

Priority Setting for Health Resource Allocation in Brazil: A Scoping Review and Ethical Analysis.

by

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Abstract

Brazil is a high middle income country where health inequities persist across two systems of health care financing and delivery. The publicly financed system (SUS) is one of the world's largest health organizations, which is charged with the constitutional mandate to provide comprehensive health care coverage to over 190 million citizens. National Health Conferences (CNS), the core forum for societal participation in health policy making for the SUS, occur every four years. Yet, managers and councillors struggle to decide on how to allocate resources to meet competing populational health needs and demands, and to comply with the directives of the SUS. The purpose of my research is to describe the three most recent CNS, based on a scoping literature review, to evaluate the ethical account of these decision making processes, and to provide recommendations for improving priority setting for health resource allocation for the SUS according to the ethical analysis.

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Chapter 1

Introduction: Research Objectives, Brazilian Health Care System and Priority Setting for Health Resource Allocation

1 Introduction

The provision of universal and comprehensive health care is elusive even in the world's wealthiest nations, which include Brazil, a high middle income country with an expanding economy that has been claimed to be the fifth largest in the world (Kleinert & Horton, 2011). Decision makers who allocate health resources are challenged with high costs of evolving medical technology and with competing societal demands for a range of public goods in addition to health care, such as energy, education, transport, infrastructure, etc. Thus, rationing decisions occur at different levels of every health care system, implicitly or explicitly (Ham & Coulter, 2001).

Mixed public-private systems, such as the Brazilian model of health care financing and delivery, present additional challenges to decision makers, because there are marked differences in governance and accountability between the privately financed and the publicly financed (SUS) systems (Ferri-de-Barros et al., 2012), which make the issue of justice and fairness of health resource allocation an extremely complex matter in the Brazilian context. Setting health priorities fairly is a core health policy challenge for the SUS (CONASS, 2009, pg. 51; Paim et al., 2011; Ferri-de-Barros et al., 2012), which I propose to illuminate with an ethical approach to priority setting for health resource allocation.

The methods followed align with the framework “*Describe, Evaluate and Improve*” proposed by Martin & Singer (2003), which is conceptually grounded in the leading ethical framework “*Accountability for Reasonableness*” (A4R) (Daniels & Sabin, 1997). A4R “is the leading ethical framework for priority setting in health care institutions because it is the only approach that is empirically based, ethically justified, and focused on process. It can be used as an analytic lens to facilitate social learning about priority setting” (Martin & Singer, 2003). I will augment my A4R ethical analysis including the “Empowerment Condition”, as proposed by Gibson et al. (2005a).

The “Empowerment Condition” states that power differences must be mitigated to facilitate effective participation of diverse members in the decision making context for priority setting in health care organizations (Gibson et al., 2005a).

A4R outlines four conditions that a decision making process for allocating health resources must meet to ensure legitimacy and fairness: to meet the relevance condition of A4R, priority setting decisions must rest on rationales (evidence and principles) which fair-minded parties (managers, clinicians, patients) can agree are relevant to deciding how to meet the diverse needs of a covered population under inexorable resource constraints. To meet the publicity condition of A4R, limit setting decisions and their rationales must be publicly accessible. To satisfy the appeals condition of A4R, there must be a mechanism for challenge and dispute resolution regarding limit-setting decisions, including the opportunity for revising decisions in light of further evidence or arguments. To satisfy the enforcement condition of A4R, there must be either voluntary or public regulation of the process to ensure that the first three conditions are met (Daniels & Sabin, 1997).

Thus, I will accomplish the “Describe” step using a scoping review of the literature on ethics of rationing health resources in Brazil. I will accomplish the “Evaluate” step applying the A4R criteria augmented with the “Empowerment Condition”, as proposed by Gibson et al. (2005a), to the processes described with the scoping review. I will accomplish the “Improve” step by offering suggestions for improving the ethical accounts of the processes described, which will flow from the “Evaluate” step. These suggestions are presented in the discussion chapter, where I have also reproduced my published work on the topic, which are tangible steps toward improvement. The application of “*Describe, Evaluate and Improve*” with the augmented A4R framework will be further described and justified in the methods chapter.

My thesis fills a gap in the international literature on priority setting by synthesizing knowledge about this complex and timely health policy issue in one of the world’s largest publicly financed health care organizations, in which public participation in health policy making is prescribed by law since 1990.

1.1 Specific Research Objectives

The aim of my research is to synthesize knowledge about ethics of rationing health resources in Brazil. This will enable researchers to design empirical studies to illuminate this complex topic, and health policy makers to improve the ethical accounts of priority setting for health resource allocation in Brazil. This is a critical health policy issue because the inequities of access to health care services have raised legitimate questions of justice and fairness of health resource allocation in Brazil (Paim et al., 2011; Ferri-de-Barros et al., 2012). Thus, following the conceptual framework *Describe, Evaluate and Improve* (Martin & Singer, 2003), my specific research objectives are:

Objective I- To *describe* priority setting for health resource allocation in Brazil, based on the current model of health policy making for the publicly financed health care system, and based on the Brazilian literature on ethics of priority setting for health resource allocation.

Objective II- To *evaluate* the description provided in meeting Objective I, according to the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) augmented with the “Empowerment Condition” proposed by Gibson et al (2005a);

Objective III- To provide recommendations for *improving* priority setting for health resource allocation in Brazil based on the description and evaluation accomplished with objectives I and II, with which “good practices” and opportunities for improvement will be identified, based on the lessons learned from the international experience with priority setting as reported in the literature.

The remaining of this chapter will provide background on three different topics: first, the Brazilian health care system; second, my personal experiences working in Brazil as a surgeon; and third the current approaches to priority setting in health care. The personal experiences are important because they provide a lens or filter with which the material is viewed and analyzed, and indeed contributed substantially to the motivation to do this work.

1.2 Brazilian Health Care System: an Overview

Two models of health care financing and delivery co-exist in Brazil: the publicly financed system, *Sistema Único de Saúde* (SUS), and the privately financed system, *Sistema Suplementar de Saúde* (SSS). The SUS is financed with revenue from taxes and social contributions from the municipal, state and federal governments. Individuals and employers finance the SSS. Since January 2000 the SSS is regulated by the *Agência Nacional de Saúde Suplementar* (ANS), which operates under the governance of the Ministry of Health. Before the ANS, private health insurance programs operated based on free market and on private agreements between providers and consumers (Paim et al., 2011). Operating with diverse administrative frameworks, several private health plans constitute the SSS, which is accessible to 25% of Brazilians who can pay for coverage of hospital care, outpatient clinics, dental services, and diagnostic tests (Paim et al., 2011).

Following the decline of the military government, the Brazilian civil society, organized in diverse groups of activists, promoted the democratic health care reform that have outlined the current framework for the SUS. This culminated in the 8th *Conferência Nacional de Saúde* (CNS), National Health Conference, in 1986. The Bill 8,080 of 1990 (*Lei Orgânica da Saúde*) was incorporated in the Brazilian constitution of 1988, and provided the legal framework (box1) for the implementation of the SUS (Paim et al., 2011). Based on the core principles of *Integrity* (a complete package of health services), *Universality* (for all citizens) and *Equity* (equitably), which are entrenched in Bill 8,080 of 1990, Brazilian citizens have secured the constitutional right to comprehensive and universal health care financed by the State.

Text box 1. Key Legislations and Legally Defined Principles for the SUS
(Source: www.saude.gov.br)

Lei Orgânica da Saúde (Law 8080, September 19 1990)- Implementation of the SUS.
Law 8142 December 28 1990-Societal control and participation in management of the SUS.

- Universal and equal access to health care, enforced by the State
- Health is a component of social welfare
- Single administration of the public system by the Ministry of Health
- Social control and social participation
- Decentralization and regionalism
- Hierarchical organization of priorities in provision of care (health promotion, prevention and curative activities are given priority based on population's epidemiologic profile)

The SUS is one of the world's largest publicly financed health care organizations, providing universal coverage for 190 million Brazilian citizens. Public participation in health policy making for the SUS is a constitutional right in Brazil. The federal law 8.142 of 1990 prescribes that health policy making for health resource allocation will occur during National Health Conferences at the municipal, state and federal levels. National Health conferences are the core democratic forum for priority setting for health resource allocation, and they occur every four years, preceding each new budget cycle of the SUS. The participants of the National Health Conferences (CNS) are elected members of the public (50%), representatives of health professionals (25%) and representatives of managers and providers of public health services (25%). Decision making in the CNS occurs with voting during the municipal, state and federal levels of the National Health Conferences. This process will be described further in the results chapter. While structured public participation is a legislated requirement for priority setting for the SUS, in the privately financed system limit setting decisions are made by the leadership of private insurance companies, in accordance with the *Agência Nacional de Saúde* (ANS) guidelines and legislation.

1.2.1 Health Care in Brazil

Since 1998, the family health program (PSF) constitutes the backbone of the SUS for providing universal “basic health care” coverage. Health care teams have one doctor, one registered nurse, one assistant nurse and 4 to 6 community health agents. Each team covers specific geographic areas and populations of 600-1000 families at the municipal level. In 2010, 85% of Brazilian municipalities had PSF teams, who are the “gate keepers” for coordinating specialized care (Paim et al., 2011).

Remarkable improvements in the social determinants of health have occurred in Brazil alongside the implementation of the SUS. Universal immunization and pre-natal coverage, as well as the provision of diverse health services to millions of Brazilian citizens, was made possible with the Brazilian health reform (Paim et al., 2011). In a recent series of articles, the Lancet Brazil Series Working group reported on the historical development of the current health system in Brazil, providing a broad health policy analysis of governmental data on maternal and child health (Victora et al., 2011), infectious diseases (Barreto et al., 2011), chronic non-communicable diseases (Schmidt et al., 2011), violence and injuries (Reichenheim et al., 2011).

Maternal and child health improved dramatically during the last three decades largely due to improved social determinants of health, such as decreased poverty and improved education of women. Millennium Development Goals for improving nutrition and decreasing mortality of children under age 5 are met, or on target for 2015. Challenges to improving maternal and child health persist, such as the world record rates of cesarean sections, regional inequities of access to health care, illegal and unsafe abortions and preventable maternal deaths (Victora et al., 2011).

Preventable infectious diseases have been well controlled with effective health policies and interventions on social determinants of health, such as universal access to immunization, improved sanitation and quality of drinking water. However, infectious diseases with complex transmission patterns, changing epidemiological profile, or for which treatment is not effective, such as dengue fever, remain difficult to control. The causes of death from infectious diseases in Brazil are currently similar to that of higher income countries (Barreto et al., 2011).

Chronic non-communicable diseases, such as hypertension and diabetes, have become the main causes of deaths, disabilities and disease burden in Brazil. Tobacco control and improved access to primary care contributed to declining mortality rates from cardiovascular and chronic respiratory diseases; however, obesity is epidemic and is leading to a growing disease burden of diabetes and hypertension (Schmidt et al., 2011).

Road traffic injuries and violence represent a major public health problem in Brazil. Hospital admissions due to injuries consume substantial health care resources in Brazil. The estimated total annual cost of road traffic injuries in Brazil in 2006 was R\$22 billion (CAD\$ 10.7 billion). The poor infrastructure of the transport system and the lack of enforcement of traffic legislation are the main barriers to injury prevention (Reichenheim et al., 2011).

Victora et al. (2011) concluded the Brazil series with a call for action of diverse actors to address the challenge of improving health care in Brazil, which according to the authors is a political [rather than a technical] matter. Their call included action items for the Brazilian government, in which the authors recommended prioritizing “diseases and conditions that are increasing in frequency, including obesity, diabetes, dengue fever and others”, suggesting an epidemiologic approach to priority setting (Victora et al., 2011).

My scoping review and ethical analysis will contribute to the recent call for action for improving health care in Brazil (Victora et al., 2011) by identifying “good practices” and opportunities for improvement of the ethical accounts of the core priority setting process for health resource allocation in Brazil, the National Health Conferences, according to a high standard of fairness and legitimacy of decision making for health resource allocation (Daniels & Sabin, 1997).

1.3 Personal Experience with “real world” Priority Setting in Brazil

In this section, I will provide background information regarding the real world priority setting dilemma that motivated my thesis work. Also, the information provided here, concerning my medical education, specialty training and early professional experience in Brazil and elsewhere, is intended to disclose the personal values that may have influenced my analysis.

I write from a privileged position because I have had access to high levels of education, and because I have trained and practiced medicine in diverse health care settings, in Brazil and internationally. Such “real world” exposure has refined my personal values and equipped me with a unique analytic view of diverse health care systems. However, as a citizen, I have always enjoyed access to health care, having utilized the SUS (as a patient) only occasionally, and in a privileged manner. As such, I make no claims of personal experience as a user of the SUS. Furthermore, I have not experienced the SUS from the perspective of the system’s managers.

During my medical education and specialty training in Brazil from 1990 to 1998, I witnessed the implementation of the SUS in one of the largest academic hospitals in Brazil, “Santa Casa de São Paulo”. Established more than four centuries ago, the private not-for-profit institution manages the largest philanthropic hospital in Latin America¹.

¹ Source: <http://www.santacasasp.org.br>

From 1998 to 2003, I worked for the SUS in one of many health jurisdictions of the State of São Paulo, which I will refer to here as jurisdiction Y, where I experienced first hand a fraction of the “real world” issues with priority setting in hospital care. During the same period of time, I have also worked for the privately financed system in the jurisdiction Y and in the city of São Paulo, in diverse private clinics, academic and non-academic hospitals (for-profit and not-for-profit). As such, although I had a broad exposure to the public and private health care sectors in São Paulo, I have not experienced the “worse case scenario” of the health care system in the poorest regions of Brazil.

1.3.1 The Priority Setting Dilemma

Inequity of access to acceptable standards of surgical services was a recurrent problem in the jurisdiction Y. Referrals to regional or tertiary hospitals were systematically denied based on overcrowding. As such, complex musculoskeletal trauma care was provided, without the required technical resources that were available in larger SUS hospitals or in private centers, as the only option for most citizens who lacked access to private health care. Wealthier patients had immediate access to private transportation to private health centers in São Paulo, and a few other patients gained access to better-equipped SUS hospitals after a few phone calls to key decision makers. This process would frequently determine, for example, who dies and who lives after a head injury requiring urgent neurosurgical intervention, or whose leg or arm would be reconstructed or amputated after a severe limb injury requiring urgent surgical care.

Patients requiring complex elective reconstructive care, such as spinal surgeries or limb reconstructions were referred to tertiary centers in São Paulo. Most of these patients waited a few months or years to be seen by specialists in the academic centers, and returned to the municipal outpatient clinics with no hope for treatment, as the wait times for elective surgeries were largely unknown, but estimated to be a few years. As a result, it became obvious to me that an unknown number of outpatients in the SUS were left with physical disabilities, most of which could have been mitigated with specialized surgical care. From our private clinics, we made direct referrals to specialized centers in São Paulo, where privately insured patients were managed within days or weeks, according to world-class standards of care. Such inequity of access to health care challenged the SUS core principles of *Integrity, Universality and Equity*, caused preventable human suffering, and raised a difficult ethical dilemma in my clinical practice.

During several collegial meetings with hospital administrators and municipal health authorities, our group of four orthopaedic surgeons presented the problem of lack of essential resources to deliver adequate musculoskeletal care in the municipal SUS hospitals of the jurisdiction Y. At that point in time, in 1999, given our moderate volume of surgeries, our requests to improve surgical care in the jurisdiction Y were proportionally modest.

It was viscerally frustrating that what surgeons perceived as basic technology for trauma care was perceived as superfluous new technology by regional health managers. The basic technology that I am referring to here was indeed new to the hospitals in the jurisdiction Y; yet, it had been an essential part of trauma care for years in many other hospitals, internationally and in São Paulo.

When presenting “the problem” to the regional health managers, we were faced with the argument that there were other priorities for the regional health budget; however, we could not understand why trauma care was not a priority in the region, because in our practices, our real patients were exposed to preventable suffering due to the lack of resources. Despite public deliberation in a few municipal health council meetings, we had no reasonable answers to our requests or to our questions. Public deliberation was based on epidemiological arguments that only a few council members could understand, and allocation decisions were supposed to be made based on those arguments.

Eventually, an elderly influential citizen in the jurisdiction Y sustained a hip fracture, which would require surgical care. She was referred to the municipal orthopaedic service. We disclosed to the patient and to her family the risks of surgical management in our setting, as compared to the risks of treatment in other settings where the basic resources for operative care were available. This particular citizen was transferred to a private hospital in São Paulo; however, she advocated for the acquisition of basic equipment for operative fracture care in the jurisdiction Y, which was then purchased by the municipal health managers. This fact illustrates a predominant principle of priority setting in the jurisdiction Y: to prioritize the demands of influential citizens.

In 2002, the municipal health managers were challenged with the task of improving rehabilitation care in the jurisdiction Y, responding to a state policy. Thus, I was appointed to lead the municipal rehabilitation center, where children and youth with disabilities received basic

assessments and physiotherapy. There, I became aware of unmet needs of surgical care for children and youth, which competed for the limited surgical resources that were largely consumed by the epidemics of road traffic injuries. As such, children and youth with musculoskeletal disorders presented to me another puzzling priority setting dilemma: to prioritize the epidemics of trauma or the children and youth suffering with disabilities?

Most children and youth had no private insurance and thus lacked access to time sensitive interventions to address, for example, the sequel of growth plate injuries, bone and joint infections, deformities secondary to cerebral palsy, neglected clubfeet, the late presentation of developmental hip dysplasia or progressive scoliosis, conditions which usually respond favorably to adequate management, and which cause disabilities if not managed in a timely and appropriate manner. Although these musculoskeletal problems were not epidemic [as injuries were] they were not less important nor did they cause less suffering to those children and to their families.

Based on this priority setting dilemma, the municipal managers supported my sabbatical leave to pursue two years of fellowship training in pediatric orthopaedics, one year in São Paulo (2003) and one year in Wilmington, Delaware, USA (2004), with the intent of developing regional capacity for delivering reconstructive musculoskeletal care for children and youth. However, when I returned from Wilmington, in 2005, the recently elected party in the jurisdiction Y had a different health policy agenda, which excluded developing capacity for surgical care for children and youth. As such, I left the jurisdiction Y and expanded my training in pediatric orthopaedics.

During my fellowship in Toronto, I had the opportunity to participate in outreach surgical work in different countries and to learn about diverse global-health initiatives lead by University of Toronto faculty. This experience inspired me to organize and obtain corporate funding for “academic surgical missions” in three distinct health jurisdictions of the State of São Paulo, which was a strategy to study the unmet needs. Hence, I presented the priority setting dilemma that I had encountered in the Jurisdiction Y to diverse scholars, and this resulted in my research proposal, graduate coursework and the *Projeto Hospitalar Infantil Canadá-Brasil* (appendix A).

The *Projeto Hospitalar Infantil Canadá-Brasil* was developed with the participation of multiple stakeholders, including local health care professionals, health care managers and corporate

sponsors in Brazil, as well as scholars and volunteer health care professionals affiliated with the University of Toronto and with the Hospital for Sick Children. The intent of this work is to develop partnerships with diverse regional health care managers in Brazil to facilitate empirical research to elucidate the reasons for the unmet needs of surgical care for children, in the context of competing health priorities at the community level, and to eventually contribute to capacity building for surgical care for children in Brazil.

1.4 Priority Setting for Health Resource Allocation

Literature Review

Priority setting for health resource allocation is one of the key health policy issues of this century for health care systems of diverse countries (Daniels & Sabin, 2008), including Brazil. Health care systems across the globe face the challenge of meeting diverse health care needs of the world's population. Health care needs are constantly changing in diverse settings as a result of epidemiologic transition, advances of scientific knowledge, and increased access (by diverse users of health services) to information about improved medical technology and treatment options for achieving better health. What does not change across health care systems is the need to define limits, because no system is equipped with unlimited resources (Daniels & Sabin, 2008).

Rationing decisions occur at different levels of every health care system, implicitly or explicitly (Ham & Coulter, 2001). Clinicians make micro level decisions for direct patient care. Regional and municipal health managers make meso level decisions for allocating resources for their jurisdictions. Health ministers make macro level decisions for allocating resources at the national level. Complex priority setting decisions must be made at all levels (e.g. amount of funding for different regions; resources for diverse hospitals, medical specialties, or health promotion programs; funding for particular diseases, treatments for individual patients) (Ham, 1997).

Evidence based medicine, clinical guidelines and technology assessment have been widely used to guide priority setting for allocation of health resources (Ham & Coulter, 2001). However, this is increasingly recognized as a limited technical approach to what is, at its core, a choice among relevant but competing values (Holm, 1998). Ham and Coulter (2001) reviewed and compared

explicit processes for rationing health resources in diverse publicly funded health care systems. Distinct values and principles emerged in each priority setting process, such as individual right to health care, cost-effectiveness, efficiency, fairness, and dignity (Ham & Coulter, 2001).

