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Inequalities in the Age of Universal Health Coverage: Young Chileans with Diabetes Negotiating for Their Right to Health

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[rh]Inequalities and Universal Health Coverage

[ab]While Universal Health Coverage (UHC) has been praised as a powerful means to reduce inequalities and improve access to health globally, little has been said about how patients experience and understand its implementation locally. In this article, we explore the experiences of young Chileans with type 1 diabetes when seeking care in Santiago, within Chile's UHC program, which sought to improve people's access to health care. We argue that the implementation of UHC, within a structurally fragmented health system, did not lead to the promised equitable health care delivery. Although UHC aimed to equitably provide universal care, locally it materialized in heterogeneous configurations forcing individuals into positions of precarity and generating new inequalities. Furthermore, for the young people in the study, UHC intersected with their health insurance and socioeconomic status, impacting on the health care

they could access, consequently making diabetes care and management a difficult challenge.

[universal health coverage, health insurance, health reform, chronic illness, ethnography]

[h1]Cristina's Story

Cristina[1] was an 18-year-old woman who was diagnosed with type 1 diabetes (T1D) at age 12. She lived with her parents and an older sibling in a two-bedroom unit in a working-class neighborhood on the southern edges of Santiago. Financially, the family depended on Cristina's mother's (Ana) part-time job as a maid and on her father's monthly pension of approximately US$200. Cristina was unemployed but was preparing to sit her final high-school exams, after dropping out of school in 2013.

When Cristina was diagnosed with diabetes in 2008, she became a beneficiary of Plan AUGE, or Plan de Acceso Universal con Garantías Explícitas (Universal Access Plan with Explicit Guarantees), and greatly appreciated the health package she received at her public hospital. This included insulin vials and a fixed amount of syringes, lancets, and reactive strips to measure her sugar levels and treat her illness. However, when Cristina and Marcela, the first author, met in May 2014, she had been trying to book a diabetes appointment for four months, even though according to AUGE protocols and guarantees, she was supposed to see her doctor every three months. In December 2014, she was still waiting.

In late November, Marcela and Cristina met outside Cristina's favorite shopping center, because she wanted to tell Marcela "all about her *telenovela* [soap opera]," referring to her long wait for a diabetes appointment. Cristina referred feeling "sick and angry" with the staff of her hospital, because they had mistreated her mother. Cristina's mother, Ana, had gone to the hospital on Cristina's behalf to find out why she had been waiting for so long, despite following the prescribed administrative procedures. In her words, Ana had sought to "right the wrongs" Cristina had experienced, as she was certain that the solution to the constant waiting involved "speaking" [meaning politely complaining] to the hospital director. Thus, Ana had visited the director's office, introducing herself to his receptionist, whose answer was shocking and unexpected for both Ana and Cristina. The receptionist had immediately dismissed Ana's claims, reassuring her that "the hospital always fulfills its AUGE obligations." Moreover, the receptionist had told Ana that there were no records of Cristina visiting the hospital in the computer system, hinting that perhaps Cristina had not visited the hospital as frequently as she had claimed. The receptionist made Ana doubt her daughter's honesty and sense of responsibility. This is how Cristina summarized her mother's experience:

> She went there to complain *por lo de siempre*; for the now *typical* situation in which I am [her emphasis]. You know that I've been waiting for a long time; I've been waiting since February. And you know what they said to my mum? *That I don't exist in the system, that I haven't gotten an appointment because I have never seen the doctor before!* [Her emphasis] How can that be possible? You know that I have seen the doctor and that I have the paperwork to prove it, right? You have been there with me! I can't believe what

> they said about me! *Tan barsas que son!* [They are shameless!] They told my mum that [not having an appointment] was entirely my fault; that if I wanted an appointment I had to queue [adhering to the hospital norms] like everyone else did on the 24th of December. What really gets to me is that I was portrayed as an irresponsible patient and a liar in front of my mum. (field notes, November 2014)

[h1]Why Type 1 Diabetes?

