interview where I identified themes from Table 3.1., and I begin to focus on specific labels for SARS-CoV-2 health conditions.

Excerpt set #1. This was set in the house of AJ, a 70-year-old man, husband, father of 6, working for a company in Santa Rosa, and MF a 68-year-old woman, wife, mother of 6, and

keeper of the small shop the family runs. This was the first house I visited in June 2020 in Santa Rosa, and WF accompanied me inside. We sat by the entrance inside the shop, they put some chairs out and left the main door open. They had several photos of saints and Jesus up on the wall of the shop. Both husband and wife, and their 6 children, had suffered with COVID-19 and recovered successfully, but several of their neighbors and friends did not.

A man came to give me the insulin, and he had his mask lowered when he was here. The next day I was struck with a fire, I had a fever. My family took me, because there was my wife in the house, the children took me there to a doctor in Tumbaco... But I felt a fire inside, the doctor told me that I had nothing [wrong]. He gave me a pill, but they were hurting me, they made me want to vomit. They [the pills] were for killing the *bicho* [bug]... I had no strength, that's why it [COVID-19] happened to me. They [family] sent me serum with a blessing... I had a cough, diarrhea, everything. No one believed me that I have a fever, the fever was inside. Now I was feeling bad, and I couldn't even move, I wanted to cry. In the night there was a santito [saint] of hers [my wife] looking at me, and it gave me something, it had been 7 days I had been talking to my [deceased] father and crying, and I saw something white here [points to the wall and begins to heavily sob for several minutes] ... And I took the serum and healed...look at this medicine too [demonstrates a box of multivitamins] it costs 25 dollars. My friend also took it three times a day and improved. This was for the defensas [immunity]... I do not have the same body as before the covid, I stayed weak, there was no food, we were searching for a foundation to donate medicines, foods, vitamins. I had friends that died, they were [doing] better than me, but they died...(Interview to AJ, Santa Rosa, June 2020)

In this excerpt with AJ, several of the themes over the inciting event for his illness, the limited access to doctors in Santa Rosa, the named symptoms, the weakness after the infection and the revelations during sickness stand out. Here we also see a label for the virus that was commonly used in interviews in Santa Rosa, the *bicho*,<sup>5</sup> which translates literally into bug. This sign for SARS-CoV-2 seemed to have been manufactured and used locally, since I did not find such a reference in other parts of Ecuador.

MF described her experience after AJ (Figure 3.1):

On the 25th of March it started, and I didn't go to work. In the market of Salinas, I caught it. My daughters told me not to go to the hospital and stay here. My daughter rubbed me all over my body, she cooked for me, made the soups. They all got sick then, her, the husband and

<sup>&</sup>lt;sup>5</sup> This term, *bicho*, is not exclusive to COVID-19, it has been used to describe other infectious diseases or even cancers in Ecuador and beyond.

babies with cough. They had phlegm, and had to get that out, the chest was filled with it, if she swallowed, she would have been contaminated with the organism. She coughed with force, she made an effort and removed the phlegm... The doctor gave us something for the covid, a prescription [she presents a box labelled *flumacil*] ... we do not have the health like before. We do not have the same life as before. I still cannot wash things, I cannot recover. (Interview to MF, Santa Rosa, June 2020)

#### Figure 0.1. Picture with MF and AJ



Source: The Author (2021)

MF also demonstrated how the chronology of infection is made by patients and the role of familial caregivers. She names her symptoms and provides some more detail, which was distinct from how AJ described his symptoms. She explains how the cough is related to the severity of infection. It is ultimately a combination of the biomedical medicines, home remedies (blessed serums, special teas made by the daughters) and spiritual experience that resolve the symptoms and suffering of this couple. The phase of post-infection is also clearly described by both AJ and MF, as they conclude that they will never be the same again in their bodies after this unprecedented experience. Interestingly, MF also introduces other labels for SARS-CoV-2, like "the organism", and "covid".

Grief was also very prominent in this family. There were long pauses of crying and shrieking as memories of the suffering surfaced, and then especially when MF recalled the death of her father:

Why did you leave father? Stay here, I used to tell you I will take care of you once you're old [sobs]...my mother had a strong cough, I saw her on a video call, she was worse than my

father. My father was alright, my brothers brought a doctor to the house, but we could not find the medicines prescribed anywhere... my sister blamed the ones who called the ambulance for his death. My niece who works in the hospital said they had everything there... (Interview to MF, Santa Rosa, June 2020)

Excerpt #2: Another interview I conducted was in a household that had lost its eldest member after suffering with COVID-19 just 3 weeks before my visit. In the interview, the daughter, IK, of the deceased, and her 3 daughters, and 3 granddaughters were present, and the son, a fisherman joined us towards the end. It was a difficult interview, IK answered most of the questions, but was still in shock and grief from her father's death with a difficulty articulating even her own recent illness, so only limited probing was done into their experience (Figure 3.2).

The excerpt below is evidence that people resented and feared sending their loved ones to the hospital. The death of the father in the hospital becomes an added reason for fear. Perhaps, all the fear driven stories in Santa Rosa started from the first death reported in the hospital and the fact that a group cemetery was built right outside the hospital (as WF, key informant, had told me before). Other themes present in this excerpt are the biomedical and home remedies taken, and the caregiving process that resulted in her own infection and consequent illness.

We were all shocked [about COVID-19]. My father died, the 6th of April. He had a strong cough. I took care of him for one day, after my sister who was taking care of him became sick. He stayed in this room, here on the side. There was a private doctor that was checking him from a distance [virtually]. Then he got worse, we were giving him eucalyptus, serum to drink. And then we had a private doctor come to see him and they sent him to the hospital. They said he was so bad he had to go already. We had a fear of sending him to the hospital, we knew the stories from there. He died there. But my sister went to the hospital and we had a fear she would die too, but she came out. (Interview to IK, Santa Rosa, June 2020).

Figure 0.2. A Picture at the House of IK with Some of her Family, and WF Standing by the Stairs in the Striped Jacket.



Source: The Author (2021)

Excerpt set #3: This interview was conducted at the hair salon of SK, a 38-year-old transgender woman. It was the end of the day, and she was getting ready to close. Only SK and WF participated in this interview. SK was very elaborate and detailed with her answers. She and her husband were recently ill with SARS-CoV-2, and they both survived.

About how it started, my husband went out without a mask, I never went out and I don't smoke either, because I am a sick with diabetes and I heard the disease enters more people with diseases. When my husband came back home, and he had been walking out where people where spread dead in the streets, so I started with fever all night, an immense fever in the morning then, and I sent him to get me medicines and *aguita* [water] with cinnamon, lemon, eucalyptus, onion colored, and menthol. And I was sick for a month, in the second week I stopped eating, I had like a ball in my stomach. My husband and I had the same illness with fever, then cough, diarrhea and blood in our stool, and I was skinnier than him. (Interview to SK, Santa Rosa, June 2020)

Again, there is a clear depiction of an inciting event, tied to the faulty behavior of a partner this time, whom did not abide to mask wearing. The home remedies pursued are mainly fruits or spices popularly available in the town. SK names symptoms, and like MF in the first interview describes in some additional detail her experience of them. The reference of "ball in my stomach" prompts an image representation of a symptom. This kind of reference in Santa Rosa symptom referencing was quite rare, since most people used symbolic words that have become common terms in labeling private health experiences (cough, diarrhea, fever etc.).

SK also described the caregiver network she had and the process of care she underwent during her path to improving:

My family came and took me and did things for me in their home. My niece rubbed my body with leaves, and another one gave me medicines, I never went to a doctor. They made me like a recycled mask to breathe oxygen from using... They tried calling the emergency lines and they said we need to go to the hospital, but no one came to take us. We wanted to go but they never sent an ambulance. Then they got me a doctor to the house, he checked me and said I was all good, healthy. Everything was normal but I asked him for a serum to drink because I felt so bad. In one week then my appetite came back...the bicho [bug] must die...now I still do not feel good, and this will stay with us, it will not go away, it's like HIV, like a cancer, we have to go hard to get out of this disease [COVID-19], we have to keep using masks, putting alcohol, and take care, I put it [alcohol] on all my clients. (Interview to SK, Santa Rosa, June 2020)

Her family was quite creative in improvising care. The biomedical doctor offered SK the reassurance to keep getting treated at home, and his diagnosis label of being all good was something she repeated multiple times in the interview. SK's willingness to go to the hospital was a rare finding. Her husband actually went to the hospital and tested positive for SARS-CoV-2 but was then sent home because there was no space in the hospital anymore.

No one else I interviewed described a readiness like hers to visit the hospital. However, SK's willingness to go, and the fact that the hospital was overwhelmed with patients with COVID-19 (meaning that a good number of people still went to the hospital despite the fear) makes me think that despite the reluctance and fear in people, there may still be an inevitable trust in the hospital as a center for care and last resort of hope. Sadly, many people arrive when they are too far gone already, and died waiting for an oxygen machine or hospital bed to become available, as one of the doctors in the hospital SK's husband attended had told me.

Figure 0.3. Picture of SK at her Hair Salon



Source: The Author (2021)

#### 3.4. Select Excerpts from Pano

Excerpt set #4: This interview was conducted at the home of one of the key informants. The 55-year-old woman, FA, was near her home when she was invited to be interviewed and enthusiastically came by. In the passage below, a resemblance to some of the excerpts from Santa Rosa is seen, as well as the distinct tone people used to describe details of local treatments and symptoms. The description of symptoms was accompanied with an animated voice changing tones to signify severity and resolution, and arm gestures, references to biomedical and non-biomedical treatments, and the reluctance to visit hospitals:

I was sick for one week with fever, diarrhea and stomach pains [uses her hands to point out the area of pain and the way it felt] ...I didn't have any taste...It started in April, after my son was ill...I went to the *seguro* [health clinic] and they gave me paracetamol...I took home remedies, vaporizations, drinking *chuchuwasu*, *animi carra*, and with that I improved...I drank a lot of water. Water, water, water...we always drink that, it helps... In Pano, all the world, family for family had passed [sick] like this...no one wanted to go to the hospital,

because you don't come back, they made a hole there. My brother-in-law was like that; he went to the hospital and he did not come back. (Interview to FA, Pano, July 2020)

Excerpt #5: This was conducted in the home of a 53-year-old man whose story of surviving COVID-19 spread rapidly in town, since he had a rather large transformation induced by his illness. His descriptions are quite vivid as well, and include a revelation with a clear turning point in his health. He can also list detailed plants he obtained locally for his illness.

I used to go about the world, drinking, not thinking that there is a father God that gave us life...I was with a friend of mine sleeping in his house, and we were drinking, and after that night I was with chills and headache for 5 days...[then] I was with pain in my throat, and could not breathe. My breathing ended...I took *charubi, matiku*, and *chantabunta*... They sent many people to the hospital, and with that they killed them. many people had fear, it's better to die at home and be burned there... I went [to the health center] in Tena and they gave me paracetamol and ampicillin for tonsillitis, because it always happens to me. My son told me let's call the doctor, and he got a good doctor. We went to the doctor he made tests and said I do not have anything, what you have is chronic gastritis, and he gave me something else. When I got home then I stopped breathing. They gave me in the muscle [an injection], I was 16 days without sleeping, I was not sleepy. I went to [another] doctor, and he gave me an injection and a pill to take in the night and day and drops, and he said it is for gastritis. I got better...yes, it was [COVID-19]. Interview to ML, Pano, July 2020)

ML was clearly fearful when he was ill and the experience shook him into change. He saw multiple doctors, went to clinics, his family prepared a mix of plants all intended to fighting off the most feared infection. In his story, he seemed to avoid the acknowledgement of the SARS-CoV-2 as the reason or cause of his illness, since the doctors were also attributing his symptoms to other causes. However, in the end of his interview, after I insinuated that it could have been COVID-19, he agreed, and made it seem like he knew all along.

I was quite surprised by this narrative. Why did he not name his condition? Why did he not say it was covid, but clearly believe it to be (since I was referred to him as a COVID-19 survivor by my informant, and he positively affirmed all my COVID-19 etiology questions of his illness)? Why did he label it with the doctor's diagnosis of gastritis and tonsillitis? Perhaps, this label evokes stigma and served no benefit in his vocabulary. To ML what was important was knowing that he would be okay, finding a doctor he could trust, which gave him hope of improving, despite going through an unprecedented personal suffering.