Holm (1998) described two distinct phases of macro level priority setting in publicly financed health care systems in Scandinavia. Phase 1 was based on “correct principles”, so decisions that were based on such principles (e.g. cost effectiveness in Oregon, necessary care in the Netherlands, severity of disease in Norway) would be regarded legitimate (Holm, 1998). Phase 1 of priority setting was compromised by conflicting interpretations of severity of disease, health care needs, and goals of the health systems. A second phase of priority setting followed, based on learning from Phase 1, with a focus on “correct processes” because principles were not sufficient to produce universally acceptable allocation outcomes (Holm, 1998). International experience with explicit processes for rationing health resources in Scandinavian countries, the State of Oregon (USA), the Netherlands and New Zealand suggest the need to focus on fair processes to facilitate societal learning on how to ration health resources reasonably (Ham, 1997). In particular, contrasting approaches pursued in Oregon (cost-effectiveness) and in Sweden (priority to the most vulnerable and seriously ill) have failed to produce acceptable allocation outcomes. Accordingly, the lessons learned from diverse contexts of macro level priority setting indicate the need to improve processes for priority setting, rather than searching for ideal principles, to achieve fair and legitimate allocation outcomes (Daniels & Sabin, 2008).

During the last decade, diverse studies about priority setting for different levels of health resource allocation have focused on processes, and the predominant approaches are grounded in epidemiology, needs assessment (Donaldson, 1991), evidence-based medicine, economics, and ethics (Daniels & Sabin, 2008; Gibson et al., 2005b). Recently, interdisciplinary approaches combining economics and ethics (Gibson et al., 2006) have been developed in the United Kingdom, Mexico and Oregon (Daniels & Sabin, 2008) and have shown promising empirical results in a pilot study in three of Ontario’s local health integration networks (Gibson et al., 2011).

1.4.1 Ethics of Priority Setting and the Describe, Evaluate and Improve Framework

Choosing among competing health priorities, in face of limited health resources, is a complex task that raises moral conflicts for decision makers. Setting priorities is therefore an ethical issue, as fairness and justice are intrinsic goals of priority setting (Martin et al., 2001). Ham (1999) described the case of a child in the UK who was denied a costly publicly funded medical treatment based on the lack of evidence for such treatment. An ethical discussion followed about the principles of “rule of rescue” and “utilitarianism”. In this case, medical evidence suggested that “rule of rescue” did not apply because the intervention in dispute could cause more harm than good, so the outcome of this limit setting decision was deemed appropriate; however, Ham (1999) argued that the processes of decision making in this case would have been more ethically acceptable if based on “*Accountability for Reasonableness*” (A4R) (Daniels & Sabin, 1997). Moreover, the author posed the hypothetical decision making dilemma in the case of funding for a costly treatment for which marginal evidence was available: in what circumstances should the rule of rescue (individual right) prevail over utilitarianism (societal right) to guide limit setting decisions (Ham, 1999)?

A4R is an ethics framework that outlines four conditions that a decision making process for allocating health resources must meet to ensure legitimacy and fairness. To meet the relevance condition of A4R, priority setting decisions must rest on rationales (evidence and principles) which fair-minded parties (managers, clinicians, patients) can agree are relevant to deciding how to meet the diverse needs of a covered population under inexorable resource constraints. To meet the publicity condition of A4R, limit setting decisions and their rationales must be publicly accessible. To satisfy the appeals condition of A4R, there must be a mechanism for challenge and dispute resolution regarding limit-setting decisions, including the opportunity for revising decisions in light of further evidence or arguments. To satisfy the enforcement condition of A4R, there must be either voluntary or public regulation of the process to ensure that the first three conditions are met. The A4R framework will be explained with further detail and references in the methods chapter. The literature review presented in this sub chapter is intentionally focused on the application of A4R with the conceptual framework Describe, Evaluate and Improve

(Martin & Singer, 2003), which I chose for my thesis based on the Brazilian health policy context as described with my scoping review.

Singer et al. (2000) studied priority setting for new technologies. The authors used case studies and grounded theory to investigate the introduction of new technology in cancer and cardiac care in Ontario, and described six domains of priority setting for new technologies: “Institutions, People, Factors, Reasons, Process and Appeals”. Singer et al. (2000) integrated these six domains into a model of priority setting, based on their case studies and based on perspectives of decision makers, and concluded that their priority setting model should be followed by studies on how to improve the ethical accounts of the process, so empirical descriptions of how priority setting decisions are made can be harmonized with the ethical account of how decisions should be made to meet the four conditions of fairness and legitimacy of A4R (Singer et al., 2000).

Martin et al. (2001) studied rationales for decision making in the case of funding new cancer drugs in Ontario, and concluded that their empirical description of priority setting facilitated learning that transcended theoretical knowledge (Martin et al., 2001). Gibson et al (2002) integrated the six domains “Diamond Model” (figure 1) with the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) in a transdisciplinary model for priority setting (figure 2) that combines the empirical root of the “Diamond Model” with the ethical justification of “*Accountability for Reasonableness*” (Gibson et al., 2002).

Figure 1 The Diamond Model of Priority Setting (from Gibson et al, 2002)

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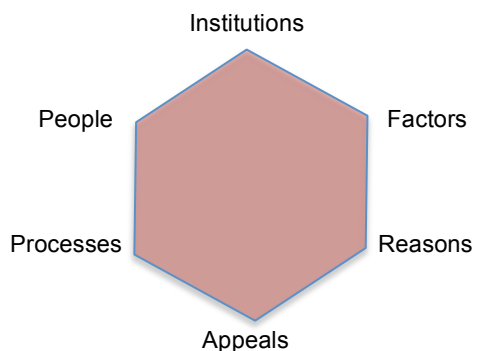
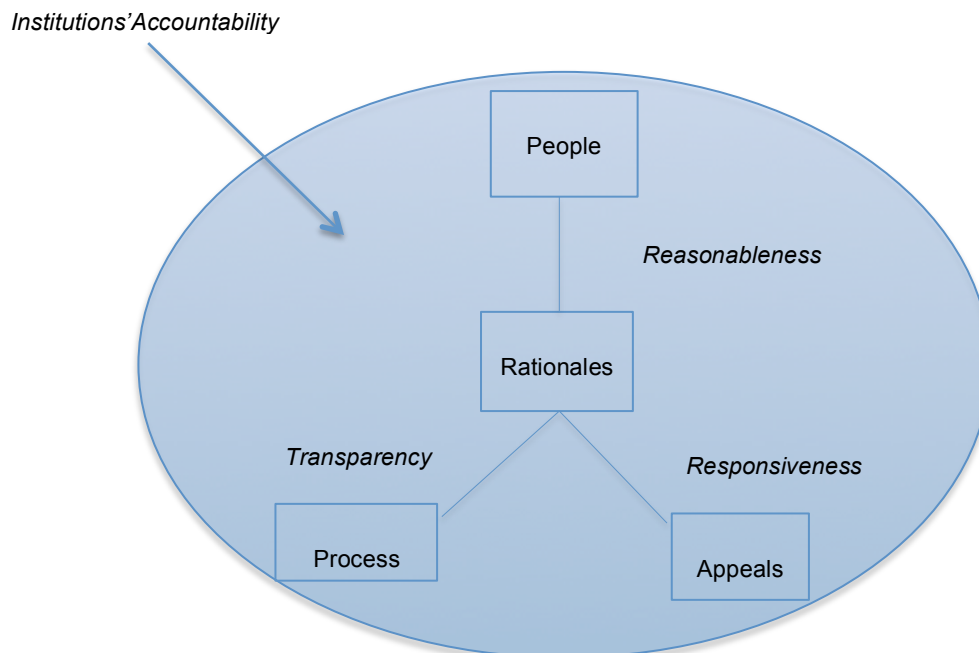


Figure 2 A Model of Accountability for Priority Setting in Health Care Institutions (from Gibson et al, 2002)

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Building on this work, Martin & Singer (2003) presented a research based approach to improve priority setting processes in health care organizations that is grounded in empirical case studies of “real world” decision making, with which priority setting processes can be described, followed by an ethical analysis of the processes using the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997). Based on the evaluation of the processes described, researchers using this model can interact with decision-makers to improve their processes in terms of intrinsic legitimacy and fairness and, with repeated cycles of *Describe, Evaluate and Improve*, action research at the community level may enable organizational learning and improved decision making (Martin & Singer, 2003).

Martin et al. (2003) applied *Describe, Evaluate and Improve* (Martin & Singer, 2003) in the context of priority setting within the strategic planning process of a tertiary academic hospital in Toronto. The authors noted that in this case study the decision making process largely met the

conditions of “Accountability for Reasonableness” (Daniels & Sabin, 1997); however, opportunities for improvement were outlined, and the hospital leadership and most participants supported the idea of integrating the recommendations for improved priority setting for future budget cycles (Martin et al., 2003).

Gibson et al. (2005a) further analyzed the case study by Martin et al (2003) from a perspective of power differences among diverse decision makers, elucidating causes for power differences and the implications of their findings on the ethical framework “*Accountability for Reasonableness*” (Daniels & Sabin, 1997). The authors recognized emerging themes that correlated with sources of power differences among diverse decision makers, “individual capacity for decision-making/preparedness”; “interpersonal factors/decision-making context; real vs. perceived authority”. These themes were validated with theoretical accounts on power differences in health services organizations (Alexander & Morlock, 2000; Young, 2000 in Gibson et al., 2005a). Based on their findings, Gibson et al. (2005a) argued that the “Empowerment Condition”, added to “*Accountability for Reasonableness*” (Daniels & Sabin, 1997), provides an improved framework to evaluate fairness and legitimacy of priority setting, and that the “Empowerment Condition” can be generalized to account for power differences in diverse health care settings (Gibson et al., 2005a).

Gibson et al. (2004) facilitated organizational learning for priority setting in three academic health care organizations in Ontario. The focus of this work was to investigate the perceptions of key decision makers of the three academic institutions with regards to criteria, processes and parameters of success of priority setting. The authors identified 8 priority setting criteria (table 1), 10 key elements of the priority setting process (table 2) and 6 parameters of success (table 3) as perceived by the institutional leadership (Gibson et al., 2004). The findings from Gibson et al. (2004) are consistent with the lessons learned from international experiences with macro level priority setting (Ham, 1997; Holm, 1998), indicating that theoretical principles for priority setting are not sufficient *per se* to guide resource allocation for clinical services. “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) provided valuable guidance to improve decision making processes in this particular context (Gibson et al., 2004).

Table 1. Priority Setting Criteria (from Gibson et al, 2004)

• Strategic fit
• Alignment with external directives
• Academic commitments – Education – Research
• Clinical impact
• Community needs
• Partnerships (external)
• Interdependency (internal)
• Resource implications
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Table 2. Priority Setting Elements (from Gibson et al, 2004)

• Confirm the strategic plan
• Clarify programmatic architecture, including program groupings and definitions
• Clarify Board/Management roles and responsibilities
• Determine who will make priority setting decisions and what they will do
• Engage internal/external stakeholders
• Define priority setting criteria and collect data/information
• Develop an effective communication strategy
• Develop a decision review process
• Develop process monitoring and evaluation strategies
• Support the process with leadership development and change management strategies
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Table 3. Parameters of Successful Priority Setting (from Gibson et al, 2004)

Outcome parameters	Process parameters
<p><i>Effect on organizational priorities and budget</i></p> <ul style="list-style-type: none"> • Priorities change; resource shift • Strategic plan supported/enhanced • Conditions for growth created/enhanced • Budget balanced 	<p><i>Efficiency of priority setting process</i></p> <ul style="list-style-type: none"> Increased ease in allocating resources Improved capacity for making priority setting decisions Perceived return on time invested
<p><i>Effect on staff</i></p> <ul style="list-style-type: none"> • Staff satisfaction neutral or positive • Staff retention/recruitment neutral or positive • Organizational understanding improved 	<p><i>Fairness</i></p> <ul style="list-style-type: none"> Stakeholders understand the process Stakeholders feel engaged Priorities are justified and seen to be reasonable Process is perceived to be consistent and fair Winners/losers issue well-managed
<p><i>Effect on community</i></p> <ul style="list-style-type: none"> • Public media recognition neutral or positive • Public acceptance or community support improved • Public perception of institutional accountability improved • Health care integration through partnerships increased • Education/research peer recognition enhanced • Emulated by other organizations 	<p><i>Conformity with conditions of 'accountability for reasonableness'?</i></p>
<p>Reproduced with permission (© 2004 Gibson et al; licensee BioMed Central Ltd)</p>	

Madden et al. (2005) *described and evaluated* (Martin & Singer, 2003) priority setting in a hospital setting in Toronto, with a particular interest in the appeals mechanism within the decision making process. The authors interviewed diverse decision-makers, analyzed key documents and observed deliberations, and concluded that the appeals mechanism was an essential element of fairness as perceived by diverse stakeholders. Moreover, the appeals mechanism improved stakeholder engagement in the priority setting process and increased overall participant satisfaction (Madden et al., 2005).

Kapiriri et al. (2007) applied *Describe, Evaluate and Improve* (Martin & Singer, 2003) in a study of priority setting at the micro, meso and macro levels of decision making for health resource allocation for hospital care in Canada, Norway and Uganda. The authors interviewed 184 decision-makers, who were predominantly acting at the micro-level. Most of the research subjects acknowledged the need for systematic and explicit priority setting processes in their institutions (Kapiriri et al., 2007). The authors perceived that the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) served as a useful guide to study priority setting. None of the priority setting processes fully met the four conditions; however, opportunities for improvement in all settings were identified, and the authors argued that the conceptual framework *Describe, Evaluate and Improve* (Martin & Singer, 2003) stood as a useful platform for knowledge sharing between diverse contexts and health care systems. The authors concluded that strategies for improving priority setting in low and middle income countries must be context specific and evidence-informed to facilitate fairer decision making processes, which are more likely to produce one of the main outcomes of priority setting in developing countries: mitigating inequities in health (Kapiriri et al., 2007).

Moreover, Kapiriri et al. (2009) investigated elements of fairness perceived by the same research subjects of Kapiriri et al (2007). Twenty three elements of fairness were reported by the research subjects, of which seventeen aligned with the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997). Thus, the authors concluded that the four conditions of “*Accountability for Reasonableness*” are applicable across health care systems and levels of decision making; however recognizing that other elements of fairness may be context specific, and as such, Kapiriri et al (2009) suggested that the “*Accountability for Reasonableness*” framework should be applied [to priority setting research] with flexibility, allowing for consideration of other elements of fairness that may not be accounted for, with the four conditions alone, in all contexts (Kapiriri et al., 2009). The findings and conclusions from Kapiriri et al. (2009) support the argument to add the “Empowerment Condition” to “*Accountability for Reasonableness*” (Gibson et al., 2005a): equal participation of all stakeholders and “balance of power” (*participatory* element of fairness) was one of the four elements (*transparency, participatory, objective and need based*) that had the highest agreement across all levels of decision making of the three health care systems described and evaluated by the authors (Kapiriri et al., 2009).

1.4.2 Economic Approaches to Priority setting

Cost effectiveness is the predominant normative principle of the economic approach to analyzing priority setting, which calls for maximizing health benefits for a given population with the resources available in their health care system. This approach contrasts with the epidemiological or needs assessment approach, which guide allocation of health resources according to epidemiological profile and disease prevalence (Donaldson, 1991).

The epidemiological approach compromises delivery of health services to citizens who suffer from less prevalent diseases, because health care budgets are exhausted with addressing prevalent diseases, before other health problems, which may be less prevalent but equally important for those who suffer from them, can be addressed (Donaldson, 1991). This is one of the key priority setting dilemmas that health economics attempts to address, *opportunity cost*: allocation decisions result in trade offs that represent lost opportunity for producing health benefits that would be achievable with different allocation decisions (Mitton & Donaldson, 2004).

Cost effectiveness analysis aims to promote *allocative efficiency*, based on the premises that health resources are limited; waste (ineffective treatments) must be reduced; effective treatments should be pursued only to the extent that benefits outweigh the costs; and that the shift of costs and benefits of resource allocation occurs at the level of service delivery. As such, reducing costs of delivering cost-inefficient services generates opportunity to reallocate resources for delivering cost-efficient services (Donaldson, 1991). This is the economic principle of *margin*: shifting available resources, by explicitly analyzing the *marginal* costs and benefits of different health services or programs, to maximize the health benefits to the population covered under the health care system or organization (Mitton & Donaldson, 2004). Cost effectiveness analysis was used in Oregon (USA), in the 1990s, as the guiding principle to set health priorities. As a result of this analysis, teeth capping was ranked as a higher priority as compared to surgical treatment for appendicitis in the Oregon health care system. As such, the cost effectiveness approach as a single principle for guiding health resource allocation has shown its limitations in real world priority setting (Daniels & Sabin, 2008).

Program Budget Marginal Analysis (PBMA) brings together the economic principles of *cost effectiveness, opportunity cost and margin*. PBMA has been applied as a priority setting framework internationally, and in diverse health care settings over the last thirty years. Mitton & Donaldson (2004) presented a guide for priority setting based on PBMA (table 4), and they recognized the need to include ethical accounts (Daniels & Sabin, 1997) of the priority setting process guided with PBMA (Mitton & Donaldson, 2004).

Table 4. Stages in a PBMA Priority Setting Process (From Mitton et al, 2004)

1) Determine the aim and scope of the priority setting exercise
2) Compile a program budget (i.e. map of current activity and expenditure)
3) Form marginal analysis advisory panel
4) Determine locally relevant decision making criteria a. Decision maker input b. Board of Director input c. Public input
5) Advisory panel to identify options in terms of: a. areas for service growth b. areas for resource release through producing same level of output (or outcomes) but with less resources c. areas for resource release through scaling back or stopping some services
6) Advisory panel to make recommendations in terms of: a. funding growth areas with new resources b. decisions to move resources from (5b) into (5a) c. trade-off decisions to move resources from (5c) to (5a) if relative value in (5c) is deemed greater than that in (5a)
7) Validity checks with additional stakeholders and final decisions to inform budget planning process
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Mitton et al. (2003) reported the application of Macro Marginal Analysis (MMA) for priority setting for allocating the health care budget of 2002/2003 in the Calgary Health Region, in Alberta, Canada. With MMA, which is a modified model of PBMA applied at the macro level, across major health services provided in a health region, the authors assisted the leadership of the Calgary Health Region to identify areas of service contraction that would allow for expansion of other services, based on context specific and locally determined criteria (Mitton et al., 2003).

Macro Marginal Analysis identified over \$40 million in resource contractions (3% of the regional budget), to be reallocated to other health services. Mitton et al (2003) recognized a few challenges with the MMA approach in the Calgary Health Region:

- 1) “Winners (services expanded) and losers (services contracted)” will be explicitly identified, so a transparent process with the involvement of all stakeholders is required to ensure fairness and legitimacy as prescribed by Daniels & Sabin (1997).
- 2) Participation and engagement of physicians is essential, as physicians play a significant role in driving health service utilization and because *physician leaders reported acceptance of hypothetical reduction in their area of practice, in the context of an explicit and credible process.*
- 3) There is a need for ongoing reevaluation to guide contraction and expansion of services (Mitton et al., 2003).

1.4.3 Economics with Ethics

Gibson et al. (2006) brought together the conceptual ethical guidance of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) and the Program Budget Marginal Analysis framework for priority setting. The authors evaluated the PBMA priority setting process for the Calgary Health Region, budget cycle 2002/2003, with the four conditions of A4R, and provided recommendations for improving the ethical accounts of the priority setting process (Gibson et al., 2006).

Building on this work, Gibson et al. (2011) have piloted the Ethics (A4R) & Economics (PBMA) approach to priority setting in three of Ontario’s local health integration networks, with the assumption that combining A4R and PBMA to guide priority setting would improve *opportunity cost* with a fair processes (Gibson et al., 2006). The authors applied an evaluation checklist for evaluating the ethical accounts of the decision making process, which will be further discussed in the methods chapter. The leadership of the pilot organizations reported that the credibility and defensibility of their decisions improved as a result of using the guiding framework.

Transparency of the rationales for decisions was a key element for perceived fairness. The chief executive officers of the Ontario’s local health integration networks approved, in April 2011,

their collaborative priority setting and decision making framework, which is based on the “Eight-Step framework” (table 5) proposed by Gibson et al, (2011). Gibson et al. (2011) argued that the “Eight-Step” priority setting model is transferable to other health care contexts.

Table 5. Eight-Step Priority Setting Framework (from Gibson et al, 2011)

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- | |
|---|
| <ol style="list-style-type: none"> 1) Step one: define the aim and scope of the priority setting activity. 2) Step two: establish priority setting committee. 3) Step three: clarify existing resource mix. 4) Step four: develop decision criteria with stakeholder input. 5) Step five: identify and rank funding options. 6) Step six: communicate decisions and rationales. 7) Step seven: provide a formal decision review process. 8) Step eight: evaluate and improve. |
|---|

1.4.4 Ethics of Priority Setting in Low and Middle Income Countries

Rationing health resources is a greater challenge for health care systems in low and middle income countries (LMIC). Acquisition of new technologies is the major driver of health care costs worldwide (Daniels & Sabin, 2008 pg.1). Technologies and health services that have shown to improve health outcomes in higher income settings need to be implemented in health care systems of LMIC to improve health outcomes for their populations. As such, the health care systems in LMIC are burdened with a large health technology gap and with challenging priority setting dilemmas, which often involve deciding who lives or who dies as a result of access [or the lack of access] to health services. Thus, the accounts of justice, fairness and legitimacy must be at the core of the priority setting processes in LMIC (Daniels & Sabin, 2008 pg. 193).