Chile has one of the highest rates of type 1 diabetes in the world, with 12% of the total population (over 1.7 million) affected by this condition (Margozzini and Pazzi 2018). T1D accounts for 5–10% of the total cases of diabetes and it represents more than 90% of childhood and adolescent diabetes (Ministerio de Salud 2013). This autoimmune condition requires constant attention and self-care. People with T1D must use multiple, daily insulin injections; regularly check their sugar levels; maintain an exercise routine; and look after their diet to prevent short- and long-term complications (Chiang et al. 2014). Clinicians urge patients to maintain a balanced metabolic control over time (blood sugar level) to reduce or slow down the risk of developing blindness, kidney disease, and chronic nerve pain, as well as to prevent macrovascular complications such as coronary artery disease, which represent the main cause of death for this group (Ministerio de Salud 2013). Before the introduction of UHC, patients with this condition paid the full cost of the treatment. They had to purchase diabetes supplies, and, on occasion, pay for pathology assessments out of pocket. Publicly insured patients experienced long waiting periods to access diabetes check-ups, while those with private insurance had different health plans with uneven coverage. Thus, AUGE's financial protection implied significant savings for all patients, which Bitrán et al. (2010) have calculated to reach approximately US$1,255 annually.

In multiple publications, Chile's UHC plan has been highlighted as an example of how to reform a health system to provide more equitable care through legally enforced health rights for priority health conditions (Cotlear et al. 2015; Frenz et al. 2014). However, little attention has been paid to understanding how this health reform impacts the everyday life of patients accessing health care in contexts of poverty or wealth. According to the best of our knowledge, within Latin American databases, there are no other qualitative studies published that explore the history and implementation of UHC in Chile from the perspective of those it is meant to serve.

While medical anthropologists have contributed to the understanding of issues related to the access to quality health care and affordability (Lock and Nguyen 2010; Rylko-Bauer and Farmer 2002), and of intervention programs (Pigg 2013), the field of health reforms and insurance schemes is yet to be addressed properly through ethnography (Ahlin et al. 2016; Dao and Nitcher 2016). Anthropologists have only recently begun to call for a critical analysis of the working of health care reforms and their impact in transforming processes of care-giving and health-seeking behavior. This has been done in the United States (Horton et al. 2014; Martinez-Hume et al. 2017), but also in low- and middle-income countries (Abadia-Barrero 2016; Bernstein 2017; Dao and Nitcher 2016; Golomski 2018).

Through their work in South India, Ahlin et al. (2016) have emphasized that instead of categorizing the implementation of health reforms as positive or not, it is more important to take a critical stance in exploring the interrelations between health reforms, institutions, and people in multiple levels. In this regard, Alissa Bernstein (2017) has explored the histories of designing health reforms in Bolivia, arguing that health policy is a historical process, not only because it is intertwined with a local context, but also with people's personal stories, frameworks and interpretations of those historical processes. Likewise, Golomski (2018) has explored the place of elder care within UHC in South Africa from the perspective of decision makers in the insurance industry. He has explored insurance as an emerging field where anthropologists can document the reconfigurations of social relations and health policy within a country's postcolonial histories. Deepening our understanding of the histories of health reforms, Clara Han (2012, 2013) has explored the interactions between mental health policy and domestic relations for poor families living in Santiago. She has connected health policy, labor insecurity, and kinship networks, weaving the micro- and the macro-levels together.

In this ethnographic article, we contribute to this discussion by adding depth and breadth from a Latin American perspective. We explore the tensions and inconsistencies in UHC and how these impacted on the lives of young people with diabetes. Through the analysis of three case studies, we argue that in the field of diabetes care, Plan AUGE[2] generated inequitable experiences of care, where a fragmented and poorly implemented health system created conditions of precarity for our informants. We suggest that the uneven functioning of the health system converged with our informants' life conditions worsening their health care experience, their understanding of AUGE, and, potentially, their health status.

[h2]Plan AUGE: Universal Health Coverage in Chile

In 2007, UHC was implemented at the national level through AUGE, which entails both a financing system and a health program. It represents the central component of a deep health reform initiated in 2000 by President Ricardo Lagos Escobar (2000–2006). At the time, Chileans experienced great disparities when accessing health care within the public and private health system, an issue acknowledged by the general population, policy makers and international health agencies (Missoni and Solimano 2010). These disparities were closely tied to structural changes introduced to the health system during Pinochet's dictatorship (1973–1990), in which a previously single, integrated, and public system was replaced by a dual one, generating a polarization of health care provision. The wealthiest and healthiest were insured by the private sector (ISAPRE[3]), and the poor, the elderly, and the severely ill by the public system (FONASA[4]) (Frenz et al. 2014). At the end of Pinochet's dictatorship, this fragmentation had generated an equity gap between the two systems:

> A private, well-provisioned network to serve ISAPRE's wealthy patients and an agonic [meaning in a terminal state] public system […] characterized by public hospitals with deteriorated heating, power and ambulances, very basic x-ray systems, beds without sheets and mattresses, a very poorly paid and unmotivated work force, and a therapeutic arsenal of only the most basic drugs. (Missoni and Solimano 2010, 7–8)

Unlike other countries, where people can complement their public health cover with private insurance, in Chile people have to "choose" to be insured either by FONASA or by ISAPRE. Both systems work almost independently of each other, having disproportionate financial, structural, and human resources, while applying different rules to define the level of care people can access.