Excerpt #6: RA is a 40-year-old woman, that appears notably older than her age. All her family felt symptoms within the same time period that included diarrhea, fever and, or cough. She was the main interviewee, but her husband and 5 children also participated when the plant treatments were discussed and demonstrated at her home. In this excerpt the narrative exploring the combined biomedical and non-biomedical treatments is apparent and the role the caregivers had in her healing:

I was sitting at home here and they told us there was a woman here sick with covid, so we stayed at home, and she came to visit us after visiting her sister, and entered the house to greet us. And then during sunrise I was with fever and the next day chills and my husband got me ginger and lemon, we did not know then to take the *matiku*, and he cooked them, and he gave me paracetamol and little of charcoal...I went to the health center and they gave me paracetamol and diclofenac three injections, my throat was dry and my head hurt, and then my mother came and gave me 23, or 25 leaves of different plants to prepare, and told me take only hot nothing cold...I did not have taste, I could not walk, I was inside my room closed from air, for 1 month I stayed without leaving my room, I did vaporizations, and washed everyday with hot water. (Interview to RA, Pano, July 2020)

# Figure 0.4. Picture of the Leaves Preparation Made by the Mother of the Patient and Stored in a Used Bottle



Source: The Author (2021)

# 3.5. The Labels Detected in the People's Experience

	Sign/Label	Object	Interpretant - concept
	Injection/Pill	A physical chemical substance	Treatment to remove symptoms for named diseases
	Health center	Building with biomedical health professionals day service	A safe place to seek medical help for disease
	Hospital	Building with biomedical health professionals 24hours service	A dangerous place to seek, a symbol for death OR A last resort for patients with severe disease
	Mask	Barrier for mouth and nose from open air	Preventer of COVID-19 or law to be followed
	Alcohol	Chemical substance	Preventer of COVID-19
Biomedica Lab test (F antibody) Taking car Serums <i>Gripe/Cata</i> (Spanish fe	Covid, corona	The SARS-CoV-2 pandemic OR The SARS-CoV-2	A new ambiguous reality to be discovered
	Biomedical doctor	The human with a stethoscope and white coat	Expert on the disease state
	Lab test (PCR, antibody)	The blood tube inside machinery tested	Validation of diagnosis and status label
	Taking care	Specific internal and external actions by the individual	Eating and exercising well, taking fruit, herbal or plant extracts, physical distancing, wearing masks
	Serums	Chemical liquid administered in IV or Oral	Medicine for strengthening one's body when weak
	<i>Gripe/Catarro/tosperina</i> (Spanish for cold)	A myriad of symptoms mainly runny nose, fever and headaches	Illness after infection with the SARS-CoV-2
	Not have nothing	Lacking specific signs of disease	To be safe from dangerous body threats
Shared labels	Caregiver	The human being	An essential role to

		providing care	maintaining health
	Plant names ( <i>animimi</i> , <i>matiku</i> )	Harvested plants from the local forests	Essential nutrient for the human health status
Pano only	Radiograph test (CT, chest x-ray)	The human lungs	Determinant of good or bad health status of lungs
	Organismo, bicho (bug)	SARS-CoV-2	An invader of the body and immune system
	Aguita (waters)	Liquid extract of spices and/or fruits	A substance able to sustain one's health
Santa Rosa only	Defensas (defenses)	Physical and energetic components within the body and the biomedical immunes system	An internal force for fighting infections and biomedical immune system

Source: The Author (2021)

Several conclusions or rather claims can be drawn at this point, based on the findings from the interviews and participant observation in the towns presented.

First, the official terms used by the Ecuadorian ministry of health (based on the WHO guidelines) to refer to the virus causing the pandemic—SARS-CoV-2, COVID-19, and novel coronavirus—were never used by any of the interviewees in the two towns I visited. The full name as published in formal communications or social media posts did not become part of the colloquial vocabulary. Instead, the symbolic labels and shortened forms of reference—covid, corona, and coronavirus—replaced them in the everyday conversations involving the new virus. Also, there were scarce new biomedical labels of medicines available and lab testing names being used in both communities, pointing to the obvious scarcity of biomedical resources to combat the pandemic in both regions. The main biomedical label, hospital, became a negative symbol at both sites, pointing to the deteriorating relationship between this institution and the people.

Second, these labels—covid, corona, coronavirus—were also rarely used within the storytelling of the illness phase. They came up at the end of interviews, or when people were describing non-illness reality, like the need to stay at home because of corona, for example. So, despite that people knew these labels and used them when referencing new regulations, behaviors or attitudes, they did not use them when talking about their personal illness story with the virus. Perhaps, the reason was stigma and the need to avoid feeling labeled by such a pandemic disease, and perhaps it was also the lack of certainty, since lab testing to give a

definite answer was not available. The only times I was told I had covid, or the doctor said it was covid, was when lab tests at the hospital or health center were done.

Also, I had to ask very specifically about whether the cause of their illness was thought to be related to *covid*. The patients were using other diagnosis labels to explain their symptoms (which initially confused me), but they did not feel that that contradicted the possibility of having had COVID-19. The labelling of their illness as COVID was not pertinent to their storytelling about the onset, symptoms and treatment of their condition. It did not change what they took and how they took it. What was relevant in their pandemic experience, was figuring out the practical aspects of what medicines work even if linked to other diagnoses (like the gastritis medicine helping), what saint to call upon, finding the best doctor to visit, and getting their neighbors or family to care for them.

Third, the doctors that were involved in the patient stories I heard from both towns rarely made a diagnosis of COVID-19 to a patient, at least based on what the patients heard or recalled. This could have been related to why patients consequently did not use the term in their own narrative, since the doctor did not provide it either. I find this particularly intriguing; the doctors' lack of labeling of COVID-19, was it driven by fear of causing bad outcomes or even stigma, or an uncertainty as to whether the label is appropriate? The diagnosis had to be assumed since no labs were available, and the diagnosis could be difficult, because the symptoms often overlap with other respiratory infections that doctors did label in some narratives. This point will ultimately connect with the ethnography on doctors in the next chapter.

Fourth, often, the subject *lo* (he/it) was used by interviewees to refer to SARS-CoV-2, *lo cogí* (I caught he or it), *lo encontré* (I met he or it). Such answers came after my typical questions of: Have you had any infection with the new coronavirus? Have you had any symptoms of COVID? Do you think what happened to you was related to COVID? This perhaps is even more evidence that the new terminology or symbols in the pandemic generated by biomedicine had not entered the common lingo for the public.

Fifth, in Santa Rosa the terms *bicho* and *organismo* I also noted were popular references. The virus had become an invader, an entity, and they gave it a label to signify its foreignness and threat, it was an entity that attacked like bugs did (the local experience with dengue perhaps weighed into that). People were very combative, and the new coronavirus was a personal attack on their lives.

Sixth, it was peculiar that the labels across the towns were not significantly different since they had very different epidemiological experiences with SARS-CoV-2; the high mortality rate in Santa Rosa most importantly. However, the themes from which the labels were extracted did show two key structural differences between the towns that my literature search had already somewhat pointed out. First, the unavailability of biomedical health centers or doctors as easily in Santa Rosa, and two, the presence of a structured folk and popular healthcare system with access to its resources in the rich jungles of and surrounding Pano. These had and will have repercussions before and beyond the pandemic.

Santa Rosa was getting eucalyptus in the local market, which was transported from neighboring towns that boosted immense fields of just this plant. The market for eucalyptus was spread across Ecuador; people wanted any possible treatment for COVID-19, including herbal or plant preparations, and this was a widely available and easily transportable one. (The scientific studies on eucalyptus are ongoing with several recommendations against its use or use with caution.) Other than eucalyptus, some people of Santa Rosa reported preparation of home remedies from available fruits and spices, but this was likely limited since most reported a general shortage in food access during the pandemic peak days. Also, most of the knowledge on eucalyptus and herbal home remedies mentioned to me were said to have been received from social media posts or forwards.

The relation of the people in Pano with plants was very much more present and detailed, and there was a sort of historical memory of pandemics (inherited from the elders of this Kichwa speaking group). The limited labels that did differ between the two communities of Santa Rosa and Pano showed that. There were tens of plant-specific labels that came up in Pano, and people related to them as powerful determinants of their health. Taking the right plant helped reduce suffering and restored health in most of the narratives. The knowledge on plants appeared to come from elders and local healers or shamans in the town. So, this knowledge was part of the popular system when derived from family members and neighbors, and from the local folk system when the healers shared their knowledge.

A closer look at one example of a healer system from the Kichwa tradition in Archidona, neighboring to Pano (in the Napo province) is next. This will bridge a better understanding of how folk systems played a role in the pandemic response in Ecuador and can demonstrate the benefits of such systems aligned with the national responses.

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#### **Chapter 4. A Professional and Folk Experience in COVID-19**

What makes ideas 'real' is the system of knowledge, the formations of culture, and the relations of power in which these concepts are located."

-Linda Tuhiwai Smith

In this chapter I present the comparison between the Kichwa midwife and biomedical doctors experience in COVID-19. I build narratives of each based on my fieldwork, and search for COVID-19 labels or rather conclusions on these labels as I go through the various examples. This comparison will highlight invisible realities from the Kichwa way of medicine, and explore the reasons or factors that allow for the biomedical way to often blindly dominate across societies and cultures.

#### Part A: The Kichwa Midwives

#### 4.1. The Midwives Before the Pandemic

A fellow FLACSO alumni, Alí Aguilera Bustos, studied life at AMUPAKIN, and presented an audiovisual ethnography in 2008. She described the process of traditional births, the handling of the body, and the modes of knowledge and its transmission in the Kichwa midwife culture (Bustos, 2018). The main conclusions, which form a vital introduction to my fieldwork, are:

- Knowledge inheritance for the midwives happens through oral Kichwa traditions.
- There is a diversity in the inherited individual powers, *pajuyuguna*, for each midwife, which is transmitted by various actors in their lives.
- The relations of the midwives with the plants, plant masters (*amos de las plantas*), the forest, and the peoples' suffering—especially women's—is central to the healing process of the midwives (Bustos, 2018, 79-81).

The ways in which the midwives practice and provide health in their community is quite relevant to the questions I ask about health labels during the COVID-19 pandemic. To understand how the midwives describe their work, I spent time collecting and preparing plants, drinking guayusa,<sup>6</sup> attending local events, helping in cleaning duties. All were activities that

<sup>&</sup>lt;sup>6</sup> The tea is prepared from the leaves of the guayusa tree, which are brewed over a high fire for hours, and commonly consumed in the early morning hours.

made the midwives willing to entertain my questions; they could see my genuine interest in their work.

One of the midwives early on in my fieldwork warned me that the *mamas* (local reference to the midwives) will not share information with me by speech, I would need to watch, see, feel, and hear what they are doing while they are doing it, so that I, myself, could understand and answer my own questions. This valuable insight by this midwife was useful not only to instruct me on how to observe and collect data, but also provided me with clues to the ways knowledge is produced and shared.

Before I present the narratives of several midwives during the pandemic, I will highlight relevant data about the context of the midwives' work. This will serve as the context for the narratives that follow, which highlight how developed, utilized and integrated into the local community the work of the Kichwa midwives truly is:

The center AMUPAKIN is used to having tourists and volunteers come by. Recently, two new events have been started at the center. One is the *wayusa upina*, starting at 3 AM, tourists, both local and international, are welcomed to a fresh brew of Guayusa tea, followed by spontaneous storytelling by the midwives present, an open discussion session for questions, and then a *limpia*<sup>7</sup> for each of the participants and sharing of *mitou*, a local traditional food preparation with fish and vegetables cooked in a big leaf on wood fire.

The other recent event started is the demonstration of the traditional birth process to the interested public. I did not observe one of these events during my stay, however, I did accompany in one of the real births that happened during my time at the center.

During this birth, I observed—and occasionally assisted at the request of the midwives—as three midwives delivered a healthy baby of a Kichwa woman who came in at 5 AM that day in labor. Specific plants<sup>8</sup> were collected from the forest and prepared in the kitchen, with the purpose of: pain control, improving contractions, and hemorrhage control. The woman's abdomen and cervix were examined depending on how strongly the midwives felt the contractions to be. Prior to examining the patient, their hands were rubbed by special creole

<sup>&</sup>lt;sup>7</sup> The *limpia* by the midwives consists of a combination of blowing of tobacco onto the recipient, and an application of carefully hand-picked leaves from select trees from their backyard forest, *chakra*. The leaves are tied together and then applied gently with stroking motions to the body of the recipient. This is followed by an application of the water of tobacco extract into the eyes, which generated short-lasting tearing, followed by a sense of relief, as reported by the recipients during the event then.

<sup>&</sup>lt;sup>8</sup> These plants include yucca tree leaves, chia panga, hierba luisa (lemon Grass), hoja de ajo (garlic leaf).

hen oil prepared with ingredients from a neighboring mountain. The same midwives accompanied the woman throughout the birth for over 8 hours, without a break.

When it was time for the mother to push as her contractions got stronger, one of the midwives, sat on the birthing chair, and the birthing woman sat facing her with their arms wrapped around each other. The midwife remained in that position for over 45 minutes, as the woman's contractions grew, and the baby began to descend. At one point the birthing woman felt defeated and weak, another midwife then entered and applied a firm spit at the crown of the woman's head, while they reassured her that the baby is coming, and she must keep pushing. Two contractions later, the baby arrived, and soon after the placenta gently slid out. The woman drank the post-delivery tea and was moved to her recovery bed where she sat welcoming her newborn.

There was a sense of calmness and composure throughout this birthing experience. There were no baby or maternal monitoring devices used, yet, the midwives seemed to know when the mother and the baby needed to be adjusted, or stimulated or talked to. The midwives only used homemade medicinal plants with their forest ingredients based on the inherited ancestral knowledge. The timing and content of these medicines were evidently intentional and specific. The only instruction or explanation provided to the woman birthing was when it was time to push, she was consistently told how to push and when. After birth, the instructions given were about the diet to follow pregnancy, and resting and rituals to be done, which she was already familiar with since this was her 7<sup>th</sup> living child.

Witnessing the birth and daily patient visits to the center also alerted me to additional aspects of the midwives' work. First, there is a personalization of the medicine prescribed by the midwives. They each use their personal expertise, combined with their special gifts, *pajuyukguna*, and ancestral knowledge to realize solutions to complex health encounters. Second, there is minimal discussion amongst them about patient health conditions and treatment plans during the treatment phase. Any discussion that does happen, occurs after the treatment is completed. Third, there are almost no medicalized, ambiguous, complex words used with the patient or even amongst each other. Rather, events and processes they encounter in their work are described: "the baby has moved...the contraction is here [pointing to the lower abdomen] ...the placenta is good...the bleeding is alright". In addition to these descriptive words, many hand gestures, body movements, facial expressions and sounds were made throughout the birthing. Sounds of approval or concern or relief became familiar to me; I would understand a midwife's assessment of a situation or the effect of a treatment provided

from the sounds made. This form of communicating was reliant on semiotic processes alive in the daily practice of the midwives.