The Bioethics Program at the Pan American Health Organization (PAHO) was established in 1994 in the context of health care systems reforms in the Latin America and the Caribbean. The initial focus of the PAHO Bioethics Unit was to provide ethical advice on public policies, genomic research and on the quality of health services delivery. Stepke (2006) acknowledges the role of the PAHO Bioethics Unit to lead bioethical deliberation to address the moral conflicts that occur in the health care systems in the Latin America and in the Caribbean, which the author attributes to the inequities of access to health care due to insufficient health care resources and to corruption in the public financing of health services (Stepke, 2006).

Leading Brazilian bioethicists and the United Nations Educational, Scientific, and Cultural Organization (UNESCO) Chair in Bioethics for Brazil proposed “Intervention Bioethics” as the preferred bioethical approach in countries facing extreme social inequities. Garrafa & Porto (2003) suggest that Bioethics in LMIC should focus on the ethical dilemmas of “persistent situations”, which “should not be happening in the 21st century”. The authors argue that the Bioethics debate of “emergent situations”, which prevail in developed countries, is not a priority for LMIC. “Intervention Bioethics” aims to address the “growing lack of political analysis of moral conflicts” in LMIC, and it calls for public policies and decisions that favor the largest number of people for the longest periods of time (Garrafa & Porto, 2003).

“Accountability for Reasonableness” has provided valuable guidance for resolving moral conflicts in decision making for health resource allocation in diverse LMIC. Daniels worked with the World Health Organization (WHO) using AR4 to guide the development of fair and legitimate processes for selecting 3 millions [out of 6 millions] patients for receiving antiretroviral treatment in low income countries with a high prevalence of HIV infections. Moral disagreement among reasonable stakeholders regarding principles for allocating treatment to a limited number of patients, over a given deadline (2005), called for a fair and legitimate process (Daniels & Sabin, 2008 pg.193-202). A case study of decision making in Tanzania provides evidence of the empirical applicability of A4R in this context. The WHO endorsed the principles of A4R to guide the development of a national plan in Tanzania for scaling up antiretroviral treatment, which was widely accepted by relevant stakeholders (WHO, 2006 in Daniels & Sabin, 2008 pg. 202).

In Mexico, the explicit priority setting process for choosing the health benefits that would be covered by the “Seguro Popular” was largely based on cost-effectiveness analysis; however, the complexity of the decision making process called for a “non-quantitative” ethical account of the process (González-Pier et al., 2006). As such, the A4R principles for fair and legitimate priority setting were incorporated by officials of the Mexican Ministry of Health to address the ethical concerns that emerged with the explicit priority setting process for the “Seguro Popular”, a publicly financed health insurance that was intended to offer a limited package of health services and “catastrophic coverage” for 50 million Mexican citizens (Daniels & Sabin, 2008 pg. 202-207).

Thus, as illustrated with the priority setting contexts in Tanzania and in Mexico, the A4R principles for fair and legitimate priority setting have been empirically applied, and widely accepted, as a useful guide to address moral conflicts in decision making for health resource allocation in LMIC (Daniels & Sabin, 2008 pg. 207).

Kapiriri & Martin (2007) proposed a model to *Describe, Evaluate and Improve* (Martin & Singer, 2003) priority setting in health care systems in developing countries. Reviewing the literature about priority setting, the authors recognized four key challenges to improve priority setting in this context:

1. Lack of information;
2. Overcoming the disconnection between who is setting priorities and who should be;
3. Overcoming the disconnection between the values that are driving priority setting decisions and the values that should be;
4. The weak institutions and meager capacity available to make priority setting decisions.

As such, Kapiriri & Martin (2007) proposed a strategy (table 6) to “*capture and share current priority setting practices; strengthen the legitimacy and capacity of priority setting institutions, and develop fair priority setting processes*” in health care systems of developing countries (Kapiriri & Martin, 2007).

Following the *Describe, Evaluate and Improve* strategy (Martin & Singer, 2003), three case studies of priority setting were performed in the South-American context: Valdebenito et al. (2009) interviewed key informants and reviewed official documents to *describe* their priority setting context, and they concluded with their *evaluate* step using A4R that hospital level priority setting in Chile partially met the publicity and the relevance criteria, and that the process did not meet the appeals and enforcement conditions of A4R. Gordon et al. (2009) presented similar findings in the Argentinian hospital context, where the authors suggested that A4R would be a useful guide to improve fairness in decision making. Ferri-de-Barros et al. (2009) analyzed official documents that *described* macro-level priority setting in the Brazilian SUS, and concluded that priority setting within the SUS has not met the ethical standards of A4R, and that inequitable distribution of decision making power under represents users in poorer areas. This work is reproduced in full in the discussion chapter.

Table 6. A Strategy to Improve Priority Setting in Developing Countries (From Kapiriri & Martin, 2007)
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Strategic focus	Issues to be addressed	Action points
Capturing current practices	Describing: - the priority setting contexts - the people involved and existing external influences - the tools used - the values and evidence that guide the decisions - the priority process	Identify the good practices and opportunities for improvement in the current actual practices
Strengthening the legitimacy and capacity of institutions	<i>How legitimate are the people/institution that set priorities?</i> What mandate do they have (appointed or elected)? Who is represented? How do they ensure that all voices are heard? <i>Do they have the required capacity?</i> What training and skills do they have? What resources (information) do they have? What is the status of the institution's information technology system?	If legitimate institutions exist, train them to ensure they have the necessary analytical capacity to use the available evidence to set priorities and to promote informed debate Mitigate the impact of the external (powerful) influences Strengthen the capacity of the institutions to use the available Information Technology to synthesize and use credible evidence in priority setting.
Developing fair priority setting processes	<i>Is the current priority setting process fair?</i> Are legitimate stakeholders involved? What rationales are considered? Do they publicize the decisions and rationales? Is there provision for appeals and revision? Are there mechanisms to ensure that the priority setting process is fair?	Ensure that the priority setting process conforms to the four conditions of 'Accountability for—Reasonableness' Enhance the knowledge and capacity of context-specific leaders to implement fair processes.

A recent literature review summarized empirical studies on priority setting for health interventions in developing countries (Youngkong et al., 2009). Eighteen studies were identified. Two studies concerned priority setting in South American countries: Vargas & Poblete (2008) examined the introduction of a prioritized list of 56 health conditions in Chile by using multiple criteria. Rubinstein, Beliza'n & Discacciati (2007) studied national level priority setting in Argentina to determine whether economic evaluations are considered and used by decision-makers, and to report the criteria decision-makers used for resource allocation. The review by Youngkong, Kapiriri & Baltussen (2009) found no study regarding priority setting in Brazil.

Building on Kafiriri & Martin (2007), Kafiriri & Martin (2010) developed a framework for evaluating priority setting in low and middle income countries. The authors searched the literature for measures of successful priority setting. Then, the authors tabulated their results and presented to 50 researchers and policy makers involved with priority setting in LMIC, with representation from 12 countries, in two rounds of Delphi interviews, with the purpose of defining *measures of successful priority setting, objectively verifiable indicators and the means for verification* (Kafiriri & Martin, 2010).

Kafiriri & Martin (2010) identified *Immediate* (within a budget cycle/fiscal year) and *Delayed* (beyond three fiscal years) parameters of success, which were internal or external to the priority setting institution. For each parameter, the authors identified in the literature an objective verifiable indicator. This original work filled a gap in the priority setting literature, providing a comprehensive evaluation tool kit for health policy makers in LMIC (Kafiriri & Martin, 2010).

1.5 Summary

The publicly financed health care system in Brazil (SUS) is evolving rapidly and it has produced broad social benefit; however, the recent literature about the SUS and my personal experience working in this system has made it very obvious to me that the delivery of health services falls far short of the intent, in terms of health care and in terms of social benefit. What motivates my research is the persistent unfairness of health resource allocation, which seems rooted in arbitrary or opaque decisions about access to resources. Therefore, I chose an ethics approach to priority setting, based on the international literature on this topic, to illuminate the reasons for the unfairness of health resource allocation in Brazil. As such, I propose a scoping review and an ethical analysis to identify “good (fair and just) practices” and opportunities for improvement in the process for macro-level priority setting for health resource allocation in the Brazilian health care system.

Chapter 2 Methods: Scoping Review and Ethical Analysis

2 Conceptual Framework

The aim of my research is to synthesize knowledge about the ethics of rationing health resources in Brazil. Specifically, I will *describe* priority setting for health resource allocation in Brazil with a scoping literature review, I will *evaluate* the description provided with the scoping review according to the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) augmented with the “Empowerment Condition” proposed by Gibson et al (2005a), and, based on my description and evaluation, I will provide and publish information that will facilitate empirical work to *improve* priority setting for health resource allocation in Brazil.

My thesis work is the first attempt to synthesize knowledge about the complex topic of priority setting for health resource allocation in Brazil. This topic presents diverse research questions that are not answerable with one specific study design, and therefore, the approach offered by scoping reviews is suitable, as an initial research endeavor, to describe priority setting for health resource allocation in Brazil. Knowledge synthesis is a critical step towards evidence based medicine and evidence informed health policy making (Mays et al., 2005). Ethics of health resource allocation has been regarded by Canadian health policy makers as a high priority issue for conducting knowledge synthesis research (Lomas, 2005). Lomas (2005) speaks to the multi-stakeholder recognition of, and the growing interest in, diverse forms of knowledge synthesis methods for addressing health policy and managerial questions, because *[Health Policy and Decision Making] is as important to patient outcomes as is the front-line application of effective clinical interventions. Policy and management also save lives (or cause deaths), albeit in a less visible and direct fashion than clinical care*” (Lomas, 2005).

Systematic literature reviews have been widely applied in clinical research to synthesize knowledge about specific research questions, by identifying and ranking the highest quality of evidence concerning a specific research question that can be addressed with well-defined study designs. Scoping review is a form of knowledge synthesis that has been applied for addressing health policy and management inquiries (Mays et al., 2005), and for mapping broad and complex research topics that can be pursued with diverse study designs (Arksey & O'Malley, 2005; Levac et al., 2010).

Of the potential frameworks for approaching this complex topic, I decided to use the *Describe, Evaluate and Improve* framework (Martin & Singer, 2003), grounded in an extended version of “*Accountability for Reasonableness*”, because this framework has been well applied in low and middle income settings, and because it focuses on processes which decision makers in Brazil could use to improve fairness and justice of their allocation decisions in health care. *Describe, Evaluate and Improve* is a research informed approach, which combines normative (based on principles and theories) and empirical (“real world”) bioethics to guide action research to improve priority setting in health care organizations, and which follows three sequential steps:

- 1) *Describe* current processes for priority setting with case studies;
- 2) *Evaluate* the descriptions provided with the case studies using the leading ethical framework “*Accountability for Reasonableness*”(Daniels & Sabin, 1997);
- 3) *Improve* priority-setting processes with community based action research.

Thus, achieving **Objective I**, I will *describe* priority setting for health resource allocation in Brazil, based on official documents that described the current health policy making process for the publicly financed health care system and based on studies about ethics of priority setting in the Brazilian context. Achieving **Objective II**, I will *evaluate* the current health policy making process in Brazil, based on the descriptions provided with Objective I, and according to the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) and with the “Empowerment Condition” proposed by Gibson et al. (2005a), operationalized with the evaluation checklist proposed by Gibson et al. (2011). Achieving **Objective III**, I will provide and publish information that will facilitate empirical work to **improve** priority setting for health resource allocation in Brazil. Objective III will flow from the **describe** and **evaluate** steps, and it will be met in the discussion chapter, which also reproduce my published work on this topic as an example of concrete steps toward meeting this objective.

2.1 Ethical Considerations Regarding this Research

This work is based on secondary data that is publicly available, as such, it neither involves human subjects nor does it include the review of non-public records; therefore, according to the Tri-Council Policy Statement, this work did not require review by the Research Ethics Board.

2.2 Objective I

To *describe* priority setting for health resource allocation in the National Health Conferences in Brazil, I conducted a scoping literature review, searching for **(inclusion criteria)**:

- 1) Documents and legislation published by the Brazilian government describing the main processes of health policy making and priority setting for the SUS;
- 2) Studies on ethics of macro level priority setting for health resource allocation in Brazil;
- 3) Commentaries or dissertations about macro level priority setting for health resource allocation in Brazil.

The purpose of this scoping review is to map the complex topic of ethics of macro level priority setting for health resource allocation in Brazil. As such, in 2008, I started screening the literature with multiple searches, using diverse terms and scrutinizing several policy documents, abstracts, full text articles, manuscripts, commentaries and opinions about the topic. As proposed by Arksey & O'Malley (2005) and endorsed by Levac et al (2010), I refined my search terms and repeated different search strategies as I became more familiar with the literature about the Brazilian health care system, health services research and priority setting. Based on my initial searches, I chose the websites displayed in table 7 as potential sources for policy documents and grey literature. Then, I developed the strategies displayed in table 8 for searching the peer-reviewed literature. Publications in all languages were considered for inclusion.

I searched the Brazilian Ministry of Health website for policy documents describing the macro level priority setting processes for health resource allocation in the Brazilian health care system (SUS). I learned from my initial searches that the Law 8080 and the Law 8142 defined that the National Health Conferences (“Conferências Nacionais de Saúde”, CNS) are the core priority setting processes for the SUS. As such, I included policy documents published by the Ministry of Health that described the rules, processes, themes and outcomes of the three most recent National Health Conferences. I contacted key authors and I manually searched diverse websites and key Brazilian journals of public health (table 7) for commentaries or dissertations related to ethics of macro level priority setting in Brazil. I also contacted librarians of the Brazilian Medical Association and the Brazilian Federal College of Medicine for commentary articles or dissertations related to the scoping review.

In February 2012, I applied the search strategies A and B displayed in table 8, which were reviewed and deemed acceptable by my thesis supervisor. I updated the searches in November 27 2012. I searched the following electronic databases: Ovid MEDLINE(R) (1946 to January Week 4 2012), Ovid Healthstar (1966 to November 2012), PsycINFO (2002 to January Week 5 2012), Embase Classic+Embase (1947 to 2012 Week 05), Health and Psychosocial Instruments (1985 to January 2012), International Political Science Abstract (1989 to December 2012), Social Work Abstracts (1968 to December 2012). Strategy A combined the key words “priority setting” or “rationing” or “resource allocation” with the key words Brazil or Brasil. Strategy B combined the words Brazil or Brasil with the words “health policy”, “ethics” or “equity”. I deliberately used 2 broad search strategies, given the paucity of articles yielded with the initial searches. With the strategies A and B (table 8), I intended to find empirical research on ethics of macro level priority setting in Brazil; however, I included any study about ethics of priority setting for health resource allocation in Brazil. I excluded studies that addressed priority setting regarding specific diseases or health programs. I scrutinized the references from included studies for additional articles (snowballing).

Table 7. Key Websites

Governmental websites

www.saude.gov.br
www.portalsaude.saude.gov.br/portalsaude/index.cfm
www.ans.gov.br/

Interest groups

www.amb.org.br
www.cfm.org.br
www.cremesp.org.br

International organizations

www.who.int/country/bra/en
www.worldbank.org/
www.idrc.ca/
www.utoronto.ca/cpsrn/html/home.html
www.acdi-cida.gc.ca
www.unesco.org/en/unitwin/access-by-domain/social-and-human-sciences/bioethics/

Brazilian journals and databases

www.scielo.br/csp
www.utoronto.ca/cpsrn/html/home.html
www.sbbioetica.org.br/
<http://www.rsp.fsp.usp.br>
www.rbbioetica.com.br
www4.ensp.fiocruz.br/csp/
www.scielo.cl/abioeth.htm

Table 8. Two Main Search Strategies

Databases: Ovid MEDLINE(R) <1946 to January Week 4 2012>, Ovid Healthstar <1966 to November 2011>, PsycINFO <2002 to January Week 5 2012>, Embase Classic+Embase <1947 to 2012 Week 05>, Health and Psychosocial Instruments <1985 to January 2012>, International Political Science Abstract <1989 to December 2011>, Social Work Abstracts <1968 to December 2011>

Search Strategy A

- 1 brasil.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (14773)
- 2 brazil.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (164703)
- 3 rationing.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (24209)
- 4 priority setting.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (3407)
- 5 resource allocation.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (37664)
- 6 1 or 2 (165457)
- 7 3 or 4 or 5 (57680)
- 8 6 and 7 (223)
- 9 remove duplicates from 8 (126)

Search strategy B

- 1 brasil.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (14865)
- 2 brazil.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (167503)
- 3 ethics.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (361899)
- 4 health policy.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (117464)
- 5 equity.mp. [mp=ti, ab, ot, nm, hw, ps, rs, ui, an, tc, id, tm, sh, de, md, sd, tn, dm, mf, dv, kw, ac, cc, ip, vo, pg, jn, pb, yr, bt, mo, op, os, pa, pi, pl, pu, ry, st, ar, bs, cf, dp, ja, so, ba, be, pp, au, tt] (26306)
- 6 1 or 2 (168267)
- 7 3 or 5 (386807)
- 8 4 and 7 (6117)
- 9 6 and 8 (71)
- 10 remove duplicates from 9 (35)

I read the full text articles and documents, highlighting the recurrent themes and collating in a separate document. A second reading of the full text articles was undertaken to ensure capture of all recurrent themes. Using a data extraction sheet, I tabulated the themes and sub-themes proposed by the Ministry of Health for the three most recent National Health Conferences (table 11 in the results section) and the themes from the studies about priority setting for health resource allocation in Brazil (table 12 in the results section).

To validate my analysis, a second native Portuguese speaker, who is familiar with the research methods, repeated the same systematic process of manual thematic analysis of the studies on priority setting for health resource allocation in Brazil and of the key findings from the official documents that described the rules and the proposed themes of the three most recent National Health Conferences. This step was particularly important because my thesis supervisors are not native Portuguese speakers. The second reviewer, MF, is a Brazilian internist and intensivist, who experienced the “front-line” reality of the Brazilian health care system since very early in his career, at all levels of service, first as a trainee and subsequently as a health care provider, having worked in large academic hospitals with federal public funding as well as in primary care units run by municipal health authorities. MF has also worked in private and public hospitals in two different states during his training and brief independent practice before moving to Canada. In addition to his “front-line” experience as a health care provider in Brazil, MF also participated in the Municipal Health Council of Curitiba – Paraná. This mid-sized state capital had a fully functioning council responsible for part of the priority setting process in the region.

We then repeated the analysis of the literature on priority setting for health resource allocation in Brazil, looking for answers or opinions about the themes proposed for discussion by the Ministry of Health. We tabulated the results independently using the same template, and by consensus, we merged our results in a separate results table (table 14 in the results section).

I addressed the validity of the findings by describing an explicit research process that is verifiable and reproducible, and by having an independent reviewer, (MF) who is familiar with the topic and with the research methods, repeat the content analysis of the literature, which we synthesized by consensus (Levac et al., 2010).

My personal experience with “real world” priority setting in Brazil adds a unique perspective to the analysis, which is disclosed in chapter 1.3. Whilst enhancing research validity, the independent analysis performed by the second native Portuguese speaker (MF), who is also an expatriate medical doctor from Brazil practicing in Canada, contributes to a similar perspective that may have influenced the analysis: that of medical doctors who have witnessed first hand, and who dislike the inequities in the financing and delivery of health services in Brazil.

2.3 Objective II

To evaluate the ethics within the process of macro level priority setting for health resource allocation in the CNS, I analyzed the tabulated studies and official documents that have set the rules for the three most recent CNS according to the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) and according to the “Empowerment Condition” proposed by Gibson et al. (2005a), operationalized with the evaluation checklist (table 9) proposed by Gibson et al (2011).

“*Accountability for Reasonableness*” (A4R) (Daniels & Sabin, 1997) is an ethics framework that was developed in the context of managed care reform in the United States, and it has been used to analyze priority setting for health resource allocation in diverse settings internationally (Ham & Coulter, 2001; Martin & Singer, 2003 ; Gibson et al, 2005a; Kapiriri et al. 2007; Daniels & Sabin, 2008; Kapiriri et al., 2009; Kapiriri & Martin, 2007), as presented in the literature review chapter (1.4). “*Accountability for Reasonableness*” (A4R) outlines four conditions that a decision making process for allocating health resources must meet to ensure legitimacy and fairness (box 2). Gibson et al. (2005a) proposed adding a fifth condition to A4R, the “Empowerment Condition”, which must ensure that power differences are mitigated to facilitate effective participation of diverse members in the decision making context for priority setting in health care organizations (Gibson et al., 2005a) (box 3).

A4R “is the leading ethical framework for priority setting in health care institutions because it is the only approach that is empirically based, ethically justified, and focused on process. It can be used as an analytic lens to facilitate social learning about priority setting” (Martin & Singer, 2003).

Text box 2. The Four Conditions of “Accountability for Reasonableness” (Daniels & Sabin, 1997)

1. **Relevance** Priority setting decisions must rest on rationales (evidence and principles) which fair-minded parties (managers, clinicians, patients) can agree are relevant to deciding how to meet the diverse needs of a covered population under required resource constraints.
2. **Publicity** Limit setting decisions and their rationales must be publicly accessible.
3. **Appeals** There is a mechanism for challenge and dispute resolution regarding limit-setting decisions, including the opportunity for revising decisions in light of further evidence or arguments.
4. **Enforcement** There is either voluntary or public regulation of the process to ensure that the first three conditions are met.