The public system, FONASA, maintains a social security approach (Unger et al. 2008), where its members contribute a portion of their wages, a 7% payroll deduction, to receive health care services according to their needs. It operates on a logic of solidarity and universality, being available to all citizens (Frenz et al. 2014). Meanwhile, the private system, ISAPRE, made up of multiple private insurance companies, offers health plans to be individually contracted by consumers. ISAPRE determines the premiums and benefits of each plan through the application of health risk assessments (Frenz et al. 2014).

To implement a comprehensive UHC plan, operationalized through Plan AUGE, the government set in motion multiple bills (Frenz et al. 2014). The passing of Law 19.966 in September 2004 (Biblioteca del Congreso Nacional 2012) set the foundations for its implementation, ensuring by law that Chileans would "receive quality health care with maximum [acceptable] waiting times and limited co-payments for priority health conditions" (Frenz et al. 2014, 718). For those publicly insured, this meant improving their access to quality health care and reducing extended waiting times; for those who were privately insured, it meant establishing minimum health packages insurance companies were required to provide (Unger et al. 2008). Progressively, between 2005 and 2009, AUGE covered 56 health problems, which were selected through an evidence-based prioritization plan. These health conditions represented 75% of the country's burden of disease (Frenz et al. 2014), and coverage for the diagnosis and treatment for T1D was considered from the beginning.

Following AUGE's principles, each health package for insured conditions had to address four principles: access to health care, financial protection, quality, and opportunity. For people with T1D, access to health care meant that—independent of their socioeconomic status and health insurance—all patients would access regular follow-ups, a monthly delivery of pharmaceuticals (insulin), diabetes supplies (glucose monitor, reactive strips, lancets), and pathology assessments (Ministerio de Salud 2013). AUGE financially protected patients by regulating co-payments for diabetes-related services. These co-payments varied according to the patient's income, identifying groups who were exempt from payment (like Cristina), while others only paid a percentage of the total cost. Regarding quality, the reform established specific criteria for AUGE providers, who had to undertake a process of registration and accreditation before offering health services (Missoni and Solimano 2010). Finally, to ensure the principle of opportunity, the reform set up maximum waiting periods for accessing health care, developing an accountability system to keep track of the fulfilment of these requirements. In the case of T1D, the maximum waiting time to access treatment after the confirmation of the diagnosis was 24 hours, while diabetes follow-ups were to take place every three months. By 2017, AUGE covered the diagnosis and treatment for 80 prevalent and/or expensive conditions, providing

25 million health care interventions for insured health problems since its inception (Ministerio de Salud 2018).

Even though Chile's UHC plan was built upon an equity framework that highlighted peoples' right to health, the reform could not change the fragmented structure of the health system (Atún et al. 2015). This can be observed through the cases presented below. In this article, we demonstrate that after the implementation of UHC, patients still experienced persistent inequalities of access, quality of care, and health outcomes. For our informants, UHC emerged in heterogeneous ways, depending on where they sought care, on their type of health insurance, and on the resistance strategies they devised to exercise their rights. For some young patients, accessing diabetes care constituted an uncertain and unfair experience and impacted their everyday understanding and experience of the health reform.

[h1]Methods

Data in this article stem from 12 months of fieldwork, from January to December 2014, carried out in Santiago by the first author. Ethics clearance was obtained in Australia, by the University of Melbourne, and in Chile, by Pontificia Universidad Católica de Chile and Universidad de Santiago, before the commencement of fieldwork. Through ethnographic methods, Marcela approached young people with T1D aged between 18 and 25. This group was selected because they were transitioning towards adulthood; moving between different social contexts and performing new social roles. Medical experts have pointed out that during this period, young people's diabetes control worsens, increasing their likelihood of developing complications in the future (Findley et al. 2015; Winocour 2014).

The 29 young people that participated in this study were diverse. Fifteen were female and 14 were male. An equal number of them sought diabetes care at private (14) and public hospitals (14), while the remaining informant accessed health care through a not-for-profit agency. Regarding their health problem, 26 of them had had diabetes for at least five years. Being a full-time student was a common occupation among them. Twenty of them were undertaking secondary (2) or tertiary education (18). Out of the other nine informants, four held part-time jobs, three full-time positions, and two were unemployed. Regarding their socioeconomic status, eight participants came from working-class families, 14 from middle-class ones, and seven from upper-class families.