# 4.2. The Vision for an Ancestral Center

Despite currently struggling to stay afloat as an indigenous led health center for the people of the community—because of finances and the limited number of trained midwives—Mama Ofelia reports the hope to open an ancestral education center, and to train more indigenous young people in the ancestral method of healthcare. In her words:

We want to become an ancestral college, to preserve the ancestral ways, so that they are not lost. Why should we continue? Because we take care, we maintain the *selva* (land), if we leave this knowledge, everything will be over. We need to preserve (the knowledge), because one day we will need it. (Mama Ofelia, my translation) (Interview with Mama Ofelia, Archidona, March 2021)

# 4.3. COVID-19 Narratives and Experiences

I spent one month at AMUPAKIN in March 2021, and shadowed and participated in daily activities with the midwives. During this time, I was mentored and came to see their understanding and experiences of the pandemic. This understanding I then depicted as a process of confrontation and adaptation to the SARS-CoV-2 reality, which the group of midwives experienced individually and collectively. In Table 4.1., I present the summarized process based on themes extracted from daily experiences, conversations and interviews recorded, followed by select excerpts demonstrating them.

# Table 0.1. Kichwa midwives' process of pandemic confrontation from the themes extracted

Midwives move to their remote forest homes with their families and restrict physical contact for at least 2 months

Midwives question what the pandemic is, through an internal and external exploration

Midwives experiment with their own medicines, prevention and cure processes

Midwives collectively share experiences, ancestral knowledge and stories, and design a novel ancestral syrup combination based on symptoms observed and plant actions

Midwives maintain an active community role: teach about self-taking-care, conduct rituals, engage in dream interpretation, directly care for the ill, and produce commercialized plant

#### syrups

Midwives personalize and improvise full-time care of patients with COVID-19: a daily reassessment and adaption of treatments is done

Midwives experience infections and illness with COVID-19

Midwives accept and resist biomedical treatment and prevention processes

The younger midwives relay pandemic related information to the older generation from social media platforms (Facebook and WhatsApp)

#### Source: The Author (2021)

All the midwives relocated to their jungle homes when the government announced the first lockdown in March 2020. They moved with their husbands and some even with their grown children and their families. They described this distancing as: "We packed our things and went", "I didn't see anyone for months", "we went and worked in the land", and "my husband I went to the jungle and only ate from our land, we ate all our chicken" (interview with the midwives, Archidona, March 2021). This was a time of new challenges, escalating warnings and threats, and the midwives knew they needed to retreat to their own circles to find answers. Some remained available via WhatsApp to consults from family, neighbors and old patients.

The questioning of SARS-CoV-2 and COVID-19 reports in the early pandemic by the midwives was apparent when I started conducting the interviews. Each one of the midwives set out to inquire into this novel coronavirus reality, and then they eventually gathered together—after returning from their jungle homes—to decide on the collective answer to this.

One interview in particular with Mama Adela stands out. I asked her about what the new virus causing the pandemic is, and how they are referencing it in the Kichwa tradition. Her reply highlighted to me how the midwives confront novel diseases or health challenges in their frameworks:

I do not know where the name covid came from, it is the invention of doctors, we used to say, *Eikulumarzo*... Now that they say covid we are going to see what that is...covid is the same, the covid as they say, comes from the flu of cough, fever, vomiting, diarrhea, pimples come out. That is why the old [medicine] cures...The *Eikulumarzo* existed with the grandparents, my grandparents time. The disease had come, there were people who did not pay attention, or children who did not drink [plants], but those who did they were cured... Overnight they [doctors] said covid, and they [people] died because they did not care of themselves... The Kichwa people all know that it is the disease they say [*Eikulumarzo*], but colonists say covid, they do not know where it comes from. They say pandemic.

With *Eikulumarzo* the breathing does [mimics heavy breathing and leans forward] ... The first day we sat thinking, what is covid, they say that it comes from China, and we are going to try... is it covid or something else? Covid what [signals with her hands]? It should be something from before, seeing that there were dead people before and now it is the same... The grandparents they told us how to heal. Those that do not value or care they die, men women children. (Interview with Mama Adela, Archidona, March 2021)

The experimentation with plants and other ritualistic approaches in the maintenance of one's health and for prevention of illness was a recurrent theme. Midwives consistently discussed plants when asked about how COVID-19 can be addressed. One afternoon, as Mama Adela and I were walking back to the house from the forest, carrying freshly harvested plants, she begins to tell me how she and her husband got ill, her symptoms, her reason for getting ill and what role the medicinal plants played in improving her health:

Mama Adela: We were out working and it was raining heavy, we said never mind keep working, and we got so wet. We got home and just a little time after, the *escalofrios* [chills] started, the next day, my husband's symptoms started. Mine stayed for 8 days, I took all my medicinal plants...My husband's symptoms they stayed for 15 days because he refused the plant medicines first, and only accepted when my daughter offered them in his *trago* [alcohol]...I knew [it was COVID] because of the pain, the *gripe* [cold], and loss of taste and smell of food. (Interview with Mama Adela, Archidona, March 2021)

Taking care of oneself—that Mama Adela mentions above—for keeping one's health well, was also discussed with other midwives. This phrase I also highlighted in Chapter 3 with the people of Pano and Santa Rosa. In each of the contexts it is used to signify or be interpreted distinctly as I had outlined in table 2. In Pano, taking care involved more spiritual and plant-based actions, not only eating and exercising as Santa Rosa's use of the phrase was. This is an important aspect in semiosis, the object and sign may be the same, but the interpreted concept, notably different. This agility in interpretation is powerful, since it highlights a multiplicity in knowing things specific to contexts. For the midwives taking care was similar to the Pano way of seeing things.

Mama Olga depicted what taking care means to her clearly one day when we were sitting by the fire waiting for the yuca (manioc) to cook:

For 15 days I have been sick, it was my fault I did not cure myself. I did not take care of myself. I was at home all this time. No one could take care of me. My daughter then came home for me and she made me a special diet, and plants...I improved...I had pains in my body, in my head, no appetite, my daughter gave me some pills also, it helped...it could have been I

was infected [with COVID]. I still have pain in my body in my bones...I still do not feel strong I do not feel strong...I need to rest still...I can't cure other people now. (Interview with Mama Olga, Archidona, March 2021)

So, caring for oneself, involves an attention to your own symptoms, taking rest, and most importantly: allowing others to take care of you. Mama Olga knew she was not well and she did not allow others to care for her, it was only after her daughter arrived that she was: taking care.

Mama Ines tells how her family got ill, and how younger people may fail to take care, because they do not know what things to cook or prepare for themselves, and do not know when or how to rest:

We all got sick. I was sick for 3 days. With plant medicines, I took and my husband we got better. We had fever, no smell, headaches, que *bestia* [expression of shock] ...My daughter from Coca she was ill and visited. Poor thing she did not know how to take care...My son he said he was okay. He was going to work in the field everyday...the next day he came home and said, oh my mom I can't take it anymore, I am not well...I felt him, he was with fever, so strong. I gave him plants medicine...he did not get better...I gave him pills...he improved the next day...the plant medicines they help...the pills they help too. (Interview with Mama Ines, Archidona, March 2021)

Taking care does not eliminate the possibility of getting infected with the coronavirus, but it will help avoid illness. This distinction in the expression between infection and illness in the Kichwa culture took a while to become clear to me, since the way it is expressed is quite different to what I was accustomed to from biomedicine where a distinction is also made in infection and sickness with the novel coronavirus.<sup>9</sup> It happened one afternoon during an interview with Mama Maria, which was not going anywhere—my questions seemed too inappropriate and filled with jargon. In my final questions I inquired about illnesses she had experienced during the pandemic. She tells me she was not sick with COVID, but I had known through the other mamas that all her family got ill at some point, so I persisted:

Author: Did you get COVID-19, coronavirus during this time?

Mama Maria: No, I did not get sick with this [SARS-CoV-2 virus] [shaking her head and rolling her eyes]

<sup>&</sup>lt;sup>9</sup> In biomedicine expression as I have explained is dominated by the ICD system in nosology. So, the classification of the human health state while infected with the novel coronavirus was set by the ICD system as a result of the research happening. Anyone testing positively by lab confirmation is considered to have COVID-19 as a disease, however the spectrum of diseases varied by: asymptomatic, mild, moderate, severe and critical. Asymptomatic symbolizing the infected but not ill, diseased persons.

Author: Did anyone you know get sick with it?

**Mama Maria:** Yes, so many, they did not take plant medicine, they did not take care. My son he got infected for days, he did not take care.

Author: Your son lives with you?

Mama Maria: Yes.

Author: Did you not get infected [contagiaste]?

Mama Maria: Yes, yes me and my husband we got infected.

Author: But you didn't get sick [enfermaste]?

Mama Maria: No no I didn't get sick. I took all my plant medicine every day.

Author: How do they say coronavirus or COVID-19 in Kichwa?

**Mama Maria:** in Kichwa we don't have that. It is pandemia, it is... In Kichwa, we say you should take care, don't stay in the rain, don't be cold, don't eat fish...we should take plant medicine, we should eat right. That is what we say.

Author: How do you refer to COVID-19 then when you speak in Kichwa language?

**Mama Maria:** [long pause] *tosperina* we can say, gripe... (Interview with Mama Maria, Archidona, March 2021)

To Mama Maria getting sick was only possible if she was not taking care. The plants, the diet, the actions one does, all kept illness away. To take care meant more than just prevention; taking care was a sort of resistance through rituals and plants. This resistance to getting ill that the midwives demonstrated, I also witnessed with Mama Catalina one time when she was describing a dream she had in March 2020, as we were walking back from the jungle.

I took Ayuahasca, alone. I saw the coronavirus as a bomb with mosquitos all around. It approached my house and I sent it away...it didn't make it to me...My husband and I stayed at home for 2 months, and ate from the land, we finished the chicken. We didn't get infected. Then, my daughter came to visit from Quito, and she was sick, I took care of her, I passed her medicinal plants. In 1 week, she was better... She had cold (*gripe*), headaches, lost her smell, diarrhea... It was [COVID]. (Interview with Mama Catalina, Archidona, March 2021)

The mamas' roles as health care advisors or consultants were also evident in many ways. Every week they had at least 10 calls or visits to AMUPAKIN by people who were looking for plant treatments for COVID-19. The midwives had come up with a plant-based medicinal liquid that contained 8 ingredients they had decided on after collectively discussing treatment options. The midwives also received multiple daily visits by people looking for treatments for common ailments, such as pain, fatigue, sadness, which were often interpreted but not always diagnosed as *mal de ojo* or *mal de viento*. The time the mamas cared for 2 patients diagnosed with COVID-19 at the center was the most insightful into their processes of care, and their method of personalizing the medicine to the patient. This experience I have included as a mini-case study with the text extracted from my field notes:

It was the day we returned from celebrating international women's day in Puyo with members from other indigenous nationalities. Two patients, a father and his son, were each given a small cabin (these were originally made for visiting tourists and learners in AMUPAKIN), across from mine, and they had confirmed SARS-CoV-2 infections based on the PCR tests that they had done a few days before arriving. The patients were mestizo (the local label used to denote the mixed origin of people, who have Indigenous and Spanish colonial ancestry) and referred by a friend of the midwives. The friend had visited the day before, but the midwife on-duty at the time had told him to take the special plant medicine to the patients, and to not bring them to the center. The next day, the president midwife, Ofelia, had reluctantly agreed to accept the patients in the center for full-time care, because they were friends of friends, and the son was still quite ill and nervous according to the friend. Protective equipment (masks and gowns) and Clorox were bought for the staff who would take care of the patients. No training or protocols or additional planning was made at this point.

Mama Adela and Maria agreed to stay in AMUPAKIN to be dedicated to the care of these patients, so that not all the midwives get exposed to the virus. They were also the only midwives who were willing to provide the care and stay for 2 weeks consecutively at the center. Some midwives were worried about getting infected themselves, and stayed away from the rooms. Mama Adela and Maria designed the care plan for the patients; they provided daily vaporizations, prepared and administered plant medicines to drink, prepared plant baths and monitored patients around the clock. The vaporizations were prepared with leaves of select trees including hoja de ajo, *matico* and *hierba luisa* that were boiled, and the pot was placed under the seat of the patient, as he was covered with cotton sheets. The content of the plant medicine drinks was prepared by the midwives based on how the daily progress of the patient was, and whether they could tolerate the plant according to the midwives' knowledge.

I was asked by Mama Adela to see the patients, since I was a doctor, and to tell her what I thought of their condition. On the first day, I found the father comfortable, with great vital signs (heart rate, breathing rate and oxygen were all within the right range for him) and his chest sounded great, I reported to Adela. The son meanwhile, was not doing too well, even though his oxygen was nearly normal at 95%, he was breathing too fast, and his chest was

congested. Both of the patients I discovered had already started a course of azithromycin antibiotics that was prescribed by their doctor based in Quito, who had sent them the prescription after confirming they had COVID-19. The son had experienced dizziness after the first day of treatment, and I believe it might have been as a side effect of an interaction of the azithromycin and the plants provided. When I told Adela about this, she agreed, and for that day she did not provide any strong plant medicines. By the next day, the patient was better, and had completed the azithromycin treatment and so plant medicines were resumed. It was quite a unique opportunity to co-participate in the care of the patients, and exchange knowledge and practices with the midwives. This experience with the patients also unveiled to me how the midwives see biomedicine. Though they may disagree with the institutions, but they do respect and seek the knowledge it claims. After 8 days in treatment, the father and son were both doing well. They felt better, the fevers, headaches and breathing problems were resolved. Despite being grateful for the care they received, they did object to the payments due for their care, which I found disappointing, since the care they received at AMUPAKIN would have cost at least triple that amount in any hospital. The midwives who had participated in their care were very glad to finally go back home to be with their families. I seemed to be the only one concerned (and Perhaps Mama Adela a little too) that they may pose a risk for their families and communities, if they were infected with the virus during the past week. Since then, thankfully, I still have not heard of any one getting ill in their social circles. (Field notes, Archidona, March 2021)

## 4.4. On the Labels for and of COVID-19 in Kichwa

By March 2021, it did not seem that the midwives were discussing much about the COVID-19 pandemic in their everyday. The pandemic topics only came up in the context of my questions, or when a new social media post relating to it came out, or when we received patients with confirmed COVID-19 at the center (happened 2 to 3 times per week). I cannot say if this was any different back when the pandemic initially started. This lack of interest in discussing COVID-19 initially made me hesitant on how much I could learn from the midwives about the Kichwa way of labeling in health. However, as time went by and the trust of the midwives in me grew and I learned to listen and observe my questions multiple findings on labels became clear to me.