Text box 3. The Empowerment Condition (Gibson et al., 2005a)

Power differences are mitigated to facilitate effective participation of diverse members in the decision-making context for priority setting in health care organizations.

I chose an ethical approach to **evaluate** priority setting because unfairness of health resource allocation in Brazil is a persistent problem and because the epidemiological and the health economic approaches fail under a tremendous burden of data requirements, and because such approaches focus on correct principles rather than correct processes. I believe from my background and my reading that a focus on processes will lead to changes that can be implemented more readily into the Brazilian health care system.

Gibson et al (2011) proposed a checklist (table 9) to operationalize the evaluation of priority setting, in the context of meso level decision making in Ontario, which applies the four conditions of “*Accountability for Reasonableness*” and the “Empowerment Condition”. The authors suggested that this framework and evaluation tools are transferable to other contexts (Gibson et al., 2011). As such, I chose the checklist to operationalize the ethical evaluation of macro level priority setting in Brazil, using the questions displayed in the table 9 as a guide for my evaluation.

Table 9. Evaluation Checklist (adapted from Gibson et al, 2011)

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<p>RELEVANCE: Decisions should be based on reasons (i.e., evidence, principles, values, arguments) that fair-minded people can agree are relevant under the circumstances.</p>
<p>Were appropriate criteria used to set priorities? (Do stakeholders agree that the criteria were appropriate?) Were available data and information sufficient to make evidence-guided decisions? (What critical gaps in data/information need to be filled for future priority setting?) Was a rationale for each decision clearly identified based on the aim and scope of the priority setting process, decision criteria and available data/information?</p>
<p>PUBLICITY: Decisions processes should be transparent, and decision rationales should be publicly accessible.</p>
<p>Were the context, aim and scope, criteria, processes and possible outcomes of the priority setting process communicated clearly from the outset and throughout to both LHIN staff and external stakeholders? Was the decision and its rationale communicated clearly to stakeholders? Was the communication plan effective in reaching affected stakeholders, including HSPs, patient/client populations and the community? (How do we know? What do we need to improve for future processes?)</p>
<p>REVISION: There should be opportunities to revisit and revise decisions in light of further evidence or arguments, and there should be a mechanism for resolving disputes.</p>
<p>If stakeholders had concerns about the decision process or the outcomes, did we provide an effective mechanism to capture and respond to these concerns in a timely fashion? (How we you know? What do we need to improve for future processes?) Were there opportunities to revisit and revise decisions on the basis of new evidence or argument, and a validation process to engage stakeholders around draft decisions? Did any decisions change as a result of these revision processes?</p>
<p>EMPOWERMENT: There should be efforts to optimize effective opportunities for participation in priority setting and to minimize power differences in the decision making context.</p>
<p>Were any stakeholder views allowed to dominate the decision making process? (What was the effect? How well did we manage this?) Were there any stakeholders that we realize in retrospect we ought to have engaged, but did not? (What are we doing now to engage them?) Given differential internal capacity across HSPs, were there mechanisms in place to support those with less capacity and ensure a more level playing field, especially in the development of project proposals? Were we attentive to the impact of our decisions on vulnerable client or patient populations? (How are we monitoring this?)</p>
<p>ENFORCEMENT: There should be a leadership commitment to ensure that the first four conditions are met.</p>
<p>Were we disciplined in our commitment to apply the priority setting framework consistently? If we needed to depart from it, were we able to articulate good reasons for this to our stakeholders? Was a formal evaluation strategy implemented to monitor progress and to identify good practices and opportunities for improvement? Is there a mechanism in place to learn from this experience to improve future iterations?</p>

2.4 Objective III

To provide recommendations for enabling researchers to design empirical studies on this topic, and health policy makers to improve priority setting for health resource allocation in Brazil, I analyzed and summarized my research findings based on the description and evaluation accomplished with objectives I and II, and based on the lessons learned from the international experience with priority setting as reported in the literature. Based on my analysis, I provided recommendations for improving the ethics of priority setting for health resource allocation in the CNS, which are found in the discussion chapter.

Also, towards meeting objective III, I published two peer reviewed manuscripts (Ferri-de-Barros et al., 2009; 2012), which are reproduced in full in the discussion chapter. They are also publicly available in English, Spanish and Portuguese from the SciELO open access database (<http://www.scielo.org>).

Chapter 3 Results

3 Description and Ethical Analysis of Priority Setting for Health Resource Allocation in Brazil

3.1 Description of Health Policy making for the Publicly Financed Health Care System-National Health Conferences

3.1.1 Policy Documents

I found two main types of policy documents that described the core priority setting processes for health resource allocation for the SUS: 1) the by laws and rules for the National Health Conferences, and 2) the final reports of the National Health Conferences. I included these two types of policy documents regarding the three most recent National Health Conferences, as they reflect the current context of priority setting for the SUS. I will describe in this section the processes for the three most recent National Health Conferences (CNS). I will base the broad description of the CNS processes on the documents which are listed in the table 10, and which are publicly available in Portuguese in the Ministry of Health website (www.saude.gov.br).

Public participation in health policy making is a legal requirement of the SUS, which is planned by the health authorities and exercised by the health council members at all jurisdictional levels of the System (figure 3). According to the federal law 8.142, planning and policy-making for the Brazilian publicly funded health care system occur during the CNS, and the participants of the CNS are organized in health councils, which must include 50% of users of the SUS, 25% elected representatives of health professionals and 25% elected representatives of managers and providers of publicly funded health services (box 4). According to the policy documents listed in the table 10, the main product of the three most recent CNS is the voted policy framework to guide health resource allocation for each budget cycle of 4 years (e.g. the 13th CNS, which occurred in 2007, produced the policy framework to guide health resource allocation for the budget cycle of 2008-2011). See text box 5 and 6 for examples of the guidelines and voted policies that resulted from the most recent (14th) CNS.

Figure 3 SUS Policy Making and Social Participation (from Paim et al., 2011)

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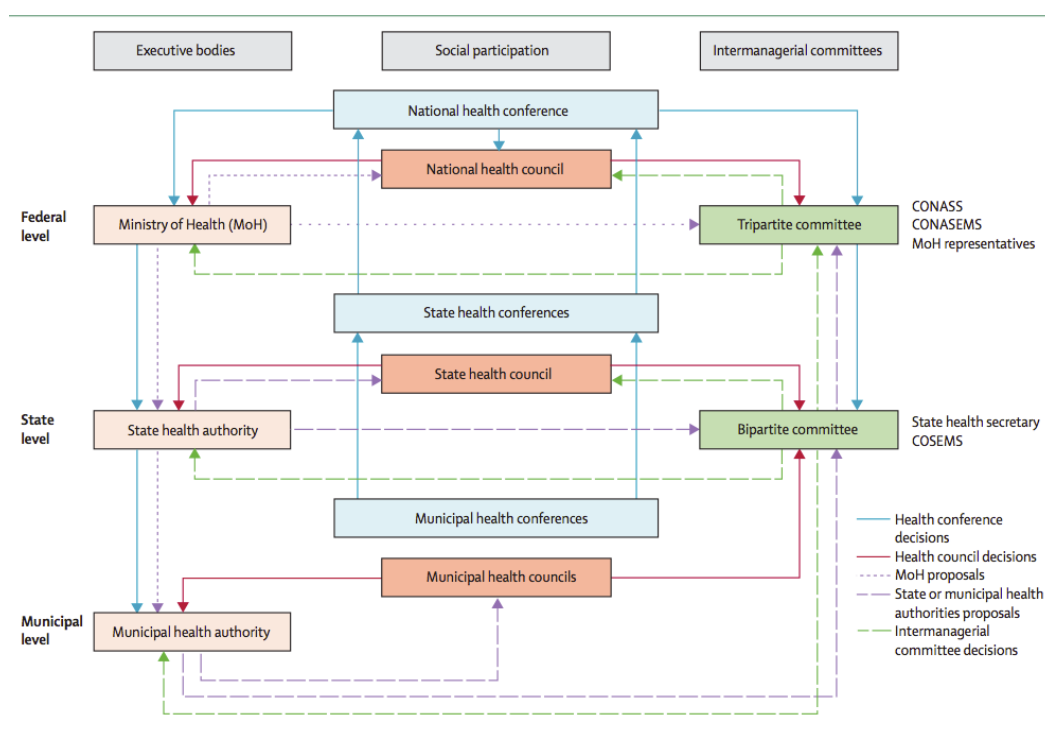


Table 10. Key Policy Documents for the Three Most Recent National Health Conferences

1) By Laws And Rules for the Three Most Recent National Health Conferences
<ul style="list-style-type: none"> • <i>Regimento da 12ª Conferência Nacional de Saúde, Aprovado em 05 De Junho de 2003, e Revisado em 06 de Agosto de 2003, Pelo Conselho Nacional de Saúde</i> • <i>Regimento da 13ª Conferência Nacional de Saúde, Aprovado na 34ª Extraordinária do Conselho Nacional de Saúde, Realizado no dia 30 de Março de 2007</i> • <i>Regimento Interno da 14ª Conferência Nacional de Saúde Aprovado na 218ª Reunião Ordinária do Conselho Nacional de Saúde, Realizada no Dia 17 de Fevereiro de 2011</i>
2) Final Reports of the Three Most Recent National Health Conferences
<ul style="list-style-type: none"> • <i>12ª Conferência Nacional De Saúde Conferência Sergio Arouca Relatório Final, Brasília, 2004</i> • <i>13ª Conferência Nacional de Saúde: Saúde e Qualidade de Vida Políticas de Estado e Desenvolvimento Relatório Final, Brasília, 2008</i> • <i>Mais Saúde, Direito de Todos 2008-2011 4ª Edição, Brasília 2010</i> • <i>Relatório Final da 14ª Conferência Nacional de Saúde Todos usam o SUS. SUS na Seguridade Social, Política Pública, Patrimônio do Povo Brasileiro, Brasília, 2010</i>

Text box 4. Numeric Representation of Diverse Stakeholders in the Health Councils (Paim et al., 2011)

50% users of SUS (i.e. members of the public);
 25% elected representatives of health professionals;
 25% elected representatives of managers and providers of public health services.

According to the by laws of the three most recent CNS, the National Health Conferences must occur in all jurisdictional levels, in three distinct phases: municipal, state and federal. Each jurisdictional health council elects an ad hoc committee to organize conferences and to produce reports regarding diverse health policy themes and sub-themes, which are pre-determined at the federal level to guide deliberation at the municipal and state levels. These themes and the dates of the three most recent CNS are displayed in the table 11. Each theme is discussed during a given timeframe, according to pre-determined scripts, at all jurisdictions, in a round table that must include all elected participants. An ad hoc committee at the municipal level is required to deliver a report to be sent to the ad hoc state committee, which then produces a combined report to be sent to the ad hoc national committee. During the federal level of the CNS, ten elected discussion groups debate and vote for diverse health policy proposals during five days. Proposed policies will come to effect upon receiving 70% of votes, and approval by 6 of 10 discussion groups. Proposals receiving 30% to 69% of votes are reconsidered in a final voting round, and may come to effect upon receiving 50% plus one vote. The ad hoc national committee combines all approved health policies in a final report that is sent to the National Health Council and to the Ministry of Health. This final document is meant to provide the health policy framework to guide four years of health resource allocation for the publicly financed health care system in Brazil (*Regimento da 12^a CNS, pg. 1-5; Regimento da 13^a CNS, pg. 1-5; Regimento da 14^a CNS, pg. 1-5*).

The 12th National Health Conference produced the health policy framework to guide the “National Health Plan” for the newly elected federal government in 2003, and its leadership suggested that the 12th Conference would be a new historical landmark for the SUS. Under the guiding theme “ The Health that We Have, the SUS that We Want”, the 12th CNS occurred in all Brazilian states and 3640 municipalities (The final report of the 12th CNS, pg. 13-18).

Table 11. Themes of the Three Most Recent National Health Conferences (Source: see table 10)

Conference	Dates and Phases	Central theme	Sub themes
12 th National Health Conference 2003	Municipal Deadline September 30 State Deadline October 31 National December 7 to 11	Health: a legal right to all and a duty of the State. The health that we have and the SUS that we want.	Right to health Social security and health The "Intersectoriality" of health actions The three governmental spheres and the construction of SUS The organization of health assistance Participatory management The work in health Science and technology and health Health financing Communication and information in health
13 th National Health Conference 2007	Municipal April 1 to August 5 State and Federal District August 15 to October 15 National November 14 to 18	Health and quality of life: State policy and development	Challenges for ascertaining human rights in the 21 st century: State, society and patterns of development Public policies for health and quality of life: SUS in social security and the pact for health Social participation in ascertaining the human right to health
14 th National Health Conference 2011	Municipal April 1 to July 15 State and Federal District July 16 to October 31 National November 30 to December 4	All use SUS, SUS in social security, public policy and Brazilian's people heritage	Access and assistance with quality: a challenge for SUS Health Policy in social security, according to the principles of integrality, universality and equity Community participation and social control Management of SUS (financing, pact for health and public vs. private relationship, management of the system, of the labor and of education in health).

There were more than 4,000 participants and 1,536 voting delegates at the national level. For the first time in the history of the National Health Conferences, following 3,100 municipal and 27 state health conferences, a synthesized report from the state level was available to guide deliberation at the national level. In the final report of the 12th CNS, the Minister of Health in charge stated in his opening remarks that “The SUS needed to address its paradoxes: whilst there are excellent services available to all citizens, such as transplants, oncologic treatments, access to medication for AIDS, there are enormous difficulties of access to basic services, urgent services and consults. It is not possible to hide this reality because just by facing these problems we can ensure the quality of the services” (The final report of the 12th CNS, pg. 13). The National Health Council acknowledged that, despite of the innovations and successes of the 12th CNS, the methodology for the CNS needed to improve, particularly in terms of strengthening capacity at the municipal and state levels to improve the quality of information and deliberation at the national level (The final report of the 12th CNS, pg. 18).

According to the final report of the 13th National Health Conference (pg. 7-10), 4,413 municipal and 27 state health conferences preceded the national level of the 13th CNS. There were 3,068 voting delegates, 302 observers and 201 guests. The central theme for the 13th CNS was “Health and Quality of Life: State Policies and Development”.

According to the final report of the most recent National Health Conference (pg. 9), the 14th CNS culminated in Brasília from November 30th to December 4th 2011, with the participation of 2937 delegates and 491 guests, who represented all states. Prior to the National level, there were 4374 municipal and state conferences in the 27 Brazilian states, which represent 78% of the expected total number of conferences. During the 14th National Health Conferences, the 2,937 delegates deliberated over 15 guidelines and health policy proposals that were generated from the 4,374 municipal and 27 state level conferences. The working groups voted and approved 343 policies, which were disseminated to the public in a final report published in 2012. Under the 15 guidelines (box 5) from the municipal and state levels, the 343 policies covered diverse priorities for health resource allocation, including human resources, diverse health programs and specific diseases (box 6). The final report of the 14th National Health Conference includes a letter to all Brazilians, in which the guiding principles of *Universality, Integrality and Equity* are strongly supported.

Text box 5. Fifteen Guidelines for the 14th CNS (source: Final report of the 14th National Health Conference- (www.saude.gov.br))

1. Defending SUS-For the Right to Health and Social Security
2. Participatory Management and Social Control Over the State: Expand and Consolidate the Democratic Model of Governing for SUS
3. Twenty Years of Sub-Financing: Fight for the Adequate Resources for SUS
4. The Unique Health System (SUS) is Unique, but the Governmental Policies are not: Ensure Unified and Coherent Management of SUS based on Building Regional Integrated Networks
5. Public Management for Public Health
6. For a National Policy that Values the Health Workers
7. Defending Life: Ensure Access and Integral Health Attention Based on Expansion, Qualification and Humanization of the Health Services Network
8. Expand and Strengthen the Primary Health Network: All Families, All People Must Have Assured the Right to a Family Health Team
9. For a Society that Defends Life and the Sustainability of the Planet: Expand and Strengthen Social Policies, Intersectorial Projects and the Consolidation of Health Surveillance and Promotion
10. Expand and Qualify Specialized [Health] Care, Urgent and Hospital Based, Integrated with the Network of Integral Health
11. For a Health System that Respects Differences and Specific Needs in Diverse Regions and Vulnerable Populations
12. Build Information and Communication Policies that Ensure Participatory and Effective Management of SUS
13. Consolidate and Expand the Policies and Strategies for Mental Health, Disabilities and Drug Addiction
14. Integrate and Expand Policies and Strategies to Ensure Care and Surveillance of Workers' Health
15. Reimbursement of SUS for Services Delivered to Clients of Private Health Plans, Having the SUS Card as an Enforcement Strategy, Prohibiting the Exclusive Use of Public Hospital Beds by those Clients

The guidelines voted at the municipal and state level (box 5) call for policies to address the sub-financing of the SUS (guideline 3), to strengthen the effectiveness of, and the social participation in the management of the SUS (guidelines 4, 5 and 12) and to address financing conflicts within the public private mix (guideline 15). They also reiterate the principles of *Universality* (guideline 1) and *Equity* (guideline 11), and particularly the principle of *Integrity* when calling for expanding and strengthening primary health care (guideline 8), health surveillance and promotion (guideline 9), specialized urgent and hospital based care (guideline 10), mental health, disabilities and addiction (guideline 13) and workers' health (guideline 14).

The policies and motions approved during the 14th CNS (box 6), which were voted based on the guidelines (box 5), reflect the principle of *Integrity*: most policies and motions call for expansion or development of publicly financed health services, which would require increasing funding for the SUS (rather than reallocation of resources based on priority setting).

Text box 6.Examples of the Policies and Motions Approved in the 14th National Health Conference
(Source: Final report of the 14th National Health Conference- www.saude.gov.br)

Guideline 1 Policy 28: Institute with the Ministry of Health lines of credit for rehabilitation...as part of home care resources...to subsidize the purchase of diapers, milk, hospital beds and enteral nutrition (pg. 17).

Guideline 2 Policy 13: Expand and improve continuous education for health councilors (pg. 22).

Guideline 2 Policy 21: Develop infrastructure and resources for the Health Councils, including indigenous Health Councils, at the three jurisdiction levels...including buildings, acquisition of motor vehicles, technological support and human resources...(pg.24).

Guideline 3 Policy 8: Ensure financing for developing oral health services in all levels, including new technology of modern dentistry: Orthodontics, Implants and prosthetics (pg. 29).

Guideline 3 Policy 12: Revise the legislation about resource shifting, allowing shifting between different programs (Pharmaceutical, Health Surveillance and Primary Care), according to local needs (pg. 30).

Guideline 3 Policy 22: Institute the participatory budget in health, to ensure public deliberation about health care spending, to improve transparency (pg. 31).

Guideline 3 Policy 23: Ensure financial resources and commitment from the three jurisdictional levels for continuity of all health programs, warranting access to all health programs to all people (pg. 31-32).

Guideline 4 Policy 2: Develop the Law of Responsibility in Health to ensure accountability of decision makers, and creating enforcement mechanisms (pg.33).

Guideline 4 Policy 6: Implement a health plan for the Amazon,... respecting the local context (pg.34).

Guideline 5 Policy 10: Institute the professionalization of decision makers for SUS at all levels...(pg.37).

Guideline 7 Policy 5: Ensure the implementation of home care nationwide, with resources from the three jurisdictions, graduating and training helpers and health care workers and professionals (pg.46).

Guideline 7 Policy 11: Expand oral health coverage in all levels of care, ...with universal and equitable access to all people, including urgent services (pg.47).

Guideline 8 Policy 17: Include sunscreen for skin and lips in the list of pharmaceuticals provided free of charge in primary care...(pg.54)

Guideline 8 Policy 25: Increase resources... to prioritize implementation and continuation of primary care, building and renewing basic health care units, building capacity for electronic medical records, acquisition of motor vehicles and other necessary equipment...(pg. 56).

Guideline 9 Policy 4: Redesign the plan for addressing chronic and non-communicable diseases, with a focus on prevention, promotion and ensuring integrality (complete package) in all forms of care (pg.57).

Guideline 10 Policy 31: Establish the epidemiological and socio demographic profile of the population as a parameter for building hospitals and health care units of medium complexity (pg.66).

Guideline 11 Policy 3: Allocate resources from the Ministry of Health budget to purchase motor vehicles with [appropriate] traction to provide services in rural areas of difficult access in the Amazon (pg.68).

Guideline 11 Policy 22: Ensure to all municipalities the financial resources to acquire mobile dental clinics, with the purpose of providing dental care to users who have mobility impairment and accessibility issues (pg.71).

Motion 11- ...Supports the inclusion of people who suffer from sickle cell disease to receive Stem-Cell Transplantation paid for by SUS...(pg.100)

Motion 18- ...Supports the inclusion of optometrist [as a professional] as part of eye care provided by SUS...(pg.06).

Motion 25-...supports the immediate regulation of home care services...to allow the implementation of home care services in less populous municipalities (pg.110)

Motion 29- ...to ensure SUS users access to speech therapy, at all levels of care, according to the principle of *Integrality* (pg.112).

Motion 32-...for patients with rheumatic diseases and their families...supports the distribution of all appropriate medicines, orthotics and prosthesis and other forms of therapy, free of charge and nationwide (pg.114)

3.1.2 Brazilian Studies on Priority Setting

In the academic literature, I found one hundred and sixty one abstracts with the search strategies described in the methods chapter. After independent review of all abstracts by two reviewers (FFB and MF), eleven articles met the inclusion criteria and were reviewed in full and thematically analyzed (table 12). Our study published in 2009 analyzed macro-level priority setting for health resource allocation in Brazil (Ferri-de-Barros et al., 2009); however, I found no empirical study on ethics of macro-level priority setting for health resource allocation in Brazil.