The recruitment process involved a not-for-profit organization in Chile, which provided peer-led diabetes education. This organization agreed to send an e-mail with general information about the study to those members who met the inclusion criteria, and posted the same information on Facebook. Once potential participants contacted the first author, they reviewed the informed consent process, which most informants deemed as irrelevant. They tended to think of Marcela as "a serious researcher" because she was a nurse undertaking a Ph.D. To avoid coercion, Marcela spent some time with potential participants talking about consent and its reason for existing.

Data were collected through participant observation and in-depth interviewing. Ethnographic research took place in multiple contexts, including the participants' university campuses and diabetes units. Marcela conducted 29 interviews in Spanish and maintained formal and informal conversations with half of the participants throughout the year. In this article, we focus on three case studies that highlight the local implementation of UHC and its unintended inequalities. Data analysis involved an ongoing process of moving back and forth between the research question, early interviews, and field notes, to then include those conducted later during fieldwork. Once data collection was completed, we used thematic analysis in a more intentional manner (Liamputtong 2009). The process, which was inductive in nature, moved away from the initial descriptive analysis to explore potential interpretations that connected local stories to the macro level.

[h1]Results

[h2]Emerging Inequalities on the Age of UHC: State-led Care as Promise and Failure

[h3]Cristina's Story: Diabetes Care as a Long-term Failure

In August 2014, Marcela began to accompany Cristina on her visits to the public hospital, where she regularly attempted to book a diabetes check-up. Even though Cristina had not succeeded, she persevered, following a bureaucratic and uncertain process. Her experience was impacted by the limited number of appointments public hospitals offered to see medical specialists, which patients could only book on fixed dates and times.

During one of their visits to the hospital, Marcela noticed that Cristina was ill. She was taking antibiotics for bronchitis, fearing that the infection would worsen her sugar levels and diabetes control. As Cristina could not afford to pay for a medical consultation, she had gotten the antibiotics "through a friend of a friend," who was a medical doctor. As they walked toward the hospital, Cristina told Marcela that the doctor had emphasized the importance of resting and staying at home to recover, also insisting that she should see her diabetes doctor as soon as possible. She just shook her head in annoyance. The hospital was located in the middle of a *población* [poor urban neighborhood], surrounded by multiple rows of three-story apartment blocks separated by muddy alleyways and high fences to protect households from robbery. They arrived there just after 8:00 am, but dozens of patients had already formed three long queues.

After waiting for 10 minutes, people in the line began to shuffle anxiously as a young receptionist appeared from an interior door, entered a glass cubicle, and sat down looking at her computer screen. She seemed unreachable behind the glass walls that surrounded her desk, accessible only via a small slot in the glass window, through which patients presented their paperwork. By 8:45 am, there were only five people ahead of Cristina. However, before she could advance any further, the receptionist came out of her cubicle with a sheet of paper that she stuck to the glass. While Marcela did not know how to interpret that event, Cristina said: "No hay más horas [there are no more appointments]. That's it." When they reached the desk and Cristina handed over her old and ragged medical referral—which stated that she needed to see her doctor in January 2014—the receptionist grabbed it without looking at her. With a red pen, she wrote something on the back of the referral and handled it back to Cristina with an apologetic look: "Sorry, but to book your appointment with Doctora Romero, you will have to come back on the 24th." "Not too bad," Marcela thought. That morning was the 23rd of August, so waiting for another day wasn't too bad. But then she looked up at the sheet of paper and finally understood: "Appointments with Doctora Romero: 24th of September" (field notes, August 2014).

The waiting was not only frustrating for Cristina, but it had come to feel heavy and paralyzing. Ignoring her current diabetes control caused her great distress and disappointment. Marcela and Cristina went to the hospital again in late September, arriving even earlier this time. Once more, however, they left with "empty hands," a phrase Cristina often used to describe the outcome of her regular visits to the hospital. In October, Cristina felt desperate, and was considering camping out in the hospital's Emergency Room so she could be the first in line when they open the hospital. In November, as we explained above, her mother attended the hospital on Cristina's behalf. However, Cristina's long wait was dismissed and diminished by the hospital personnel, placing the responsibility on Cristina for not accessing medical care in a timely manner. In opposition to this institutional view of Cristina's behavior as a patient, the system still allowed her to pick up her insulin vials and diabetes supplies. Cristina adhered to her treatment, even though she ignored how her diabetes was progressing.