There was a mixed response on my enquiry on labels among the midwives. Early on, when I asked about what or how midwives label or name COVID-19 infections they are treating, I received a blank face. To most of the midwives it seemed obvious that how they express the

diagnosis of a specific condition depends on their symptoms, most times calling the diagnosis by the symptom itself, like the patient has a cough, or they have diarrhea, or their walk is not stable, they rarely use grouped or classified disease names to refer to the condition being treated.

From the COVID-19 and non-COVID-19 related conversations we had, I came to appreciate their descriptive nature in approaching disease and health processes. In a free listing exercise where I asked the midwives to list the categories of disease they usually manage, only a handful of diagnoses (all being words they had picked up from the biomedical practice) were mentioned: anemia, epilepsy (they would have to discuss among each other to remember this one), infection, dehydration, tumor, and cancer. I understood that the name does not matter too much to how they treat diseases, because to them it is about the features of the disease state, it is about *what* the patient has. Interestingly, some diseases to them should not even be named or described to patients, because the name can cause *susto* (a type of illness resulting from shock and manifests as diverse neurological symptoms), and hence, it—the disease—should be treated in *oculto*, hiding.

With my newfound understanding that midwives do not create typically labels for the conditions they are treating, I rephrased my question on COVID-19 naming, and asked what others said and what term they used themselves in speaking to people about the pandemic. The names of *catarro, gripe* (the latter two words translate to cold from Spanish), *tosperina* (Spanish for cough), and *Eikulumarzo* came up. Only 3 of the 9 midwives mentioned Eikulumarzo as a name for the infection by the virus. Rather than names as labels for COVID-19 infections, I was being told descriptions of what it was causing. I had to suffice with that.

Others use the term *kashaunguy* or the thorn-virus to describe COVID-19 because the image of the actual virus looks like a thorny seed that can be found in the forest. In general, COVID-19 is an *unguy* or illness of which there are several kinds, but *unguy* usually refers to an infectious disease. So, in general, people were mapping COVID-19 onto their understandings of past epidemics and using terms similar to those to describe other respiratory diseases like the flu.

Meanwhile, the most recurrent labels I did hear during my time in AMUPAKIN pertaining to the virus were linked to the plants used, *matico, hoja de ajo (sacha aju), hierba luisa, chia panga, baslamo, jengibre,* etc... Though I initially met this reality with frustration, since it

certainly was not what I expected to find (I imagined there being a labeling system that connected their diagnosis and treatment—a very biomedical prejudice from my end I must confess now in retrospect), I later appreciated that this was pointing me towards what was important to the midwives. The label for plants was more important than that for disease, because that is where their main power laid.

Moreover, the midwife president Mama Ofelia had mentioned to me on multiple occasions how heavily researched some of the plants have now become by foreigners and *Mestizos* coming to visit the center and ask the midwives about them. There have been growing publications in phytochemistry (study of chemicals derived from plants) and ethnobotany (study of plants) demonstrating the medicinal power of these plans they were utilizing at the center.

# 4.5. Relating to and with the Clinical and Public Health Biomedical System in Ecuador

Menéndez's (2004) conclusions detailing traditional medicine as a system in an ongoing process of renewal and revision, rather than an untouched practice of the past was quite clear to me throughout my time in AMUPAKIN. There were multiple types of relations between the midwives' system and the local national health system, and each was a result of preceding events and processes between the two that I came to learn about during my time at AMUPAKIN.

First, there is an ongoing tension between the biomedical clinical professionals in the health centers and hospital in Archidona and Tena respectively, and AMUPAKIN midwives. This tension arises from a competition for patients, specifically pregnant women. AMUPAKIN midwives encourage local community members to have their births at the AMUPAKIN center, while the health center doctors aim to have 100% of women deliver at the hospitals (the indicator of gold standard quality care for pregnant women). The tension also rises from a failed attempt in constructing an inter-cultural health center in 2017. It was created based on a ministerial decree that encouraged the incorporation of traditional midwives in biomedical work (MSP 2010). Through this experience, the midwives report having been mistreated by the biomedical doctors that did not appreciate the work they did, and did not allow them to provide the care they knew to provide. They also reported being unpaid, and felt that their center was used without benefit to AMUPAKIN and its mission.

Unmet promises for valorization of midwife knowledge and work also contributed to the tension. Despite that the ministry of health issued multiple statements supporting traditional medicine and the people's right to it, the application of this has been significantly lacking, according to the midwives. Traditional midwives have been recruited to work in hospitals as nurse midwives, and have been consequently underpaid and underappreciated with their skills and knowledge. She sees that all efforts by the ministry of health and local biomedical doctors have focused on empowering the biomedical practice of birthing and undervaluing or disregarding the traditional midwives' knowledge.

A second type of relationship the midwives have with the biomedical system is their consumerism of biomedical services and medicines. Several of the midwives reported that they have visited the health center and or hospital locally for their children, for vitamins during pregnancy, for bone fractures, for treatments of dengue and malaria and even for having their own baby delivered. In the latter case, the midwife reported: "I was visiting a friend at the hospital and I was pregnant...it was my time...and when my contractions started...my daughter, she studies chemistry, she did not let me go home, she told me to deliver in the hospital" (Interview with Mama Catalina, Archidona, March 2021).

Moreover, there are certain medications that are generally accepted and commonly used by the midwives, such as, paracetamol—which one midwife carries in her bag at all times. Also, antibiotics like Ampicillin and Augmentin were accepted as appropriate treatments by the midwives for infections of the lungs or skin if the patient did not get better with the plant medicine. Most of the conversations that reported the use of biomedical services came in casual conversations I had with the midwives during work hours, and almost never during interviews, even when I was asking specifically about biomedicine applications.

A third aspect is the conditional yet very present respect and appreciation for the biomedical process in their own lives. This was evident in multiple conversations summarized along the following themes: the appraisal of a certain indigenous biomedical doctor or nurse who is familiar with indigenous symptoms and complaints. The referral of pregnant women to the hospitals if they had alarming signs according to the midwife. The referral of patients for biomedical testing and diagnostics if not improving with the midwives' treatment provided, and the referral of patients with primarily biomedical diseases like dengue and malaria.

In conclusion, the midwives' narrative during the pandemic demonstrates a strong and developed ability to analyze, be agile, adapt and advance an ancient traditional medical system they have inherited from multiple teachers. Though the Kichwa system described

above is certainly not one that can be easily replicated or taught, since it involves select inheritance of knowledge and abilities, locally available resources and is reliant on oral tradition rather than written text, there are certainly many lessons to derive from their experience. Their lack of emphasis on labels to frame disease or illness to describe the condition to the patient, coupled with their vast dictionary of labels in identifying plants (and their various parts- leaves, bark, roots, etc.) were a cue to their healing-centered approach with the patient and community. The process of identifying disease is very personal to the midwife, none of them could (or perhaps wanted to) tell me how it is done, and for that reason the creation of labels for naming the culprit diagnosis was irrelevant to them. This also demonstrates their faith in the medicines they do have to offer, and their encouragement of the patient and community to focus on what can be done, rather than dwell on the fear and doubt that may come with a disease label that carries negative connotations (such as with COVID-19). The Kichwa midwife experience is a prime example of community resilience and local resource application, it is a personalized form of medicine, one that takes time and effort to design and apply, and it should be studied accordingly. I cannot study Kichwa midwife practices with a biomedical lens looking for equivalents of COVID-19 labels there. The very foundation and way of practicing Kichwa medicine is truly distinct; that was perhaps the biggest lesson I learned and one that appreciates the unknown realities that Santos refers to in the medical sciences at least.

### **Part B: The Biomedical Doctor**

#### 4.6. The Professional Biomedical Doctor Pandemic Narrative

I wrote the following passage on March 17, 2021:

A friend called me in late January 2020 asking if she should cancel her family vacation plans to Bali, I, like many physician colleagues of mine at the time did not comprehend the magnitude of this infectious disease coming at us. I told her she could possibly go and take care in the airports. Before and after January 2020 marks two very distinct eras in biomedicine. My current logic believes I was significantly at fault in my advice to that friend. (Personal notes, Quito, March 17, 2021)

An anthropology of the biomedical experience during the pandemic is a huge task, and despite being useful to my questions on labels, it is beyond my scope here. So, I chose to only focus on one actor in biomedicine, that is quite familiar to me given my own background, and whom I encountered throughout the months of fieldwork during the pandemic, the doctor.

At the onset of the pandemic, I got involved with the medical NGO (MG) to do voluntary assessments to raise awareness and funds in support of the people in Santa Elena and Guayaquil. My work involved many interactions with a number of physicians working with MG, the municipalities of Santa Elena and Guayaquil and the ministry of health of Ecuador. With the doctors at MG, I was planning and coordinating training sessions for Ecuadorian intern doctors. With the municipality and ministry doctors I was conducting assessments of the local health situation. Consequently, I collected a number of emails, saved documents and publications, interviews and field notes, which generated my insight into the process the average doctor (clinical and public health aspects considered) experienced throughout the pandemic, from March 2020 through March 2021. Next, I summarize the themes of the biomedical process with select excerpts from the data, beginning with the Table 4.2. outline that presents a similar frame to how the midwife process of confronting the pandemic was done.

# Table 0.2. General biomedical doctors process in the pandemic confrontation

Doctors question, resist and accept the new threat of SARS-CoV-2

Doctors work through confusion and doubt, with limited resources, weak local and national health systems and raging politics leading to mental stress and illnesses

Doctors experiment with different treatment applications guided by biomedical theory and experience, and share individual results and recommendations through forums and blogs

Doctors struggle to maintain a functional and useful doctor-patient and doctor-community relationship, as they combat "misinformation" over biomedical pharmaceuticals and home remedies in the community/public

An exponential rise in publications and guidelines on treatment of patients with SARS-CoV-2, with various contradictions in conclusions, led by universities, pharmaceuticals and other research centers

Popularity of select pharmaceuticals as potential medicines for COVID-19 leads to their scarcity, drives up prices, and leads to controversy among doctors.

Doctors' health suffers with SARS-CoV-2 infections, which adds a burden to the public healthcare system

Doctors adapt to the rapidly changing clinical recommendations for patient care almost daily,

while applying their own experience and logic to final treatment decisions

Doctors adopt the ICD language for reporting on SARS-CoV-2 related diseases

Doctors have mixed perspectives on certain herbal and plant remedies.

First there was doubt and disbelief. Before the WHO announced the officially recognized global pandemic on March 11, 2020, more than 2 months of debate had passed in the medical community over the seriousness of the SARS-CoV-2. Text messages with colleagues working in hospitals that still had not seen a surge in infectious disease cases made them skeptical of what SARS-CoV-2 could do, and doubted the relevance of the China experience. One colleague that works as an infectious disease specialist in the United States wrote me on January 20, 2020 with the following: "It's probably like MERS, we just need to watch our borders better, not let it get in and if it does, we just manage it in the hospitals. I doubt it's more infectious, it's just a coronavirus." (Mary, Whatsapp call, January 20, 2020) (MERS is a reference to the middle eastern respiratory virus that is also from the coronavirus family, and had spread in the news as a potential global threat in 2012.)

The mental frameworks and personal experiences of doctors made them disbelieve the possibilities of this new coronavirus (similar to what happened with me). The knowledge doctors had, made it almost impossible for them to imagine the consequences of the data coming from China at the time, on the work and social life. The SARS-CoV-2 with its novel behavior and characteristics as a coronavirus, was demanding that doctors think differently and accept the unknowns that this novelty introduced on a global biomedical scale.

At MG, the team was organizing a one-week free medical clinic in early March 2020 in Colombia. I was scheduled to join as a medical doctor. Two days before the intended travel date, and after 5 doctors had pulled out due to their hospital regulations in the United States, the project was cancelled. The leading doctors on the team, who were well into their fifth decades of medical work, initially remained skeptical of canceling due to this new coronavirus.

By the end of March 2020, the skepticism was gone. The pandemic was now real to everyone on the frontlines. The email communications from MG staff refocused on planning COVID-19 medical activities in the ten countries where it works. Meanwhile in Ecuador, the skepticism mostly disappeared by March, after the intensive care units in Guayaquil and Santa Elena became saturated, and scenes of dead bodies laid in the streets were shared in social media. Doctors—like most of the public—now believed that this virus is real and dangerous, and they needed help.

My doctor community of friends, colleagues at MG, and several municipal and government doctors I met in Guayaquil and Santa Elena all felt and expressed fear for oneself and community, through the months of March to June. They also commonly expressed frustration coupled with sadness and pain over the reality of patients suffering and health systems failing.