Searching the key websites (table 7), I found one manuscript published by the “Conselho Nacional de Secretários de Saúde do Brasil” (CONASS, 2009) and one manuscript published by the World Bank (La Forgia & Couttolenc, 2007), which described macro level health resource allocation for the SUS, and therefore will be included in my analysis. Also, scrutinizing the references from the academic literature, I found a recent series of articles published by the Lancet Brazil Series Working group. These articles are cited in the introduction chapter, as they also summarize valuable background information regarding the historical development of the current health system in Brazil. Specifically (Paim et al., 2011) provided a broad health policy analysis of governmental data relating to health resource allocation for the SUS, and as such, I included Paim et al. (2011) in my ethical analysis. I found no additional manuscripts after contacting key authors and librarians of the Brazilian Medical Association and Brazilian Federal College of Medicine.

The CONASS report (2009), a report commissioned by the National Council of Secretariats of Health in collaboration with the “Secretaria de Gestão Estratégica e Participativa” (SGEP) of the Ministry of Health, described the historical development of the CNS, based on academic and grey literature and based on the final reports of all the CNS. The authors highlighted successes and opportunities for improvement of the CNS processes, which I will present in the ethical analysis. The “*Conselho Nacional de Secretários de Saúde*”(CONASS) challenges the SUS principle of *Integrity*, when they acknowledge the need [for the CNS] to set priorities explicitly and more objectively in the publicly financed health care system in Brazil (CONASS, 2009, pg.33). The National Council of Health Secretariats (2009) supports the view that “setting

priorities does not mean to disregard other health services...but to recognize areas that need special attention. If the National Health Conferences are not capable of identifying which [health services] are more relevant, and if everything is equalized with regards to importance, it becomes impossible to identify actions that must be prioritized, compromising the effort of analyzing and following the governmental planning and actions, which must be done by the health councils” (CONASS, 2009, pg.33).

La Forgia & Couttolenc (2007) performed an economic analysis of the SUS, which was commissioned by the Brazilian Ministry of Health and performed by the World Bank. The authors applied the Public Expenditure Tracking Survey (PETS) in a sample of 49 SUS hospitals of 17 municipalities of 6 States. “PETS” is a quantitative method of economics that tracks the flow of money within bureaucratic organizations, which has been widely applied to measure corruption of resource allocation for education and health care (Reinikka, 2003).

La Forgia & Couttolenc (2007) highlighted the lack of accountability and evidence-based planning for health policies and interventions in all jurisdiction levels of the SUS. Resource allocation in the states and municipalities was regarded compromised by the “lack of capacity to develop evidence-based plans to guide their [states and municipalities] health policies and interventions”. La Forgia & Couttolenc (2007) concluded that planning for allocating health resources occurs as a legal formality and is insufficient to provide an evidence-base for health policy making.

Paim et al (2011) suggested in their recent analysis of the SUS that epidemiological transition, underfunding of the SUS and the increasing support that the federal government has provided for the growing private health sector are the main challenges for meeting equity goals and improved health outcomes in Brazil, and that the systems’ financial framework needs to be restructured and realigned with the organization’s goals of *Universality* and *Equity*. According to Paim et al. (2011), the public-private mix needs to be redefined to ensure the sustainability of the SUS, and “ultimately, the challenges facing the SUS are political because they cannot be resolved in the technical sphere but through only the concerted efforts of individuals and the society” (Paim et al., 2011). The authors’ observations align with the economic analysis performed by La Forgia & Couttolenc (2007).

A few authors produced most of the academic literature on ethics of health resource allocation in Brazil, which is published in Portuguese, English, Spanish and French. Fortes & Zoboli (2002) studied Brazilian citizen's values about micro-allocation of scarce medical resources in a single municipality of the State of São Paulo. The authors interviewed 395 randomly selected citizens, who were visiting patients in a public regional hospital, with regards to principles for allocating a single hospital bed, for two hypothetical competing patients, in eight simulated medical emergencies. The hypothetical competing patients were different in age, gender, family status (provider or dependent) and lifestyle. Fortes & Zoboli (2002) reported a trend towards prioritizing the more vulnerable hypothetical patients, and a balance between utilitarian (maximization of welfare) and deontological (equity) values. Seventy two percent of those interviewed prioritized children and youth over adults for receiving medical care. This is in keeping with the federal law 8069 of 13th of July 1990, which states that children and youth must have priority of access to health care (Fortes & Zoboli, 2002).

Wendhausen (2006) studied decision making processes for health resource allocation in a municipal health council of the State of Santa Catarina, Brazil. The author systematically analyzed legal documents and meeting reports; observed meetings and conducted interviews for studying the quality of decision making during health council meetings, with a special focus on describing the participation of diverse council members (Wendhausen, 2006). This study reported that the numeric distribution of council members did not meet the legal requirements defined by the bill 8142/90 because there were 10% more (than what is legal) members of the government and 8% less health care professionals participating as council members. Moreover, non- members of the government had fewer opportunities for participating during diverse debates about municipal health care issues, as members of the government controlled the discussions autocratically, imposing their ideas. The authors concluded that there is significant power imbalance among diverse health council members, in terms of quantity and quality of participation in health policy making, thus suggesting that empowerment of diverse health council members is critical for ensuring true democratic participation (Wendhausen, 2006).

Wendhausen & Cardoso (2007) suggested that educating and informing diverse health council members is critical for ensuring legitimate societal participation in health policy making, because education and information are determining factors for true participation and because there is

marked inequity of education, and of access to key information, among diverse health council members in Brazil (Wendhausen, 2007). Martins et al. (2008) reviewed the development and the current status of municipal health councils. Since 1988, there have been significant advances in legislation that prescribe societal participation in health policy making in Brazil; however, there is no enforcement for such legislation. Another barrier for ensuring true societal participation is the fact that empowered members of society do not participate in the public health policy debate because this socio-economic class in Brazil relies on private health care. Martins et al. (2008) agree with the argument proposed by Wendhausen & Cardoso (2007) that there is an urgent need for educating and informing diverse health council members because power imbalance has been a recurrent theme in diverse studies concerning societal participation in policy making in municipal health councils of several Brazilian states (Martins et al., 2008).

Fortes (2008) examined the principles of social utility and equity for priority setting of health resource allocation in Brazil. Each principle posed diverse priority setting dilemmas. Given there is insufficient public health care financing to address the current health needs, the author argues for explicit rationing of health resources, increasing funding, improving efficiency, and strengthening true community participation in the complex process of rationing health resources (Fortes, 2008). Zoboli & Fortes (2008) described the development and the role of Bioethics in the health policy debate in Brazil. The authors report that, since 1990, Bioethics plays a key role in the health policy debate in Brazil, and they argue that extensive multi-stakeholder deliberation is required to ensure that the principles of *Universality* and *Equity* of the SUS are met (Zoboli & Fortes, 2008).

Fortes (2009) interviewed 20 Brazilian professors of Bioethics to study the meaning of *Universality* (health care for all citizens) and *Integrity* (a complete package of health services), which are legally defined principles of the SUS. The author concluded that Brazilian bioethicists differ with regards to what constitutes a fair health care system; however, most bioethicists, in the context of a hypothetical reform of the Brazilian constitution, would endorse the principle of *Universality* and would reject the principle of *Integrity* because *Integrity* is “difficult”, “impossible”, “illusory” or “utopian” (Fortes, 2009). In a similar study, Fortes (2010a) studied the meaning of equity for Brazilian professors of Bioethics and concluded that there are diverse interpretations for the meaning of equity in the context of health care among Brazilian

bioethicists (Fortes, 2010a). Fortes (2010b) interviewed 21 Brazilian professors of bioethics who had diverse professional backgrounds (Medicine, Dentistry, Nursing, Anthropology and Theology). Using a semi-structured questionnaire, the author examined diverse principles for rationing health care resources in Brazil. The content analysis suggested diverse moral values among research subjects regarding principles for guiding health care rationing in Brazil (box 7) (Fortes, 2010b).

Text box 7. Core emerging themes reported by Fortes (2010b)²

- | |
|---|
| <ol style="list-style-type: none"> 1. Difficulty to ration and prioritize scarce health resources; 2. It is valid to ration health resources; 3. Few emerging criteria for rationing: <ol style="list-style-type: none"> a. to exclude desired health services (vs. needed) b. to exclude high cost procedures 4. Health resources should not be limited according to age or social groups 5. Favoring of citizens with no access to private care (exclusive users of SUS) 6. Maximization of health benefits (cost-benefit/utilitarianism) 7. Blaming (illness as a result of unhealthy habits): divergent opinions <ol style="list-style-type: none"> a. If individual choice of unhealthy habits, individual should pay for own health care b. This issue requires very prudent analysis. |
|---|

Ferri-de-Barros et al. (2009) studied macro-level priority setting in Brazil. The authors analyzed policy documents, which described the 13th National Health Conference, under the lens of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) and according to the core recommendations for health equity by the Commission on Social Determinants of Health of the WHO (CSDH, 2008). The authors concluded that the process for health policy-making did not meet ethical or equity conditions and that the public-private mix exacerbates inequities of health resource allocation in Brazil (Ferri-de-Barros, et. al., 2009). Ferri-de-Barros et al. (2012) argued that explicit rationing of health resources across the public private-mix in the Brazilian health care system is required for ensuring societal education and legitimate participation in the complex task of distributing limited health resources fairly and reasonably (Ferri-de-Barros et al., 2012). These two articles are reproduced in full in the discussion chapter.

Table 12 summarizes the academic literature about ethics of health resource allocation in Brazil.

² The author was the president of the Brazilian Society of Bioethics (2009-2011) and is a full Professor and vice-dean of the School of Public Health of the University of São Paulo.

Table 12. Brazilian Studies on Ethics of Health Resource Allocation

Study	Subject	Objectives	Study design	Conclusions
Fortes & Zoboli, 2002	Ethics of resource allocation micro-level	Analyze ethical dilemmas in micro allocation decisions	Individual interviews of 395 random citizens	Co-existence of deontological and utilitarian values, tendency towards favoring the destitute
Wendhausen 2006	Quality of decision making in a municipal health council	Describe and evaluate the decision making processes	Document analysis, participant observation and individual interviews with key informants	Composition of members does not meet legal requirement, power imbalance among non-governmental and governmental council members
Wendhausen & Cardoso, 2007	Decision making and health councils	Describes a theoretical framework of democratic participation in decision making for health resource allocation in Brazil	Review article	Power imbalance among health council members
Martins et al., 2008	Health councils, decision making, and social participation	Historical analysis of the development process for the health councils	Review article	Need for empowerment for democratic participation, Need for further studies regarding health councils
Fortes, 2008	Bioethics reflection regarding priority setting	Describe priority setting in Brazil, examining utilitarianism and equity principles	Review article	Need for explicit priority setting and strengthening of social participation in decision making for health resource allocation

Table 12. Brazilian Studies on Ethics of Health Resource Allocation

Study	Subject	Objectives	Study design	Conclusions
Zoboli & Fortes, 2008	Bioethics and public health policy in Brazil	Describes the development and the role of Bioethics in the health policy debate in Brazil	Review article	Bioethics plays a key role in the health policy debate in Brazil. The principle of Universality of SUS should be enforced
Fortes, 2009	Brazilian bioethicists and the principles of universality and integrality in the SUS	Study bioethicists' values regarding the principles of Universality and Integrality of Brazil's health care system	Semi-structured interviews with 20 Brazilian bioethicists	Bioethicists diverge on what constitutes a fair health care system. Most bioethicists are emphatically in favor of Universality and consider Integrality utopic
Ferri-de-Barros et al. 2009	Macro-level priority setting for the public health care system	Describe and analyze macro-level priority setting according to the ethical framework "Accountability for Reasonableness" and with the core recommendations for health equity by WHO	Document analysis	Decision making process does not meet ethical or equity conditions. Public-private mix exacerbates inequities of health resource allocation
Fortes, 2010a	Equity in the health care system	Understand the meaning of equity amongst Brazilian bioethicists	Individual interviews/discourse analysis	Diverse views of what constitutes an equitable and just health care system
Fortes, 2010b	Priority setting for the public health care system	Bioethicists' values regarding principles for guiding priority setting	Semi-structured interviews with 21 bioethicists	Need for explicit priority setting process with multi-stakeholder participation
Ferri-de-Barros et al, 2012	Priority setting and the public private mix	Argument for explicit rationing of health care resources in Brazil	Review article	Need for explicit rationing across the public private mix

We identified three themes of the three most recent National Health Conferences that were explicitly addressed in the literature on ethics of health resource allocation in Brazil:

1) **Societal participation** is one of the key principles of the SUS since its implementation in 1990. This principle has been a recurrent theme in the three most recent National Health Conferences (table 11). The literature on ethics of health resource allocation in Brazil suggests that legitimate societal participation has been compromised by power imbalance among decision makers of the SUS (Martins et al., 2008) in terms of numeric distribution and effective participation of decision makers within municipal health councils. Members of the public lack information, knowledge and voice as compared to members of the government (Wendhausen, 2006). The National Council of Health Secretariats (CONASS, 2009) states that it is not uncommon for health care managers to depart from the governing rules for public participation in decision making that are defined by the Brazilian constitution of 1988. Considering regional and age group differences in access to the privately financed health care system, the current distribution of voting participants underrepresents users from poorer regions, children and youth who depend exclusively on the SUS for health care (Ferri-de-Barros et al., 2009).

2) **The principles of *Integrity*** (a complete package of health services), ***Universality*** (for all citizens) and ***Equity*** (equitably) were sub-themes of the 14th National Health Conference. The work by Fortes (2009) suggests that most Brazilian bioethicists would enforce the principle of *Universality* and reject the principle of *Integrity*, which was regarded “utopian” (Fortes, 2009). The CONASS report (2009) also rejects the principle of *Integrity*. The principle of *Equity* has been addressed directly or indirectly in the scoping review. Ferri-de-Barros et al (2009) analyzed *Equity* in the Brazilian healthcare system considering the public-private mix and the differences in representation (voting power) of citizens from diverse regions of Brazil and diverse age groups. The authors concluded that the current voting process is inequitable, as it underrepresents users from poorer regions, children and youth (Ferri-de-Barros et al., 2009). Fortes (2010a) studied the meaning of *Equity* amongst Brazilian bioethicists and concluded that there were diverse views of what constitute an equitable health care system (Fortes, 2010a). Paim et al (2011) suggests that the SUS financial framework needs to be restructured and realigned with the organization’s goals of *Universality* and *Equity*.

3) **The public-private mix** was a sub-theme in the 14th National Health Conference (*public vs. private relationship*). Martins et al. (2008) discussed the (self) exclusion of citizens who have access to privately funded health care from the social participation processes for health policy making for the SUS, due to the fact that their health care needs are addressed in the privately financed system. As such, members of society who are empowered to drive and demand improvements of the publicly financed system have lost their interest to participate in the decision making processes for the SUS (Martins et al., 2008). Ferri-de-Barros et al. (2009) discussed inequities resulting from the public-private mix. Building on the theme of self-exclusion by Martins et al. (2008), Ferri-de-Barros et al. (2012) argued for explicit rationing of health resources across the public-private mix in Brazil.

Table 13 summarizes the three recurrent themes of the CNS, which are explicitly addressed in the academic literature about ethics of priority setting in Brazil.

Table 13. Recent CNS Themes and the Literature on Ethics of Health Resource Allocation in Brazil

CNS themes	Societal Participation	Integrity, Universality and Equity	Public-private mix
Studies themes	<p>Power imbalance among diverse decision-makers.</p> <p>Composition of municipal health councils does not meet the legal requirement (8142/90).</p> <p>Voting process underrepresents user from poorer regions, children and youth.</p> <p>Empowerment of users of the system is required for legitimate societal participation.</p>	<p>Integrity is challenged.</p> <p>Universality is widely accepted.</p> <p>Equity is a predominant concept that is endorsed; however, there are diverse views regarding principles to guide fair allocation of resources.</p> <p>Need for explicit priority setting processes.</p>	<p>There is no formal priority setting process for the privately financed system.</p> <p>Public- private mix increases inequities and inefficiencies of health resource allocation.</p>
<p>CNS= <i>Conferências Nacionais de Saúde</i> (National Health Conferences)</p>			

In summary, based on the policy documents listed in the table 10, macro level priority setting for health resource allocation for the SUS follows a well structured process, which is intended to ensure societal participation in health policy making. The National Health Conferences (CNS) occur every four years to guide the formulation of health policies for the SUS, which are intended to guide priority setting for health resource allocation, at all jurisdictional levels, for every budget cycle of the publicly financed health care system. Most policies and motions voted with public participation in the most recent 14th CNS echo the principles of *Universality, Integrality and Equity*. The principle of *Integrality* (a complete package of health services) is revealed in the final report of the 14th CNS with a large number of policies calling for expansion or development of health services, such as guideline 7 Policy 11: Expand oral health coverage in all levels of care, ...with universal and equitable access to all people, including urgent services (pg.47); or motion 18- ...Supports the inclusion of optometrist [as a professional] as part of eye care provided by the SUS...(pg.06); or motion 29- ...to ensure SUS users access to speech therapy, at all levels of care, according to the principle of *Integrality* (pg.112).

Economic analysis of the SUS by the World Bank (La Forgia & Couttolenc, 2007) reveal the lack of managerial capacity at all jurisdictional levels of the SUS to formulate evidence-informed health policies, which compromise accountability of health resource allocation in the publicly financed health care system. The recent analysis of secondary data by Paim et al. (2011) supports the findings from La Forgia & Couttolenc (2007). According to Paim et al. (2011), the public-private mix needs to be redefined to ensure the sustainability of the SUS, and this is a political (rather than a technical) matter. The “*Conselho Nacional de Secretários de Saúde*” (CONASS, 2009) challenges the SUS principle of *Integrality*, when they acknowledge the need (for the CNS) to set priorities explicitly and more objectively in the publicly financed health care system in Brazil (CONASS, 2009, pg.33)

The academic literature about ethics of priority setting in Brazil is scarce and it lacks empirical data. Fortes & Zoboli (2002) study reveals a diversity of values among Brazilian citizens’ regarding micro-level priority setting for health resource allocation. Similarly, Fortes (2009), (2010a) and (2010b) empirical work suggest a diversity of values regarding priority setting among Brazilian bioethicists’, who disapprove the principle of *Integrality* for the SUS. Wendhausen’s (2006) empirical work suggests power imbalance in decision making for the SUS.

3.2 Analysis with the four Conditions of *Accountability for Reasonableness* (Daniels & Sabin, 1997) and the with *Empowerment* Condition (Gibson et al., 2005a) Operationalized with the Evaluation Checklist (Gibson et al., 2011)

In this section, I will use the questions from the evaluation checklist (table 9) proposed by Gibson et al. (2011) to evaluate the compliance of priority setting in the SUS with the four conditions of A4R (Daniels & Sabin, 1997) and with the “Empowerment Condition” (Gibson et al., 2005a). This evaluation will be based on the description of the three most recent National Health Conferences, according to the scoping literature review that I presented in the previous chapters.

Relevance condition: Decisions should be based on reasons (i.e., evidence, principles, values, arguments) that fair-minded people can agree are relevant under the circumstances.

Were appropriate criteria used to set priorities? (Do stakeholders agree that the criteria were appropriate?)

Priority setting for health resource allocation occurs implicitly in Brazil (Fortes, 2008; Ferri-de-Barros et al., 2009) therefore the criteria used to set priorities is unknown. As such, my scoping review falls short on directly answering this question. According to the policy documents, the criteria to set health priorities should reflect the values of the Brazilian citizens, which are exercised with the CNS. Health policies and motions (box6) (which are voted and approved at the national level of the CNS) are intended to guide priority setting for health resource allocation in all jurisdictional levels of the SUS. Such policies are developed based on guidelines (box 5), which are set based on voting at the municipal and state levels of the National Health Conferences. The voted guidelines (box 5) are developed based on the themes (table 11) set by

the Ministry of Health as a framework for deliberation at the CNS. The themes and sub-themes reflect the values of the leadership of the Ministry of Health, the National Health Council.

The guidelines voted at the municipal and state level reflect the values of their participants. The policies and motions approved at the national level reflect the values of the diverse interest groups represented at the National Health Conferences. Priority setting for allocating health resources should be based on the voted policies and motions, and health council members at all levels are charged with the role of ensuring that decision making at their jurisdictional level reflects the approved policies and motions (CONASS, 2009).