By December 2014, Cristina had been waiting for 12 months to access diabetes care. Ironically, every time she attended the hospital, she would see a large information display on the wall, which depicted patients' rights and obligations when accessing health care. The sign was entitled "Exercise your rights and fulfill your obligations," making explicit reference to one of the fundamental principles of the reform: the right to health. There, one could read that patients had the right "to receive safe and good quality health care, according to the established protocols." At the same time, patients were expected "to know how to complain if necessary." After passing by the sign a few more times, Marcela suggested that maybe Cristina could file a complaint to end her long waiting, but she disregarded this suggestion, saying that it wasn't worth it.

[h3]Cristobal's Story: Health Care as a Slippery Promise

In contrast to Cristina, Cristobal was well aware he had the right to complain, making it explicit whenever he needed to. He was a 24-year-old junior high school teacher who had had diabetes since his early teens. He lived with his family in a middle-class neighborhood, where they ran a corner store. This was the family's only source of income. Even though Cristobal wanted to move out of his parents' house, his wages were insufficient to do so. He used most of it to pay off a loan his father had taken out to buy his insulin pump. Cristobal was one of only three informants who used a pump to administer insulin, because this technology was expensive (around US$8,000) and it was not included in AUGE's diabetes package. Considering that the minimum monthly wage for a full-time job was around US$350, Cristobal's family had made a huge effort to purchase the pump. However, he was adamant in explaining that it had greatly improved his diabetes control.

Cristobal sought care at Santa Marta Hospital, a public facility that—compared to Cristina's—followed different administrative procedures to manage patients' medical bookings. His doctor always booked Cristobal's next appointment during the consultation, ensuring the continuity of care. While that aspect of Cristobal's care ran smoothly, his visits to the hospital pharmacy were a different story. There, his insulin pump had become a source of "trouble," as he had to "fight" with the staff to receive insulin cartridges instead of vials, which were not compatible with the pump. Sometimes, the staff reacted to his request for cartridges with surprise (some had never seen a pump before), but more often, his request was met with annoyance and disregard. This response added greater complexity to Cristobal's otherwise good health care experience. There, he was compelled to resist the arbitrary restrictions imposed by the pharmacy staff, having to decide how to maintain his right to health:

> Often, I get there *very calmly* [his emphasis] and after greeting la señora—a female staff member—I explain to her that I use an insulin pump, so I cannot use insulin vials, as it is impossible to fit them inside the pump. Usually, la señora looks at me clueless and I get it: She doesn't know what a pump is, what it may look like, and sometimes they don't even know that it exists. So I show her mine. Sometimes la señora understands immediately, and after commenting on how much technology has changed over time, she gives me the right kind of insulin. On other occasions though, la señora may look at me disinterested, with an air of superiority. She might say that my pump "is none of their business," that "I just have to accept whatever is available." [...] The staff can be really pedantic, bossy and paternalistic, pushing you to sign the book where they keep the pharmacy records. If you sign it, you are lost, because you are accepting whatever they want to give you, even if you won't be able to use it. On those occasions, I have to go [perform] hard-core.

By using the term "hard-core," Cristobal evoked a more assertive response as a patient, which he needed to combine with a polite attitude to avoid being labeled as "aggressive." If this happened, he feared the hospital would cancel his AUGE benefits, leaving him financially unprotected to cover the cost of his treatment. For him, the promise of accessing better health care was conditional on his behavior and the goodwill of the pharmacy staff.

> *I know my rights very well* [his emphasis] and I let that be known to the lady behind the counter—always with respect, you know? I tell her very directly, that if she doesn't give me the insulin cartridges, I will stay right there, waiting in front of her until I have a diabetic coma [a life-threatening complication] because of her neglectful decision to deny me the appropriate insulin treatment. I remind her that if something bad happens to me for not getting my treatment, she would be held accountable and that I won't accept whatever she wants to give me, because that is not what I am supposed to get!

Cristobal often felt he was "being punished by the system" for purchasing the pump, struggling to understand "why the staff is against me instead of being with me." The pharmacy represented a liminal space where uncertainty and precarity emerged from his interactions with health personnel. For both Cristobal and Cristina, hospital workers came to embody the bureaucratic power of the health system (Auyero 2012; Strathmann and Hay 2009), even though in reality, they held little power.

[h3]Pedro's Story: The Other Side of the Coin

While Cristina and Cristobal sought care in the public system, Pedro did so in the private sector, presenting a different landscape to explore the ramifications of AUGE's implementation. He was a 21-year-old rugby player who lived with his family in a wealthy and exclusive sector of Santiago. Pedro studied at a private university, where the monthly fee for his degree was the equivalent of two minimum wages. He had been diagnosed with T1D at age two, and had always been privately insured. In contrast to Cristina and Cristobal, who believed that AUGE had improved their diabetes care by dramatically reducing the cost of supplies, Pedro considered that including T1D under the auspices of AUGE was "a problem instead of a solution." Since the implementation of UHC, Pedro had felt "obligated by the system" to waste his time, having to regularly see two different diabetes doctors. We have called his health care–seeking practice "double-private," the intricacies of which we detail below.