In Ecuador, the doctors I met were fearful for the infection they could spread to their families at home. One odontologist who was recruited to work as a director in a municipal COVID-19 center in Guayaquil, in April 2020, told me how he became severely depressed and anxious after starting his job. He was obsessively fearful of infecting his mother, whom he lived with. He worked 12 hour shifts some days, and then went home read new research on the virus and uncontrollably checked social media, which made him most anxious.

Now, by June 2020, he was numb, just trying to survive, and to take care of his mother, while avoiding the intrusive thoughts of getting infected and dying. He made a decision that he has to stop checking social media, the stories of all the dead in Guayaquil were haunting him. The odontologist and his colleagues also had lost several colleagues due to COVID-19 and had limited resources to protect themselves in the hospitals and clinics.

Most doctors I met between April and May in Guayaquil had been infected with COVID-19, or lost a colleague that works in the hospital or community, which also brought on sadness and pain. The system that doctors were entrusted with was falling apart. Doctors felt paralyzed: no protective personal equipment, no oxygen access, no beds, no support staff and no control over what was happening inside and outside the hospitals.

Doctors also seemed to be struggling with their relations in and with the community. I heard from multiple doctors working in hospitals how the community is not doing enough to prevent infections. An infectious disease doctor in Guayaquil annoyingly remarked how people stayed in the markets and did not take care, and they were to blame for the rapid disease spread and the local hospital problems.

Also, some doctors preferred to work in areas of the hospital or clinics not attending to COVID-19 patients, and that made the division of work difficult for administrators. Meanwhile, doctors thought that patients with chronic conditions were fearful to come to their clinic appointments, because they thought they would get infected with the new virus there. This made it difficult for doctors that worked at public institutions to continue to help their patients, and caused the deterioration of the health status of many people with diseases like diabetes and high blood pressure.

The relation of the doctors with the central and provincial government—in Guayaquil specifically—did not go well either, at least in the period of March through June 2020. In April, most of the municipality personnel, including the mayor, and the public health experts were ill with COVID-19. The lead epidemiologist that was designing the response plan with the mayor passed away due to COVID-19 early in April, and that led to a panic within the mayor's office, which managed the hiring process of the affiliated public health department. Meanwhile, the mayor and the central government were not getting along, and entered a televised debate blaming each other for the dead corpses in the streets, and poorly managed COVID-19 response. Physicians in Guayaquil suffered the consequences of the politics happening, since it prevented the design of an adequate emergency health response. Both the national hospitals led by the ministry of health and the municipality-run health centers, were understaffed and lacked the basic equipment to attend to the climbing numbers of infected people.

The same was true in Santa Elena regarding being understaffed and underequipped, however there was no political tension between the municipality and central government. This small province lacked the financial assistance and health infrastructure to maintain a health response during the pandemic. The doctors were overworked, underpaid and getting infected. Health centers had to close in multiple neighborhoods because their staff was infected, and that subsequently, left people without access to primary care (and justifies the fear people had over attending health centers). The bridge between community and hospital was lost in Guayaquil and Santa Elena. The doctors and the public were terribly frustrated, and left helpless in the most critical time of the pandemic.

## 4.7. Examples of the Biomedical Knowledge and Beliefs Transformation

In the months of January through March 2020, there was little official data about how COVID-19 manifests and its potential treatments. This was evident by the single page outlines that summed up the existing evidence of the time to guide COVID-19 management and treatment. Doctors were equally as bewildered as patients by COVID-19, despite the familiarity with and knowledge of other viruses. Adapting to working with COVID-19 implied an acceptance of its novel, unprecedented existence first. The first clinical guidelines

that colleagues made at MG and circulated to their global clinics for doctors to follow, were vague and focused more on infection prevention and control, rather than treatments. These same guidelines were changed almost weekly, and the final result had little similarity to the original. Consequently, many doctors embraced this scientific unknown. They relied on their general knowledge of viruses and infectious disease to deduce potential treatments in the hospital—as one physician in Santa Elena remarked to me.

Doctors working inside hospitals with patients with COVID-19 shared horrific stories of suffering from severely infected patients, and questioned how this virus works in the human body. Multiple theories emerged on how SARS-CoV-2 was working inside the body, i.e. the pathophysiology of the virus. These theories were important because they dictated which framework for confronting SARS-CoV-2 the doctors explored, tested and, or adopted in their practice.

For example, observations on infection patterns led different medical groups to theorize diverse transmission patterns: contact, droplet, airborne, and even the fecal-oral route transmission were entertained at one point. The transmission was important because it determined what protective equipment was used, and which standards followed.

The number of research and publications investigating diagnosis lab and radiology testing and treatments began to grow exponentially by March 2020. Research was (and still is) happening too fast, and doctors had to adapt to a new treatment protocol everyday based on emerging studies from multiple centers, while considering their own experience. The research was also not organized by a single global entity, so it made it difficult for doctors to synthesize a single, clear meaning. Different research groups were proving and disproving each other.

An intensive care doctor in Guayaquil summarized it well with the following example: the question of when to intubate or provide other respiratory support to patients was largely debated (still is even now, like most themes relating to SARS-CoV-2). Initially the intensive care medical community said intubate early because this is a respiratory failure kind of pathology induced by the virus, then new research came out and said that early intubation could be causing excess mortality from the virus, and it's more of an inflammation in the lungs, so intubate later; the later the better. There was also question about non-invasive respiratory support like continuous positive airway pressure therapy, initial data said not to do it, because we spread infections and then a few months later, it turned out maybe we harmed the patients we did not provide the therapy for. The same happened with steroids, we did not

want to give it, then we said we should because the virus triggers an inflammatory process. The same happened with the infection prevention and control recommendations for the use of masks, disinfectants and hospital protocols. We do not know what's right and wrong, and in what context.

For the specific pharmaceutical medications explored, the research process was more selective, but still fast. Any designated university or research institute (including pharmaceutical companies), public and, or private could theoretically study any medication or treatment protocol its experts deemed fit. The main limiting factor to this was funds and research personnel. So, in reality, only a limited number of universities and research institutes were studying COVID-19 related clinical themes, and even a more limited number of medical doctors and virology scientists were steering the studies. Not surprisingly, the research centers were also mainly focused in Northern America and Europe (India and China were also producing notable research too, which perhaps was not given as much attention by the global biomedical community). Also, several centers initially took shortcuts in making recommendations on potential medicinal drugs, and justified it with the logic that the world is confronting an emergency.

Early in the COVID-19 pandemic, this research reality was highlighted with the case of hydroxychloroquine (HCQ). Didier Raoult, a physician and microbiologist in France proposed HCQ as a potential cure for COVID-19, based on his expertise in infectious disease having discovered several multiple bacteria. He demonstrated the effects of HCQ on SARS-CoV-2 in vitro first, and then did a trial on 36 people. His publication within days transformed the standard of care of patients with COVID-19; numerous media outlets, research journals and academic universities believed (or wanted to believe) Raoult's claims on HCQ as a definitive treatment and promoted its use. Consequently, countries worldwide witnessed a surge in its usage. In Ecuador, HCQ became a controlled substance, which meant it could only be dispensed with a doctor's prescription (unlike most medications in the country).

All the physicians I discussed the hydroxychloroquine studies with, in April 2020, in Guayaquil and Santa Elena supported its use. A prominent business organization announced the donation of thousands of doses of HCQ to the municipality hospitals. HCQ had certainly become a popular medication.

However, this medication was still controversial, and its efficacy was still under question. By April 2020 there were already reports against HCQ usage based on critiques to Raoult's study. A few months later, new studies were published that clearly refuted the original proposal of Raoult, and made conclusions against the use of HCQ.

As of December 2020, the debate on HCQ has substantially subsided, and the WHO final recommendation is to not use HCQ for COVID-19. Still, for physicians that had a good experience using it in the early months of the pandemic, the practice of prescribing it persisted (for both treatment and prophylaxis). I noted its continuous prescription in Archidona, Napo in March 2021 from conversations with local pharmacies. The proponents of HCQ from what I gathered from online opinion articles on physician blogs and medical news pages were saying that even though you couldn't conclusively prove HCQ does work, you couldn't prove that it does not work (a faulty logic based on biomedical principals), and their daily work supported its use, hence the choice to continue its use.

An infectious disease expert in Guayaquil demonstrated this decision-making process when he described to me his use of steroids, also a controversial treatment back in May 2020. He was providing high doses of steroids to patients in his own personalized protocol that he believed in, based on his own reasoning of how the virus works inside the body. He was practicing this, despite knowing that his protocol was not approved by any scientific institution. He believed that most of the virus infections caused severe inflammation and giving steroids early must be better, even though there were few studies saying otherwise. He believed he should do what is logical to him, since we do not have many studies yet anyways. A few weeks later he changed his protocol and lowered the steroid dose, because he noticed many of his patients were getting problems from the high dose steroids, such as kidney failure.

So, even though the official and publicized medical protocols are based on select medical science research centers, individual doctors felt a liberty to customize (through their own deductive reasoning) the treatments they delivered to patients with COVID-19. The scientific uncertainty in the treatment of people having COVID-19 led to a type of accepted medical creativity in the medical encounter with doctors. Experimenting with patient positioning in the hospital beds, debating which existing viral medications could have the best chance for success, considering what supportive treatments can improve outcomes of non-hospitalized patients, were a few of the topics that doctors discussed in virtual platforms.

Science in medicine, for a brief time, seemed to detach from absolute truths and embrace a purely investigational and practical approach in confronting an unknown novel threat. The consequences of this in the public were also notable, since misinformation became its own

problem, and led to the infodemic that the WHO now even has trainings on. Doctors were not sure what was right, so how could the biomedical institution control what the public thought was right, everything could be imagined and written as scientific.

Eventually, by June 2020 protocols by recognized universities globally—specifically European and North American—for the treatment of patients with COVID-19 were emerging. Some consistency was starting to emerge across doctors' practice on the initially suggested medicines, but now there were new ones being put on the stand, and the cycle was restarting with them.

## 4.8. The medicalized Symbolic Labels

Based on the above summaries I concluded three specific uses in COVID-19 labels of health conditions. One, in my initial communications with doctors and public health professionals at the NGO, as well as the clipped readings I saved from January 2020 to mid-April 2020 the main term used to refer to the pandemic—including epidemiological and clinical topics—was the coronavirus or the corona: the coronavirus treatment, the corona problem, the corona infections, etc. In March, after the official declaration by the WHO of the global pandemic, the language used even in casual settings, increasingly included the term: COVID, and less so coronavirus. The terms SARS-CoV-2 and COVID-19 had been released by the WHO a month earlier in February 2020.

Two, clinical doctors—since February 2020—were also building an intuitive language that served the purpose of communication and sharing of experiences in this novel and developing clinical practice of COVID-19. The language used recognized terms in medicine applied to the COVID-19 context. So, new terms arose like: the asymptomatic and symptomatic COVID-19, with the latter consisting of mild, moderate, severe and critical categories, as well as, a description of the organs impacted, like pulmonary COVID-19 vs renal, dermatological or neurological COVID-19.

Three, the epidemiological inspired labels used for coding and reporting in the hospitals and clinics, were those designated by the ICD system discussed in chapter 1. These included two new additions released in March 2020 by the WHO: code name U07.1, indicating COVID-19, virus identified and code name U07.2, indicating COVID-19, virus not identified. U07.1 was for confirmed cases (people with) COVID-19, and U07.2 was the looser diagnosis that was assigned when the symptoms suggested COVID-19 or there was exposure to the virus but no

testing done or inconclusive test results (WHO 2020). In Ecuador, these were adopted into the official communications of the Ecuadorian epidemiological surveillance system (INEC 2010). Additional epidemiology labels, ICD codes, were added in December 2020 by the Center for Disease Control in the United States: "Encounter for screening for COVID-19, Contact with and (suspected) exposure to COVID-19, Personal history of COVID-19, Multisystem inflammatory syndrome, Other specified systemic involvement of connective tissue, Pneumonia due to coronavirus disease 2019" (CDC 2021). These codes certainly reflect aspects of clinical care that doctors needed to know more about, and were a common topic for discussion in the US medical literature. However, these terms are not yet included in the ICD of the WHO as of April 2021, despite circulating widely within global medical journals and news.

In Ecuador, these specific codes above are not being used in reporting at the level of the ministry of health, but the description of the code is certainly relevant and pertinent clinically. For example, screening for, personal contact with and pneumonia caused by SARS-CoV-2 have been explored in protocols, but not given specific labels or representative codes based on documents I reviewed from Ecuador and conversations with doctors in Santa Elena and Guayaquil.

In conclusion, this review of the biomedical doctors' experiences, especially the centralized process of official labels that often missed many realities needing attention through revised and practical labels for the biomedical practice of doctors, is starkly different from a Kichwa midwife experience. The biomedical doctor is extremely dependent on a written order of doing medicine, and reliant on global-set standards from the North often, which lack personalization or adaptation to a setting that may be very different in its features, including resources. So, the biomedical doctor was left somewhat isolated, with controversial labels in treatments, and major gaps in the labels of diagnosis that the doctor is very reliant on to understand how to do medicine. The biomedical doctor was often unable to advise the community on applicable medicine or resources for health (such as the hospital), because of major controversial information being received by the public on biomedical services and options during the pandemic. This was also evident in the stories of patients we explored in prior chapters.