Since 2006, the “Pact for Health” strengthens the commitment of decision makers in all jurisdictional levels to align resource allocation with the health plan elaborated with the National Health Conferences (Paim et al., 2011). The bipartite (state level) and tripartite (federal level) committees were developed to make consensus based decisions to ensure that each level of government supports the implementation of the health policies developed at the national level of the CNS (Paim et al., 2011). However, priority setting for allocating health care resources occurs implicitly at all jurisdictional levels of the SUS. There is no accountability mechanism described in the policy documents of the three most recent National Health Conferences that ensures that the allocation of health care resources occurs according to criteria defined by the guidelines, health policies or motions approved during the three phases of the National Health Conferences. As an example of this gap, following the 13th National Health Conference, the Ministry of Health released a document with allocation decisions for the 2008-2011 budget cycle (R\$ 86.949.738.066,04) (1R\$=0.4 CAD\$ in January 2013): “*Mais Saúde, Direito de Todos*”. In this document, the Ministry of Health presents an action plan for prioritizing diverse health services and programs (box 8); however, the rationale for each measure is not explicit. As an example, the rationale for the Ministry of Health allocating R\$ 1,926,263,423 to expanding oral health and R\$ 22,856,462 to improving the network of public diagnostic laboratory services is not publicly available. The allocation decisions are arguably justifiable based on the text of the voted policies, such as “expand oral health coverage in all levels of care”, or “strengthen diagnostic laboratory services”. The unanswered question is “to what extent”?

Thus, although there is public participation in decision making for health policy making at all jurisdictional levels of the SUS, and the voted health polices reflect the values (or demands) of the elected representatives of all Brazilian citizens, the voting process in itself does not ensure that the final allocation decisions are based on “reasons that fair-minded people can agree are relevant under the circumstances” because the rationale for the final allocation decisions rests at the diverse management levels of the SUS, and thus the criteria used to set priorities is not explicit to all stakeholders.

Were available data and information sufficient to make evidence-guided decisions?
(What critical gaps in data/information need to be filled for future priority setting?)

This question could not be answered based on the policy documents of the three most recent National Health Conferences; however, according to La Forgia & Couttolenc (2007) planning for allocating health resources “...is conducted mainly as a formal exercise to comply with the legal requirement rather than as an instrument to implement policy or as a basis for resource allocation”. Resource allocation is based on historical data (budget from previous years) or on guidelines proposed by the Ministry of Health. States and municipalities lack the required capacity to formulate an evidence-based plan to address the health priorities in their jurisdictions. As such, La Forgia & Couttolenc (2007) suggest that the available data is usually insufficient to guide evidence-informed decisions for the SUS.

Under the guideline 2 (box 5) “*Participatory Management and Social Control Over the State: Expand and Consolidate the Democratic Model of Governing for SUS*”, from the 14th National Health Conference, diverse policies aim to indirectly address the lack of capacity for decision making at all levels, by proposing diverse measures for strengthening the municipal health councils and for developing regional health councils. Policy 7 of guideline 2 (pg. 21) suggests that health council members must take possession of the available information...to work effectively based on the local health situation...to plan health actions based on local reality.

Was a rationale for each decision clearly identified based on the aim and scope of the priority setting process, decision criteria and available data/information?

The aim and scope of the priority setting process (National Health Conferences) is to develop health policies based on voting, according to the guidelines developed during the state and municipal levels of the CNS, which should reflect the values of the Brazilian citizens and guide priority setting for health resource allocation in all jurisdictions, for a four years budget cycle. The document “*Mais Saúde, Direito de Todos*” is an example of an action plan, following the 13th National Health Conference, for prioritizing diverse health services and programs (box 8) for the budget cycle of 2008-2011. This document presents diverse allocation decisions made by the Ministry of Health; however, the rationale for each decision is not “clearly identified based on the aim and scope of the priority setting process, decision criteria and available data/information”.

Text box 8. Example of the Allocation Plan for 2008-2011

Source: “*Mais Saúde, um Direito de Todos*” (publicly available at www.saude.gov.br)

Measure 1.8- Strengthen and Expand the National Network of Integral Care for Workers (pg.21) Total Budget 2008-2011 R\$ 373,630,000
Measure 1.3- Expand actions for Family Planning (pg.23) Total Budget 2008-2011 R\$ 583.377.082
Measure 1.3.4-Expand the number of tube ligation surgery, from 50,000/year to 51,000/year in 2008 and 5% increase per year until 2011 (pg.24) Budget 2011 R\$ 70,223,734
Measure 1.4-Stimulate Breast Feeding (pg.24) Total Budget 2008-2011 R\$ 6,187,000
Measure 1.6-Establish Educational and Communication Programs to Promote Behavior that Reduce the Risk of Diseases (pg.26) Total Budget: R\$ 216,958,723
Measure 2.2-Expand and Build Infrastructure for the Service of Urgent Mobile Health Units (ambulance) (pg.36) Total Budget 2008-2011: R\$ 1,917,000,000
Measure 2.23-Modernize the National Network of Public [Diagnostic] Laboratories (pg.38) Total Budget 2008-2011: R\$ 22,856,462
Action 2.1.3-Expand the Program “ <i>Brasil Sorridente</i> ” Increasing the Number of Oral Health Teams from 16,500 in 2007 to 22,000 until 2011, Expanding Coverage from 41% to 60% of the Population (pg. 40) Total Budget 2008-2011: R\$ 1,926,263,423

Publicity: Decision processes should be transparent, and decision rationales should be publicly accessible.

Were the context, aim and scope, criteria, processes and possible outcomes of the priority setting process communicated clearly from the outset and throughout to both internal and external stakeholders?

The context, aim and scope, criteria, and processes of the National Health Conferences are pre determined by the Ministry of Health, according to the by laws of the National Health Conferences, which are clearly communicated to the public in the Ministry of Health website. The possible outcomes of the National Health Conferences are the voted policies and motions, which are intended to guide the allocation of health care resources in all jurisdictional levels, for every budget cycle of four years for the SUS. The voted policies and motions are also clearly communicated to the public in the final reports of the CNS, which are also publicly available in the Ministry of Health website.

Was the decision and its rationale communicated clearly to stakeholders?

The final reports of the CNS are intended to communicate to the wide public the approved health policies and motions for resource allocation for the SUS (rationales), and the final reports of the three most recent CNS do communicate to the public all policies and motions approved with voting during each respective CNS. However, the allocation plans for each budget cycle are not communicated in the final reports of the CNS. The allocation plan for the budget cycle 2008-2011 was communicated to the public following the 13th CNS in the document “*Mais Saúde, Direito de Todos*” (table 10); however, this document does not disclose the rationale for the allocation decisions. I did not find similar documents regarding the allocation plan following the 12th or the 14th CNS.

Arguably, the allocation plans (decisions) align with the voted policies and motions (rationales), which were communicated clearly to the wide public in the final reports of the CNS; yet, the voted policies and motions are broad enough to justify diverse allocation decisions based on the principle of *Integrity* (e.g. expansion and contraction of diverse health services). Thus, based on the by laws and final reports of the three most recent CNS, the allocation decisions and

rationales for allocation decisions were not communicated to the public, and as such, rationing of health care resources have occurred implicitly in the SUS.

Was the communication plan effective in reaching affected stakeholders, including health services providers, patient/client populations and the community? (How do we know? What do we (decision makers/health councilors) need to improve for future processes?)

The law of public participation defines the communication plan, which does not ensure that the rationales for the decisions made, during the three phases of the National Health Conferences, are disseminated to the public. Therefore, the *publicity* condition of “*Accountability for Reasonableness*” has not been fully met in the three most recent National Health Conferences. To improve future processes, the rationales for allocating health resources should be based on “explicit reasons that that fair-minded people can agree are relevant under the circumstances”. As such, because allocation decisions inevitably result in rationing (opportunity cost), the core principle of *Integrity* of the SUS must be revised, so explicit reasons for setting health priorities for the SUS can be developed based on fair processes.

Revision: There should be opportunities to revisit and revise decisions in light of further evidence or arguments, and there should be a mechanism for resolving disputes.

If stakeholders had concerns about the decision process or the outcomes, did we (decision makers/health councilors) provide an effective mechanism to capture and respond to these concerns in a timely fashion? (How do we know? What do we need to improve for future processes?)

Final decisions, made at the federal level after deliberation at the municipal and state levels, come into effect based on voting. Proposed policies will come into effect upon receiving 70% of votes, and approval by 6 of 10 discussion groups. Proposals receiving 30% to 69% of votes are reconsidered in a final voting round, and may come into effect upon receiving 50% plus one vote. Thus, voting is the mechanism described for resolving disputes in the CNS. There is no formal appeal mechanism to revert the voted policies after concluding the final voting rounds

described in the by-laws for the three most recent National Health Conferences; moreover, because the rationale for allocation decisions is not publicly available, it is not possible to determine how the voted policies and motions (appealed or not) guide allocation decisions.

Health council members at all levels are in charge of ensuring that managers comply with the approved policies to guide allocation decisions. Social participation in decision making occurs with deliberation at the municipal and state levels, where the health councils are charged with the task of evaluating and disputing allocation decisions [made by local/regional health care managers] to ensure that the local health policies are aligned with the outcomes of the National Health Conferences and with the local health needs. However, according to the National Council of Health Secretariats (2009), there is an important gap between managers, health conferences and health councils that impair priority setting for the SUS (CONASS, 2009, pg. 51). In 2006, following the 12th National Health Conference, the federal government approved the development of a national agency to support, monitor, hear and audit participatory management for the SUS, “Secretaria de Gestão Estratégica e Participativa”, (SGEP). SGEP is responsible for accelerating and perfecting the practices of strategic and participatory management for the SUS (SGEP, 2009, pg. 11); however, SGEP in itself does not ensure an effective appeal mechanism to revise allocation decisions.

Were there opportunities to revisit and revise decisions on the basis of new evidence or argument, and a validation process to engage stakeholders around draft decisions? Did any decisions change as a result of these revision processes?

This question could not be answered based on the scoping review. Empirical research will be required to address this question.

Empowerment: There should be efforts to optimize effective opportunities for participation in priority setting and to minimize power differences in the decision making context.

Were any stakeholder views allowed to dominate the decision making process? (What was the effect? How well did we manage this?)

In the official documents that set the rules for the three most recent National Health Conferences there is no description of means to account for power differences. Although the CNS are intended to be broadly inclusive, this in itself does not mitigate power imbalances to ensure effective participation of diverse stakeholders.

Wendhausen (2006) reported that the numeric distribution of health council members, in a municipal health council in the South of Brazil, did not meet the legal requirements defined by the bill 8142/90, because there were 10% more (than what is legal) members of the government and 8% fewer health care professionals participating as councilors. Moreover, non- members of the government had fewer opportunities for participating during diverse debates around municipal health care issues, as members of the government systematically controlled the discussions (Wendhausen, 2006). The authors concluded that there is significant power imbalance among diverse health councilors, in terms of quantity and quality of participation in health policy making, thus concluding that empowerment of diverse councilors is critical for ensuring true democratic participation (Wendhausen, 2006). As described in the work by Martins et al. (2008), power imbalance has been a recurrent theme in diverse studies concerning societal participation in policy making in Municipal Health Councils of several Brazilian states (Martins et al., 2008). According to the National Council of Health Secretariats (2009), “ it is important to highlight the need [for managers] to recognize their role as agents of the public interest, and to respect the institutional hallmark of the health care system, overcoming [their] authoritarian and patrimonialistic attitudes...however, despite of efforts to promote this concept, managers commonly refuse to comply with their role, presenting inadequate behaviors that preclude transparent management that should respect the interests of the public” (CONASS, 2009, pg. 37).

Were there any stakeholders that we realize in retrospect we ought to have engaged, but did not? (What are we doing now to engage them?)

Ferri-de-Barros et al. 2009 described regional differences in voting power in the 13th National Health Conference, when accounting for effective representation of users of the system from different regions of Brazil (Ferri-de-Barros et al., 2009). Health policy-making occurs based on voting. The number of voting participants per State in the National Health Conferences (CNS) is proportional to the State population. As an example of two extremes, in the 14th CNS there were

836 voting participants representing 53 million people from the poorer Northeastern States (1 per 63,000), as compared to 956 voting participants from the most prosperous Southeastern States representing 80 million people (1 per 84,000). Thus, voting participants from the Southeastern States outnumber voting members from the Northeastern States. Moreover, in the Northeast, 97% of people rely exclusively on the SUS for an effective representation of 1 per 61,000 users, whereas in the Southeast only 50% of people rely exclusively on SUS for an effective representation of 1 per 42,000 users (table 14).

Table 14. Proportional Representation of Users who Depend Exclusively on SUS: Northeast and Southeast

National Health Conferences	Regions	Estimated Population	Number of Voting members	Representation per capita	Effective representation per capita
12th CNS 2003	Northeast	47,741,711	672	1/71,044	1/68,913
	Southeast	72,412,411	1023	1/70,784	1/35,392
13th CNS 2007	Northeast	51,609,027	716	1/72,080	1/69,917
	Southeast	79,561,095	1092	1/72,858	1/36,429
14th CNS 2011	Northeast	53,078,137	836	1/63,491	1/61,586
	Southeast	80,353,724	956	1/84,052	1/42,026

Sources: Official documents by the Ministry of Health (table 10) (www.saude.gov.br) and *Agência Nacional de Saúde Suplementar* (www.ans.gov.br)

Brazilian children and youth have less access to privately financed health care than do adults and elderly (16.5% versus 24.3%). This difference is even more striking on a regional basis – for example of the extremes, only 6.7% of Brazilian children and youth of North and Northeast have access to private health care compared to 43.3% of adults and elderly of São Paulo State (ANS, 2009). This means that the current voting process underrepresents users from poorer regions, children and youth (Ferri-de-Barros et al., 2009), thus the number of voting participants should be adjusted accordingly.

Martins et al. (2008) discussed the [self] exclusion of citizens who have access to privately financed health care from the democratic processes for the SUS, due to the fact that their health care needs are addressed in the privately financed system. As such, members of society who are empowered to argue for improvements of health care in Brazil, have lost their interest to participate in the health policy debate and decision making processes for the SUS (Martins et al., 2008). The increasing support that the federal government has provided for the growing private health sector (Paim et al., 2011) may represent a challenge to engage all relevant stakeholders in the health policy debate for the SUS.

Given differential internal capacity across health services providers, were there mechanisms in place to support those with less capacity and ensure a more level playing field, especially in the development of project proposals?

Leveling the playing fields to empower health councilors and to educate Brazilian citizens about the SUS has been a recurrent theme in the voted policies of the three most recent National Health Conferences. The “*Secretaria de Gestão Estratégica e Participativa*” (SGEP) was developed following the 12th National Health Conference to facilitate effective societal participation in decision making for health resource allocation for the SUS (CONASS, 2009). The Guideline 2 for the 14th National Health Conference, voted at the municipal and state levels, “*Participatory Management and Social Control Over the State: Expand and Consolidate the Democratic Model of Governing for SUS*” led to 42 policies that aim to level the playing field of decision making and social participation. As an example, the policy 27 (pg.25) pledges “to add basic knowledge about the SUS and social control in the curriculum of elementary and middle schools”, and the policy 24 (pg.25) asks “to create regional forums for the municipal health councils”.

Were we [decision-makers/CNS participants] attentive to the impact of our decisions on vulnerable client or patient populations? (How are we monitoring this?)

There are diverse policies and proposals voted during the three most recent National Health Conferences that aimed to protect vulnerable populations. As an example, the guideline 11 for the 14th CNS, voted at the municipal and state levels, specifically states: “For a system that respects differences and specific needs of vulnerable regions and populations” (pg.68). Under guideline 11, 28 policies aimed to protect vulnerable populations and regions were approved,

including, but not limited to, specific policies for the Amazon (policies 2,3 pg. 68), for indigenous populations (policy 7 pg. 69), for the elderly (policy 10, pg. 69), for the disabled (policy 12, pg.69), for the children (policy 15, pg.70) and for the obese (policy 16, pg. 70). There are no policies or motions voted during the three most recent CNS that specifically describe means of monitoring the impact of allocation decisions on vulnerable populations. Based on this scoping review, I was not able to determine how decision makers are monitoring the impact of their decisions on vulnerable populations.

Enforcement: There should be a leadership commitment to ensure that the first four conditions are met.

Were we (decision makers/health councillors) disciplined in our (their) commitment to apply the priority setting framework consistently? If we needed to depart from it, were we able to articulate good reasons for this to our stakeholders?

This question is not answerable with our study design. Empirical studies of the decision making process, in diverse jurisdictions, would be required to evaluate the commitment of the leadership to ensuring that the four conditions of A4R and Empowerment are met. Based on the statements by the National Council of Health Secretariats (2009), and based on the work by (Wendhausen, 2007) and (Martins et al., 2008), it is not uncommon for health care managers [the leadership] to depart from the governing rules for public participation in decision making that are defined by the Brazilian constitution of 1988 (CONASS, 2009, pg.39). As such, the hypothetical commitment of the leadership to the ethical conditions evaluated here appears to be a challenge.

Was a formal evaluation strategy implemented to monitor progress and to identify good practices and opportunities for improvement?

There is no formal mechanism to monitor progress and to identify good practices and opportunities for improvement described in the by laws of the three most recent National Health Conferences. The by laws and the final reports of the National Health Conferences have been publicly available, allowing for analysis such as the one performed with my research, which is an informal strategy to capture good practices and to suggest opportunities for improvement.

According to the National Council of Health Secretariats (2009), public participation in decision making for health resource allocation during the National Health Conferences has improved steadily since the 8th National Health Conference, in terms of the number of the municipal and state conferences that preceded the national level, the number of participants in the CNS and the number of polices and recommendations that have been proposed. In their evaluation of the CNS, the CONASS (2009) suggested that the increasing number of voted policies in the National Health Conferences might be compromising the identification of health priorities for the SUS (CONASS, 2009, pg. 23).

Is there a mechanism in place to learn from this experience (the CNS) to improve future iterations?

The “*Secretaria de Gestão Estratégica e Participativa*” (SGEP, 2009) can be seen as a mechanism to facilitate learning and improved communication between the diverse jurisdictions (CONASS, 2009). According to the official documents of the three most recent CNS, there is no explicit mechanism to facilitate learning from previous CNS to improve future iterations; however, because these documents are publicly available, diverse theoretical analysis of the CNS, such as the one presented with my thesis, can be performed towards improving future processes based on previous experiences.

In summary, based on this ethical analysis, the three most recent CNS processes fell short in meeting the four conditions of A4R (Daniels & Sabin, 1997) and the “Empowerment Condition” (Gibson et al., 2005a). The organization of the CNS with a well defined leadership, with the legislated requirement for broad public participation in health policy making for the SUS, and with the public dissemination of official documents describing the rules and the final reports of the CNS are “good practices” towards ethical priority setting for the SUS, which partially align with the principles of publicity, relevance and enforcement of A4R. The voting process in the CNS is the mechanism to revise polices and motions, which are intended to guide allocation decisions; however, because the rationales for allocation decisions are not publicly available, it is not possible to evaluate whether revision of voted policies would change allocation decisions based on reasons, therefore, voting in the CNS does not fully comply with the revision condition of A4R.

The “Empowerment Condition” (Gibson et al., 2005a) has not been met because decision making in the CNS has been compromised with multiple forms of power imbalance among diverse categories of decision makers.

The CNS processes would be ethically improved if the rationales for the allocation decisions were made available to the public, if the final reports of the CNS clearly reported allocation decisions based on the voted policies and motions, if there was an appeal mechanism to dispute allocation decisions based on further reasoning and if the leadership of the CNS ensured that power imbalances in decision making were mitigated. To improve societal participation in health policy making in Brazil, enforcing the current legislation and empowering diverse decision makers is required. The voting process in the CNS must be revised to account for differences in access to the privately financed system. Social participation in health policy making for the privately financed system needs to be developed and integrated with the decision making processes for the SUS, because resource allocation for the privately financed system directly impacts resources for the SUS (Paim et al., 2011; Ferri-de-Barros et al., 2012). These “opportunities for improvement” will be further discussed in the next chapter.

Chapter 4

4 Discussion

To the best of my knowledge, this is the first scoping review about priority setting for health resource allocation in Brazil. I described macro level policy making for health resource allocation in the Brazilian health care system based on policy documents and on a representative sample of the literature on this complex topic.

I found no empirical study on ethics of macro-level priority setting in Brazil. A recent literature review summarized empirical studies about priority setting for health interventions in developing countries. Youngkong et al. (2009) found no empirical study regarding priority setting in Brazil. The authors concluded that the increasing number of empirical studies regarding priority setting for health resource allocation in developing countries, during the last decade, indicate that replicable and verifiable methods for explicit priority setting are developing (Youngkong et al., 2009).

Mitton et al. (2009) performed a scoping review on “public participation in health care priority setting”. No studies regarding public participation in priority setting for health resource allocation in Brazil were captured with their search strategy. This review suggests that governments in diverse countries appear to be interested in promoting public participation in health policy making. Participation in different health care systems occurs with diverse approaches. The authors highlighted the need of further research to refine methods for evaluating “public participation in health care priority setting” (Mitton et al., 2009).

Despite of the challenges with public participation in decision making in the National Health Conferences, the World Health Organization has acknowledged the Brazilian model of National Health Conferences as an example of advancement of public participation in decision making for health resource allocation (The World Health Report, 2008, pg. 110, in CONASS, 2009, pg. 50).

Thus, my thesis fills a gap in the international literature on priority setting by synthesizing knowledge about this topic in one of the world’s largest publicly funded health organizations, in which public participation in health policy making is prescribed by law since 1990.

As such, the information provided in this manuscript can be useful for health services researchers and policy makers in diverse settings, particularly in Brazil, where the politics of health resource allocation has been recognized as the main barrier for improving populational health (Victora et al., 2011).