When the reform was implemented, it sought to reduce inequalities for patients insured by the public and the private system. For the former, the government created minimum health packages to cover the diagnosis and treatment of highly prevalent health conditions including T1D. For the latter, the government passed a law to regulate the obligations of ISAPRE toward their clients, forcing insurance companies to also offer health packages without extra charge for patients. ISAPRE had to provide patients with a list of medical providers from whom they could claim their AUGE benefits, however, becoming an AUGE doctor was optional for specialists (including endocrinologists), and some declined to adhere to this policy. Consequently, some privately insured patients who already had a long-term relationship with an endocrinologist, began to see two doctors regularly, or double-private health care. They would visit an "AUGE doctor" to access the benefits of UHC (monthly provision of insulin vials, diabetes supplies, and pathology assessments at a lower cost), while maintaining regular appointments with their long-term endocrinologists. While the former was seen as a gatekeeper to access diabetes benefits, the latter was considered responsible for overseeing our informants' treatment.

> I already have *my* doctor [his emphasis], whose name is Roberto, Roberto Andrade. But [Pedro breathes deeply] AUGE doesn't work. They [his ISAPRE] have changed my [AUGE] doctor many times. I used to see a female doctor who gave me all the prescriptions [benefits] quickly; I only needed to present my blood tests results. I only had to demonstrate that I was well. She never said a word about my treatment because she knew that I had Roberto and that he was the one who made decisions regarding my insulin. My critique of the system is that if I already have *my* specialist [his emphasis], he should be able to give me the prescriptions and the orders for pathology tests. […] Instead, ISAPRE obligates me to see a stranger [AUGE doctor] that I have never seen before and who they change whenever they want. In the last three or four years, I have had six or seven [AUGE] doctors. Every time I see a new one I immediately say: "Look, my doctor is Roberto Andrade, I just need a new insulin prescription," and they often

> reply: “OK then.” Having to see an external person just to give you a signed piece of paper to pick up supplies is really stupid.

If Pedro had decided not to accept AUGE’s health benefits, he would have had to pay the regular market price for his diabetes supplies, with a fourfold increase in the cost of his monthly treatment. In addition, Pedro ignored the fact that by benefiting from AUGE’s diabetes package, he was still able to access better care than his peers in the public sector. This gap in the quality of health care became evident for us when accompanying our informants to pick up their supplies. While the standard AUGE diabetes package established that patients covered by FONASA could receive up to 125 reactive strips to monitor their sugar levels, those privately insured were not limited to the same amount. For example, Pedro requested 250 reactive strips monthly, which allowed him to monitor his sugar levels at least eight times per day. With the limited amount available to public patients, they could only check their sugar levels four times per day, a number that did not consider the fluctuating nature of diabetes with its lows and highs.

When complications occurred, our participants were obligated to “juggle” their supplies, as Cristina put it, using more whenever they had a low or a high, and skipping measurements when their sugar levels were more stable. Additionally, a large number of medical appointments with AUGE doctors were wasted in the private system, as the patients who maintained double-private care did not acknowledge them as experts in diabetes, but as administrative workers. Moreover, patients did not queue to book appointments if they were privately insured, using instead the internet or their insurance company call center to do so. Those insured by FONASA were not able to do the same, as the public system had neither an online record for all patients, nor a website that centralized medical appointments in each hospital nationally.

Through these case studies we have aimed at delineating the dynamic and different ways that diabetes care was experienced by young people within Chile’s UHC. Despite the introduction of AUGE and its promise of better health care *for all*, we suggest that access to quality diabetes care was not a given for everyone. These case studies illuminated our understanding of the challenges that emerged after the implementation of UHC regarding health inequalities, suggesting ways through which these can manifest.

[h1]Discussion

[h2]A Brief History of Health Reforms in Chile

While most countries in the world have moved toward neoliberal policies as a consequence of broader economic and socio–political trends, scholars have highlighted the case of Chile for its quick and deliberate transition to neoliberal reforms, embraced by all sectors of government (De Vos and Van der Stuyft 2015). In the case of the United States and the United Kingdom, for example, neoliberalism was adopted as the dominant economic paradigm progressively, over a 40-year period (Birn et al. 2016), between the end of World War II and the mid 1980s. In contrast, Chile’s adoption of neoliberal policies took place in less than a decade during the early years of Pinochet’s regime (Birn et al. 2016; Valdés 1995).