So, the midwives were a group of introspective, oral tradition followers, inspired by their ancestors and local resources to heal and support their community, focusing their labels on

those that promoted health and wellbeing through local medicines. Meanwhile, the biomedical doctors were a group of individuals connected through a written tradition that was in constant flux with the urgent matter at hand, the pandemic, and were battling to remain updated and true to the science they learned, while falling short consistently in supporting their patients and community given all the challenges they faced. The systems these groups belonged to are significantly different in how they prepare their practioners, and the invisible realities of how the midwives go about performing their medicine is what was revealed and shown to be effective through the pandemic narratives presented. Surely, my argument is not that traditional medicine trumpets biomedicine, since they are of different foundations and purposes and cannot be compared so easily (biomedicine is a global directed one-size fits all science, and Kichwa medicine is birthed from community-specific theory and resources). But rather, the argument is that traditional medicine is credible and its invisible realities may help generate important public health interventions within their context and model communitycentered and driven approaches in pandemics.

#### **Chapter 5. Concluding Analysis: Recreating Lines**

Returning from fieldwork to begin writing the thesis was challenging. Fieldwork was transformative, without a doubt. The transformation happened within, in how I saw and understood things. My mind felt different, but it took a while to articulate it and connect the various narratives developed. Writing out the last two chapters brought much needed perspective into how the months of fieldwork across Ecuador and the virtual world played into my professional and personal life.

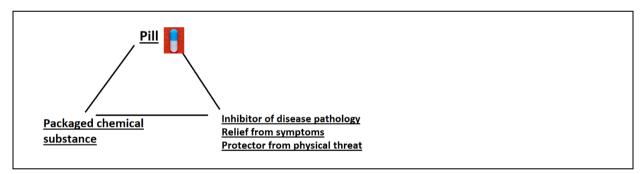
In this final chapter the connection is made between the various parts I have studied in the preceding ones. A display of all labels collected and analyzed is provided from the experience of the public in Santa Elena and Pano, the midwives of AMUPAKIN and the network of doctors I came across throughout fieldwork. Again, I return to using figures for outlining ways of thinking derived from the label's investigation, and engaging with the theories I introduced in chapters 1 and 2. I study the form of labels and where it is that they relate to the visible and invisible realities in medicine.

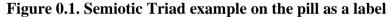
#### 5.1. The Summary: Official and Unofficial Labels through the Theory of Health Lens

Labels are classifications. They are classifications that create important differentiations in health care, and are ultimately what shape the communication around the spectrum of health. The official labels encountered in COVID-19 narratives, centered on disease, with the ICD codes and other epidemiological terms used by biomedical institutions and groups of physicians in communications for clinical care and reports. The unofficial labels (those not part of any national or international consensus policy for naming) in COVID-19 related health conditions were identified as those classifications that pertained to other dimensions of health beyond disease: the normal, social and private (or individual) domains, as Filho categorized them.

I incessantly contemplated the idea of unofficial labels as I read through the themes concluded in the tables of chapters 3 and 4. The themes were summaries of experiences in the pandemic, and within those summaries I could identify specific phrases and objects that labelled important aspects of health conditions. So, labels I deduced were collections of terms that recurrently came up and contained the features of a semiotic triad I described in chapter 2 (sign, object, interpretant). Moreover, these labels were essential to my findings and conclusions as I pointed out in chapter 2 that: By studying what symbolic, iconic and indexical sign processes prevail in a specific reality, I can imagine the silhouette that the thought of that reality is assuming. These processes highlight how signs are being understood by their various users.

For example, the word pill, *pastilla*, was quite recurrent across all actors I studied. Its use as a label or sign process was different. The pill was a creation of the biomedical institution; however, its meaning and implications took on a large role in people's understanding of how health is made, broken or fixed. This analysis is quite basic in what it is saying. However, it is an invitation to unfold how biomedicine has constructed the world of communication in most of health care, by dominating labels through symbolic signs. Labels stick with us, they become a part of everyday life. The pill, to the general public, becomes a representation of that which relieves the patient of suffering; the pill, regardless of what it is, carries hope of cure or improvement (and that is partially what placebo studies have worked on). While to the doctor the pill is not a specific symbol, it is a category of potent treatments that need to be utilized within algorithms to eliminate or reduce disease based on their pathophysiology (Figure 5.1).





Source: The Author

Through such unofficial labels our ideas in health and its conditions are constructed, and the form of the knowing process is made, in the public, scientific and individual realms. This making of form can be better appreciated by an elaboration of other select labels, like the pill.

Another example here is of the chest x-ray that is an image designed by the biomedical institution to resemble the lungs to identify any pathologies in it, and yet when the chest x-ray is referenced in discussions on sickness by the public it can be interpreted as a sign of complete health or disease (for example, her chest x-ray was good she is healthy...). This way of using signs shows how the publics means of knowing health is being transformed by labels

used in biomedicine. When there are symptoms of disease or illness experienced, these biomedical designed labels enter the vocabulary and become the visible reality of knowing. Similarly, the official labels on disease (COVID-19, pneumonia, flu...) draw the form of knowing what is being sick that is understood by patients and the public, even though they come short of describing the grand experience of health as outlined by Filho. People begin to associate being sick or ill, through the various symptoms experienced, with disease categories they are familiar with but may not be correct or relevant. This at times leads to misuse of pills, since the pill is assumed to help with any disease and distinctions are lost when the labels of disease and pill are matched in the public's way knowledge process (pneumonia needs the white pill, COVID-19 needs a blue pill...). Also, beyond misuse of biomedical treatments, this use of labels promotes an excessively simplified model of health for people to adapt. Meaning, people begin to rely on biomedical disease labels to explain their health status when ill or sick, underestimating the vast spectrum of being ill or sick or diseases that exist beyond the form offered to them by biomedicine labels they have been exposed to.

This limitation in popular global labels in health conditions, and the reality of the importance and dominance of biomedical labels, draws us to look at, with closer attention, other labels that still exist in the day to day of health communication and hold clues to the form of the invisible reality of knowing health. This is particularly important in communities that have managed to maintain an active practice of folk and popular medicine (the Pano community).

In Table 5 I summarize the labels I have found in the narratives conducted that come from the biomedical and non-biomedical worlds. I present these labels outlining their semiotic triad, and highlighting any interpretive differences across the three actors using them, public of Santa Elena and Pano (popular), midwives (folk) and doctors (professionals).

Sign	Object	Interpretant – Public	Interpretant – Midwives	Interpretant - Doctors
				Substances that
		Treatment to		interact with the
		remove		human chemistry
	A physical	symptoms for	Treatment for	to reduce or limit
Injection/Pill	chemical	named	unspecified	pathophysiological
Symbolic	substance	diseases	symptoms	disease changes
	Building with	A safe place to	A place they are	
	biomedical	seek medical	weary of OR a	A place of work
Health center	health	help for	place to receive	for low-acuity
Symbolic	professionals	disease	free medications	health care

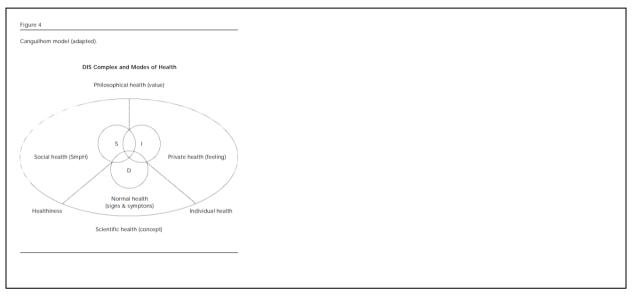
Table 5.1. A Display of Labels From Themes of Chapters 3 and 4

	day service			
		A dangerous		
		place to seek, a		
	Building with	symbol for		
	biomedical	death OR A		A place of work
	health	last resort for	A dangerous place	for high-acuity
	professionals	patients with	to seek, a symbol	with high-risk
Hospital	24hours service	severe disease	for death	work
1105p1001	2 1110 0110 501 1100			Essential
		Preventer of		protection
	Barrier for	COVID-19 or	Preventer of	equipment from
	mouth and nose	law to be	COVID-19 or law	infectious disease
Mask	from open air	followed	to be followed	agents
WILLOW		10110 // Cu	Used in certain	ugents
			rituals to purify	Necessary
	Chemical	Preventer of	the patient or the	chemical for
Alcohol	substance	COVID-19	space	disinfection
	substance	A new	59400	
Covid,		ambiguous	A new ambiguous	A new ambiguous
Pandemia	The SARS-CoV-	reality to be	reality to be	reality to be
(pandemic)	2 pandemic	discovered	discovered	discovered
(pandenne)		discovered	discovered	Team leader in
			One who imposes	biomedicine and
	The human with		upon their practice	one who diagnoses
Biomedical		Expant on the	OR one who	-
	a stethoscope	Expert on the		and manages
doctor	and white coat	disease state An invader of	advises on disease	disease
Organismo, bicho				
		the body and		
(organism	SARS-CoV-2	immune	NA	NA
bug)		system A substance	INA	INA
Aquita	Liquid extract of			
Aguita	spices and/or	able to sustain	NT A	NT A
(waters)	fruits	one's health	NA	NA
	Physical and	An internal		
Defense	energetic	force for		
Defensas	components	fighting	NIA	NIA
(defenses)	within the body	infections	NA	NA
	Chamicallinit	Medicine for		Transfer and a las
	Chemical liquid	strengthening		Treatments to be
Comment	administered in	one's body	NTA	administered in
Serums	IV or Oral	when weak	NA	select diseases
Labert	The block 1	Validation C		Component of
Lab test	The blood tube	Validation of		algorithmic study
(PCR,	inside machinery	diagnosis and	NTA	of disease in the
antibody)	tested	status label	NA	body
D 1' 1		Determinant of		Component of
Radiology		good or bad		algorithmic study
test (CT,	The human	health status of		of disease in the
chest x-ray)	lungs	lungs	NA	body
No tiene nada	Lacking specific	To be safe	NA	To not have a

(To not have	signs of disease	from		biomedical
nothing)	signs of disease	dangerous		diagnosis for
notning)		body threats		U
		body tilleats		symptoms
		Esting and		experienced
		Eating and		
		exercising		
		well, taking		
		fruit, herbal or	Fating states and	
		plant extracts,	Eating right and	
		physical	avoiding specific	
		distancing,	foods in illness,	
		wearing masks. In Pano	taking plants daily,	
	Creatific internal		avoiding hot and cold	Fallowing
	Specific internal and external	its also about		Following
		allowing others to care	disequilibrium,	biomedical rules
Taking com	actions by the individual		being taken care of	and regulations for public health
Taking care	marvidual	for you once ill An essential	by others	public health
	The human	role to	An essential role	
	being providing		to maintaining and	
Caregiver	01 0	maintaining health	restoring health	NA
Calegiver	care	Essential		INA
		nutrient for the		
		human health		
		status (Santa		
		Rosa) and an	Most central	
		essential	sources for	
		element to life	maintaining and	
Plant names	Harvested plants	especially	restoring the	
(animimi,	from the local	taking care	individual health	
matiku)	forests	(Pano)	and taking care	NA
	A myriad of	(	8	
	symptoms	Illness after		
Gripe/Catarr	mainly runny	infection with	Illness after	
0/	nose, fever and	the SARS-	infection with the	
Tosperina	headaches	CoV-2	SARS-CoV-2	NA
				An infectious
				agent able to
	A new			replicate within
	submicroscopic			human cells and
	collection of			damage organ
SARS-CoV-2	genetic code	NA	NA	functions
				Essential terms to
				organize
				biomedical
				diagnosis of
	Sets of grouped			disease and
	symptoms, and			manage
	lab and			epidemiological
ICD codes	radiology tests	NA	NA	surveillance

#### Source: The Author (2021)

The unified health approach of Filho can help situate where and how the labels come together in the amplified approach to health introduced in the first chapter, and highlight their relevance in invisible realities. Next, I weave the labels of Table 5.1. into the map Filho reproduced as a unified theory of health and see what unfolds (Figure 5.2).





Source: Filho (2013)

Starting with the DIS complex at the core of the theory of health, the disease labels encountered were several biomedical terms representing the new virus and its biomedical approach, and these were the ones largely considered as official: COVID-19, SARS-CoV-2, lab test (PCR, antibody), radiology test (CT scan, chest x-ray), and multiple ICD codes. When questioned, midwives referred to *Eikulumarzo, catarro and tosperina* in labeling the new coronavirus diseases, but they did not use them in their day-to-day encounters. The surviving patients interviewed referred to *catarro*, *gripe* and covid as names for the disease with the new virus when questioned. However, in their own narrative of the experience, they avoided specific naming as I elaborated in chapter 3.

For illness labels, the most prominent were terms that the patient used to describe personal feelings of getting ill, like: "a fire within," "breathing ended," "without air," "no force," or "staying weak".<sup>10</sup> This way of labelling symptoms is specific to the interior realm of ill health

<sup>&</sup>lt;sup>10</sup> These terms, similar to terms like *bicho* and *organism* can fall within the work done on metaphors in health by Susana Santog and several other authors exploring how the expression of health happens by the patient. By referring to these terms as labels I do not mean to refute them as metaphors in health, they very well may be too,

experience and the terms were similar, across most patient and patient family interviews. Also, there were certain indexical signs (which I do not include in the table) that I observed surviving patients use when recalling their time of illness: holding their fist to the chest (representing the uneasiness they felt there), and crying (representing grief and relief at times).

Sickness labels can be considered as those generated at the community level to communicate theories and, or knowledge about the pandemic and complexities of staying healthy during it. *Bicho* and *organismo* became the labels in Santa Rosa to identify the disease agent that should be avoided and fought. Covid or *pandemia* were the names of the mysterious contagious spread of bad health and the label in which all ambiguity could be referred, and these labels were burrowed from the national media rather than birthed within the community. Caregiver label uncovered a crucial role during the pandemic that often goes unrecognized. To combat sickness, we need the support of those around us, whether in a hospital or at home. Though no patient referred to the word caregiver in Spanish as a label, they almost all identified individuals who cared for them, and this I considered as an indexical sign for a caregiver in the pandemic. Identifying such signs as labels can cue important roles in health conditions.