Ham & Robert (2003) compiled analysis of macro-level priority setting with “*Accountability for Reasonableness*” in the New Zealand (Bloomfield in Ham & Robert, 2003), Canada (Martin & Singer in Ham & Robert, 2003), United Kingdom (Robert in Ham & Robert, 2003), Norway (Norheim in Ham & Robert, 2003) and in The Netherlands (Berg & Van der Grinten in Ham & Robert, 2003). The authors concluded that priority-setting processes for health resource allocation in the New Zealand and in the UK were closely aligned with the *Publicity* and *Relevance* condition of A4R, whereas in Canada, in The Netherlands and in Norway the *Publicity* and *Relevance* conditions were not met. Only in Norway and in the UK the *Appeals* condition was met. The *Enforcement* condition of “*Accountability for Reasonableness*” was not met in any of the five health care systems (Ham & Robert, 2003).

Ferri-de-Barros et al. (2009) used a similar approach to analyze the rules and processes of the 13th National Health Conference in Brazil, and building on this work, I added the “*Empowerment Condition*” (Gibson et al., 2005a) to A4R to analyze the policy documents of the three most recent (12th, 13th and 14th) National Health Conferences, and I included in the analysis the literature on ethics of health resource allocation in Brazil.

My analysis of the official policy documents and of the literature is an original approach to ethics of health policy making in Brazil; however, nuances of the “real world” processes at all jurisdictional levels could not be explored in depth, and this represent one of the limitations of the scoping study methodology (Levac et al., 2010). A few studies in the Brazilian literature on ethics of priority setting analyzed “real world” processes (Martins et al., 2008; Wendhausen, 2006) and they were accounted for in the ethical analysis; however, these studies were limited by restricted sample sizes (e.g. performed in a few health jurisdictions). Moreover, although I used broad strategies to search the literature on ethics of priority setting in Brazil, my strategies may have failed to capture all the academic and grey literature about this topic.

Nevertheless, the thematic analysis of the literature performed independently by two researchers achieved a saturation of concepts (Levac et al., 2010), which enhanced the description of the current priority setting process in the CNS and facilitated my ethical analysis.

Whilst the use of secondary data represent a limitation of my study design, the use of primary data in macro level health policy analysis would also present challenges and limitations, in terms of feasibility of empirical data collection and of validity of data analysis. As disclosed by Kafiriri et al (2007), their primary data (transcribed interviews of key informants) about priority setting processes of three levels of decision making in Uganda, Norway and Canada might have reflected the perception of their research subjects, thus potentially *portraying* priority setting (Kafiriri et al., 2007).

On a reflexive account, I have learned during my thesis research that there have been remarkable improvements in the decision making processes for health resource allocation in Brazil due to the implementation of the SUS. Such process developments correlated with improved primary health outcomes in Brazil, which occurred alongside substantial economic growth, followed by improved social determinants of health (Victora et al., 2011). Preventable poor outcomes of surgical care persist in Brazil, due to inequities of access to appropriate health care resources in different health jurisdictions. This fact motivated my thesis research, based on the assumption that improving the processes for health resource allocation for the SUS will correlate with improved outcomes of surgical care in Brazil, and based on the assumption that surgical outcomes, in contrast with primary health outcomes, are less likely to improve solely as a result of economic growth and improved social determinants of health.

Equity of health resource allocation continues to be a strong personal value, which drives my interest in priority setting research, particularly in Brazil where health inequities persist. Economic growth will most likely continue in Brazil, regardless of what health services researchers do or do not do; however, health services researchers may be able to facilitate significant improvements in health outcomes in Brazil by elucidating reasons for health inequities, thereby empowering diverse stakeholders to drive meaningful changes towards fair and legitimate health resource allocation. My scoping review and ethical analysis is a small contribution to facilitate empirical health services research on this complex topic.

My analysis of key policy documents, and of the literature, suggests that the current processes for macro-level health policy making in Brazil fall short of fully meeting the four conditions of “*Accountability for Reasonableness*” (Daniels & Sabin, 1997) and the “Empowerment Condition” (Gibson et al., 2005a). Yet, a well-structured framework for public participation in decision making for the SUS does exist. According to my ethical analysis, the National Health Conferences (CNS) represent a fundamental starting point for developing ethical priority setting for health resource allocation in Brazil because:

1. The CNS include broad stakeholder participation at all jurisdictional levels of the SUS;
2. The rules and the by laws of the CNS are publicly available;
3. There is a voting process to vet health policies;
4. There is a well defined leadership for the CNS;
5. Recent policies approved during the 14th CNS aim to mitigate power imbalances in decision making. (e.g. Guideline 5 Policy 10: Institute the professionalization of decision makers for the SUS at all levels...(Final report of the 14th National Health Conference, pg.37).

Although current legislation supports broad public participation in health policy making for the publicly financed health care system in Brazil, some challenges to ensure fair and legitimate priority setting for the SUS persist because:

1. Current legislation for broad public participation is not enforced (Wendhausen, 2006);
2. Planning for allocating health resources “...is conducted mainly as a formal exercise to comply with the legal requirement rather than as an instrument to implement policy or as a basis for resource allocation” (La Forgia & Couttolenc, 2007), and this means that the rationales for allocating health resources might not rest on reasonable reasons;
3. Rationales for decisions are not publicly available and there is no formal mechanism to appeal allocation decisions (Ferri-de-Barros et al., 2009);
4. There is marked power imbalance among diverse decision makers (Wendhausen, 2006; CONASS, 2009; Ferri-de-Barros et al., 2009)
5. There is no formal mechanism for public participation in priority setting for the privately financed system (Ferri-de-Barros et al., 2009; Paim et al., 2011; Ferri-de-Barros et al., 2012).

The conditions of “*Accountability for Reasonableness*” (A4R), and the “Empowerment Condition”, may be regarded as utopian if taken as strict measures of ethics of priority setting. Daniels & Sabin (2008) suggested that there is no evidence to support claims that applying A4R to decision making leads to improved decisions, processes or health outcomes (Daniels & Sabin, 2008); however, Gibson et al. (2011) provided empirical evidence, in a pilot study, that the decision making process, and the perception of fairness of priority setting, improved as a result of applying a modified version of A4R to guide priority setting in three health care organizations in Ontario (Gibson et al., 2011).

According to “*Accountability for Reasonableness*”, fair and legitimate health policy making occurs with leadership that ensures decision making rests on reasons and rationales that are publicly available and that all stakeholders can understand as reasonable. Moreover, there must be a mechanism to appeal decisions based on further reasoning (Daniels & Sabin, 1997). According to the “Empowerment Condition”, power differences must be mitigated to facilitate effective participation of diverse members in the decision making context (Gibson et al., 2005a).

Thus, according to my description and analysis of the three most recent National Health Conferences in Brazil, and according to my review of the Brazilian literature on ethics of priority setting, the ethical accounts of priority setting for health resource allocation for the SUS would improve with the following recommendations (Objective III):

- 1) The principle of *Integrity* (the State must provide a complete package of health services) must be revised, acknowledging the need to set priorities for allocating health resources (CONASS, 2009; Fortes, 2009; Fortes, 2010b). This means that some health services will need to be compromised, so that other health services can be developed. Explicit priority setting processes will be required to ensure fairness and legitimacy of decision making (Daniels & Sabin, 1997)
- 2) Building capacity at all jurisdictional levels is required to improve planning of health resource allocation (La Forgia & Couttolenc, 2007), including capacity for continuously and systematically assessing the diverse medical needs of diverse populations, enabling decision makers to formulate, and to inform to all stakeholders, rationales for ethical evidence-informed health policy making.

3) Educating health councillors and enforcing current legislation for societal participation is required to empower diverse decision makers (Wendhausen, 2006; 2007; Martins et al., 2008). Further research is required to study reasonable means to educate and facilitate the participation of members of the public and of health care professionals in the municipal health council meetings for decision making.

4) According to my ethical analysis, within the current CNS framework, the reasons and rationales for the voted and approved health policies and the allocation decisions must be actively disseminated to the wide public, and discussed in all jurisdictional levels prior to implementation (Ferri-de-Barros et al., 2009). This is required to develop an appeal mechanism, for diverse municipalities and regions, based on further reasoning specific to the local context.

5) The municipal and regional leadership must encourage and create incentives for the participation of diverse members of society in the municipal health council meetings, including users of the privately financed system who have been excluded from the health policy debate for the SUS (Martins et al., 2008).

6) According to my ethical analysis, the themes for the National Health Conferences are currently pre-determined by the Ministry of Health. This must occur with the participation of the wide public, prior to the National Health Conferences, so citizens can participate in deciding what are the critical health policy issues to be discussed and voted for, every four years, at all levels of decision making. This should be preceded by a comprehensive assessment of diverse health needs, services and programs in all jurisdictions. Moreover, the themes and sub-themes need to specifically guide the setting of priorities among competing services and programs, so deliberation can occur objectively for allocating the health care budget to meet the prioritized health care needs (CONASS, 2009).

7) According to my scoping review, there were no studies concerning the values and perceptions of members of the government or of health care professionals with regards to priority setting for health resource allocation. Further research is required to elucidate the values and perceptions of diverse stakeholders with regards to rationales for reasonable rationing, including members of the public from diverse regions and socio-economic backgrounds, health care professionals, administrators of private health insurance companies and members of the government.

8) The number of voting participants in the National Health Conferences needs to account for differences in access to the privately financed system (Ferri-de-Barros et al., 2009), until an improved framework that integrates health policy making for the two systems can be developed and implemented.

9) Leadership for the municipal health councils must be free from conflicts of interest with members of the government, who must be moderated to enable legitimate participation of members of the public and of health care professionals in the municipal health council meetings (Wendhausen, 2006; Martins et al., 2008; CONASS, 2009).

10) Until health policy making for both systems (publicly and privately financed) can be integrated, a legal framework for shared decision making, with multi-stakeholder participation, needs to be developed to ensure legitimate societal participation in decision making for health resource allocation in the privately financed health care system (Ferri-de-Barros et al., 2009; Paim et al., 2011; Ferri-de-Barros et al., 2012). Martins et al. (2008) suggested that citizens who have access to privately financed health care have been self excluded from the priority setting discussions for the SUS. In the privately financed system, limit setting decisions occur without public participation; however, according to the law 9656/98, private insurance companies are not allowed to set limits on specific medical services or procedures (Paim et al., 2011). This law substantiates an argument for societal participation in decision making for health resource allocation in the privately financed health care system.

In the next section, I reproduced in full my published work on this topic, which are tangible steps toward meeting my research objective III: to provide recommendations for *improving* priority setting for health resource allocation in Brazil. My published work provides further arguments for the recommendations 1,4,6,8 and 10.

4.1.1 My Published Contribution to the Priority Setting Literature

4.1.1.1 Inequitable Distribution of Health resources in Brazil: An Analysis of National Priority Setting

Fabio Ferri-de-Barros, Andrew W. Howard, Douglas K. Martin
(Acta Bioethica 2009; 15 (2): 179-183) reproduced with permission.

Abstract: The purpose of this paper is to describe the national priority setting process for the public health system in Brazil, evaluating the process using the ethical framework Accountability for Reasonableness, and equity considerations highlighted in the 2008 WHO Commission on Social Determinants of Health. We searched the Brazilian Ministry of Health website for documents that described priority setting within the Brazilian Universal Health Care System (SUS). The National Health Conference (CNS) has been defined by the Ministry of Health as the democratic priority setting forum for SUS. The most recent such conference (13th CNS, 2007) is the subject of this paper.

Our analysis suggests that the process of priority setting within SUS has not yet achieved the ethical standards of legitimacy and fairness, and that inequitable distribution of decision making power under-represents users in poor areas. The unmet need for hospital care for children in Brazil, which reflects a remarkable inequality of opportunity for human development, may be a product of poor priority setting processes and inequity in representation.

Key words: priority setting, public health, inequitable distribution

Distribución Injusta de los Recursos en Salud en Brasil: un Análisis del Establecimiento de Prioridades Nacionales

Resumen: Este artículo pretende describir el establecimiento de prioridades nacionales en el proceso de cuidado del sistema de salud en Brasil, evaluando el proceso con el empleo del marco ético de Administración Razonable, y de consideraciones de equidad destacadas por la Comisión sobre Determinantes Sociales de la Salud de la Organización Mundial de la Salud (OMS).

Buscamos documentos que describieran el establecimiento de prioridades dentro del Sistema

Único de Salud brasileño (SUS) en el sitio del Ministerio de Salud Brasileño. La Conferencia Nacional sobre Salud (CNS) ha sido definida por el Ministerio de Salud como el foro del SUS para el establecimiento de prioridades democráticas. La 13a CNS, 2007 –la más reciente de dichas conferencias– constituye el tema de este artículo.

Nuestro análisis sugiere que el proceso de establecimiento de prioridades dentro del SUS no ha alcanzado aún los patrones éticos de legitimidad y justicia, y que la distribución injusta de las instancias de poder de decisión no representa realmente a las áreas más pobres. La meta aún no alcanzada de necesidad de hospitales para niños en Brasil significa una notable falta de igualdad en las oportunidades para el desarrollo humano y puede que sea producto de la mala definición del proceso de prioridades y de la falta de equidad en la representación.

Palabras clave: establecimiento de prioridades, salud pública, distribución injusta

Distribuição Injusta Dos Recursos Em Saúde No Brasil: Uma Análise Da Definição De Prioridades Nacionais

Resumo: Este artigo pretende descrever a definição de prioridades nacionais no processo de cuidado do sistema de saúde no Brasil, avaliando o processo com o emprego do marco ético de Administração Razoável e de considerações sobre a equidade, destacadas pela Comissão sobre Determinantes Sociais da Saúde da Organização Mundial da Saúde (OMS). Buscamos documentos que descreveram o estabelecimento de prioridades dentro do Sistema Único de Saúde brasileiro (SUS) no site do Ministério da Saúde brasileiro na web. A Conferência Nacional de Saúde (CNS) foi definida pelo Ministério da Saúde como o fórum do SUS para o estabelecimento de prioridades democráticas. A 13a CNS, 2007 –a mais recente das citadas conferências– constitui o tema deste artigo.

Nossa análise sugere que o processo de estabelecimento de prioridades dentro do SUS não alcançou ainda os padrões éticos de legitimidade e justiça e que a distribuição injusta das instâncias do poder de decisão não alcança realmente as áreas mais pobres. A meta ainda não alcançada da necessidade de hospitais infantis no Brasil, o que significa uma notável falta de igualdade de oportunidades para o desenvolvimento humano e pode ser produto de uma má definição do processo de prioridades e da falta de equidade na representação.

Palavras-chave: definição de prioridades, saúde pública, distribuição injusta.

Introduction

The 2008 World Health Organization (WHO) Commission on Social Determinants of Health recommended promoting health equity through actions on the social determinants of health (1). Brazil was a partner on that commission, and the federal government has been proactive to address social inequities. National policies such as *Bolsa Família*, the largest conditional cash transfer program in the world, received special recognition for equalizing income distribution (2). *Bolsa Família* was meant to improve access to primary education and health care for the poorest families. In addition, the Family Health Program (PSF) developed by the federal government, during the last 18 years, has led to remarkable improvements on health indicators across the emerging Brazilian nation (1).

Despite improvements in primary health care, the Brazilian Universal Health Care System (SUS) currently faces challenges in delivering universal and equitable health care to 190 million Brazilians (3). Allocation decisions and planning occur at National Health Conferences held every four years in accordance with federal law 8.142. The most recent one (13th CNS, 2007) is the subject of this paper.

The ethics framework Accountability for Reasonableness (A4R)(4) outlines the conditions that decision makers must fulfill to ensure legitimate and fair priority setting. A4R has been recognized as a significant advance in studying priority setting in health services research (5). Developed in the context of managed care reform in the United States, the framework has been validated in the Canadian [public] health system (6) and in several other countries (4).

The purpose of this paper is to describe the priority setting process for the public health system in Brazil, and evaluate it using the conditions of A4R and the equity considerations highlighted in the 2008 WHO Commission.

Methods

We have searched the Brazilian Ministry of Health website www.saude.gov.br for documents that described priority setting within SUS. The CNS has been defined, by the Ministry of Health, as the democratic priority setting forum for SUS. The 13th CNS was held in 2007 with the following objectives:

1. Evaluate the status quo of health in Brazil according to the SUS framework;
2. Define the guidelines to ensure health as a fundamental human right and State policy;
3. Define the guidelines to enable strengthened social participation to ensure full implementation of SUS.

Shortly after the 13th CNS the Ministry of Health published the four-year plan for allocating R\$ 89.4 billion for 73 measures and 165 goals for SUS. The legal document that has set the rules for the 13th CNS, as well as the document *Mais Saúde: Direito de Todos*, the four-year (2008-2011) priority setting plan for SUS, were analyzed using the four conditions of A4R (see Box 1)(7). Equity concerns were addressed by considering decision making power of users of the system as recommended by the 2008 WHO commission (1).

Box 1: The Four Conditions of A4R (7)

1. **Relevance:** Priority setting decisions must rest on rationales (evidence and principles) which fair-minded parties (managers, clinicians, patients) can agree are relevant to deciding how to meet the diverse needs of a covered population under required resource constraints.
2. **Publicity:** Limit setting decisions and their rationales must be publicly accessible.
3. **Appeals:** There is a mechanism for challenge and dispute resolution regarding limit-setting decisions, including the opportunity for revising decisions in light of further evidence or arguments.
4. **Enforcement:** There is either voluntary or public regulation of the process to ensure that the first three conditions are met.

Results

The priority setting context

The 13th CNS occurred in all jurisdictional levels in three distinct phases: Municipal, State and Federal, through the following process: each jurisdictional health council was required to elect an ad hoc committee and produce a priority setting report for health policies concerning a core subject pre-determined by the CNS committee. In 2007 the theme was “Health and Quality of Life: State Policies and Development”, which was broken down in 3 sub-themes:

1. Challenges to ensure health as a human right in the XXI century: State, Society and Development Patterns.
2. Public health policies and quality of life: (the role of) SUS in Social Security and the “Pacto pela Saúde” (Pact for Health).
3. Societal participation in the accomplishment of health as a human right.

Each sub-theme was to be discussed, according to pre-determined scripts, in a round table format. The municipal reports were sent to the State committee and the State reports, along with the Federal District report, were sent to the ad hoc national committee. Ten discussion groups during the last five days of the National Health Conference debated and voted for the health policies proposed by the State jurisdictions. Proposed policies receiving 70% of votes and approval by 6 of 10 discussion groups became policy. Proposals receiving 30% to 69% of votes could become policy upon receiving 50% plus one vote in a final voting round. The policies were gathered in a final report and sent to the National Health Council and to the Ministry of Health. This final document is meant to provide the basis for four years of priority setting for the Universal Health Care system in Brazil.

The participants

The participants of the 13th CNS included:

- 50% users of SUS (i.e. members of the public);
- 25% elected representatives of health professionals;
- 25% elected representatives of managers and providers of public health services.

Analysis using Accountability for Reasonableness

Relevance

The rationales for the themes and sub-themes of the 13th CNS and the decision making process to formulate those rationales were not stated in the document that set the rules for the CNS. The reports from the Municipal and State levels with the proposed health policies and the rationales for the policies were sent exclusively to the ad hoc national committee. Because the rationales were not publicly accessible it was not possible to determine whether the relevance condition had been met.

Publicity

The comprehensive document *Mais Saúde: Direito de Todos*, describing the allocation of resources for SUS from 2008 to 2011, was made available in the Ministry of Health website (www.saude.gov.br). This document does not describe the rationales for the specific allocation of resources, nor were the rationales the subject of active public debate. Therefore, the publicity condition of Accountability for Reasonableness was not met.

Appeals

There is no appeal mechanism described in the priority setting process of the 13th CNS. Although there is a clearly structured leadership, that did not in itself guarantee the participants an opportunity to appeal decisions.

Enforcement

There was no explicit mechanism to ensure that the above three conditions were met. Therefore, the enforcement condition of Accountability for Reasonableness was not met.

Equity Considerations

The number of participants per State was proportional to the State population. From the poorer Northeastern States there were 358 SUS users representing 51 million people (1 per 142,000), as compared to 546 participants from the most prosperous Southeastern States representing 79 million people (1 per 145,000). In the Northeast 97% of people rely exclusively on SUS for an effective representation of 1 per 137,000 users; whereas in the Southeast only 50% of people rely exclusively on SUS for an effective representation of 1 per 73,000 users.

Discussion

Health care is important in human development and societal welfare (2). In Brazil, two health care systems co-exist: the public system (Unified Health System-SUS) and the private system (Supplementary Health System-SHS). The report by the World Bank on SUS (3) highlights the lack of accountability and evidence-based planning for health policies and interventions in all jurisdiction levels. The priority setting process in the states and municipalities was considered

compromised by the “lack of capacity to develop evidence-based plans to guide their [states and municipalities] health policies and interventions”(3). Those findings, in agreement with our analysis using the ethical framework Accountability for Reasonableness, suggest that the process of priority setting within SUS has not yet achieved the ethical standards of legitimacy and fairness.

The percentage of the population relying exclusively on SUS varies according to the geographic region from a low of 50% to a high of 97% (8). This means that proportional representation by population under represents users in poor areas, the reverse of what would be appropriate where equity concerns guide representation as suggested by WHO. Furthermore, the vast majority of children from 0 to 19 years of age do not have access to the Supplementary Health System (8), and there is clear evidence of unmet need of hospital care for this age group (3,9,10) as well as in other countries (11,12), representing a generational equity challenge and a challenge to the notion of equality of opportunities.