Until the late 1970's, health care provision in Chile was organized into a unified, public health system called Sistema Nacional de Salud (SNS), which, by the mid-1950s, had achieved free, basic, universal health care for all citizens, becoming an example for other Latin American countries (Arteaga et al. 2002). Chile's SNS was comparable to the U.K.'s National Health Service, providing comprehensive health care for workers, their dependents and the poor (De Vos and Van der Stuyft 2015; Waitzkin 2015). However, after the military coup of 1973, a series of neoliberal reforms were introduced, transforming a previously integrated health system into a dual one, FONASA and ISAPRE (Unger et al. 2008).

Pinochet's health reform began in 1979, when the military government replaced the SNS with FONASA that became responsible for the management of public health care (De Vos and Van der Stuyft 2015). The following year, Pinochet reformed the Chilean Constitution, framing the concept of health as a consumer good; a product that could be purchased by citizens (Burrows 2008). This was a necessary step to then introduce, in 1981, private insurance companies into the local market, a process that was backed up by global financial institutions, conditioning the lending of funds to Latin American countries on the implementation of structural adjustment policies (Abadia-Barrero 2016). By 2002, the consequences of this reform were visible in national statistics, where even though ISAPRE only insured 22% of the population, they accounted for 43% of the national health expenditure (De Vos and Van der Stuyft 2015).

To deal with the poor state in which the public health system was left after Pinochet's dictatorship, the first two democratic governments that followed focused on implementing structural measures to increase the national public health expenditure. They sought to improve a weak health care infrastructure, acquire better and newer health equipment, and hire more clinicians and administrative personnel. Over a decade, the national health expenditure increased from US$15 million per year in the 1980s, to US$86.5 million per annum in the mid-1990s (Missoni and Solimano 2012). After these two governments, President Lagos focused on initiating the health reform. Aside from the epidemiological transition the country was experiencing, Navarrete Yáñez and his colleagues (2013) have argued that Lagos's commitment was encouraged by the release of the "2000 World Health Report," in which Chile's health system was ranked in position 168 in regard to fairness. This report highlighted the segregation and unequal access to health care most families were subjected to and the financial risk to which they were exposed whenever one of its members became ill.

[h2]Contributing to the Anthropological Study of Health Insurance Programs

Achieving UHC has become a priority in the global health agenda, and as such, it has also been incorporated into the targets of the United Nations' (UN) Sustainable Development Goals. However, the term "coverage" has taken on a very specific and narrow meaning, departing from previous claims to achieve health care for all (Birn et al. 2016; Waitzkin 2015). For example, the World Bank has stated that achieving UHC means providing people with "access to the health care they need (WHO 2014), while the UN has narrowed the term down to the provision of "quality essential health-care" with financial risk protection (WHO 2017). Both approaches reflect a departure from previous more integrated global health calls (e.g., the Alma-Ata Declaration of 1978) to provide public, unified and comprehensive health care (Birn et al. 2016; De Vos 2015). Through the case studies, we were able explore the intricacies of the narrow definition for the term *coverage* in Chile, highlighting issues in access and quality of care within the public and private system.

We have contributed to the anthropological study of the "social life of health insurance programs" (Dao and Nitcher 2016, 123) adding depth and breadth to the existing discussion, by providing ethnographic data within the Latin American context. Even though UHC programs may be seen by policy makers as "the solution" to reducing health inequalities and providing health care with financial risk protection, health policies such as Plan AUGE are not static tools, but processes deeply tied to sociocultural and historical contexts that come to interact with existent structures, community values, beliefs, and ways of being. Considering the work of Emily Mendenhall (2016), which discusses the syndemic relationship between multiple diseases and their interaction within broader social, political, and economic circumstances, we have suggested an alternative path for slippages in diabetes care. For some patients, *AUGE*, the perceived solution to address inequalities, came to deepen a crisis in the provision of chronic care. In this regard, Grundy et al. (2014) have suggested that instead of understanding health systems as "a set of technically engineered and interconnecting managerial classifications or 'building blocks' (WHO 2009), health systems can also be viewed as dynamic social constructs that are being continually re-shaped" (p. 186). The achievement of UHC in any health system should be seen as the result of a long-term process that involves consistent government effort and commitment to improving population health. This process represents a continuum through which countries with UHC plans move through in stages (Bennett et al. 2010; Chemouni 2018; WHO 2014).