Other labels that stood out in the sickness realm included *defensas*, serums, plant names, alcohol, and mask. These were all labels that were either incorporated into the community lingo or birthed within the community as a response to the health threat. Engaging with what each of these labels signifies in relation to what their intended manufacturer designed them to signify (similar with how pill and chest x-ray was reviewed) can help uncover misconceptions in biomedical health concepts. Examples of this are highlighting that the mask itself is not the preventer of the virus, but rather the proper use of a mask as an equipment with specific instruction for its protection function. Also, the labels in the sickness realm can uncover important sources of resilience and/or relevant medicinal resources to the community at hand—like the valuable role of plants in Pano and Archidona.

There is a wealth of labels in the sickness realm and this is consistent with the work that has been done in SmpH (system of signs, meanings and practices of health) by Bibeau and Corbin that I introduced in chapter 2. The concept of labels (as signs, classifications etc.) I am applying and finding here is consistent with the signs that these authors had defined. That is to say that the anthropology community has been recognizing important terms, objects and expressive actions that inform us of their understanding, knowing and experience of health.

however, I am looking at these terms from a semiotic angle too considering how symbolism too can be found in them. The terms can symbolize a state of health the people have grown familiar with in specific contexts.

However, the fact that most, if not all, of the labels I have outlined in illness and sickness above are not accounted for in biomedicine algorithms, or national or global official publications (reviewed in chapter 3) points to an invisible form of knowledge. This form of knowing medicine through the health experiences is not utilized as a form of knowledge even though it is the most real, since it involves individuals, real people experiences. Next, I will highlight where the utility of labels may be considered, as I delve into the other layers Filho outlines in his theory.

The complimentary dimensions of disease, illness and sickness are normal, private and social health respectively. These dimensions share the labels of their compliments in the most part. It is usually a lack of the label that is expressed or an adjective added to the label to guide its use in the normal (like no COVID-19, symbolizes normal health, a person that is not with disease), the private (breathing improved, a sign of illness resolving and private health resumed) and the social (strong *defenesas*, used as an indexical sign of those that would get infected but not sick) health dimensions.

Taking care is an important label to outline here given its recurrence (across the Pano and Santa Rosa public and midwives) and centrality in both the sickness and social, and the illness and private realms. The taking care label is especially intriguing, since it shows how labels can provide a common framework within which health discussions can be framed. Taking care is an essential phrase in the folk and popular sector, and prevention and infection control discussions over COVID-19 could have used it in messaging and communication efforts to better empower health campaigns at the time. So, using a commonly used phrase that functions as a symbolic sign of being well and healthy could have made improved the relations between biomedicine clinics, hospitals and the national public health system with its public.

More lessons such as the latter can be derived when the intersections in the health circles of the social, normal and private meet per Filho. For example, normal and social health (with their complements of sickness and disease) come together to make public health. This is to say that public health labels should be theoretically influenced by the labels not only for disease and its absence, but also by social health labels.

This is quite intuitive, and is the foundation of social determinants of health or social determination of health (as the global south terms it). Public health labels should be using signs that are personalized to appropriate social groups, and not just generic labels from

disease theory brought from the WHO or academic institutions. This is crucial to building resilient health systems from within, but still not applied enough in practice. The example of taking care applies here. Other examples include using the symptoms that people defined and termed in promoting awareness of health experiences to be aware of or cautious with.

For individual health, it is the aggregate or result of disease/normal and illness/private health dimensions, and is the state of health of the person as measured by him or herself and the medical systems he or she engages with.<sup>11</sup> Doctors often forget this essential domain here. The individual health is not only the disease or lack of it, it is also the person and his or her illness. So, whether the patient did or did not have COVID-19 on a laboratory test was not sufficient to deem them as in good health. There had to be a consideration of the illness/private world of the patient in every and all assessments of patients by the doctors and health care systems. Moreover, when doctors' express symptoms of COVID-19 or want to provide information to the patient about their health, a consideration of the illness, not only the disease, needs to be incorporated into their language and their algorithms for determining treatments. Not being diagnosed with COVID-19 because the diagnostic test is negative, or the test is not available, does not mean that no medical management is needed. The doctor needs to consider what management can be provided based on the illness voiced by the patient. This is something that some of the doctor encounters by patients of Santa Rosa and Pano included, such as the prescription of medication relieve burning in the stomach and calling the diagnosis gastritis.

From the patients' perspective, it is interesting to note the influence that the disease and normal health labels have on the person's expression of their individual health (this is in contrast to the doctor's expression of their patient's state of health). The person has private and illness labels generated by the direct experience of being ill (like breathing ending, no air), and once the illness is defined as a disease or lack of disease, the dominating label in the person's expression of health changes from being one that represents a direct experience to a label that is birthed by the biomedical institution (ICD). So, as the individual health unfolds to the patient (through seeking medical attention), the dominant labels given to the experience become less personal and speak more of the biomedical way of doing and knowing health, than the actual individual's knowing of their health.

<sup>&</sup>lt;sup>11</sup> There is an important overlap with sickness and social health on this point too, and varies according to the community being considered. In Kichwa culture of Pano the private health was very closely knit to the social health, and in Santa Rosa where people were less united in faith or traditional practice the private and social health was less overlapping.

This relates to the initial point in this section highlighting how biomedical labels are increasingly dominating how people see and define their health (the pill, the x-ray, etc.) and where many of the studies I outlined in chapter 2 (that look at the positive and negative impacts of labels on patient outcomes) are situated. Informing someone that they are with COVID-19 can be harmful, especially when the disease label is not well defined to the patient. For example, not all COVID diagnoses are the same, and the spectrum of COVID-19 should have been better defined to the public and to the individuals that were being diagnosed and confirmed with the disease, especially in the rural areas where my study focused. Speaking of severe versus mild infections may have helped avoid some of the frenzy experienced in labeling individuals with COVID-19, and helped the patients know how to manage their symptoms and when to seek help (this did eventually happen in later campaigns by the national health system) rather than put them in despair. Certainly, even different labels would not have changed the difficult reality in Santa Rosa and Pano since the very basic elements of a health system were failing in both (no available hospital beds, closed clinics, limited doctors, lack of diagnostic testing and treatments).

Moreover, there is the point on stigma that arises from covid becoming a label and term that is feared and hated. As I was wrapping up my studies in labels, I came upon an article by the WHO that recognized this stigma and encouraged healthier communication with and amongst people over COVID-19. This was a result of a lack of attention to how diagnostic science labels are then shared to and with the public and have their own ripple effect.

This point on the influence of the medical system on the person's perception of health was also seen in the remark of one of the midwives in chapter 3, where it was noted that some diseases in the Kichwa tradition system should be treated in occult, so as not to frighten or worsen the patients' condition. I am not saying here that a patient's diagnosis should be hid from them, but rather that patients should not be delivered medical jargon without understanding the context and impact of the labels to be presented by the doctor or other professional.

Within the realm of scientific health, are the elements from both public (including epidemiology) and individual health. This concept which is mainly used for and by healthcare professionals and scientists, is now increasingly being accessed by the public due to SARS-CoV-2 and COVID-19, given the numerous ongoing debates. The scientific world on this virus has become of increasing interest to the general public, so theories of how the virus invades the body, which receptors are activated, how the virus moves from the respiratory

tract to the blood stream, though scientific concepts, have become of increasing importance to many given what is at stake.

The labels relevant to the scientific health include of course the disease names (ICD codes and doctor generated names), the epidemiology terms (transmission rate, fatality ratio etc.) and many other terms that appear in research and news articles on SARS-CoV-2 and COVID-19, and which I have not included in my study summary of chapter 4 (since they were beyond the scope). Within the labels of scientific health that I have focused on and demonstrated in the physicians' narratives, are the various ways COVID-19 is understood or interpreted as a symbol. If a doctor says that a patient has COVID-19 it could mean that the patient is suffering from select signs and symptoms that could be caused by the new threat virus. It could also mean that the PCR test of someone, who was exposed to the virus but has no symptoms, is positive for the virus. For a hospital administrator, a staff member having COVID-19 in the hospital could mean that the infection prevention control guidelines failed. For an intensive care doctor, a patient having COVID-19 could mean they are less likely to intubate them or that they start them on a blood thinner.

Here I invoke the discussions on the multiplicity of disease, inspired by Mol and her work on understanding the interpretation of the atherosclerosis label across various medical departments. This multiplicity Mol speaks of in atherosclerosis is equally evident in the COVID-19 handling across the biomedical field. The multiplicity was likely even more amplified since there was a lag in designing COVID-19 ICD official labels and other clinical terminology to support the overall management during COVID-19. Also, the disease labels were limited in summing the disease state promoted by biomedicine of SARS-CoV-2 infections. So, COVID-19 was the same label given to someone who was infected with the virus but was not ill, and the person who was in the intensive care getting a breathing tube inserted because of the same cause of viral infection. The same disease label became a central sign to the work of the entire scientific community, however, the multiplicity of it was of little concern in communication and perhaps contributed to the frenzy and infodemic<sup>12</sup> that confronted the world.

Finally, I must address the value of being healthy during the pandemic that the philosophical realm in Filho's figure highlights as a combination of the sickness/social and illness/private

<sup>&</sup>lt;sup>12</sup> Infodemic was the term the WHO introduced to describe the misinformation pandemic that was impacting the world, with rising social media content on COVID-19, a lot of wrong information was shared as facts, and a lot of correct information was displayed out of context and consequently was wrong.

constitutes. With all the novelty that the pandemic brought to the world, the communities and persons impacted had to adapt to the reality with new appreciations and acceptances of what it means to be healthy. This is where the differences between the community experience of Pano and Santa Rosa become most evident, in the morale over how to stay healthy. In Santa Rosa it was almost impossible to remain healthy, with a collapsed health care system, fishing (the only monetary income and food source for many) prohibited, and almost near isolation from nearby towns and cities, people—whether infected with the new virus or not—found it difficult to continue living well. The people of Santa Rosa lacked basic amenities, they needed food, vitamins and medicines, as one of my interviewees said. Most of the labels relating to the value of health during the pandemic in Santa Rose rendered images of despair and fatigue, with lots of grief given the high death toll experienced. All the survivors I spoke to in Santa Rosa labelled their own health as weak, poor and different.

Meanwhile, in Pano, the community with lush backyards (banana, plantain, yuca and much more) and their own medical knowledge, still had a positive outlook towards being healthy from the outset. Their overall attitude was clearly more positive and optimistic. The survivors of COVID-19 mostly labelled their health as strong, improved and energetic. Also, the community used labels implying hope and resilience, most importantly the plant names.

The philosophical value of health and its tendency towards being positive or negative in its outlook is a crucial factor it appears in the pandemic battles. This is an essential point discovered here.

In summary, in this section I weaved the various labels into the theory of health of Filho and its specific components. Through that I made a practical application for the theory and identified deficiencies in current pathways of knowing and/or creating knowledge in the management of the pandemic at the various levels explored. I also detected several points where invisible realities could be further examined, mainly: the illness experience of the patient, the plants of Pano and the midwives, and the philosophical health label tendencies (positive or negative) in communities during the pandemic, as a factor for the outcomes.

## 5.2. A Note on the Midwives' Experience: Where there are No Labels

The midwives clearly had their own system of understanding the events of the pandemic and its consequences on the community. Their disease representations were useful for their community, whom understood life in a similar way. The representations made by the midwives cannot always be considered labels, because they involved a way of doing things, rather than a particular symbolic, iconic or indexical sign. Also, here I have to make another note of the greatest limitation in my study of the midwives being my lack of familiarity and short-time spent with them. I did not have the opportunity to delve into the study of Kichwa medicine outside of the pandemic context. This of course limits how much I can genuinely speak to the labels in the pandemic.

Mama Maria (one of the oldest midwives) once said in response to my question on what COVID-19 is called in Kichwa: *we call it taking care*. The diseases of SARS-CoV-2 became representations of failure to consume plants, failure to abide by environmental rules, and failure to retreat to the forest. These descriptions cannot be made to labels. The only label I could extract from such descriptions was *taking care*. Perhaps, this was the only label from the Kichwa medicinal tradition, other than the numerous plant and medicinal preparations they made of course. Certainly, the midwives used words like covid and pandemic, but they used them in public and scientific health discussions more so than describing their own disease representations. This is a crucial distinction for cognitive justice in medical care of folk systems.

This brings me to the next crucial point learned from this study on labels; they are only one part of the story in classifying health conditions of the SARS-CoV-2.

As much as I tried to expand the understanding of labels in health conditions, to include phrases and buildings and people and not just diagnoses, the theme of labels remains too limited to encompass what happens in the midwives' knowledge realm on disease or sickness. A doctor's knowledge on COVID-19 could easily be recognized based on their use of medicalized labels to explain its disease, the midwives meanwhile, had no equivalent label system. The themes of the pandemic process in their lives demonstrated their knowledge of COVID-19, however the labels were invisible to me, though very present for the midwives, since they were able to reach consensus on treatment and manage patients with health conditions relating to the virus quite smoothly.

The midwives repeatedly refused to label diseases (at least in Spanish translations) they encountered. Every time a patient visited their clinic, I would ask them what the diagnosis was, and they would avoid the question, eventually describing to me how the patient's body and being has changed, and demonstrate which plants and, or rituals they offer. These processes of care by the midwives are not labeled. It is not within their way of doing

knowledge to label, since communicating knowledge does not depend on symbols or icons or indices.

Knowledge is inherited by observation and practical learning from ancestors, and then by direct experience in one's life in combination with individual powers of the midwives. They do not tell each other how to manage diseases by name, they describe the cases in detail, and state what they can about the treatment. Several aspects of treatment are considered secret or only relevant to their powers so they cannot be shared across midwives. So, summarizing labels could not get me closer to understanding how midwives think or do disease. However, this exercise in labels and experience with the midwives certainly made me experience the invisible ways of knowing that their Kichwa system entails.