The priority setting process we have described and evaluated concerns exclusively the public health care system (SUS). This is an important limitation of our study. The (private) Supplementary Health System (SHS) accounts for more than 50% of health care expenditure in Brazil, although it serves less than 30% of the population (8). Evidence suggests the two systems compete unfairly for resources and, therefore, priority setting in either system will have an impact on the other (13,14). Specifically, the private system will draw human resources from the public system and will not necessarily allocate according to considerations of medical need, legitimate process, or health equity (15). Accordingly, the public health system in Brazil faces an even larger challenge to meet these ethical goals.

Conclusions

According to the documents analyzed:

1. The priority setting process for SUS does not meet the ethical standards set by the four conditions of Accountability for Reasonableness;
2. People in poorer regions have less voting power in the priority setting process within the public system, as well as less access to private insurance;

3. The unmet need for hospital care for children, which reflects a remarkable inequality of opportunities for human development, may be a product of poor priority setting processes and inequity in representation.

Contributors

FFB and DKM were responsible for study design and concept development. FFB collected the data. FFB, AWH and DKM analyzed the data. FFB drafted the manuscript. AWH and DKM revised and critically edited the manuscript. All authors have read and approved the final version of this manuscript.

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4.1.1.2 An Argument for Explicit Rationing of Health Resources Within the Public-Private Mix in Brazil. *Um Argumento a Favor da Racionalização Explícita de Recursos de Saúde no Sistema Misto Público-Privado no Brasil*

Fábio Ferri-de-Barros, Jennifer Gibson, Andrew Howard

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Three years ago, the forum on the rationing of health services ¹ provided an excellent starting point for discussing means of distributing healthcare resources more reasonably within Brazil. Recently, an overview of the Brazilian healthcare system concluded that the most sizeable barrier to securing the right of healthcare for every Brazilian is, in fact, political ². World Bank policy analysts have recommended the building of accountability for the improvement of poor performance in Brazilian public hospitals, which consume 70% of the nation's public spending on healthcare ³.

In this manuscript, building on the forum for the rationing of health services, we shall argue that, as a minimal requirement for the securing of the right of health care for all Brazilians, decision-makers must be accountable for the rationing of limited healthcare resources across the mixed public/private system, ensuring equitable access to essential health services for all citizens and engaging citizens in the determination of how this should be done. Explicit rationing will be required for building accountabilities within the public/ private mix and for ensuring legitimate societal participation in the difficult task of distributing limited healthcare resources fairly and reasonably ⁴.

Rationing within the Brazilian public/private mix

The provision of universal and comprehensive health-care is intangible, even in the world's wealthiest nations, including Brazil ⁵. Decision-makers who allocate resources are challenged with the high costs of evolving medical technology and competing with societal demands for a range of public goods, in addition to health care, such as energy, education, transport,

infrastructure, etc. Rationing decisions occur at different levels of every healthcare system, implicitly or explicitly^{4,6}. Mixed public/private healthcare systems present additional challenges to decision-makers, because there are marked differences in governance and accountability between the private and public systems. A recent analysis of the Supplementary (privately financed and delivered) system in Brazil suggested major discrepancies between the government's neoliberal approach towards the private healthcare sector and the actual focus on the private healthcare insurance companies⁷. Evidence suggests that the two systems compete for limited health resources^{8,9,10,11}. As a result, the Supplementary system draws human resources from the public system (Brazilian Unified National Health System – SUS), thus decision makers for SUS are left scrambling to staff their health services in a sustainable way.

Private health care accounts for more than 50% of health care expenditure in Brazil, although it serves only 25% percent of the population¹². Brazilian children and youth have less access to the Supplementary healthcare system than do adults and the elderly (16.5% versus 24.3%)¹². This difference is even more striking on a regional basis. For example, only 6.7% of Brazilian children and youth, from the North and Northeast, have access to the supplementary healthcare system, as compared to the 43.3% of adults and elderly of the state of São Paulo¹². Interest groups and empowered citizens, who drive health policy changes in Brazil, generally have access to privately financed healthcare and are not used to waiting for medical services in the same line in which 75% of the population must wait. For 25% of Brazilians who have access to the Supplementary healthcare system, or who pay out of their own pockets for the same, healthcare services can be purchased as commodities of variable quality, just like cars or flat screen TV's. As such, the empowered civil society in Brazil doesn't see the problem of access to healthcare in their backyards. However, citizens who enjoy access to privately financed (and delivered) healthcare are exposed to inappropriate delivery of healthcare services in the form of, for example, unnecessary surgical procedures. Brazil's standing as the world record holder for cesarean deliveries² is but a single example of this fact. National Health Conferences occur every four years at the municipal, state and federal levels in order to provide guidance for the implicit rationing of the SUS, however, there is no parallel process that explicitly governs rationing in the Supplementary system¹³.

Principles for rationing healthcare resources

Ham & Coulter⁶ reviewed and compared explicit processes for rationing healthcare resources in diverse publicly funded healthcare systems. Distinct values and principles emerged in each priority setting process, such as individual right to healthcare, cost-effectiveness, efficiency, fairness, and dignity. International experience with explicit processes for the rationing of healthcare resources in the State of Oregon (USA), Scandinavian countries, the Netherlands and New Zealand suggest the need to focus on fair processes to facilitate societal learning on how to ration healthcare resources reasonably^{4,6}. Similarly, in Brazil, neither random citizens¹⁴ nor Brazilian bioethicists¹⁵ can agree on what constitutes reasonable allocation of healthcare resources. Nevertheless, building upon the forum for the rationing of healthcare services¹, we argue that the explicit rationing of healthcare resources, both in the public and Supplementary systems, must occur in order to enable societal education and legitimate participation in the shaping of modern societal values in Brazil regarding the financing and delivery of healthcare services.

Contributors

F. Ferri-de-Barros developed the argument and written manuscript. J. Gibson edited the manuscript for intellectual content. A. Howard revised the text for intellectual content.

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Chapter 5

5 Conclusions

Public participation in health policy making for the SUS is a hallmark of the system, which is a fundamental starting point towards improving the ethical accounts of priority setting in Brazil. The existence of such a well structured framework for broad stakeholder participation in the National Health Conferences, at all jurisdictional levels of the SUS, represent a unique opportunity for conducting empirical research in priority setting for health resource allocation in one of the world's largest health care organizations.

Improving priority setting for health resource allocation in Brazil will require long term commitment to empirical work on this complex topic. The politics of health care financing and delivery in Brazil have been identified as the main challenge to improving health care for Brazilians (Victora et al., 2011). The literature on priority setting presents lessons learned with diverse experiences, successes and failures in diverse settings. Similarly, my scoping review outlines accomplishments and challenges of the current framework for health policy making in Brazil. Thus, my theoretical recommendations for improving priority setting for the SUS logically aligned with building on successful experiences, while avoiding the repetition of failures.

In this scoping review, the analysis with the four conditions of A4R and with the “Empowerment Condition” elucidated reasons why the current health policy-making processes for the Brazilian health care system are not aligned with its constitutional principles of *Universality, Integrity and Equity*, recognizing opportunities for improvement of the processes for the CNS.

Specifically, I identified reasons why the current CNS processes are falling short to meet ethical standards for fair and legitimate priority setting, and thus have compromised the full potential of the SUS to ensure the constitutional right of access to health care to all Brazilians. Thus, based on these reasons, I made recommendations towards improving priority setting for health resource allocation for the SUS. These recommendations are important steps to improve the politics of health care financing and delivery for the SUS, and thus contribute to the recent call for action for improving health care in Brazil (Victora et al., 2011).

Nevertheless, I recognize that my thesis research is an academic exercise, and I feel humbled by the work of others, who have made tremendous “real world” efforts in developing the current framework for the Brazilian publicly funded health care system, which has been recently acknowledged as a model of public participation in health policy making (The World Health Report, 2008, pg. 110, in (CONASS, 2009). I also acknowledge the growing body of literature and empirical work in priority setting, which has guided my thinking and analysis.

Chapter 6

6 Future Directions

Implementing the objective recommendations outlined in the previous chapter involve interactions with diverse stakeholders in all levels of decision making. As such, to act on my recommendations, disseminating the results of our scoping review to the leadership of the Ministry of Health will be required. This would facilitate designing and implementing further research to elucidate the values and perceptions of macro level managers with regards to the current processes for priority setting in Brazil.

Based on my scoping review, the leadership of the “*Conselho Nacional de Secretários de Saúde*”(CONASS) agree with the argument for setting priorities explicitly and more objectively in the publicly financed health care system in Brazil (CONASS, 2009, pg.33), as such, the leadership of CONASS represent a group of stakeholders who might have a keen interest in collaborative action research to improve macro level priority setting in Brazil.

At the meso and micro levels, the municipal health councilors, local health care professionals and health care managers can be excellent collaborators for developing empirical research on priority setting. Based on our previous experiences in diverse jurisdictions of the State of São Paulo, the municipal health councils and the health care managers must be engaged with the research plan at the beginning of the four years mandate of the elected municipal government, during which data collection for the empirical case studies must be completed.

The “academic surgical missions” served as an excellent strategy to engage stakeholders at the municipal and regional levels, and to secure corporate funding for conducting research that is otherwise poorly funded. My involvement in Brazil will continue to include surgical missions, and in fact further such visits are planned for 2013 and beyond. These missions provide a context in which I can make local and national academic collaborations and further the empirical work on the ethics of health resource allocation in Brazil.

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Appendix

Appendix A- Example of published documents regarding the academic surgical missions

Pg. 99- Example of paper published by the local media about the first academic surgical mission

Pg. 100- Motion of honor presented by the local government after the first academic surgical mission

Pg. 101-Example of paper published by the local media about the second academic surgical mission



**Prefeitura Municipal
de Caraguatatuba**

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Fale Conosco

Caraguatatuba, 23 de Novembro de 2007. 10:00 hs

Mais Notícias

24/11/2007
Caraguá faz mutirão de Mamografia para suprir demanda

23/11/2007
Sebrae oferece novo curso de Atendimento ao Cliente de 3 a 6 de dezembro em Caraguá

23/11/2007
1ª Feira Cultural da EMEF do Casa Branca leva cultura e informação a centenas de pessoas

23/11/2007
Caraguá terá Festival do Mexilhão em dezembro

23/11/2007
Morador de Caraguá pode fazer declaração de isento do Imposto de Renda até 30 de novembro

23/11/2007
Caraguatatuba lança Super Verão

22/11/2007
Caraguá segue com Campeonato para veteranos

22/11/2007
Caraguá disputará Liga Valeparaibana de Tênis de Mesa

Busca

Críanças de Caraguá e Ubatuba foram avaliadas por equipe canadense

Os médicos canadenses que estão na região oferecendo tratamento médico - ortopédico especializado de qualidade internacional, com base em evidência científica e adequado às condições hospitalares locais, para crianças carentes e com deficiências físicas, estiveram no domingo, dia 28, em Caraguá avaliando os pacientes de Caraguá e também de Ubatuba. Dez pacientes, sendo 4 de Caraguatatuba e 6 de Ubatuba foram avaliados e de acordo com o médico Pediatra e Coordenador médico do PSF – Programa de Saúde da Família de Caraguá, dr. Alexandre Andrechuck, dos pacientes do município avaliados, apenas um precisa de cirurgia, que acontecerá na sexta-feira, dia 2, em Ilhabela, um outro paciente necessitou apenas de um gesso e os outros dois não precisam de tratamento especializado, além do que já recebem da rede municipal.

Segundo Andrechuck a visita ao município foi muito importante, pois os fisioterapeutas da rede tiraram dúvidas sobre diversos casos que conduzem no dia-a-dia. "Eles gostaram da participação dos nossos profissionais durante a avaliação no domingo, eles disseram que o fato foi inédito nesse projeto", disse.

Na tarde desta segunda-feira, 29, Dr. Alexandre Andrechuck teve um encontro com a equipe que tirou suas dúvidas sobre pediatria e saúde em geral. "O encontro foi muito importante, pois trocamos experiências. Foi um intercâmbio muito válido, pois o que aprendi com eles servirá para aplicar na rede municipal de saúde."

O Projeto

O idealizador do projeto, Dr. Fábio Ferri-de-Barros é ortopedista pediátrico e atuou na rede pública de Ilhabela e de São Sebastião durante 5 anos. Ele mudou-se para os Estados Unidos no ano de 2003, após um ano de sub-especialização em Ortopedia Pediátrica no Hospital das Clinicas da Universidade de São Paulo, quando iniciou um ciclo de especializações no exterior que incluiu estágios na Austrália, Suíça e Canadá. Atualmente, Fábio encontra-se em Toronto, Canadá, onde concluiu este ciclo de especializações e associou-se a equipe de Ortopedia Pediátrica do "Hospital For Sick Children". Iniciou também um ciclo de estudos na Universidade de Toronto, programa de PhD do Departamento de Saúde Pública, focalizado no estudo de estratégias para a melhoria da atenção médico-hospitalar pública, para crianças do Brasil, com base em modelos internacionais bem sucedidos.

Foi exatamente por ter atuado na região que ele direcionou o projeto ao Litoral Norte de São Paulo, já que conhece bem as dificuldades dos hospitais locais, que muitas vezes dependem da rede hospitalar dos municípios do Vale do Paraíba, como São José dos Campos e Taubaté, para a prestação de serviços especializados.

A equipe de médicos do Canadá será composta por 6 pessoas. O Dr. Ferri-de-Barros, ficará responsável também pelo contato médico-paciente durante a atuação no Litoral, em conjunto com Dr. Andrew Howard, professor associado do departamento de ortopedia do "Hospital for Sick Children" da Universidade de Toronto e diretor do "Office of International Surgery" da Universidade de Toronto. Também haverá a atuação de duas anestesistas canadenses, uma enfermeira e um enfermeiro, todos com ampla experiência internacional voluntária.

Os profissionais do "Hospital for Sick Children" prestarão atendimento voluntário e tratamento especializado, conforme normas internacionais reconhecidas no Brasil e de acordo com as condições dos hospitais municipais, em conjunto com os especialistas locais do litoral norte de São Paulo no período de até 3 de novembro. Cabe ressaltar que também doarão material cirúrgico padronizado, ora escasso ou inexistente nos nossos hospitais públicos municipais.

Este projeto conta com o apoio do Instituto Kat Schürmann para a divulgação e a organização administrativo-financeira no Brasil. Fundado em 1997, o Instituto Kat Schurmann é uma entidade sem fins lucrativos que desenvolve ações sociais e educativas colaborando com as comunidades de baixa renda no litoral brasileiro.

mais notícias



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ILHABELA
Capital da Vela

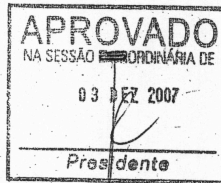
Câmara Municipal da Estância Balneária de Ilhabela

Rua Benedito Cardeal Sobrinho, nº 40 - Centro - Ilhabela - SP - CEP. 11.630-000
CNPJ. 50.320.415/0001-10 - Fone: (12) 3896-9600 - Fax: (12) 3896-9622
site: www.camarailhabela.sp.gov.br - e-mail: camara@camarailhabela.sp.gov.br

"Deus trabalha para
aqueles que nele espera"
(Isaias, Cap. 64, vers.04)

MOÇÃO Nº 092/2007

APRESENTA MOÇÃO DE LOUVOR À EQUIPE MÉDICA E COLABORADORES, QUE ATUARAM NO LITORAL NORTE REALIZANDO DIVERSOS ATENDIMENTOS CLÍNICOS E CIRÚRGICOS EM CRIANÇAS COM PROBLEMAS ORTOPÉDICOS DE ALTA COMPLEXIDADE.



Senhor Presidente,
Senhores Vereadores:

Apresentamos à Mesa, ouvido o Plenário, na forma regimental, **MOÇÃO DE LOUVOR** à equipe composta pelos médicos voluntários do Hospital For Sick Children e da entidade "No Bondaries" (Sem Fronteiras), Dr. Fábio Ferri de Barros, médico brasileiro, atualmente residente no Canadá e que teve a iniciativa de trazer os voluntários para o Brasil, Dr. Andrew Howard, Ortopedista canadense, Dr. Paul Jellicoe, Ortopedista inglês, atualmente residente no Canadá, e Dra. Shelang Kemp, Anestesista canadense, pelos enfermeiros canadenses, Leine Locsin e Ron Tuner, pelo estudante de medicina canadense Farhan Merali e pela médica residente Dra. Tatiana Bravo dos Santos, brasileira que estuda no Canadá e auxiliou a equipe no Brasil, pela realização no período de 28 de outubro a 03 de novembro no Litoral Norte e, especialmente em Ilhabela, de diversos atendimentos clínicos e cirúrgicos em crianças com problemas ortopédicos de alta complexidade, ao Diretor Clínico do Hospital Mário Covas Júnior, Dr. Ricardo Ângelo Storti que não apenas autorizou as cirurgias, mas também participou do projeto, aos Srs. Vilfredo de Oliveira Schürman e Heloísa Carneiro Ribeiro Schürman, Diretores do Instituto Kat Schürman e a todos os profissionais da equipe brasileira do referido Instituto que participaram da organização do evento, bem como a Petrobrás pelo apoio concedido ao Projeto através do Instituto Kat Schürman e a todos as autoridades, servidores e voluntários que contribuíram para o sucesso da iniciativa.

JUSTIFICATIVA:

A medicina sempre exigiu dos que se aventuram a exercê-la mais do que simples empenho.

"Ilhabela" - Cidade brasileira campeã de preservação da Mata Atlântica



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Novas especialidades médicas, novos serviços regionais, ampliações e obras que garantem eficiência e qualidade aos usuários.

NOTÍCIAS:

[Voltar](#)

Crianças e adolescentes com problemas ortopédicos serão atendidos no HRVR



O hospital é referência mundial no tratamento de doenças ortopédicas pediátricas.

Regional – Equipe especializada de médicos e enfermeiros do Hospital For Sick Children, liderada pelo ortopedista brasileiro Fábio Ferri-de-Barros, e profissionais brasileiros, entre eles o médico Márcio Bazzo, do HRVR – Consaúde, realizarão atendimento e cirurgias ortopédicas a vinte crianças e adolescentes do Vale do Ribeira no HRVR-Consaúde, entre os dias 4 e 10 de agosto. Os casos foram pré-selecionados em meio a 80 crianças da região em dois meses de atendimento. O hospital canadense é referência mundial no tratamento de doenças ortopédicas pediátricas.

A ação faz parte do Projeto Saúde Hospitalar Infantil Canadá-Brasil idealizado pelo ortopedista Fábio Ferri de Barros, que trabalhou por cinco anos na rede de saúde pública do Litoral Norte. Atualmente, o médico integra a equipe de Ortopedia Pediátrica do Hospital Canadense.

No ano passado, o projeto, que tem apoio da Petrobrás, do Grupo No Bondaires (Sem Fronteiras) e do SickKids Foundation, foi realizado nos municípios do Litoral Norte. No Vale do Ribeira, conta com parceria com o Consaúde e o Rotary Clube de Pariqueira-Açu.

O médico Márcio Bazzo, do HRVR-Consaúde, explicou que as equipes canadense e brasileira iniciarão os atendimentos entre a segunda 4/8 e quarta 6/8, no HRVR. Na quinta 7/8, os médicos estarão na Faculdade ABC, na capital, e na sexta 8/8 e sábado

9/8, ministrarão palestra sobre Ortopedia Pediátrica no anfiteatro do Consaúde para os profissionais ligados à área do Vale do Ribeira. "Além de oferecermos atendimento especializado às crianças e adolescentes que aguardavam vagas em grandes centros, também temos a oportunidade de trocar experiências e informações sobre casos mais complexos da área de ortopedia pediátrica", destacou o médico Márcio Bazzo.

Integram a equipe canadense os ortopedistas Fábio Ferri-de-Barros, Cristina Alves e a fisioterapeuta Bárbara Harvey. Do Brasil, os médicos Marcelo Saad, Luiz Teruo Minami, Márcio Bazzo, a enfermeira Dagmar Simoncello e a assistente administrativa Tânia Ladaga. O projeto também contempla a doação de material cirúrgico padronizado ao HRVR.

A superintendente do Consaúde, Maria Cármen Amarante Botelho, afirmou que a parceria com o Hospital Canadense é muito importante para o constante aprimoramento do atendimento médico oferecido pelos profissionais do Consaúde. "O projeto nos oferece conhecimento e tratamento médico-ortopédico especializado e humanizado de qualidade internacional", destacou. Maria Cármen agradeceu ao empenho dos médicos responsáveis pelo Programa, ao Sick Kids Foundation, Petrobrás, ao No Bondaires, ao Rotary e anunciou que o Consórcio tem grande interesse em contribuir para que o programa tenha sequência na região. "São iniciativas como essa, de grande empreendimento humanitário, que contribuem para que possamos fazer a diferença no atendimento à saúde pública com a melhor tecnologia mundial e o máximo empenho de nossos profissionais". O projeto também abre portas ao intercâmbio profissional permanente e a educação continuada dos profissionais do complexo Consaúde.

Publicada em 31/7/2008 13:58:59

ENVIE ESTA NOTÍCIA POR E-MAIL

IMPRIMA ESTA NOTÍCIA

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