Additionally, we have expanded on the history and implementation of a health policy from the perspective of the patients the reform was supposed to serve. We have demonstrated that moving away from Pinochet's health reform and into a fairer and more equitable health system has been a difficult transition. During the first few years of the regime, the role of public institutions was reduced, and social policies were transformed to fit the principles of the free market. Health became a consumer good (rather than a right), and principles such as individual freedom, justice, property rights, and subsidization were applied to the provision of health care. Moreover, Pinochet's regime caused a society-wide disruption, accompanied by a loss of control and empowerment for individuals, families, and communities. Citizens were stripped of their rights and subjected to military control in all areas of their lives (Pinto and Salazar 2002).

By considering Chile's recent history, one can seize the challenge posed by Lago's health reform to the government, the health system, and its patients, bringing back to health policy values that had been previously ignored. Learning how to approach, engage with, and interpret this reform has defied multiple actors; health care providers, policy makers, other stakeholders, government officials, and, more importantly, patients. We were able analyze how health policy intertwines with patients' experiences through our informants' histories.

Cristobal highlighted the importance of behaving politely when dealing with administrative staff, suggesting that patients were still expected to be careful and respectful when trying to exercise their rights with figures of authority. This not only evoked power differences between patients and staff members, but Chile's violent and authoritarian past. Another manifestation of this connection emerged through Cristina's story, as she did not believe lodging a complaint at her hospital would solve her situation. During the dictatorship, people avoided filling out official documents as it was seen as a dangerous endeavor. Many Chileans were detained and tortured due to police complaints lodged against them, which portrayed them as Pinochet's detractors (Pinto and Salazar 2002). Forty years later, some Chileans still feel uneasy when signing official documents or complaining about the poor quality of government-related services. Finally, Pedro's story comes to reflect the consequences of the privatization of health care, engaging with AUGE from the perspective of a consumer. While the implementation of UHC had financially protected him, he had to compromise by attending check-ups with an AUGE doctor despite his negative assessment of the doctor's performance.

Even though in principle Chile has come a long way in implementing UHC, this research shows that in practice the country still has a set of unresolved problems to address before the goal of UHC is achieved. While access to health care is considered universal, there is no specific mechanism in place to prevent discrimination of access encountered by lower socioeconomic classes (Missoni and Solimano 2010). Local research in the field of public health has reported that equity has been a difficult goal to achieve due to the complexity of the reform, a lack of clarity in its implementation strategies (Letelier and Bedregal 2006) and for positioning all socioeconomic groups at the same level, as if all patients had the same health needs and required equal support from the government (Missoni and Solimano 2010). Moreover, guaranteeing care by Plan AUGE in a public sector that suffers from a lack of funds and resources, has only worked in favor of the capitalization of the private sector (Missoni and Solimano 2010), exacerbating the gap of access to services between upper and lower income groups. There is also the problem of inadequate training of the public health workforce (Valdivieso and Montero 2010), which has inhibited the smooth functioning of AUGE.

While our informants acknowledged Plan AUGE's contribution to their health by reducing the monthly cost of the treatment, some young informants came to understand the process of accessing diabetes care in the public system as a challenge that tested their resilience rather than a program that eased their "burden of disease." Arguably, the inequalities of access to health care experienced by the young people will have an enormous outcome on their long-term health care. While the two participants from lower socioeconomic classes, Cristina and Cristobal, had to battle to receive the care they were entitled to, Pedro enjoyed the benefits of both the public and private systems.

This ethnographic article is an account of the everyday experience of the exacerbating gap between the rich and the poor regarding accessing quality health care in Chile. Even though academics and researchers of health reforms have written and theorized about the uneven and inequitable distribution of health resources in this country previously, this study adds richness to the analysis by presenting everyday scenes of care and disregard, constructing a paradoxical path to claiming the right to health within the public system. Furthermore, it provides current evidence for this theorization from the perspective of young patients struggling to find their way through a difficult and challenging health system. In doing so, it demonstrates how these young people have to struggle against established protocols to claim the rights they are supposed to receive. The impact this has on people's lives and the health system in general are areas that future research needs to explore in more depth.

[h1]Notes

1. All names of individuals and clinics are pseudonyms.

2. The government coined the term "Plan AUGE" during the process of development and early implementation of the health reform. Later, this term was replaced by "GES," or Explicit Health Guarantees. While we acknowledge this change, we decided to use the original term as this was the manner in which our informants spoke of the reform and its health benefits.

3. ISAPRE or Instituciones de Salud Previsional (Private health insurance system).

4. FONASA or Fondo Nacional de Salud (National Health Fund).

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