#### 5.3. Significant Findings and Lessons Learned on Labels

The exercise in label production, across a unified theory of health in practice, has presented a number of findings and recommendations.

First and foremost, there is an intertwined narrative of professional, folk and popular health care sectors. This comes with an intertwined understanding of health across its dimensions and parts. The popular labels are made from biomedical institutions and folk systems, as well as personal experiences shared in the community. Popular labels can also reflect a strong folk health system presence (Pano and the Kichwa people`s emphasis on plants and taking care meanings), which in turn can be factors for stronger health resiliency in and beyond pandemics. The folk systems can use professional labels but still practice and believe differently in and of the pandemic. Labels are clues to the invisible forms in which medical knowledge is made beyond the disease/normal health circle in the grand theory of health.

Two, people seek descriptions to understand their own personal health deteriorations or fluctuations. They want security and predictability in defining their health experience, hence the utility of a label even if it is temporary or not bio-physiologically conclusive. These illness/private labels can be drawn from the narratives of people, to make them more relatable and applicable to patient communication. The recommendation here is for the ICD system or other equivalent systems (that may arise) to integrate health concepts from the illness/private domain into their publications: a shift in labeling of health conditions is crucial and needs to account for the disease-illness-sickness complex and the authors of each respectively (doctors-individuals-community). The product would be a dictionary or reference of illness

labels. This lesson learned is not entirely new, since the medical anthropology field has already been accumulating a significant number of studies on illness narratives.

Three, we need more agile labels in the disease realm. We need labels that can withstand multiplicity, which Mol has previously demonstrated the utility of in clinical practice. This multiplicity would help science in opening up to the human diversity it has to work with, be it in the body or the mind. These agile labels with multiple meanings can consequently be understood within a semiotic framework, which can be a key to facilitating healthy non-reductionist communication in this scientific technological era.

Four, the DIS complex had clearer and known labels than their complements of normal, social and private health. Perhaps labels are more necessary in suffering to create a sense of solidarity during the experience and less so in good health. However, this can be a clue to the fact that invisible realities in normal, social and private health exist and need to be further investigated. Perhaps a wider engagement with the spectrum of the non-DIS health definition in labels could help reduce medicalization of all aspects of the human health experience. These labels would ideally arise from a deeper look at what makes communities and individuals well and healthy, such as the popular use of plants in the everyday life of the Kichwa people. A label here could be the plant-reinforcement for private health. These labels would also logically need to be dictated by communities rather than lab-oriented research institutions.

Five, labels in the daily work of doctors during COVID-19 served the purpose of organizing guidelines, maintaining reporting for epidemiology systems, and communicating between doctors and with patients. The labels were constructed with the input of various biomedical experts on infectious disease, the centers that were studying the virus in the lab and creating diagnostic tests and drugs to combat it, and the researchers tracking patient clinical outcomes from computer epidemiological models. This also goes to demonstrate the multiplicity in biomedical diagnostic labels and aligns with Mol's work on it.

Six, the midwives did not overtly work based on labels. Though they did have their own process in COVID-19 confrontation, their work did not necessitate that the pandemic be labeled (except when questioned by me). *Eikulumarzo* was a label for COVID-19 that was rarely used, but agreed to represent a historical event that resembled the pandemic we currently face. The knowledge inheritance mode and individual powers of the midwives, along with the emphasis on plant medicine in their practice was not related to diagnostic

labeling of conditions. Rather, there was an embodied process of knowing distinct within each midwife, and which was communicated through the specific rituals, and plant mixes they made. Despite this variability in their practice, the midwives were still able to design a plant-based syrup that promoted taking care of oneself, strengthening the body defenses, and was also used in treating specific sickness during the pandemic. This is the most essential finding on invisible realities that my study reached, and one that will certainly need further study to investigate.

Seven and lastly, the positive tendency of labels in the sickness/social and illness/private domain in Pano clearly showed a successful combat of the COVID-19. Despite the tremendous shortage in biomedical resources and against many odds, the Kichwa, in Pano and the communities of the AMUPAKIN midwives, resisted and overcame the first wave of the COVID-19 infections. The role of medicinal plants from the Ecuadorian Amazon and the collective responsibility and action in taking care and providing care to others had a clear positive outcome in the health of the people in those areas. This is in contrast to the poor outcome and devastating loss experienced in Santa Rosa, a place that depended on and was extremely disappointed by what the biomedical system could offer.

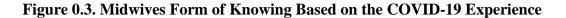
#### 5.4. From Labels to Form

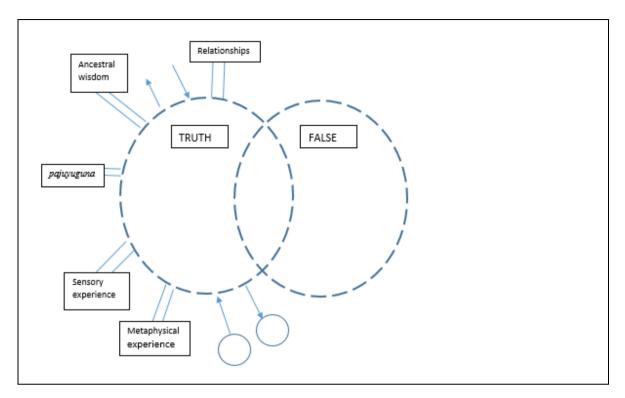
The tension and intertwinement in the relation of the biomedical and traditional systems was well-exemplified in my fieldwork. In the fourth chapter, I describe how tension arose from the biomedical national institution of health forcing a top-down partnership with the Kichwa midwives at their own center, which they had labored hard to create. This tension has become even more clear to me after my own pursuit of labels that yielded no major novelty in COVID-19 label processes. Biomedical professionals (even us, the open-minded good-intentioned ones) rush to make sense of things, often ending up in great misunderstandings and harm done (countless numbers of biomedical treatments are contested and proven harmful).

I wanted to include alternative and traditional medicine in my studies of COVID-19, but started off with a theme not so relevant to the way of doing medicine in the midwives' system of healthcare. I could not possibly understand the form of knowing in Kichwa medicine of the select midwives if I just searched for labels without attention to other processes happening around me. The participation with the midwives and people in Pano (which were two very connected experiences among people of the same cultural group) made me truly believe in the invisible that Santos speaks of. This invisible that is kept as such through the practice of the visible reality (biomedicine) that claims a clear line between truth and falsehood in medicine according to its own standards. I sensed the process of identifying and curing disease that the midwives practiced, but my language and own practice limited me from explaining or practicing it myself. The birthing process I witnessed with the midwives was particularly useful in that sense. The midwives had an unwritten method of performing the birth, and they orchestrated that amongst each other in various spoken and unspoken ways. My visible reality would refuse to approve their practice as valid since my way of knowing good and bad, true and false, birth practices are very distant to that unwritten invisible way of knowing.

There was no written book that the midwives at AMUPAKIN followed that I could read. They taught their knowledge through practical observation and direct care. Keen Kichwa volunteers from the neighboring communities have arrived to AMUPAKIN to learn from the midwives the treasured secrets of the Kichwa medicinal approach, and only select volunteers would be offered the gifts of each midwife by the midwife herself. Once a person becomes a midwife or an official trainee with a midwife, their own knowledge and way of doing medicine would depend on multiple factors, like their own ancestry, their interaction with other modes of medicine including biomedicine, their personal illness stories and other colleague midwives they practice with.

These details of the midwife tradition that I have come to appreciate through my work have led me to deducing the following form of knowing in the midwives' tradition illustrated in Figure 5.3. This is an initial attempt at reproducing the invisible form of knowing felt and experienced in the midwife's world.





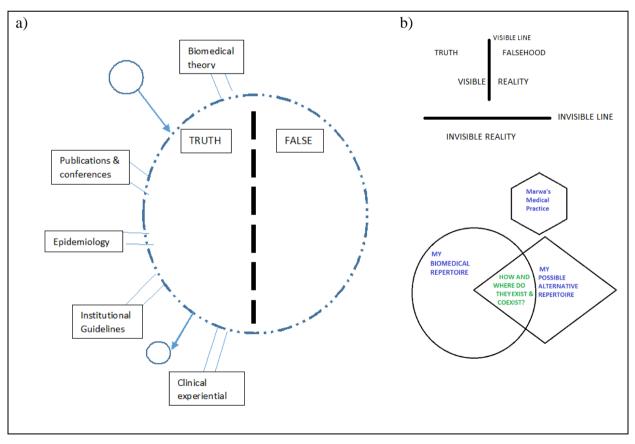
Source: The Author (2021)

True and false in their practical world is still there, since they each have a clear notion of what is true and false in the medicine they make and provide. However, in this truth and false, there is an area of overlap where knowledge can move between the circles and not be contradictory. Their truth is brought upon by the diverse inputs summarized as experiences, relationships and inherited wisdoms or gifts. Examples of these contradictions and overlaps in truth and falsehood were: the hospital was bad but you needed it sometimes, the doctor could be acceptable if they listened to you, the medicines worked if used right with what they knew, and the middle man is always problematic (in relation to their failed experience setting up a shared clinic with the government health center).

The drawn-out form of the knowing process of midwives ultimately gave me the insight to recreate the lines of my own form through understanding the transformation I had gone through. I understood that the abyssal thinking Santos suggests as dominating modern knowledge, was now being challenged by the SARS-CoV-2. Truth and falsehood were no longer marked by a visible line sustained by invisible infrastructures. The new coronavirus has made us confront the invisible, and delve into ways of knowing that are more agile and flexible than the rigid visible fixed line (Figure 5.4.a and 5.3.b.).

True and false are not separated by a hard line, it is dotted allowing for knowledge to seep across given the constant influx of new information determining what is in the repertoire of knowing. Knowledge for the biomedical doctor consists of various inputs, which I experienced in the narrative of chapter 4. The biomedical theory dominates what we believe to be true or false, but there are multiple other determinants like new guidelines, publications, clinical experiences. All of these were very present as guiding factors in making the form of knowing, and expanding the possibilities of the restraints of knowing. Doctors were more trusting of their direct experience, sometimes so much that it had negative consequences (like doctors that chose to believe against the lethality of the virus because they experienced many asymptomatic patients or anti-vaccine doctors that did not have any direct experience with COVID-19 patients and denied that reality). Doctors also have relations with other systems of medicine, depicted with circles in figure 5.4.a. and 5.4.b., and that determined what truth could be for their practice.

Figure 0.4.a. COVID-19 inspired Thinking Form for Biomedical Doctors and 5.4.b. Abyssal Thinking and my Proposed Original Form



Source: The Author

I personally experience and have this open form of thinking and knowing. I realize that perhaps this form is closer to my own practice. I initially believed I could maintain two repertoires of knowledge of separate medical systems and apply them as needed (Figure 5.4.b). But knowing is not separated within us, it is a single process. My form of knowing is primarily biomedical. However, my own knowledge of plant and herbal medicine, as well as Ayurveda, expands or modifies the circle of truths that I practice, while maintaining a clear separation between what can be true and false. My biomedical way of knowing did not allow me to have an overlap in a truth and a falsehood; the medicine either works or not for a specific population with a specific demographic and laboratory profile. The hospital was always the place to seek care, and it was difficult to confront the stories of the interviewees that resisted this. The disease either is or is not the label in question.

So, how can biomedicine still recognize other systems of medicine foreign to it if the visible, now dotted line remains there to mark what is right and wrong in making health. Well, the answer lies in the entirety of the work I have produced. It lies in recognizing that biomedicine is a large part of modern healthcare, being a determinant of common scientific, public and individual health labels. Biomedicine is also not all of health. The study I presented demonstrates how successful health responses (Pano and Napo) at the community level can be with an organized community action and using resources that go beyond what biomedicine alone can provide, home caregivers, medicinal plants and networking. Meanwhile, failed health responses (Santa Rosa) are also not only dependent on biomedicine availability, but also on operation of health facilities and structures, access to economic and agricultural resources in crisis, as well as organized community action within the group involved.

To answer my original question driving my anthropological curiosity, how can we better integrate biomedical clinical practice with alternative medicine available globally? Well, I realize that my reason for asking this question was primarily in pursuit of improving our global health systems. I also realize, now, that to create more just and inclusive global health systems we do not need to teach some biomedical doctors how to become alternative medicine specialists and integrate the best of all medical systems of the world (perhaps artificial intelligence will get to that sooner than the natural intelligence). Rather, we need to transform biomedical education to teach all doctors about the invisible unknown that we must remain appreciative of, especially in global health and settings foreign to one's own social and individual health circles (where illness and sickness may be more difficult to decipher). Folk illness cannot be summed up in biomedical labels, but rather must be afforded their own circle of knowing that connects to our own as biomedical providers. Alternative treatments for diseases cannot be summed up in a table, they need to be imagined as a network of lines and knots, inspired by the work of Ingold here.

Multiplicity in practice is ultimately what we are pursuing as social scientist doctors, how we manifest this, is perhaps more of an ongoing experiment in the clinic, hospital and community. The lives of people are filled with this multiplicity, they can seek care at the local healers home then visit the biomedical clinic, and pass by a naturopath pharmacy. The health reasoning of all these 3 systems is clear and multiple to the individual. Similarly, the biomedical system and professionals need to get more comfortable and transparent with the multiplicity, and labels is one starting point. I hope that this study can support young physicians exploring their own forms of knowing, to situate the biomedical knowledge base they are trained in, and set them on the path of appreciating how diverse and intertwined medical systems are.

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